

Barriers and facilitators to health care access for children in a low-income area in Cape Town

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Abstract

Background

In Cape Town the under-5 mortality rate has plateaued to 20 per 1000 live births. The southern subdistrict has the largest paediatric population in Metro West and accounts for 31% of deaths in Metro West. Across the metropole 60% of child deaths are out of hospital. We investigated barriers to accessing health care for children in the False Bay Hospital drainage area.

Methods

Quantitative and qualitative methods were used: community survey (n=62), qualitative interviews (n=11) with caregivers of children who presented critically ill or deceased (January 2017 - Dec 2020) and a modified nominal group meeting of community based and clinical services managers to identify and achieve consensus on solutions.

Results

Community members (74%) experienced barriers in accessing care and only 60% knew the correct emergency contact numbers. Knowledge of basic home care for common conditions was limited. Interview themes showed barriers of affordability, acceptability, access, as well as household and facility factors. The nominal group technique suggested that improvement in community-based services, transport access and lengthening service hours would alleviate some of the challenges in accessing care.

Conclusions

The barriers to accessing care seem insurmountable to those who encounter them, yet solutions and community assets do exist. The optimal utilization of services and community assets have the potential to improve access to care with resultant decreased out-of-hospital deaths and improvement of the under-5 mortality rate. A well-coordinated Community Orientated Primary Care (COPC) program with intersectoral collaboration and government commitment needs to be implemented.

DECLARATION

I, *Luke Brian Profitt*, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Introduction

The poorest and the most rural communities are usually the worst affected by high childhood mortality rates.⁽¹⁾ This is demonstrated in the differences in under-5 mortality rates (U5MR) between high income countries (e.g. Spain) of 5 per 1000 live births and in Sub-Saharan Africa with 76 per 1000 (50% of the global child deaths).⁽²⁻⁴⁾ In response to the poverty related burden of illness, the United Nations published Millennium Development Goals (MDGs).^(5, 6) The 4th MDG was to reduce deaths under 5 years by two thirds. Globally, there has been only a 50% drop in under 5 mortality.⁽⁶⁾ The MDG's were replaced in 2016 with the sustainable development goals (SDGs),⁽⁵⁾ following the 2015 report that noted the interplay of poverty and health, with vulnerable children living in poverty suffering double the mortality compared to those from the richest quintiles of society.⁽⁶⁾ The SDG's are less specific than the MDG's but attempt to address the social determinants of health (SDH)⁽⁷⁾ that reflect the circumstances in which people live such as education levels, sanitation, and nutrition.^(1, 6, 8)

Barriers to accessing health care are common⁽⁹⁾ in developing countries and vulnerable populations across the globe and have been described in terms of availability, affordability and accessibility.⁽¹⁰⁾ Accessibility includes access to transportation and communication in one's own language.^(11, 12) Availability of health care facilities tends to vary between urban and rural settings, with 62% of African people having a clinic within walking distance.⁽⁹⁾ Affordability relates to both the direct cost such as user fees and medication costs and the indirect costs such as loss of income or transport costs.

South Africa has reduced its U5MR from 75 per 1000 in 2008 to 34 per 1000 in 2016; this varies by province and population group reflecting both the Apartheid segregation and rural urban divide.^(2, 13) The Western Cape Province U5MR plateaued in 2018 at 20 per 1000 live births⁽¹⁴⁾ from 24.1 in 2011.⁽¹⁴⁾ By 2015, the City of Cape Town had succeeded in a 33% drop in the under 5 mortality rate.^(15, 16) The plateauing of the death rate has been linked to out of hospital preventable deaths making up 50-70% of all under 5 deaths in the Western Cape. This is similar to the rest of Southern Africa where 50% of deaths are out of hospital,⁽³⁾ from pneumonia, gastroenteritis, trauma and sepsis.^(12, 15, 17, 18) Pathway to care⁽¹⁹⁾ studies have shown delays in seeking care are due to failure to recognise illness or severity thereof, lack of transport, health care facility issues and other barriers.^(3, 20) In a retrospective study of under 5 deaths in metro west in 2011, Reid et al showed that up to 15% of children

dying at home had received care within the week that they died.⁽¹⁸⁾ In Cape Town it was noted that there are complex pathways with multiple delays in assessment and transfer to a Paediatric Intensive Care Unit (PICU) resulting in many potentially avoidable deaths.⁽²¹⁾ Common barriers to care within Cape Town include communication challenges, facility barriers including staff attitudes and access issues.⁽²²⁾ The majority of patients attending the Red Cross War Memorial Children's Hospital (RCWMCH) report walking to access health care with a median distance to a 24 hour facility being 6km from their home.⁽²¹⁾ In the same study 70% of patients traveled by foot to the nearest facility with some having to walk 13km.^(21, 22)

South Africa is in a fairly unique situation, being classed as a middle income country and having a per capita percentage health spend comparable with European countries (SA 8.11%, Italy 8.8%, European Union 9.87%).^(23, 24) South Africa however faces political antecedents, historical disparities and the quadruple burden of disease,⁽²⁵⁾ as well as many poor communities in both rural and periurban settings/settlements. Primary Health Care (PHC) (defined as first contact, continuous and comprehensive care provided to [undifferentiated] populations...⁽²⁶⁾) together with Community Orientated Primary Care⁽²⁷⁾ (COPC) has been advocated as a solution to this burden and South Africa along with many countries has undertaken PHC re-engineering. The Western Cape has further prioritized reduction of childhood mortality in the First 1000 days program.⁽²⁸⁾ The program aims to reduce harms children face from conception to their second birthday in order to improve the long term quality and prosperity of their lives.

Study Purpose

This study aimed to determine and understand barriers to health care access of sick children in the drainage areas of False Bay Hospital (FBH) in Cape Town and to propose solutions using existing community assets and a COPC approach.

Study Objectives

1. To describe the health seeking behaviour and basic health care provision at home by caregivers in the community.
2. To describe the demographic and clinical characteristics of the paediatric patients (0-18 yrs) who presented severely ill (triaged red or blue) between January 2017-December 2020.

- 70 3. To explore caregivers' experience when accessing health care for their critically ill child.
4. To determine health care providers' solutions and obtain their consensus on best methods and local assets available to overcome the barriers and SDH impacting negatively on health care access.

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Methods

Study design

This cross-sectional mixed methods case study was conducted utilizing a community survey, semi-structured interviews and the nominal group technique to collect
80 qualitative and quantitative data.

Study setting

The study was conducted at FBH and the associated health and community-based facilities including Masiphumelele clinic and Ocean View clinic

The City of Cape Town is divided into eight health sub-districts,⁽²⁹⁾ namely the
85 Northern, Khayelitsha, Tygerberg and Eastern sub-district which make up Metro East and the Western, Southern, Klipfontein, and Mitchells Plain sub-district which make up Metro West. The Southern sub-district is one of the largest - comprising 13% of Cape Town's population.⁽³⁰⁾ The southern sub-district has the largest paediatric population in Metro-west and 31% of paediatric deaths occur in this subdistrict with
90 60% of these are occurring outside of hospital facilities.⁽¹⁶⁾ Up to 10% of childhood deaths at the RCWMCH PICU are from the False Bay Hospital (FBH) catchment area.⁽³¹⁾ FBH is a district family physician led hospital with 76 inpatient beds, of which 6 are paediatric beds.⁽³²⁾ The emergency centre (EC) receives both adult and paediatric patients who are either self-referred or referred in from the surrounding
95 clinics. All patients are triaged according to the South African Triage Score (SATS). Common paediatric emergencies include gastroenteritis with shock; pneumonia or bronchiolitis with severe respiratory distress; status epilepticus and acute exacerbations of asthma.

Areas that refer to FBH include Masiphumulele, Ocean View, Red Hill, Fish Hoek,
100 Simon's Town and Muizenberg, which are commonly referred to as the Far South. Masiphumulele is a large peri-urban informal settlement with approximately 40000 people of multiple nationalities, 75% of whom live in informal housing and half of the population is unemployed⁽³³⁾ Primary Health Care (PHC) is provided by the local

Masiphumelele clinic run by the City of Cape Town Municipality. Non-Governmental
105 Organizations (NGO's) such as the University of Cape Town's (UCT) Students
Health and Welfare Centre's Organisation (SHAWCO) provide evening clinics once
or twice per month⁽³⁴⁾ mostly for adult patients. The clinics in these areas are only 8-
hour facilities. Metro EMS has only one ambulance servicing households and
interfacility transfers in the Far South. COPC is coordinated by the family physician at
110 FBH with quarterly meetings with Community based services (CBS) – who are given
oversight by Living Hope, an NGO partnering with local health services for more than
two decades⁽³³⁾ – along with local clinic managers and hospital staff. The CBS
Community health workers (CHW) have received basic training in child health.

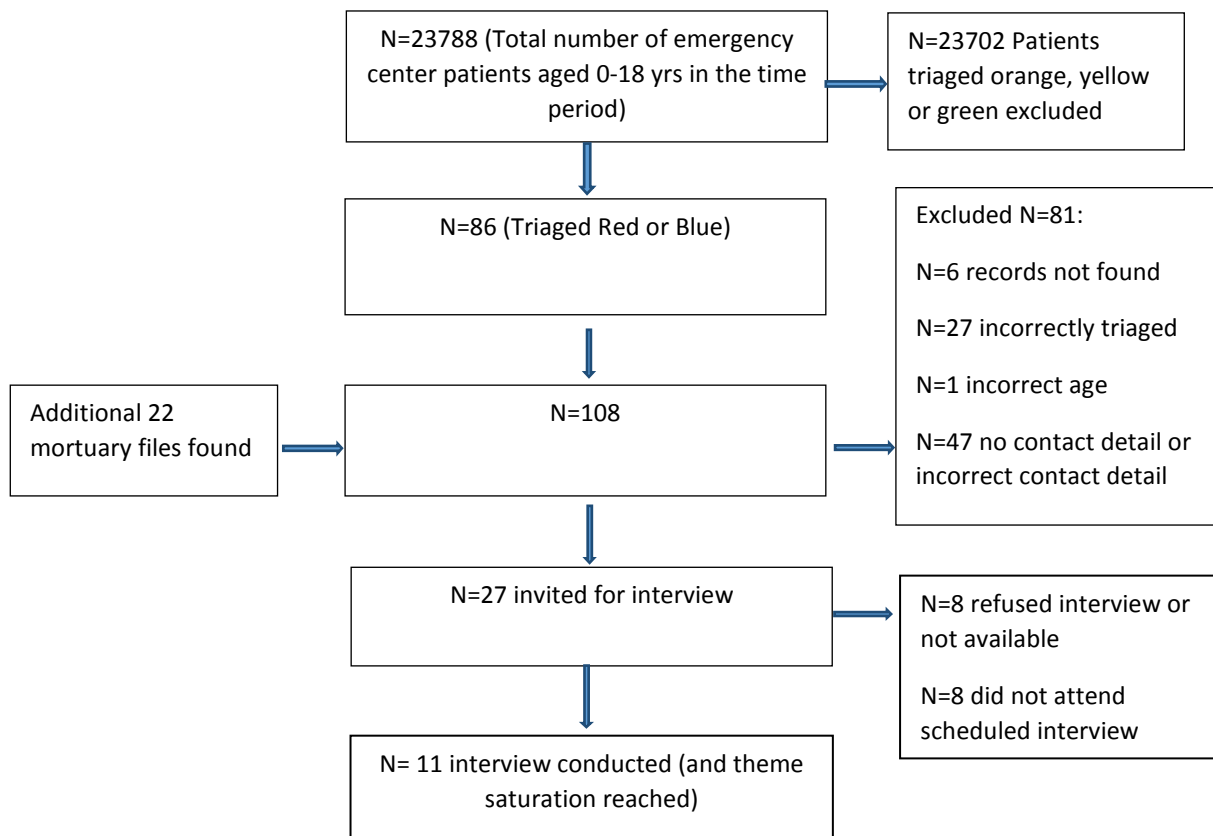
115 **Selection of study population and sampling:**

1. Community Survey

A survey was conducted amongst voluntary consenting eligible adult persons in the
community who self-identify as caregivers and are able to answer a questionnaire in
written or verbal form in English, Afrikaans, isiXhosa, Chichewa or Shona. This was
120 done in each of four quadrants of Masiphumelele using a map drawn by Living
Hope.⁽³³⁾ Adults who were not care givers or could not communicate in any of the five
languages were excluded.

The sample size was calculated using an online sample calculator⁽³⁵⁾ at 62 in order to
obtain a representative response from the population of 40000 representing 10000
125 households with an expected rate of 80% experiencing barriers; a margin of error
(precision) of 10%; and confidence interval of 95%.

2. Parent/Caregiver Interviews



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Figure 1: Flow diagram of participants in the interviews

The (FBH EC) patient register was searched retrospectively for children (0-18y) who presented between Jan 2017 and Dec 2020 and were triaged red (severe acute illness) or blue (no signs of life).⁽³⁶⁾ The clinical record for each of these was retrieved to confirm triage score and clinical outcomes. Demographic data, clinical condition and disposition were extracted for analysis. A dataset was compiled of critically ill children from which to invite parents or caregivers for interview. Eligible parents or caregivers were contacted telephonically, verbal consent was obtained, and one-on-one, face-to-face (n=10) or web based (n=1) interviews were set up at a time convenient for the parent or caregiver. Written consent was signed at the time of the interview, except in the case of the web-based interview where verbal consent was taken. Caregivers were excluded if they were under 18 years of age; unable to communicate in South African languages dominant in the Western Cape including Xhosa, Afrikaans and English; no translator was available for their preferred language; contact details were unavailable; unable to attend the interview or those who were incorrectly triaged. The additional files found were returned from the mortuary and added to the database. See figure 1.

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150 3. Nominal Group Technique

The Nominal Group Technique⁽³⁷⁾ was conducted amongst 11 participants. The group consisted of five community health workers, the family physician of FBH, one clinic nurse, two nurse supervisors for community health workers, the outreach paediatrician and the head of Living Hope organization. This group forms an existing
155 COPC structure known as the Far South Clinical governance forum, it is a group of stakeholders who meet monthly to discuss clinical governance issues in the far south geographical area. The group was selected for the NGT as it represented invested stakeholders. EMS are also representative in the group but were excluded as they were not available on the day. Each participant provided signed written
160 consent to participate in the NGT part of the study.

Data collection tools and analysis

Data collection tools included a community survey questionnaire, interviews with caregivers and a nominal group technique-based meeting with health care workers.

1. Community Survey Questionnaire

165 A questionnaire was developed based on the WHO verbal autopsy^(38, 39) to interview parents and caregivers in the community. The WHO verbal autopsy is a tool used to postulate cause of death and possible reversible causes in areas where there is less access to formal mortuary and diagnostic services. An initial pilot of the questionnaire was done with five respondents, feedback was obtained, and the survey was
170 adapted accordingly. Further to this, feedback was obtained from the translators and amendments made. The survey translations – Afrikaans, Xhosa, Shona – were checked by a second native speaker for accuracy. The questionnaire was administered by a research assistant or self-administered in paper-based (n=50) or an electronic format (n=12) (Google forms) between April and September 2020.
175 Convenience sampling was used for ease of conducting the survey. Parents and caregivers were approached randomly and invited to participate in the survey. The survey data were captured and securely stored in Google sheets (MS Excel equivalent) and analysed using basic spreadsheet analysis and thematic analysis of the qualitative responses. Health seeking behaviour was classified in categories of
180 Diarrhoea and vomiting, cough and fever and injury by the researcher on a Linkert scale as poor, good or excellent based on caregiver advice in the Road to Health Booklet (RTHB).⁽⁴⁰⁾

2. Parent/Caregiver Interviews

Interviews were conducted from a mixed phenomenological and grounded theory perspective^(41, 42) with parents or caregivers whose children died or survived a major critical health event. Phenomenological perspectives capture people's experiences of a phenomenon, situation or event while grounded theory builds an explanation of the why of behaviour, these can be combined to reflect both the experiences and reasoning which was adopted here. Interviews were conducted between November 2020 and May 2021. The interview schedule followed a semi-structured approach with demographic information, and the experience of caregivers in accessing care was explored. This included language fluency, physical barriers and social factors associated with access to health care. Eleven face-to-face one-on-one Interviews were conducted by an independent trained research assistant – a professional counsellor – and recorded on digital devices. A translator was used during the interview for non-English language speakers. Thereafter recordings were transcribed verbatim by a separate assistant. The primary researcher checked the transcriptions for accuracy and anonymity by comparing audio recordings with transcripts. Key phrases from the transcriptions were manually coded using NVIVO12 for windows (2021, QSR international) electronic data coding program by the primary researcher and confirmed independently by the other authors to determine themes from within the narratives of the interviews. Interviews were completed once theme saturation had been reached and no new data emerged. All data collected was de-identified and stored in a password protected computer file. Interviewees experiencing grief reactions were offered voluntary counselling with a local NGO (Hospivision).

3. Nominal Group Technique

The NGT key stakeholders formed a physical group of eleven consenting adults over the age of 18 and tasked with answering the question "How can we improve access to health care for children in the Far South?" Due to constraints (COVID related) the final NGT stages (5&6) could not be reached in the in-person meeting. The NGT was therefore modified to allow for electronic (email) ranking of the items (responses) generated. Each participant was emailed a copy of the categorized responses (see Table 3) together with five ranking categorisations discussed at the meeting. Email responses were correlated against the list of attendees before the data was entered into the spreadsheet (anonymously). The researcher's ranking for obtaining on feasibility consensus with scoring is in brackets

- 1 Most feasible to implement immediately (Score 5)
- 2 Feasible to implement in the medium term (Score 4)

3 Long term implementation (Score 3)

220 4 Dream to implement (Score 2)

5 Not currently useful. (Score 1)

Participants were given one month to respond electronically. Responses were collated in an Excel (Office 365) spreadsheet. Data was analysed as per the NGT method outlined in Figure 2 below. Provided all participants responded, the maximum score an item could receive was 55 and the minimum score was 11.

1. Presentation of Question: How can we improve access to health care for children

2. Silent phase: Participants record answers

3&4. Item generation, clarification and categorization

5. voting and prioritization

6. Group consensus

Figure 2: Graphic representing Nominal group stages to consensus

230 **Ethical Considerations**

Ethics approval was obtained from UCT Health Research Ethics Committee (Reference number: HREC 869_2019) and permission was obtained from Western Cape Government health and wellness (WCGHW) (WC_202003_020) and the City of Cape Town (Ref:8306) to conduct this research study. Participation in every section was voluntary, anonymous and by means of informed consent. Data for each of the three methods was anonymized and stored securely after being captured and electronic data stored in a password protected electronic storage.

Results

240 1. **Community Survey**

Table 1 Results of community survey

Surveys completed	62
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Gender of participant	Female	48	(77%)		
	Male	9	(14%)		
	Undisclosed	5	(8%)		
Nationality	South African	47	(76%)		
	Zimbabwean	10	(16%)		
	Malawian	5	(8%)		
Housing	Brick	18	(29%)		
	Wendy (informal wooden housing)	4	(6%)		
	Shack (wood, plastic and iron sheeting)	38	(61%)		
Schooling completed	Never attended school	3	(5%)		
	Primary	11	(18%)		
	Secondary	40	(65%)		
	Tertiary	6	(10%)		
	Other	1	(2%)		
Home language	Xhosa	39	(63%)		
	Shona	7	(11%)		
	Chichewa	3	(5%)		
	Afrikaans	3	(5%)		
	English	1	(2%)		
Fluency in local languages	High fluency	Moderate fluency	Poor fluency	Very poor fluency	
	English	28 (45%)	16 (26%)	15 (24%)	3 (4%)
	Afrikaans	5 (8%)	8 (13%)	14 (23%)	33 (53%)
	Xhosa	45 (73%)	4(6%)	7 (11%)	6 (9%)
Languages that health centre communicated to patient is:	Xhosa	18	(29%)		
	English	17	(27%)		
	Mix of Xhosa and English	22	(35%).		
	Other	5	(8%)		
Frequency of health care visits	Seldom (< 2 visits per year)	15	(24%)		
	Infrequent (2-4 visits per year)	40	(65%)		
	Regularly (5-6 visits per year)	11	(18%)		
	Frequently (>7 visits per year)	9	(14%)		

Experienced difficulty in accessing care for children		45	(74%)
Barriers experienced	Multiple barriers	17	(27%)
	Long waiting times	49	(79%)
	Staff attitude	17	(27%)
	Transport	8	(13%)
	Language	7	(11%)
	Knowledge of system	5	(8%)
	Fears	5	(8%)
	Cost	4	(6%)
I feel the health services are accessible		55	(89%)
Mode of transport to health care facility	Walking	21	(34%)
	Neighbours car	11	(18%)
	Own transport	7	(11%),
	Ambulance	8	(13%)
	Public transport	11	(18%)
Correct Knowledge of emergency services number		36	(60%)
I feel the staff attitude towards me is	Good	6	(10%)
	Caring	10	(16%)
	Abrupt	1	(1%)
	Too busy	15	(24%)
	Helpful	5	(8%)
	Bad	1	(1%)
	Good and caring	1	(1%)
	Kind	17	(27%)
	Did not answer	6	(10%)
I believe the health system (ambulance, clinic, hospital) is	Poor	20	(32%)
	Moderate	6	(10%)
	Good	4	(6%)
	Excellent	22	(35%)
Reason	I heard so	9	(18%)
	my experience	35	(56%)

	I don't know	18	(29%)
	they can't speak my language	5	(8%)
Health seeking behaviour			
Diarrhoea			
When your child becomes ill with diarrhoea, what should you do?	initiate sugar salt solution at home	20	(32%)
	take to the clinic first	25	(40%)
	take the child straight to the hospital	11	(18%)
	give traditional medication	1	(2%)
When your child is sick with diarrhoea	restrict food and water	2	(3%)
	give sugar salt solution	22	(35%)
	take the child to clinic	21	(33%)
	take the child to hospital	10	(16%)
When in the illness would you take child to clinic or hospital	immediately	16	(25%)
	once loose stool and thirst	25	(40%)
	when becoming weak	8	(12%)
	when too weak to take sorrol	9	(14%)
If a child in your care is sick with runny stools (diarrhoea) I would take them to	clinic	41	(66%)
	use home or plant remedies	1	(2%)
	take the child to hospital	12	(19%)
	give sugar salt solution	5	(8%)
Vomiting			
If a child in your care is sick with vomiting, I would take them to	clinic	47	(75%)
	take to spiritual healer/spiritist to drive out spirits afflicting them	4	(6%)
	take the child to hospital	5	(8%)
	give sugar salt solution	2	(3%)
Cough with fever			
If a child is coughing with a fever, when do you need to take them to hospital or clinic?	within hours	11	(18%)
	when cough and fever	11	(18%)
	when looks ill	10	(16%)
	if not improving after 1 day	18	(29%)
	if not improving after 2 days	5	(8%)

	if struggling to breathe	2	(3%)
If a child in your care is sick with cough with fever, I would take them to	clinic	43	(69%)
	private GP	1	(1%)
	pray for them	7	(11%)
	use over the counter medicines	1	(1%)
	take the child to hospital	9	(14%)
	give sugar salt solution	2	(3%)
Injury	91% of respondents would take their child to hospital if there is any level of pain following trauma. This was clarified further with the following question based on the Wong-Baker pain faces		
I would take my child to hospital (Wong-Baker pain faces)	no hurt	2	(3%)
	hurts a little bit	11	(18%)
	hurts a little more	0	(0%)
	hurts even more	19	(31%)
	hurts a whole lot	11	(18%)
	hurts worst	4	(6%)

Survey qualitative data

The written response section of the survey showed overall poor health seeking behaviour and knowledge of home treatment of basic conditions including fever, cough and diarrhoea or vomiting. Five themes emerged from analysis of the qualitative section of the survey, namely accessibility, affordability, acceptability, household factors and facility factors.

Affordability

“I find it difficult to get the money”

“I will not stay because I am bread winner in this house” “...once I take off day. yho!”

Accessibility (transport)

“I am working and I don’t have a car to carry my family to the hospital if they fall sick especially during the night”

Acceptability

“Most of the nurses are rough to patients, they will be social media so they won't have time and patient to gave children health care because of cell phones”

“We find it difficult to access health services especially during the night, hospital workers hesitate to attend to patients”

“Get more sickness” “Corona”

Facility factors

“because of a long waiting time”

“I will not stay because I don't understand the English they use in hospital”

“I will not stay because I may not find a place for me to sleep with the child”

“I am a foreigner”

Household factors

“I'm not educated for taking care of children”

“Who will take care of my children”

Transport is a variable barrier with transport cost for travel to health facility ranging between R0 and R500. Foreigners experience a greater cost in transport to access care especially at night, with the Chichewa respondents reporting the highest range of cost (R250 to R500) compared with other respondents (range 0-R45) except for one South African that reported that it costs R350 at night.

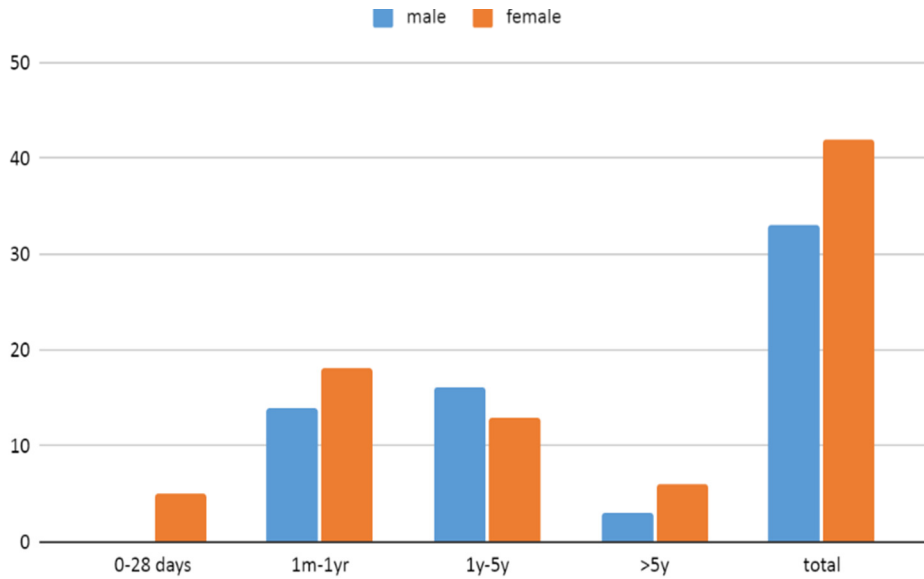
Some of the community assets recognised by survey respondents to overcome these barriers included the unity of the community, a care for the environment and education.

Characteristics of paediatric patients at FBH

FBH had 23788 children attend the EC between January 2017 and Dec 2020 with an average of 5947 per year. Of these 86 were triaged red or blue code according to the SATS. This is an average of 21 (0.35%) per year. The files were evaluated according to inclusion criteria.

The records identified 108 children as being red or blue code. Two children presented multiple times (both known with epilepsy/seizure disorder) and 27 were coded incorrectly and excluded as they were neither triaged red nor blue, 1 was incorrectly recorded as a child. The data for 78 patients was represented as 80 EC visits, 41% of these were male. The age category - 1 month to 1 year was the largest, with a female predominance – see figure 3. The most common presenting complaint or diagnoses were respiratory illnesses (53.8%), seizures (11.3%), gastrointestinal conditions (6.3%), sepsis including neonatal sepsis (2.5%), Presumed Sudden infant death syndrome (3.8%), injuries (3.8%) and poison ingestion (2.5%). Other illnesses included one case of chicken pox, one diabetic ketoacidosis and one foreign body inserted into the nose. See figure 4 below. Of the files audited 11% had missing data, within the file or the whole file could not be found.

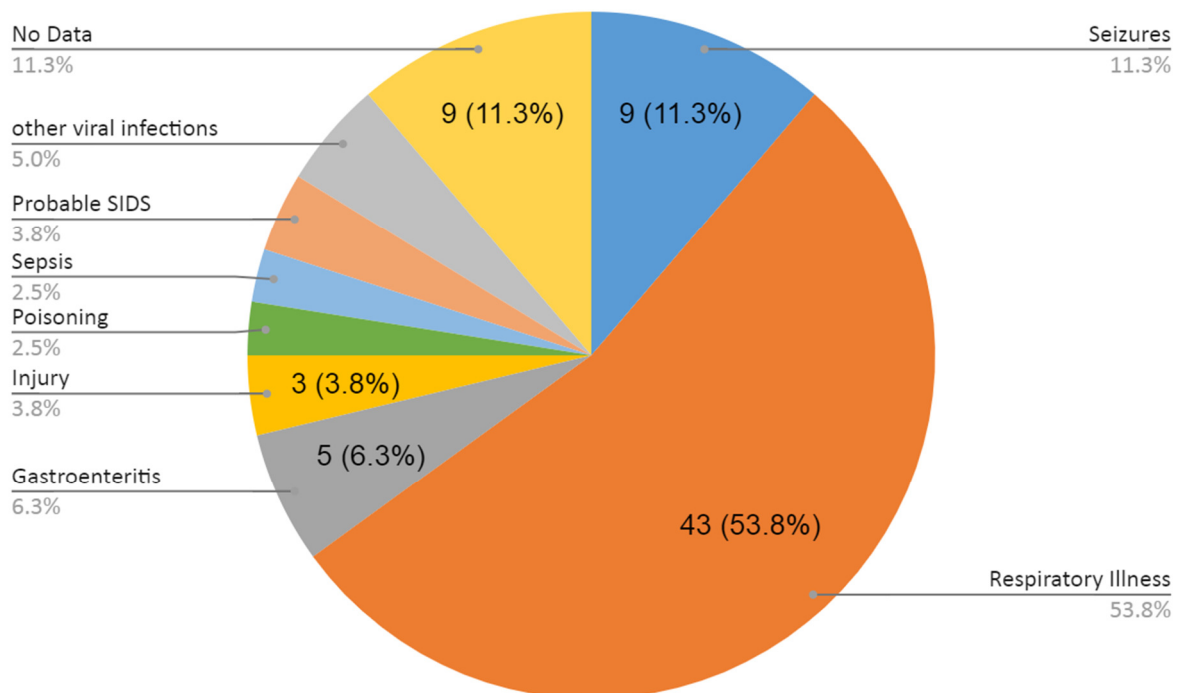
Figure 3 Distribution of Paediatric emergency visits by age and gender



The clinical dispositions of these patients

The following clinical dispositions were recorded: Fifteen children were transferred to higher levels of care (Level 2 or Level 3), 20 were admitted at district level (non-paediatrician care) five were declared dead in the EC and five were dead on arrival, for four deaths there is not enough data to confirm whether they were confirmed as in or out of hospital deaths, 4 absconded before being seen and 13 had no record of their outcome, 41 were discharged home.

Figure 4 Diagnoses or presenting complaint



2. Caregiver Interviews

300 Data analysis of interviews revealed six categories – Affordability, Acceptability, Accessibility, Availability, knowledge/ understanding and facility factors – with associated subcategories.

A further article is needed to give the full impact of the interviews, but the following quotes are pertinent

Affordable

305 1.1 Transport

A28: “Not enough money for the taxi sometimes...”

1.2 Private versus public health care

A65 “...I’ve got medical aid so that I can provide and pay ... to get the best sort of access to the best”

310 1.3 loss of income

A59 “...you need help you get even more frustrated because you specifically set up that day [and not able to earn]”

Acceptable

2.1 staff attitudes

315 A1 “she asked the security to help her because the child, ... was getting dizzy but the security ignored her.”

A58 “... you can’t speak to them because they are irritated”

2.2 waiting times

A58 “Well, it’s like, if you come in for emergencies, like, you wait forever”

320 2.3 discrimination

A4: “Everything is perfect, I know and I tell you as a foreigner we experience no different...”

Accessible

3.1 Safety

A59 “...For safety reasons because the area that the clinic is in, there’s always gangsters around”

325 3.2 distance

A1: “Makhula. It’s ah a little bit far”

3.3 language

A2: “Some of the-the words I didn’t understand

3.4 Transport

330 A66 “...we just called Uber to come and get him to the hospital ... I didn’t think about [calling ambulance] because he... it take long...”

3.5 lack of carer

A39 “...because most of the time he is with my mother because I work a lot so ...”

3.6 social capital

335 A33 " ... I've got one lady who I am working for. Sometimes he help me a lot..."

3.7 Facility capacity

A65 "...sometimes people are turned away because they just can't. They don't have the capacity to deal with you today..."

Available

340 A58: "Only once a week on a Tuesday ... I just think if there was a facility closer, she would have been here today"

Knowledge and understanding/household factors

5.1 Illness

345 A66 "... his daddy stopped him and uh he take some soap and he cleaned the mouth..." [home treatment for toxin ingestion]

5.2 System

A33 "When I want to come to hospital... They said you must go to clinic first and then one will send you here. It's just their rules, I don't know why"

5.3 Ambulance contact number

350 A65: "...it's interesting we all know the nine-one-one for America but we don't know our own one..."

Facility

6.1 Cleanliness

A32: "Um, and also that hospital is more clean"

6.2 Continuity of care

355 A32: "...Our folders are not complete, um, most of the time the folders are missing ..."

6.3 Communication

A58 "...it's almost like they are trying to show me, they tried to do something but they are not... Three / four doctors they didn't say much, they just said sorry until I had to go and get something to calm myself."

6.4 food

360 A32 "...that they maybe just offer the child a snack...There would be parents sitting ... They think they are just going to see a doctor and then go home so they don't pack a snack."

6.5 Staff attitudes

365 A4 "...you almost died and they didn't care about it." A65 "...I think they're not trained well enough to engage themselves into the lives of people that come..."

6.6 burden of illness

A66 "... I leave my problem that I have because I see other people with more serious problems come in hospital..."

370 Data was triangulated with community survey data and experiences of Jones⁽²²⁾ et al.

3. NGT with health care providers

375 The analysis of responses – Summation of scores – is included despite consensus not being obtained (limitations). Those marked in bold should be investigated further for implementation – scores of 8 or more are highlighted (the upper quartile of responses) – having been scored higher by the NGT respondents.

Table 3 Recommended solutions to overcome barriers to accessing health care

<u>Recommended solutions to barriers to accessing health care</u>	<u>score</u>
<u>Transport</u>	
Improve access to Emergency care after hours by strengthening state and private sector ambulance services	13
Print Ambulance number into Road to health book/put a sticker into book	11
Educate community on Ambulance service	6
Signs in community with ambulance numbers	6
Healthnet for transport for follow-up visits	4
Subsidy for transport to health care facilities	3
Facility	
Ocean View clinic to extend operating hours	11
Relationships strengthening	9
Nurse/community relationship improvement	9
Increase availability of emergency services within 2km e.g. fire station, police station	8
Becoming compassionate	8
Improve family planning access/services, especially for teens	7
Improve pregnancy counselling services	7
Increase access to 24-hour facilities in community i.e. at clinic not hospital	6
Mobile child health services in community doing health care, education and mental health to strengthen care of children	5
Free care in hospitals - issue vouchers [current cost at hospital R40 or 2-3USD for unemployed people]	5
Training of all support staff e.g. security officers and clerks in emotional intelligence and handling people going through emergency situations	5
Prioritizing children in Emergency unit	5

Dedicated child health queue in clinic with triaging at door	5
Starting a family clinic - everyone in a family can be seen on the same day	3
Cut down queues by having appointments	2
Education	
Educate moms on family planning, Alcohol and substances	7
Community education - services available	4
- pamphlets to be distributed with CBS home services	4
Educate parents - when child is sick - when to take child to hospital	4
Education of community re immunizations	4
Environment	
Crime prevention strategies in Ocean View	6
Policy and external changes	
Perinatal/antenatal - identify those at high risk and refer to CBS; Community Health workers must then walk-through 1st 1000 days with parent, educating on breast feeding, substances etc, this will empower moms to seek care and increase accountability.	9
Increase preventable health care budget	8
Community liaison person for where to access help	4
Focus on 1 st 1000 days	4

380 Discussion

The study aimed to determine barriers and facilitators to health care for children in the FBH drainage area and to identify solutions directed at reducing paediatric mortality. The Western Cape, particularly Cape Town compares favourably with the national U5MR, but more can be done to reduce the U5MR. While working at FBH, the principal investigator (LP) observed multiple “dead-on-arrival” cases and hypothesized that many of these deaths were due to poor caregiver health seeking behaviour as well as barriers to accessing care. We defined children as 0-18 years in line with international nomenclature. We conducted a community survey and interviewed caregivers whose children had experienced a critical event, and triangulated the results for a more holistic understanding of the barriers caregivers faced in accessing care for children.

390 The results from the community survey show that participant demographics (Table 1) concur with
experience working in the area which is a multicultural community with high unemployment, poor
education and mostly inadequate housing - SDH that are common in South Africa.⁽¹⁴⁾ Almost one
quarter of survey respondents were foreign nationals who experienced additional barriers to
accessing services such as language and poor attitudes of health care workers to foreigners, the
395 same issues have been noted in other parts of the country.⁽⁴³⁾ Transport was also a barrier,
especially for Chichewa respondents who noted that it can cost in excess of R350 (approx. 24USD)
to access health care after hours, the equivalent to the monthly social relief grant.⁽⁴⁴⁾

Health seeking behaviour

Our findings show that basic knowledge of health care for children at home is poor. Most caregivers
400 do not know when to give oral rehydrate, which conditions can be managed at home, or which
needs immediate assistance at a health facility due to the severity. Only a third of survey
participants would use the World Health Organization (WHO) standard of sugar salt solution
(SSS)⁽⁴⁵⁾ to treat diarrhea. This reflects poor insight into home based care for children with
gastroenteritis, a common condition accounting for 10% of childhood deaths in the metro-west area
405 of Cape Town.⁽¹⁸⁾

Despite most respondents indicating a preference for western medicine over traditional medicine,
overall healthcare seeking behaviour is poor. Every child born in South Africa is given a RTHB
which details what to do and where to go in the event of a sick child. Our study highlights that these
guidelines are not followed, defying one of the key principles of the 1st 1000 days program.⁽²⁸⁾ In
410 addition, recognition of severity of illness is poor. Some caregivers either rush to take their child to
clinic at the first signs of a cough, fever or after the first loose stool, or seek help too late. Poor
recognition of illness severity is a global phenomenon.^(46, 47) Too many presentations of mild, self-
limiting illness have the potential to overburden services. Recognition of the severity of illness can
however be difficult even for health care providers.⁽²¹⁾

415 An interesting finding is that there were very few neonates (under 28 days) presenting to the
hospital EC during the study period. There were similar numbers for those under 1 year and those
under 5 years, with a male predominance under 1 and female predominance under 5. Presenting
conditions followed South African trends⁽²⁹⁾ of causes of death in under 5yrs with pneumonia first,
followed by seizures and diarrhoeal diseases.

Caregivers' experiences

It is not surprising that 74% of respondents experienced barriers to accessing care, given what is
known from national and international literature.^(3, 10-12, 20, 21, 48-50) The literature shows that foreign
nationals experience greater barriers with respect to language, staff attitudes, transport, xenophobia

and documentation.^(11, 43, 50) The former three featured prominently in interviews and surveys, while
425 some survey respondents felt discriminated against because of their ethnicity.

Barriers to access elicited by the survey were similar to those expressed in interviews. The barriers
experienced were related to the associated cost of health care (affordability), with transport costs
and loss of income for days spent at hospital being the dominant concerns. Many found waiting
430 times and staff attitudes unacceptable. Accessibility was influenced by language barriers, distance
to health care facility, safety of the area, inadequate capacity of the facility, and lack of ambulance
services. One interview highlighted the difficulty caregivers face in accessing care after-hours in an
area serviced only by a mobile clinic on a weekly basis (availability). Household barriers evident in
both the interviews and survey were mostly related to inadequate knowledge of treating the illness
435 at home, recognizing the severity of illness and practices such as washing the child's mouth with
soap after a poison ingestion. Many would not initiate SSS at home for diarrhoea or vomiting; and
some would wait for signs of respiratory distress before taking a child with a respiratory illness to
hospital. Many did not know the emergency medical services number.

The Coronavirus pandemic impacted health care attendance. Child health visits were noted to be
reduced by up to 60% in some areas of the country.⁽⁵¹⁾ Local data from another sub-district in Cape
440 Town showed a reduction in child emergency presentations.⁽⁵²⁾ Those who did present were
generally more ill compared with pre-pandemic presentations⁽⁵²⁾ which may indicate a delay in
health seeking behaviour. The disruption of health services due to the pandemic is likely to have a
long term impact on access to care⁽⁵³⁾ due to reduced vaccination coverage, deworming, vitamin A
supplementation and nutritional and TB screening, with a potential future worsening of mortality.
445 Work on interventions to improve paediatric care and to reduce barriers to accessing care will have
to consider recurrent waves of Coronavirus infection, the worsening economic climate and their
impact on PHC.

Providers ideas on improving access to care for children

The findings of the NGT conducted with providers concur well with those of the caregivers'
450 experiences. While the barriers faced are in keeping with those reported globally,
understanding/knowledge of caregivers' experience emerged as important in devising solutions
proposed by providers. The top ranked items from the combined list generated by participants in
(stages 2-4) involved improving ambulance services, extending service opening times (to 21h00 or
24 hours) at the local clinic and including ambulance and emergency telephone numbers in the
455 RTHB. Solutions proposed by the nominal group will be relayed to the district paediatrician to be
addressed by future research e.g. piloting interventions. Providers noted the role of outside
stakeholder solutions – e.g. by higher management – such as improved government funding for
PHC, transport vouchers, ambulance availability and adjustment of clinic service hours.

Recommendations

Recommendations have been categorized into the themes of barriers experienced for ease of reading, however some recommendations will affect multiple barriers. These recommendations are a combination of the recommendations from the NGT and the researchers recommendations.

1. Affordability

The problem of affordability could be addressed through transport vouchers or improving private public partnership. The utility of this community asset has already been illustrated in Masiphumelele with private ambulances assisting state patients when state ambulances are not available. Lost income for days spent at clinic may be alleviated if existing appointment systems are improved, opening hours extended and families seen by the same doctor rather than at separate appointments. The differences noted in private and state health care may be addressed with the implementation of the proposed National Health Insurance (NHI) by narrowing the access gap between those who have and those who do not have health insurance. This strategy is some time away.

2. Acceptability

Acceptability of the health care service may be enhanced by staff training in interpersonal communication and the sensitive handling of patients and family members. Relationship strengthening between health workers and the community and increasing Health worker compassion were noted by NGT participants as worthy interventions. It would be worth investigating how this could be achieved in our area, examples include compassionate care training.^{(54,}

Summary of recommendations

1. Affordability

- Transport vouchers
- NHI to bridge gap between public and private health care costs
- Appointments and longer clinic hours to prevent loss of earning

2. Acceptability

- Staff training on management of people in emotionally charged environments
- Appointments to reduce waiting times
- Training of all workers including security, clerical and healthcare workers in compassionate care.

3. Access

- Community interventions to reduce crime and improve safety
- Longer clinic working hours
- Translation services
- Transport solutions – ambulance partnerships, vouchers
- Improved social capital – people available to safely care for children when parents are working
- Increased PHC spend to improve capacity at facilities

4. Availability

- Clinic hours adjustment

5. Household Factors

- CHWs to do more home visits and educate on home care of illness
- Education via media platforms
- Publication of emergency numbers - 112

6. Facility factors

- Increase scope of work of CHW to include vitamin A administration, deworming; to reduce burden on facilities

Broad recommendations

- MWCAN to focus on respiratory illnesses
- Implement levels of training and remuneration for CHWs
- Electronic registers for improved data collection and improving triage consistency
- Standardization of process of dead-on-arrival children across health care facilities

Further studies

- Assess to improve Facility preparedness to handle emergencies
- Artificial intelligence (AI) to assist with efficient allocation of resources
- Investigate the impact of communication of non-medical staff with patients on health care
- Intervention planning studies such as determining if increasing CHWs (reduced CHW to household ratio) reduces mortality and improves knowledge or household care for children.

495 ⁵⁵⁾ Training could include using a calm tone of voice, listening to the complaints and concerns and having methods to defuse a situation. Both clinical and non-clinical staff should be trained in this regard. Family friendly methods of accessing care should be sought e.g. family-orientated clinics and / or clinics available after hours for working care givers.

3. Access and 4. Availability

500 A community based ambulance service would be a logical expansion of the fledgling Emergency First Aid Responder⁽⁵⁶⁾ (EFAR) program within the community, an asset to fulfilling this role. EFARs could assist with basic home care, directing the ambulance to the location when called and to ascertain if an ambulance is really warranted. Strategies to address language barriers such as on-site translators or 24-hour access to the folio translation service are needed. High crime rates require community-wide interventions such as community policing, community development and employment projects. FBH is the only 24-hour facility in the far South. Extended opening hours at local PHC services will improve the availability of services and may overcome some transport barriers.

5. Household factors

510 CHWs should focus on health promotion and education for appropriate health seeking behaviours. WBOTs should utilize profile mapping in order to focus resources on high-risk families. Health education at multiple levels is needed. This will include community health promotion, education at primary and high schools, using social media, radio and television; and educating pregnant women and parents to recognize when a child is sick and what home care can be provided. Improved community-based services that include frequent home visits and health education will help overcome knowledge gaps in home care for common illnesses.

Broad recommendations

520 It is also recommended that the Maternal, Women, Child, Adolescent and Neonate (MWCAN) forum gives as much attention to respiratory illnesses in children now as it did with diarrhoeal diseases over the past decade. This is imperative given the findings of higher death rates from respiratory illnesses rather than gastroenteritis in this as well as other studies. While no consensus was obtained in the NGT it was felt that PHC could be enriched by a full COPC approach. Home visits by the CHWs could relieve factors of knowledge and home care and thus improve child health literacy.⁽⁵⁷⁾ This however mammoth task falls to the already over-stretched community-based services.^(15, 17, 58, 59) The importance of primary and then secondary prevention needs to be stressed. 525 It would be of great benefit to our communities to increase the number of community health workers. These workers are only paid minimal wage and have only a basic education in health care. We

530 recommend standardisation of training and tiered remuneration progression as further training is completed. This model has been met with success at Philani⁽⁶⁰⁾ a local NGO active in the Western Cape for more than 40 years. The training of community-based workers under different NGO's is often disparate thus standardisation of the CHW curriculum is needed.⁽⁶¹⁾

535 When compiling the interviewee list, we observed that not all dead-on-arrival children were captured on emergency registers – files sent to the mortuary were returned to FBH. This highlights the need for a standard operating procedure across all the services regarding facility level data capturing. At the time of the study, FBH used a paper-based register system. Advances in technology such as the HECTIS system (electronic triage and emergency record keeping for emergency centers with electronic prompts for SATS data to be imputed) used at other hospitals in the metro have the potential to improve data capturing and reduce triage errors.

540 Our findings should lead to policy considerations and discussions relating to how staff across the board relate to the patients and handle difficult situations. Research into implementing solutions is needed. Further research should focus on potentially reducing out of hospital deaths through improved CBS e.g. reducing the CHW to household ratio to improve education and improved home care of sick children. These measures are encouraged by the 1st 1000 days program and COPC and PHC policies. The PHC budget needs to be increased and studies should examine whether
545 there is a relationship between child mortality and number of homes each community health worker visits.

Technologies including Artificial intelligence could be studied to determine more effective ways of utilising current resources. Having an ambulance base in the far south could influence ambulance availability. A 24-hour CHC facility within the far south is important for improving access to care.
550 Although not addressed by our study, it is likely that providers have lower confidence in handling paediatric emergencies due to seeing them infrequently (average two per month), which is consistent with a recent publication by Amien⁽⁶²⁾ et al. This confidence in handling emergencies could be addressed with manikin-based simulation trainings on a regular basis, although further study to address this is needed.

555 Local assets and changes suggested in this study should however be investigated further to reduce mortality in line with the Western Cape Provincial department of health plan.^(28, 30) The SDH are known; they affect Masiphumelele and the far south in the same ways as the rest of the country and globally. Health systems need to be strengthened through COPC and reduction of the SDH to achieve the SDGs.⁽⁶³⁾

560

Limitations

The study faced a number of constraints. A potential limitation was the interpretation of data represented in other languages however translators were used to ensure the integrity of the data.

565 Not all registers or files were available and triaging errors excluded some potential interviewees. Not all potential interviewees meeting criteria for interview were contactable, this could introduce bias as those who are uncontactable may experience more barriers to accessing care. Interviews were conducted by a trained research assistant with counselling experience; however, some interviews were more structured and some more semi-structured reflecting educational and language difficulties in the interviews. This was however not felt to detract from the quality of the data and did not impact on saturation of themes. A potential bias of qualitative data collection and representation is the subjective views of the researcher being incorporated into data through suggestive questioning or selective quotation. This was mitigated however by the electronic recording of all responses which were transcribed verbatim. All transcripts were reviewed by multiple researchers and comparison made to confirm themes represented to ensure credible, dependable and reliable 570 representation of the data. Member checking was not done and those interviewed were not contacted again to confirm what they said or if they were happy with the transcripts.

The presence of a representative from emergency medical services and a nursing sister in charge of Masiphumelele clinic in NGT would have strengthened the results. These key stakeholders will be engaged in implementing recommendations. Due to restrictions imposed during the Coronavirus pandemic, in-person voting and prioritisation (stage 5) did not take place at a follow-up meeting. 580 These were replaced by ranking and voting by email and did not include the whole group – a further limitation. Despite the constraints forcing a modification of the NGT, generation of ideas (stages 3 and 4) in response to the question posed was ensured.

The constraints notwithstanding, a strength of the study is the inclusion of caregivers', community and providers' voices that also permitted triangulation and integration of data. 585

Conclusion

Solutions proposed by the NGT present a strong voice for change e.g. transport solutions, CBS solutions and facility based solutions. Ultimately there are already good solutions that exist with the commitment to improve PHC, COPC and the 1st 1000 days program. The implementation, however, 590 needs to be upscaled and more uniformly applied. The study results suggest an association between poor caregiver care at home for sick children combined with barriers to health care access and the higher childhood mortality in the out-of-hospital group in this sub-district. The solutions offered by the providers could be a springboard for more research as well as community and Government led change to reduce under 5 mortality. This will require a well-coordinated effort 595

emphasizing health promotion and prevention and improving emergency medical services through PHC utilizing a COPC approach. The barriers highlighted in this study are likely to reflect those in the rest of South Africa, however solutions need to be locally designed and involve the participation of all key stakeholders (a COPC approach). This approach may be the most cost effective as it involves the strengthening and utility of existing community assets and programs rather than the design of new services. Health care planners should examine the barriers within their geographic areas of responsibility to determine the best way forward to reduce childhood out of hospital deaths. The study findings are based on the experiences of users and providers of child health services and concur with other studies locally and internationally. They suggest that existing PHC, COPC and 1st 1000 days policies have not been adequately implemented. Further studies are needed to assess this as well as the assessment of facility preparedness to deal with childhood emergencies; equitable allocation of resources; the assessment of staff attitudes as well as research into the effects of improving community health worker to population ratio.

Authors information

615 Authors: Main author: LP did final study design and oversaw the research doing collection with research assistants and did analysis of data and write up. This study was done as part of a degree program (MMed in Family Medicine). BVS, LR, and GB assisted with study design, GB also assisted by training LBP in Nominal group technique. GB, LR and BVS assisted with editing of the manuscript.

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Disclaimer

635 The research and paper is the work and opinion of the researchers only. The research findings and recommendations do not represent an official view of the City of Cape Town, the Western Cape Government Health and Wellness or the University of Cape Town.

1. Källander K, Counihan H, Cerveau T, Mbofana F. Barriers on the pathway to survival for children dying from treatable illnesses in Inhambane province, Mozambique. *Journal of global health*. 2019;9(1).
- 640 2. Mortality rate, under-5 (per 1,000 live births) Online: The World Bank Group; [updated 2021. World Bank]. Available from: <https://data.worldbank.org/indicator/SH.DYN.MORT>.
3. Price J, Lee J, Willcox M, Harnden A. Place of death, care-seeking and care pathway progression in the final illnesses of children under five years of age in sub-Saharan Africa: a systematic review. *Journal of global health*. 2019;9(2).
- 645 4. (UN UNI-aGfCME, IGME). Levels & Trends in Child Mortality: Report 2019, Estimates developed by the United Nations Inter-agency Group for Child Mortality Estimation. New York, USA: United Nations Children's Fund; 2019.
5. Nations U. Sustainable Development Goals [Available from: <https://www.un.org/sustainabledevelopment/sustainable-development-goals/>].
6. Way C. Millennium development goals report 2015, United Nations 2015 24/7/2019. Available from: [https://www.un.org/millenniumgoals/2015_MDG_Report/pdf/MDG%202015%20rev%20\(July%201\).pdf](https://www.un.org/millenniumgoals/2015_MDG_Report/pdf/MDG%202015%20rev%20(July%201).pdf).
- 650 7. Sachs JD. From millennium development goals to sustainable development goals. *The Lancet*. 2012;379(9832):2206-11.
8. Thornton RL, Glover CM, Cené CW, Glik DC, Henderson JA, Williams DR. Evaluating strategies for reducing health disparities by addressing the social determinants of health. *Health Affairs*. 2016;35(8):1416-23.
- 655 9. Armah-Attoh D, Selormey E, Houessou R. Despite gains, barriers keep health care high on Africa's priority list. 2016.
10. O'Donnell O. Access to health care in developing countries: breaking down demand side barriers. *Cadernos de saude publica*. 2007;23(12):2820-34.
- 660 11. Loganathan T, Rui D, Ng C-W, Pocock NS. Breaking down the barriers: Understanding migrant workers' access to healthcare in Malaysia. *PloS one*. 2019;14(7):e0218669.
12. Rees CP, Hawkesworth S, Moore SE, Dondeh BL, Unger SA. Factors affecting access to healthcare: an observational study of children under 5 years of age presenting to a rural Gambian Primary Healthcare Centre. *PloS one*. 2016;11(6).
- 665 13. Africa SS. Under Five Mortality Rate, Findings from Census 2011 and other data sources. Pretoria, South Africa; 2019. Contract No.: ISBN 978-0-621-47086-2.
14. Mbombo NE, B. Western Cape Department of Health Annual Performance Plan 2019/20 2019 [07/09/2019]. Available from: https://www.westerncape.gov.za/assets/departments/health/app_2019-2020_19022019.pd.
15. Doherty T, Kroon M, Rhoda N, Sanders D. Ending preventable child deaths in South Africa: What role can ward-based outreach teams play? *South African Medical Journal*. 2016;106(7):672-4.
- 670 16. Hendricks MK. Child Death Review, Metro West:2016-2017. [presentation at Southern ISDMT]. In press 2019.
17. Doherty T, Kroon M, Rhoda N, Sanders D. Child mortality in South Africa: Is the Sustainable Development Goal (3.2) target achievable with current efforts? *SAMJ: South African Medical Journal*. 2018;108(10):795-.
18. Reid AE, Hendricks MK, Groenewald P, Bradshaw D. Where do children die and what are the causes? Under-5 deaths in the Metro West geographical service area of the Western Cape, South Africa, 2011. *South African Medical Journal*. 2016;106(4):359-64.
- 675 19. Waldmann R, Survival BSfIC, Bartlett AV, Campbell CC, Steketee RW. Overcoming remaining barriers: the pathway to survival: BASICS; 1996.
20. Price J, Willcox M, Dlamini V, Khosa A, Khanyile P, Seeley J, et al. Care-seeking during fatal childhood illness in rural South Africa: a qualitative study. *BMJ open*. 2021;11(4):e043652.
- 680 21. Hodkinson P, Argent A, Wallis L, Reid S, Perera R, Harrison S, et al. Pathways to care for critically ill or injured children: a cohort study from first presentation to healthcare services through to admission to intensive care or death. *PloS one*. 2016;11(1):e0145473.
22. Jones CH, Ward A, Hodkinson PW, Reid SJ, Wallis LA, Harrison S, et al. Caregivers' experiences of pathways to care for seriously ill children in Cape Town, South Africa: a qualitative investigation. *PloS one*. 2016;11(3).
- 685 23. Bank W. Current health expenditure (% of GDP) 2020 [Available from: https://data.worldbank.org/indicator/SH.XPD.CHEX.GD.ZS?name_desc=false].
24. Statista. Health expenditure as a percentage of gross domestic product in selected countries in 2018: Statista; 2019 [Available from: <https://www.statista.com/statistics/268826/health-expenditure-as-gdp-percentage-in-oecd-countries/>].
- 690 25. Mayosi BM, Benatar SR. Health and health care in South Africa—20 years after Mandela. *New England Journal of Medicine*. 2014;371(14):1344-53.
26. Starfield B. Is primary care essential? *The lancet*. 1994;344(8930):1129-33.

27. Longlett SK, Kruse JE, Wesley R. Community-oriented primary care: historical perspective. *The Journal of the American Board of Family Practice*. 2001;14(1):54-63.
- 695 28. Government WC. First 1000 days: Grow, love and play 2019 [Available from: <https://www.westerncape.gov.za/first-1000-days/>].
29. Massyn N PY, Padarath A, editors. District Health Barometer 2017/18. Durban, South Africa: Health Systems Trust; 2019 January 2019.
30. Perez G CK, Engelbrecht EH. Cape Metro District Health Plan 2018/9-2020/21. 2018.
- 700 31. Wege MPISRCCsH. 2019.
32. trust FBh. Learn more about False Bay Hospital Online: False bay hospital tust; 2021 [20/11/2021]. Available from: <https://fbht.org/false-bay-hospital/>.
33. Hope L. Who we are Online: Living Hope; [Available from: www.livinghope.co.za].
34. Moya Eybers HoMaE, SHAWCO Health. Data from Masi. In: Profitt L, editor. email ed2021.
- 705 35. LLC MTI. Sample Size Calculator online: Maple Tech International LLC; [Available from: <https://www.calculator.net/sample-size-calculator.html?type=1&cl=95&ci=10&pp=80&ps=10000&x=74&y=23>].
36. Twomey M, Cheema B, Cohen K, de Sa A, Louw P, Ismail M, et al. Vital signs for children at triage: a multicentre validation of the revised South African Triage Scale (SATS) for children. *South African Medical Journal*. 2013;103(5):304-8.
- 710 37. Van de Ven AH, Delbecq AL. The nominal group as a research instrument for exploratory health studies. *American journal of public health*. 1972;62(3):337-42.
38. D'Ambruoso L, Kahn K, Wagner RG, Twine R, Spies B, Van Der Merwe M, et al. Moving from medical to health systems classifications of deaths: extending verbal autopsy to collect information on the circumstances of mortality. *Global health research and policy*. 2016;1(1):2.
- 715 39. Baiden F, Bawah A, Biai S, Binka F, Boerma T, Byass P, et al. Setting international standards for verbal autopsy. *SciELO Public Health*; 2007. p. 570-1.
40. Health Do. Road to Health Booklet. In: Health, editor. 2018.
41. Chun Tie Y, Birks M, Francis K. Grounded theory research: A design framework for novice researchers. *SAGE open medicine*. 2019;7:2050312118822927.
- 720 42. Clandinin DJ. *Handbook of narrative inquiry: Mapping a methodology*: Sage Publications; 2006.
43. Apalata T, Kibiribiri ET, Knight S, Lutge E. Refugees' perceptions of their health status & quality of health care services in Durban, South Africa: A community-based survey. Durban, South Africa 2007.
44. Government SA. Social relief of Distress Coronavirus COVID-19 lockdown online: Government of South Africa; 2022 [Available from: <https://www.gov.za/services/social-benefits/social-relief-distress>].
- 725 45. Organization WH. Diarrhoeal disease online2017 [13/12/2021]. Available from: <https://www.who.int/news-room/fact-sheets/detail/diarrhoeal-disease>.
46. Geldsetzer P, Williams TC, Kirolos A, Mitchell S, Ratcliffe LA, Kohli-Lynch MK, et al. The recognition of and care seeking behaviour for childhood illness in developing countries: a systematic review. *PloS one*. 2014;9(4):e93427.
- 730 47. Argent AC. From home to definitive care for critically ill children: Barriers and solutions. *Current Treatment Options in Pediatrics*. 2015;1(2):119-31.
48. Fenny AP, Asante FA, Arhinful DK, Kusi A, Parmar D, Williams G. Who uses outpatient healthcare services under Ghana's health protection scheme and why? *BMC health services research*. 2016;16(1):174.
49. Lungu EA, Biesma R, Chirwa M, Darker C. Healthcare seeking practices and barriers to accessing under-five child health services in urban slums in Malawi: a qualitative study. *BMC health services research*. 2016;16(1):1-11.
- 735 50. Meyer-Weitz A, Asante KO, Lukobeka BJ. Healthcare service delivery to refugee children from the Democratic Republic of Congo living in Durban, South Africa: a caregivers' perspective. *BMC medicine*. 2018;16(1):1-12.
51. Siedner MJ, Kraemer JD, Meyer MJ, Harling G, Mngomezulu T, Gabela P, et al. Access to primary healthcare during lockdown measures for COVID-19 in rural South Africa: an interrupted time series analysis. *BMJ open*. 2020;10(10):e043763.
- 740 52. Akuaake LM, Hendrikse C, Spittal G, Evans K, Van Hoving DJ. Cross-sectional study of paediatric case mix presenting to an emergency centre in Cape Town, South Africa, during COVID-19. *BMJ paediatrics open*. 2020;4(1).
53. Murray J vSB, Wessels T, Shand L, Morden E, Rahim S, Shung-King M & Hendricks M. . Disruption of routine health services. Cape Town: Children's Institute, University of Cape Town. 2021.
- 745 54. Scarlet J, Altmeyer N, Knier S, Harpin RE. The effects of Compassion Cultivation Training (CCT) on health - care workers. *Clinical Psychologist*. 2017;21(2):116-24.
55. Ling D, Petrakis M, Olver JH. The use of common humanity scenarios to promote compassion in healthcare workers. *Australian Social Work*. 2021;74(1):110-21.

56. EFAR. EFAR Emergency First Aid Responder [Webpage]. online [Available from: <https://www.efarsystem.com/>].
- 750 57. Velardo S, Drummond M. Emphasizing the child in child health literacy research. *Journal of Child Health Care*. 2017;21(1):5-13.
58. McKerrow N, Doherty T, Coetzee M, Bezuidenhoutd NNM, Rispele L. Building a workforce for a child-and family-centred health service. *Child and adolescent health*. 2019:200.
- 755 59. Padayachee T, Chetty N, Matse M, Mampe T, Schneider H. Progress in the establishment of Ward-based Outreach Teams: experiences in the North West Province. *South African health review*. 2013;2013(1):73-9.
60. The mentor mother programme online: Philani; 2014 [Available from: <http://www.philani.org.za/what-we-do/the-mentor-mother-programme/>].
61. Naidoo D, Govender P, Naidoo S. Community healthcare worker response to childhood disorders: Inadequacies and needs. *African Journal of Primary Health Care and Family Medicine*. 2019;11(1):1-10.
- 760 62. Amien N, Bresick G, Evans K. Preparedness for paediatric cardiopulmonary resuscitation amongst medical doctors working in primary health care facilities in Cape Town, South Africa. *South African Family Practice*. 2022;64(1).
63. Travis P, Bennett S, Haines A, Pang T, Bhutta Z, Hyder AA, et al. Overcoming health-systems constraints to achieve the Millennium Development Goals. *The Lancet*. 2004;364(9437):900-6.