

ORIGINAL ARTICLE

QUALITY OF COMPASSIONATE CARE AMONG CHILDREN WITH CHRONIC HEART FAILURE AT TIKUR ANBESSA SPECIALIZED HOSPITAL: A CROSS-SECTIONAL ANALYSIS

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ABSTRACT

Background: Compassion is a deep awareness of the suffering of another coupled with the wish to relieve it. Heart failure/HF is a progressive clinical and pathophysiological condition caused by cardiovascular and noncardiovascular abnormalities. The study aimed to assess compassionate care among children with chronic HF at Tikur Anbessa Specialized Hospital.

Methods: This observational cross-sectional study employed an Amharic 12-item Schwartz Center Compassionate Scale (SCCS) to assess compassionate care. Children aged 7 years and above were included in the study. Logistic regression models were used to assess predictors.

Results: The study included 155 chronic HF subjects, females 56.1% (87). Majority of the respondents, 75.5% (117), lived in an urban setting within 100-kilometers from health facility, 58.7% (91). The mean age at diagnosis and duration of follow-up was 5.2±3.8 years and 5±3.5 years, respectively. Congenital heart diseases, 55.5% (86) and rheumatic heart disease, 36.1% (56) were common causes for chronic HF. Successful compassionate care was reported in 25.2% (39) (95% CI: 18.5-32.8) of study subjects. Study subjects who lived within 100-kilometers from the follow up health facility had two times higher odds of reporting successful compassionate care, [AOR: 2.24, 95% CI: 1.06-4.75, P 0.035]

Conclusion: In this study, only one fourth of study subjects with chronic heart failure had received compassionate care. Distance from the follow up health facility predicted successful compassionate care. Modalities to improve access including decentralization of clinical services for children with chronic heart failure and further mixed studies are recommended to assess how distance from a health facility relate to compassionate care.

Keywords: compassion, compassionate care, Children, heart failure, chronic heart failure, Ethiopia

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Background

Compassion is a deep awareness of the suffering of another coupled with the wish to relieve it (1). The World Health Organization (WHO) has put it as a measure of a patient-centered quality of health care services (2). Ethiopia took compassion and compassionate care as a pillar of quality of health care services in the aim of achieving universal health coverage (3-5). Compassionate care has been shown to reduce patient anxiety, improve patient-physician communication, increase patient sense of responsibility/adherence, and patient trust on health professionals (6-10).

Lack of pre-service training on compassionate care for health professionals; lack of time, support and resource in the health system; clinician burnout, high case load; and patient factors like age were documented as barriers for compassionate care (9). Assessment of compassionate care in the health care has been challenged by the difference in culture, religion, health care setting and competency of the health professionals (11). Patient compassionate care assessment tool was developed to assess compassionate care among cancer patients with advanced disease and palliative care recipients (12, 13). Nursing care compassionate care assessment tool in acute care was developed as another compassionate care assessment tool (14). The 12-item Schwartz Center Compassionate Scale (SCCS) was developed to measure patient assessment of a care provided by physicians (11). SCCS tool is con-

sidered a reliable and valid measure of patients' perceptions of compassionate health care of physicians and the healthcare team. The items were developed by a group of people from patients, family members, policy-makers, and advocates and finally adapted through a focus group discussion with patients, physicians, and nurses. Patients complete the items of the tool using a ten-point scale from 1 (not at all successful) to 10 (very successful) (11,15). Amharic version was prepared and validated for clinical use in Ethiopia (16).

Heart failure/HF is a progressive clinical and pathophysiological condition caused by cardiovascular and noncardiovascular abnormalities. It usually culminates with cardiac dilation, thinning of walls and dysfunctional contractility (17). Common causes of HF in children include structural heart diseases and infectious diseases (18,19). Ethiopian studies documented structural heart diseases, congenital heart disease or rheumatic heart disease, as a common cause of childhood HF (20,21). Severity of HF is graded clinically into four based on modified Ross or New York Health Association (NYHA) Classification with class I and IV representing mild and severe symptoms, respectively (22, 23). HF management includes correction of the underlying cause and precipitant factors (24). As opposed to western settings, patients in sub-Saharan Africa depend on mission-based volunteerism and correction of an underlying cause for HF is

not readily available (25). To the best of our knowledge, there are no studies that assessed compassionate care among children with chronic heart failure. This study aimed at assessing compassionate care among children with chronic heart failure and limited access to definitive care in a national tertiary cardiac referral hospital for Ethiopia.

Methods

Study Setting

The study was conducted in Tikur Anbessa Specialized Hospital (TASH), Addis Ababa, Ethiopia. It is the teaching hospital of Addis Ababa University, College of Health Sciences, and School of Medicine. It is also the national referral hospital in Ethiopia with multiple specialties and sub-specialties. Pediatric cardiac clinic provides follow up for outpatient care of pediatric patients with congenital and acquired cardiac problems. It gives service on all of the five working days. The clinic is attended by consultant pediatric cardiologists, pediatric cardiology fellows, pediatric residents and trained nurses. Based on the clinic registry, there were 258 children between the ages of 7 and 18 years with chronic heart failure enrolled in the follow up.

Study population

All children aged 7 years and above with chronic heart failure and attending follow up at the pediatric cardiology clinic during the study period.

Study Design and Study Period

The study used cross-sectional study design

during the periods of March and September 2022.

Sample size and sampling procedure

A sample size of 155 was calculated with correction formula for finite population using EPI info version 7 statistical packages for sample size and power calculation taking an assumption of successful compassionate care among HF patients as 50%, 95% confidence level with 5% margin of error and a power of 80%. Proportion of 50% was used due to lack of previous local or international study on compassionate care among children with HF.

Inclusion and Exclusion Criteria

All children aged 7 years and above with NYHA II and above functional status with established echocardiographic diagnosis and enrolled in chronic care for over 6 months were included. Study subjects with developmental issues like cerebral palsy and Down syndrome were excluded as these limit their ability to self-report compassionate care.

Data collection

Demographic and clinical data were collected using structured questionnaire which was pre-tested in non-participating patients. Compassionate care was assessed using an Amharic validated 12-item Schwartz Center Compassionate Scale (SCCS), the only validated tool in Ethiopia. SCCS tool is considered a reliable and valid measure of patients' perceptions of compassionate health care of physicians and the healthcare team. The items were developed by a group of people from patients,

family members, policymakers, and advocates and finally adapted through a focus group discussion with patients, physicians, and nurses. Patients complete the items of the tool using a ten-point scale from 1 (not at all successful) to 10 (very successful) (11, 15). It was tested and used in many parts of the world, and an Amharic version was prepared and validated for clinical use in Ethiopia (16). Clinical and sociodemographic data were collected using pre-tested questionnaire by BSc Nurses, and one-day training was given by the investigators. The quality of daily collected data was checked by investigators.

Variables

The dependent variable was compassionate care assessment scale. Age, sex, place of residence, educational status, family size, age at diagnosis of cardiac disease, type of heart disease, frequency of follow up, duration of follow up, pill burden, NYHA status, distance from the follow up health facility, health cost coverage and any surgery/intervention for cardiac illness were independent variables.

Operational definitions

NYHA functional status was a functional classification of study subjects according to cardiac functional capacity using the New York Health Association at the time of data collection (23). Chronic heart failure was considered by the presence of class II and above NYHA symptoms that lasted for over six months. Compassionate care was a deep awareness of the suffering of another coupled with the wish

to relieve it (1). Successful compassionate care was considered when a total score of 10 was obtained on SCCSS scale while unsuccessful for the rest of the summation points. Compassionate care assessment scale is a score that a study subject puts in 1-10 rated scale about how the health care providers were treating him or her as assessed by the 12-item Schwartz Center Compassionate Scale (SCCSS) (15).

Data analysis

After checking for data completeness analysis was done using statistical software for social sciences 25. Univariate association with dependent variable was assessed using chi-square test. Variables with p value less than 0.05 were selected for final multivariable logistic regression model to ascertain association. Previously studied variables (age, sex, education, and frequency of follow up) in relation to patient self-report of compassionate care were also included in the final model (26, 27). P value less than 0.05 was taken as statistically significant and association was reported using odds ratio with its 95% confidence interval.

Results

Sociodemographic characteristics and compassionate care among children with chronic heart failure

A total of 165 patients were approached and ten were excluded (one had cerebral palsy while 9 had clinical evidence of Down syndrome). Finally, 155 study subjects, between

the ages of 7 and 18 years, were included in the study. The mean age of study subjects was 11.4 ± 2.6 years. Females dominated the study population, 56.1% (87). Almost half of study subjects resided in the study area, 48.4% (75). Majority of the study subjects came from an urban setting, 75.5% (117). About sixty percent, 58.7% (91), lived within 100-kilometers from the follow up health facility. The most

distant residing subject came from 800-kilometers.

Concerning education, majority were enrolled in primary education, 92.9% (144). Majority lived in a family size of ≤ 5 , 58.1% (90). Concerning health related costs, 58.1% (90), were medically insured. (See Table 1).

Table 1. Sociodemographic profile of children with chronic heart failure having follow-up at Tikur Anbessa Specialized Hospital, 2022

Variable	Category	Number	Percentage (%)
Age (in years)	7-10.9	68	43.9
	11-18	87	56.1
Gender	Male	68	43.9
	Female	87	56.1
Place of residence	Urban	117	75.5
	Rural	38	24.5
Distance from follow up health facility (kilometers)	≤ 100	91	58.7
	> 100	64	41.3
Educational level	Primary school	144	92.9
	Secondary school	11	7.1
Family size	≤ 5	90	58.1
	> 5	65	41.9
How is your health cost covered?	Out of pocket payment	65	41.9
	Medically insured	90	58.1

There was no difference between boys and girls in terms of report of successful compassionate care. Moreover, no association was documented between successful compassionate care and sociodemographic variables (age,

place of residence, educational status, family size, and access to health insurance). However, distance from the follow-up health facility showed association with successful compassionate care. (See Table 2)

Table 2. Univariate analysis outputs of variables about successful compassionate care provided for pediatric chronic heart failure patients at Tikur Anbessa Hospital, 2022

Variable	Category	Successful compassionate care		COR (95% CI) P value
		Yes	No	
Age (in years)	7-10.9	15	53	0.74(0.35-1.56), 0.43
	11-18	24	63	1
Sex	Male	18	50	1.13(0.55-2.35), 0.74
	Female	21	66	1
Residence	Urban	25	92	0.47(0.21-1.03), 0.06
	Rural	14	24	1
Family size	≤5	18	72	0.52(0.25-1.09), 0.08
	>5	21	44	1
Age at diagnosis (years)	≤5	18	68	0.61(0.29-1.26), 0.18
	>5	21	48	1
Duration of follow up	≤5	21	66	0.88(0.43-1.83), 0.74
	>5	18	50	1
Type of heart disease	Congenital heart disease	18	68	0.61(0.29-1.26), 0.18
	Rheumatic heart disease or others	21	48	1
How is your health cost covered?	Out of pocket payment	15	50	0.83(0.39-1.73), 0.61
	Medically insured	24	66	1
Frequency of follow up	Monthly/every two month	16	43	1.18(0.56-2.48), 0.66
	Every three/six month	23	73	1
Cardiac oral medications/ pill burden	Multiple	27	75	1.23(0.56-2.68), 0.60
	Single or none	12	41	1
NYHA functional class	II	17	66	0.59(0.28-1.22), 0.15
	III or IV	22	50	1
Distance from health facility (kilometers)	≤100	17	74	0.44(0.21-0.92), 0.03*
	>100	22	42	1
Education status	Primary	37	107	1.56(0.32-7.53), 0.58
	High school	2	9	1
Any surgery or intervention?	Yes	2	18	0.29(0.07-1.33), 0.11
	No	37	98	1

Clinical characteristics and compassionate care among children with chronic heart failure

More than half of the study subjects had congenital heart disease as a cause for chronic heart failure, 55.5% (86); rheumatic heart disease contributed to 36.1% (56) of study subjects. From congenital heart disease, acyanotic form predominated 36.1% (56). The mean age at diagnosis of an underlying cardiac disease was 5.2 ± 3.8 yrs. Majority of study subjects were on every three months follow up visit schedule, 51.6% (87). The mean duration of follow up was 5 ± 3.5 yrs.

Concerning associated comorbidity, only 7.1% (11) had associated comorbidity. All rheumatic heart disease subjects, 36.1 % (56), were on benzathine penicillin secondary prophylaxis. Majority of the study subjects were on multiple cardiac oral medications, 65.8% (102), at the time of study. A little over one tenth of the subjects, 12.9% (20), had surgery or intervention for their underlying cardiac illness. Successful compassionate care was reported by 25.2 % (39) (95% CI: 18.5-32.8) of study subjects. (See Table 3)

Table 3. Clinical characteristics and compassionate care among children with chronic heart failure at Tikur Anbessa Specialized Hospital, 2022

Variable	Category	Number	Percentage (%)
Underlying heart disease	Congenital heart disease	86	55.5
	Rheumatic heart disease	56	36.1
	Dilated cardiomyopathy	3	1.9
	Others	10	6.5
Age at diagnosis of underlying cardiac illness (in yrs)	≤1	36	23.2
	1-5	38	24.5
	≥5	81	52.3
Frequency of follow up	Monthly	20	12.9
	Every two month	39	25.2
	Every three month	80	51.6
	Every six month	16	10.3
How long have you been in the follow up? (years)	≤5	87	56.1
	>5	68	43.9
NYHA functional class status	II	83	53.5
	III	68	43.9
	IV	4	2.6
Cardiac oral medications/ pill burden	Single	12	7.7
	Multiple	102	65.8
	None	41	26.5
Any surgery or intervention for underlying heart condition?	Yes	20	12.9
	No	135	87.1
Successful compassionate care	No	116	74.8
	Yes	39	25.2

No association was documented between successful compassionate care and duration of follow up, frequency of follow up, type of heart disease, pill burden, NYHA class, any surgery or intervention for underlying heart disease (See Table 2)

Factors associated with successful compassionate care among children with chronic heart failure

Study subjects who lived within 100-kilometers from the follow up health facility had two times higher odds of reporting successful compassionate care, aOR 2.24(95% CI: 1.06-4.75, P 0.035). Age, sex, educational status and frequency of follow up didn't show any association with successful compassionate care. (See Table 4)

Table 4. Factors associated with successful compassionate care among children with chronic heart failure at TASH, 2022

Variable	Category	Compassionate care		COR (95% CI), P value	AOR (95% CI), P value
		Yes	No		
Age (in years)	7-10.9	15	53	0.74(0.35-1.56), 0.43	1.37(0.63-2.99), 0.429
	11-18	24	63	1	1
Sex	Male	18	50	1.13(0.55-2.35), 0.74	0.89(0.42-1.89), 0.768
	Female	21	66	1	1
Education status	Primary	37	107	1.56(0.32-7.53), 0.58	0.49(0.09-2.54), 0.400
	High school	2	9	1	1
Distance from health facility (kilometers)	≤100	17	74	0.44(0.21-0.92), 0.03	2.24(1.06-4.75), 0.035*
	>100	22	42	1	1
Frequency of follow up	Monthly/ every two month	16	43	1.18(0.56-2.48), 0.66	0.88(0.41-1.91), 0.749
	Every three/ six month	23	73	1	1

Discussion

In this study, only one fourth of children with chronic heart failure received compassionate care. Majority resided in an urban setting within 100-kilometers from the follow up health facility. Distance from the health facility predicted successful compassionate care.

In the current study, majority came from an urban setting. This is in agreement with previous Ethiopian studies (28, 29). This could be related to improved awareness and health care seeking behavior among urban dwellers compared to rural residents (30). However, this is

as opposed to the higher odds of congenital (31) and rheumatic heart diseases (32) among rural residents. While much is to be studied in a larger scale, a poor chronic follow up attendance of a rural child with heart disease could also signal centralization of the care provision leaving them vulnerable.

In our study, chronic care recipients lived within 100-kilometers from the follow up health facility. This is in agreement with another study (29). While this may be considered as a proxy for service accessibility it must be interpreted in light of the challenge that a child

with chronic heart failure will have to travel long distance for a follow up. Costs related to transportation were also pointed out as a challenge for the child coming from far (33).

No association was documented between age and successful compassionate care in this study. This is in agreement with Ethiopian studies that documented similar finding among older study subjects (26, 27). However, an Egyptian study documented more vigilance of elderly patients on compassionate care provision (34). Comparison of our finding could not be made to similar report due to unavailability of published data among children with cardiac illnesses. Similarly, no association was documented between gender and successful compassionate care in our study. This is similar to another Ethiopian study (27). In our study, education status was not associated with the patient self-report of compassionate care. This is as opposed to another study where educated patients reported low compassionate care from the healthcare providers (26). The noted difference might be due to the difference in the age of study subjects where the later included adults. We report no association between frequency of health visits and compassionate care. However, patients who had three and more health visits had poor compassionate care in another study (26).

Distance from the health facility predicted compassionate in our study. Those who resided within 100-kilometers reported successful compassionate care. Distance from a health

facility was reported as a barrier to child health visits in another study (35). This could be related to indirect health related costs like transportation and foods. Qualitative studies are recommended to assess the details of barriers and facilitators. Modalities of decentralization of pediatric cardiac follow up services should be considered to improve the patient's satisfaction.

The strength of our study included use of an Amharic compassionate care assessment tool that is approved for use among patients with chronic illness, collection of sociodemographic and clinical variables on prospective basis. However, our study is not without limitation. First, it is a single center study. Second, we didn't include qualitative assessment. Thirdly, we have employed an Amharic tool that was validated among older subjects and that might have an effect in younger subjects. However, our study reports the level of compassionate care and its predictor among school enrolled children in their second decade of life with chronic heart failure. This study helps policy makers to design modalities to decentralize clinical chronic heart failure management services among children including timely attention to access to definitive treatment or interventions. Further multicenter mixed studies will help in formulating and designing health care policy for children with chronic heart failure.

Conclusion

In this study, only one fourth of study subjects with chronic heart failure had received successful compassionate care. Children in the

second decade of life living in an urban setting with structural heart disease (CHD and RHD) dominated. Distance from the follow up health facility predicted report of successful compassionate care. Decentralization of clinical services for children with chronic heart failure and further mixed studies are recommended to assess how distance relate to compassionate care are recommended.

Declarations

Ethical Approval

Ethical clearance was obtained from the Research Ethics Committee, Department of Pediatrics and Child Health, School of Medicine, College of Health Sciences, Addis Ababa University on 16/3/2022 with minute number of DRPC/006/14. Informed written consents from parents of children was obtained. A verbal assent was secured from children between the ages of 12 and 18. Confidentiality of collected data was ensured.

Availability of data

The datasets analyzed during this study are available from the corresponding author on reasonable request.

Authors contribution

HT conceived the idea, wrote the proposal, prepared data collection tool, supervised data collection, analyzed the data, and wrote the manuscript. TM commented on different versions of the proposal and data collection tool, and manuscript.

Competing interests

The authors declare no conflict interests relat-

ed to this manuscript.

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