

Determinants of Home Based Care Program Supports to Hospital Based Care for Children Aged 1-14 years with Chronic and Terminal Illnesses in Meru County Kenya

ABSTRACT

Introduction: Chronic and Terminal illnesses continue to increase and aggravate the burden of disease and the diminish space in our hospitals and communities, Worldwide, 57 million persons died in 2008, an estimated 40 million were in need of HBCP, 6.6 - 10.8 million Children died, 98% Chronic and Terminal illnesses (CI/TI) are found in low and middle-income Countries. Chronic and Terminal illnesses in Children are on the rise in Sub Saharan Africa. Kenya lags in implementation of Home Based Care to mitigate effects of CI/TI. WHO, 2017 and Ministry of Health-Kenya 2013 shows that Children are affected by these Illnesses. These illnesses have made families' to suffer psychosocial and economic hardships. Evaluation of determinants of Home Based Care Program (EHBCP) services by assessing if effective and quality delivery of HBCP Supports Hospital Based Care is key.

Aims: Determine the extent which Home Based Care Program services Support to Hospital Based Care for Children aged between 1-14 years diagnosed with selected Chronic and Terminal illnesses in Meru County Kenya.

Study design: A descriptive Cross Sectional Survey.

Place and Duration of Study: Meru County, Kenya between June 2018 and Dec 2019.

Methodology: Methodology: Descriptive Cross Sectional Survey of 245 Caregivers of Children diagnosed with Chronic and Terminal illness were selected by proportionate to size sampling and simple random sampling from Meru County Health Facilities.

Results: Delivery of quality and effective Home Based Care Program was positively associated with age, return rate of over 100% was achieved with about 245 respondents being interviewed (132%), experience of Health Care Workers (HCWs) 4.8 [95% CI = 1.06 – 21.68, P = 0.041]. HCWs profession, gender and years of work were positively related to Hospital Based Care services 3.03 [95%CI = 1.64 – 5.59, P<0.001]. Use of minimum HBCP package was found to be useful in support of hospital care, as 50.4% reported that its support was of a good or great extent. The trend was observed in all aspects of the minimum HBCP package studied, with 52.4%, 54.4% and 46.4% having the opinion that use of the package by caregivers, in management and mitigation of complications supported hospital care by a good or great extent respectively.

Conclusion: Need for an urgent adoption of holistic approach on health care system strengthening by putting up a well-integrated Home Based Care Program with quality Minimum HBCP essential package to support the mainstream health care system. In addition adopt better management practices, planning strategies, resource allocation and monitoring for effective HBCP programmes as per the current guidelines to bridge the gaps identified in planning, management practices to fill the disjointed policy implementation and resource inadequacies in implementation of HBCP services to support Hospital Based care for ultimate delivery of quality care among the Chronically and Terminally ill Children.

Keywords: *[Determinants, Chronic/Terminal Illnesses, Children, Home Based Care Program, Health Care workers, Supports and Hospital Based Care]*

1.0 INTRODUCTION

According to WHO, Lopez and Mathers [9,25,36], 80% of chronic disease deaths worldwide occur in Lower and Middle Income Countries (LAMICs). In the year 2005, the burden of non-communicable diseases was assessed in twenty three low and middle income Countries and the data shows that they account for 50% of the total disease burden [1,10]. However, in these Countries Chronic diseases and Terminal illnesses develop at an earlier age than in high-income Countries, often resulting in prolonged period of disability before death [1]. In the face of rising health care costs, there is growing interest in moving more patient care out of health facility based Care to Home Based Care settings [10, 22, 42]. These efforts to facilitate effective and quality delivery of child health care or home based care services which enables a larger percentage of Chronically and Terminally ill Children to receive ultimate health care in their homes [9, 15]. As home health care technologies develop, so does the range of Home Based Care Program services and with growing body of evidence suggesting that the location in which Children receive, palliative care has serious implications. When Home Based Care Program services are provided in home based settings, parental satisfaction appears to be high, subsequent adaptation and child health outcomes for parents, relatives, siblings and community drastically improve [9, 20, 21]. The client or a Child who is cared for in a familiar home based environment, usually suffers less stress and anxiety compared to the one in hospital, clinic or nursing home. When people are in a familiar environment their illness is more tolerable and they continue to participate in family matters. Those who are heads of their families continue doing so and can be consulted on various family issues. It is quite difficult when one is in hospital or a clinic to make a decision. When one is at home close to family members, friends and relatives, there is a sense of belonging. This is not the case if one is in a hospital setting where the caregivers are strangers who keep changing with every shift. When one is in close contact with familiar people they are likely to accept their conditions and illnesses. The acceptance contributes to quicker recovery and may assist in better management of the syndrome or any Chronic/Terminal illness [9, 14, 20, 21].

2.0 MATERIALS AND METHODS

This study was conducted in Meru County, between June and September 2019. The study was a descriptive cross-sectional survey. A sample of 245 respondents comprising of the health workers/caregivers were selected using proportional to size, simple random sampling to select the six health facilities across Meru County. Descriptive analysis, multivariate logistic regression, and Odds ratios were pulled from Statistical Package format (IBM SPSS) version 25. Determining the extent to which HBC program services supports Hospital Based Care was used as the dependent variable. Variables such as Provision of Clinical, Nursing services, Minimum essential Package support Hospital Care, Health education and Health Promotion, age, sex, gender, parent/caregiver/guardian age, determinants HBCP support to provision Hospital Based Care, delivery of HBC program services, determinants of HBCP services delivery points, preferred health facilities for provision of Children HBCP services, Socio- economic, Cultural factors, skills, care competences acquired by Health care providers, HBCP caregivers, impact and processed skills reinforcing concepts through quality delivery of Home Based Care were used as independent variables.

2.1 Sampling method

The required sample size was computed using Taro Yamane formula [48], proportion to size of the population was used to estimate the minimum required sample for the study. A sample of 241 caregivers of Children diagnosed with selected chronic and terminal illnesses under Home Based Care Program as respondents was selected.

$$n = \frac{N}{1+N(e)^2}$$

Where:

n = Minimum required sample;
 N = Population size;
 e = Degree of tolerance error; with a significance level put at 95%,
 the degree of error term was 5% (i.e. 0.05). Therefore:

$$n = \frac{611}{1 + 611(0.05)^2}$$

n = 241 hence a Sample size of 241. Adjusting the sample upwards for 10% non-response, the sample is;

$$n_1 = \frac{241}{1 - 0.1}$$

Hence n was 268 respondents. Further, since the target population was less than 10000, the sample size was adjusted downwards using finite population correction factor (f.c.f) as follows;

$$n_{f.c.f} = \frac{n_1}{1 + \frac{n_1}{N}}$$

Where $n_{f.c.f}$ = the minimum desired sample size.

$$n_{f.c.f} = \frac{268}{1 + \frac{268}{611}}$$

$$n_{f.c.f} = 186$$

To ensure that we have a representative sample size, the study utilized proportional to size sampling method with the aid of the proportionality formula was thus used to allocate participants per site:

$$Q = \frac{A}{N} * n \quad \text{Where:}$$

Q = the number of the questionnaire to be allocated to each proportion.

A = the proportion of each segment.

N = the total population of all the segments.

n = the estimated sample size used in the study.

2.2 Data Collection and Analysis

The survey was carried out after thorough evaluation by the Meru University of Science and Technology (MUST) Institutional Research Ethics Review Committee (MIRERC) to ensure compliance to the ethical standards. A structured Likert questionnaire was administered. The questionnaire were pre-tested in neighbouring Tharaka Nithi County at Chuka teaching Referral Hospital. Chuka teaching and Referral Hospital County which borders Meru County. The instruments were tested for reliability and yielded a Cronbach's alpha of 0.75 and therefore considered reliable. The data was entered and analyzed using SPSS Software Version 25. Descriptive analysis, multiple regression, and Odds ratios were pulled with utilization and delivery of HBCP services being the dependent variable. The results were presented using descriptive and inferential statistics.

3.0 RESULTS

3.1 Socio Demographic Characteristics

3.1.1 Gender and Age

Five out of seven demographic factors was positively associated with level of Home Based Care for Children with selected Chronic and Terminal illness, $P < 0.05$. Age category of the participants was significantly associated with increased level of utilization of Home Based Care which has direct bearing to Hospital Based Care. The proportion of participants indicating that utilization of HBCP was good/very good/excellent for Children with CI/TI was observed among participants aged 31 – 40 years and 41 – 50 years compared to participants aged 21 – 30 years while participants aged 31 – 40 years were 63% 0.37 [95%CI = 0.20 – 0.68, $P = 0.001$] less likely to indicate that that the utilization of HBCP was

good/very good/excellent compared to participants aged 21 – 30 years., Likewise, participants aged 41 – 50 years were at 66% 0.34 [95%CI = 0.15 – 0.77, P = 0.010] less likely to indicate that utilization of HBCP was good/very good/excellent compared to participants aged 21 – 30 years. The findings shows that there were equally as many female (49.4%) as there were male (50.6%) respondents included in the study. The results agrees with Muthuri *et al.*,^[31] who found that 61.3% of healthcare workers in both public and private sectors in Meru County were female, although both genders are well represented in employment in the public hospitals.

3.2 Extent to which Home Based Care Program Supports Hospital based Care

The study was to evaluate the extent to which Home Based Care Programs services supports Hospital-Based Care for Children aged between 1-14 years with selected Chronic and Terminal illnesses. Consequently, respondents were asked questions to gauge the extent to which Home Based Care Program supports Hospital-Based Care. Likert scale was used to score the extent to which various aspects of Home-based Care Program supports Hospital Based Care, ranging from 1-5, representing not at all, very little, to some extent, to a good extent and to a great extent.

3.3 Extent of Clinical and Minimum Package Support to Hospital Based Care

Participants exhibited varied responses as to what extent Clinical services support hospital-based care, with majority (38.5%) stating that this aspect of Home-based care supported to a very little extent, 21.5% reported that it supported to some extent, while 29.6% felt that it was supportive to a good and/or great extent. Results presented in Table 1 further showed that Clinical services offered in home-based care did not sufficiently support hospital care, with a mean of approximately 3 (mean=2.86) depicting little support. Pooja *et al.*,^[33] stated that there are a number of challenges that deter clinicians and other health care workers from participating in home-based care, including home visits and management of patient needs at home. This could hint on why the home-based care program seems not to be able to provide support to hospital-based care, especially with poor staffing, according to the Kenya Health workforce report^[21].

Table 1 Extent to which Clinical Services Provision at Home Supports Hospital care

S/No.	Likert Items	1F (%)	2F (%)	3F (%)	4F (%)	5F (%)	Mean
1.	Clinical home visits services	11(8.1)	56(41.5)	27(20)	27(20)	14(10.4)	2.86
2.	Home treatment	14(10.4)	47(34.8)	39(28.9)	18(13.3)	17(12.6)	
3.	Prescription at home	19(14.1)	41(30.4)	31(23)	23(17)	21(15.6)	
4.	Pain management and analgesia services at home	15(11.1)	46(34.1)	34(25.2)	23(17)	17(12.6)	
5.	Physical Assessment	17(12.6)	45(33.3)	25(18.5)	31(23)	17(12.6)	
Extent to which Clinical services provision at home Supports Hospital Based Care score		14(10.4)	52(38.5)	29(21.5)	23(17)	17(12.6)	

Key: Frequency Number (1F, 2F, 3F, 4F and 5F)

3.2 Early Screening and Diagnosis of Chronic and Terminal Illnesses

Findings on early screening and diagnosis indicate that efforts are being made to conduct screening for chronic and terminal illnesses among Children, as majority (36.8%) agreed that screening was conducted to a good extent. It however needs improvement as close to a third (25.6%) felt that very little screening was being conducted while 9.6% felt that it was not being done at all, as illustrated in Table 2. Further, it is evident that early diagnosis of these illnesses contributed substantially in support of hospital-based care, with 48.0% stating a good and/or great extent of support. Fragala *et al.*, [15] noted that early screening and diagnosis enables early detection and prompt treatment of chronic diseases, preventing disease progression. As evident in these findings, the County's health sector is making strides towards this, with majority of the interviewed participants finding it supportive towards hospital care.

Table 2 Early Screening and Diagnosis of Chronic and Terminal illnesses

S/No	Likert Items	1F (%)	2F (%)	3F (%)	4F (%)	5F (%)	Mean
1.	Screening of Children for early detection of chronic and terminal is done	12(9.6)	32(25.6)	27(21.6)	46(36.8)	8 (6.4)	3.14
2.	Early diagnosis of chronic and terminal illness in Children Supports hospital care is done	13(10.4)	20 (16)	32(25.6)	45 (36)	15 (12)	
Early screening and diagnosis of chronic and terminal illnesses score		9 (7.2)	21(16.8)	32(25.6)	44(35.2)	19(15.2)	

Key: Frequency Number (1F, 2F, 3F, 4F and 5F)

3.3.1 The Level of Home Based Care for Children with selected Chronic and Terminal Illness in Relation to Extent of HBCP Support to Hospital Based Care

Two out of six factors on extent of Support to Hospital Based Care were significantly associated with the level of Home Based Care for Children with selected chronic and terminal illness, $P < 0.05$.

Table 3: Home Based Care for Children with selected Chronic and Terminal Illness in Relation to Extent of Clinical Services

Variables	Good/Very Good/ Excellent		Poor/ Fair		OR	95%CI		P-Value
	N	%	n	%		L	U	
Extent to which Clinical services Provision at Home Supports Hospital care								
Not at all/Very little	25	37.9%	41	62.1%	Ref			
Somewhat/Available/To great extent	54	78.3%	15	21.7%	5.90	2.77	12.60	<0.001

Legend: Ref = Reference, OR =Odds Ratio, CI confidence Interval

The extent to which Clinical services are provided at home supports hospital care in table 3 above was significantly associated with level of home based care. High proportion of participants indicating that the level of home based care was good/very good/ excellent was observed among participants who revealed that Clinical services provision at home to support hospital care was somewhat/available/to great extent 54 (78.3%) done compared to participants who revealed that Clinical services provision at home to support Hospital Based Care was not at all/very little 25 (37.9%) done. Participants who revealed that Clinical services provision at home to support Hospital Based Care was somewhat/available/to great extent done were 5.90 [95%ci = 2.77 – 12.60, p < 0.001] times more likely indicate that the level of home based care was good/very good/excellent compared to participants who revealed that it was not at all/very little done.

3.4 Stepwise Multivariate Logistic Regression to Determine the Level of Home Based Care for Children with selected Chronic and Terminal illness

Stepwise multivariable logistic regression was fitted on all significant (P<0.05) factors at bivariate analyses to model factors determining the level of Home Based Care for Children with selected chronic and terminal illness. Backward conditional method was specified and variable removal threshold set at P < 0.05. Four factors were retained in the reduced model after nine iterations were run. Participants who had worked in the health facility for a period of 1 – 3 years were 5.29 [95%CI = 1.45 – 19.34, P = 0.012] times more likely to indicate good/very good/ excellent level of Home Based Care compared to participants who had worked for 7 or more years. Participants who revealed that Clinical services for Children with selected CI/TI were occasionally/frequently/very frequently provided were 5.17 [95%CI = 1.81 – 14.82, P = 0.002] times more likely to indicate good/very good/ excellent levels of Home Based Care compared to participants who revealed that clinical services for Children with selected CI/TI were never/very rarely/rarely provided. Participants who revealed that health education and promotion to Children with selected CI/TI occasionally/frequently/very frequently existed were 5.14 [95%CI = 1.81 – 14.56, P = 0.002] times more likely to indicate good/very good/ excellent levels of Home Based Care compared to participants who revealed that health education and promotion to Children with selected CI/TI never/very rarely/rarely existed. Participants who revealed that clinical services provision at home to support hospital care was somewhat/available/to great extent done were 3.15 [95%CI = 1.13 – 8.75, P =0.028] times more likely indicate that the level of Home Based Care was good/very good/excellent compared to participants who revealed that clinical services provision at home supports Hospital Based Care was not at all/very little done as shown in Table 4 below.

Table 4 Reduced Model of factors Used to Determining the Level of Home Based Care for Children with selected Chronic and Terminal illness

Variables	AOR	95% C.I		P-Value
		Lower	Upper	
Years have you worked in this Health facility				
1 – 3 years	5.29	1.45	19.34	0.012
4 – 6 years	2.03	0.56	7.31	0.278
7 years or more	Ref			
Provision of Clinical services for Children with selected CI/TI				
Never/Very rarely/Rarely	Ref			
Occasionally/Frequently/Very frequently	5.17	1.81	14.82	0.002
Health education and promotion to Children with selected CI/TI				
Never/Very rarely/Rarely	Ref			
Occasionally/Frequently/Very frequently	5.14	1.81	14.56	0.002
Extent to which Clinical services provision at home Supports Hospital care				
Not at all/Very little	Ref			
Somewhat/Available/To great extent	3.15	1.13	8.75	0.028

Legend: Ref = Reference, AOR =Adjusted Odds Ratio, CI confidence Interval

4.0 Discussion

The study involved 245 Health Care Providers and Caregivers of Children diagnosed with selected Chronic and Terminal illnesses and it sought to determine the extent to which Home Based Care Programme Supports Hospital Based Care provide HBCP services for Children aged 1-14 years diagnosed with selected Chronic and or Terminal illnesses by evaluating Essential Home Based Care Program minimum package from selected study Health Care Facilities of Meru County [19].

The 245 Health Care Workers were sampled from one Level 5 Teaching and Referral Hospital and five sub county hospitals with mean age of 34.4± 9.06 (SD). Majority (46.1%) of the study participants were aged between 21 – 30 years while a small percentage (8.2%) were more than 50 years, this agrees with studies conducted elsewhere in the world revealed that Public Health interventions requires skilled health care workers [26, 29]

4.1.1 Extent of Home Based Care Program Services Support to Hospital Based Care

About 50.4% of the participant's revealed that utilization of minimum HBCP essential package by caregivers in management of CI/TI complications support Hospital Based Care hence reducing the burden of chronic and terminal illness, this agrees with study conducted in US Likewise, about 50.4% of the respondents indicated that efficient outreach for immunization of Children at home settings, horizontal Referral, vertical Referral, linkages and networks of HBCP centers [5], development and linkage of community based HBCP centers were some of the available effective HBCP approaches and strategies supporting Hospital Based Care for Children diagnosed with selected Chronic and Terminal Illness. This agrees with a studies by Brust *et al.*[6], Brust *et al.*[7], and Goodson *et al.*[17] who concluded that harmonization and integration of HBCP programme into mainstream health care system reduces the burden of disease in Health Care Facilities. Majority of the participants revealed that provision of clinical services at home supports very little 52(38.5%)of hospital care.

However majority of the participants indicated that early screening and diagnosis of Chronic and Terminal Illnesses is available 44(35.2%); to support hospital based care. Likewise, a large number of participants indicated that HBCP services by caregivers was somewhat 35(28%) available 34(27.2%) supports hospital care which agrees with a study by Gans *et al.*, [15]

4.4.2 Composite Scores and Extent to which HBCP Services Supports Hospital Based Care

Majorly, respondents rated the extent to which Clinical services, Early screening and diagnosis of Chronic and Terminal Illnesses, HBCP services by caregivers, Minimum HBCP essential package, Effective referral system and linkages and Health education and Health promotion as 5.3% not at all, 19.1% very little, 32.9% somewhat, 33.6% available and 9.2% to great extent supports hospital based care. These agrees with a study conducted in (Parker *et al.*, 2012).

5.0 CONCLUSION

There is need for an urgent need for adoption of a holistic approach focusing on health care system strengthening, by putting in place a well-integrated Home Based Care Program minimum HBCP essential package services being adopted into mainstream Health Care System. In addition there is need for adoption of better management practices, planning strategies, resource allocation and monitoring for effective HBCP programmes as per the current guidelines to bridge the gaps identified in planning, management practices, to fill the disjointed policy implementation and resource inadequacies in implementation of HBCP to enhance service utilization to support hospital based care for ultimate delivery of quality care among the chronically and terminally ill Children. The extent to which Clinical services are provided at home supports hospital care in table 3 above was significantly associated with level of home based care at 5.90 [95%ci = 2.77 – 12.60, $p < 0.001$] times more likely indicate that the level of home based care was good/very good/excellent compared to participants who revealed that it was not at all/very little done.

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UNDER PEER REVIEW

DEFINITION OF OPERATIONAL TERMS

Activities of Daily Living: Refers to the routine activities (ADL) that person Undertakes every day with or without the need of assistance, such as: eating, bathing, dressing, toileting, transferring (walking) and continence control.

Caregiver: Refers to the guardian or biological parent who has been taking care of a child for the last six months.

Children: Refers to a person who is equal to one year or less than 14 years of age.

Client: Refers to any child who resides in a home-based Care centers Majority of Children referred to home based care are the subject of Protective services Intervention.

Chronic Illness: Refers to Health problems/conditions that requires ongoing management over a long period or decades as stated in WHO.

Effectiveness: Refers to the level or degree of achievement or accomplishment of HBCP services by HBCP offering health facilities or centers as set in accordance with WHO set standards.

Evaluation: Refers to assessment or judgement of various aspects HBCP services for Children with chronic and terminal illness management in terms of its context, inputs, processes and products as presented in CIPP model.

Health Care Provider: Refers to various medical and allied professionals involved in care for Children diagnosed with chronic and terminal illnesses.

Hindrances: Refer to infrastructural, utilization of HBCP services, policy issues, and Stakeholder's involvement attributes limiting Home Based Care Program services for Children with selected chronic and terminal illnesses.

Home Based Care Program (HBCP): Refers to planned set of activities, procedures and processes of care designed for provision of home based care services to Children diagnosed with selected chronic and terminal illnesses that is extended from the health facility to the clients' home through family participation and involvement within available resources according to World Health Organization/UNAIDS set standards.

Minimum Essential Package: Refers to the WHO defined components Prescribed for provision of Home Based Care Programme services for Chronically and Terminally ill Children.

Program: Refers to "any set of organized activities supported by a set of resources to achieve a specific and intended result."

Selected Chronic and Terminal Illnesses: Refers to identified conditions such as Tuberculosis, Asthma, Cancer, Heart conditions, congenital abnormalities, Stroke, and among other Chronic and Terminal illnesses.

Training: Means deliberate process of educating caregivers/Health Care Workers to develop HBCP services delivery skills and competences that are required in management of Children with selected Chronic and Terminal illness.

Terminal illness: Refers to disease (s) or medical conditions with fatal outcome irrespective of management options provided.

Quality Means delivery of real time effective and efficient HBCP services to Children at Home in accordance with WHO/UNAIDS set HBC program standards.

ACRONYMS, ABBREVIATIONS

ADL	:	Activities of Daily Living
AOR	:	Adjusted odds Ratios
CDC	:	Center for Disease Control
CI	:	Chronic Illness
CoC	:	Continuum of Care
CIPP	:	Context, Input, Process and Product
CPSG	:	Psychosocial Support Groups
CS	:	Community Strategy
DOH	:	Directory of Health Facilities
EHBCP	:	Evaluation of Home Based Care Program
GoK	:	Government of Kenya
HBCP	:	Home Based Care Program
HBCPs	:	Home Based Care Program Services
HICs	:	High Income Countries
IHBCDPs	:	Institutionalized Home Based Care Delivery Points
KDHS	:	Kenya Demographic and Health Survey
MEP	:	Minimum Essential Package
MoH	:	Ministry of Health
MUST	:	Meru University of Science and Technology
NCDs	:	Non-Communicable Diseases
OIs	:	Opportunistic Infections
TI	:	Terminal Illness
UNAIDS	:	The Joint United Nations Programme on HIV/AIDS
UNGA	:	United Nations General Assembly
WHO	:	World Health Organization

APPENDIX 1.0 ETHICAL APPROVAL

