

EXPECTATIONS OF CLIENTS ENROLLED IN A COMMUNITY AND HOME-BASED CARE PROGRAMME: INSIGHTS FROM ZIMBABWE

P. Mataure, D Litt et Phil student
University of South Africa
Department of Health Studies

G.B. Thupayagale-Tshweneagae, D Tech
HOME-BASED University of South Africa
Department of Health Studies
Corresponding author: tshweg@unisa.ac.za

ABSTRACT

The past two decades have witnessed a transition from in-patient hospital admission and care to community and home based care (C&HBC) due to the surge in chronic health conditions in most of southern Africa, including Zimbabwe. The purpose for this study was to explore whether C&HBC met the expectations of clients enrolled in such a programme.

A mixed-method approach, combining qualitative and quantitative data collection and analysis, was used. Data from both approaches, qualitative and quantitative, were collected concurrently. Equal weighting was allocated to both sets of data. Interviews and focus group discussions were used to collect data from home-based care clients, family care givers and health providers. Quantitative data were collected from clients and primary caregivers using questionnaires.

Specific data entry templates were developed for the purpose of entry and analysis in NVivo. Data were synthesised and analysed according to themes. Quantitative data were collated and entered into a CSPro data entry template, before being exported to MS excel and to the Statistical Package for Social Sciences (SPSS) version 20.0 for analysis. The quantitative questions were pre-coded before data collection and analysis.

The unmet expectations included financial assistance, improved nutrition, availability of medications and improved access to health care providers.

KEYWORDS: community based care in Zimbabwe, expectations of community and home-based care service users, home-based care in Zimbabwe

INTRODUCTION AND BACKGROUND INFORMATION

Chronic illnesses have been a common worldwide phenomenon for many years, with a higher prevalence in developed countries than in third world countries (Beaglehole, Ebrahim, Reddy, Voute & Leeder, 2007:2152; WHO, 2008:2). However, Africa is gradually showing signs of an increase in chronic illnesses (Aikins, Unwin, Agyemang, Allotey, Campbell & Arhinful, 2010). This increase is problematic in that the health delivery systems in Africa are generally weak, inadequately funded and largely unable to cope with the growing demand for multi-faceted health care required for such conditions. (WHO, 2008b:4)

The past two decades have witnessed a transition from in-patient hospital admission and care to community and home-based care (C&HBC), due to the surge in chronic conditions in most of southern Africa including Zimbabwe. This is caused by the heightened HIV and AIDS epidemic particularly in Sub Sahara Africa (SSA), and in Zimbabwe. UNAIDS (2012:6) reported a reduction in the HIV incidence by more than 25% in southern Africa within the last decade. Health systems in the region have responded to the HIV pandemic by enabling less qualified community health workers to provide care for chronically ill patients in their homes.

Definitions of key concepts

Community-based care (CBC) is care provided in homes, which encourages active participation by the community, responds to the expectations of people, encourages traditional community life and creates responsibilities (Shimeles, 2010:6).

Expectations refer to the act or state of anticipation or that which is expected or looked for (Little Oxford Dictionary, 2005:322)

Home-based care (HBC) is the provision of health services by formal and informal caregivers to sick people in their homes (Mahillal, 2009:62).

PROBLEM STATEMENT

The number of chronically ill clients being cared for at home is increasing in Zimbabwe. According Zimbabwe's Demographic and Health Survey (DHS, 2010:11-26) there were 154 000 chronically ill clients enrolled in C&HBC in 2009 compared to 32 000 in 2005. There are limited attempts to evaluate the C&HBC programmes' successes and weaknesses in attaining the programmes' goals and clients' (end users') expectations. This study aimed to bridge this gap. An understanding of clients' expectations, relating to their satisfaction with services provided, is critical for improving services. Satisfaction

with care rendered differs according to context, values and expectations (Hasson & Arnetz, 2011:1428).

Purpose of the study

The purpose for this study was to explore whether C&HBC programmes met the expectations of the clients enrolled in the C&HBC programmes. Based on the study's findings, recommendations can be submitted to policy makers for improving the C&HBC programmes.

Objectives of the study

The objective of this study were to:

- explore and describe the health care needs and experiences of chronically ill clients enrolled in a community and home base care programme
- determine whether the C&HBC programme interventions are meeting the intricate goals of chronically ill clients.

RESEARCH METHODOLOGY

This is a cross sectional explorative and descriptive study of the C&HBC service using a combination of qualitative and quantitative methods (David & Sutton, 2007:38). The qualitative and quantitative research was conducted concurrently. Study sites were stratified according to urban and rural settings.

Population, sample and sampling technique

The research used a criterion-based purposive sampling approach (Johnson & Christensen, 2012:235). The sample was drawn among available and consenting members of the community who had experiences of home based care for chronic illness in the urban and rural areas of Harare city and Marondera district. The views of those who were not involved in home-based care were solicited from community leaders and other community volunteers involved in other community-based programmes. Maximum variation sampling was used, which is described by Johnson and Christensen (2012:236) as purposively selecting a wide range of cases from rural and urban settings. Participant selection and recruitment also included those at home, and those who were able to meet the research team at a community meeting centre near to the clients' homes. This method ensured that the view of all types of cases with diverse experiences of care were heard. A total of 206 participants were recruited in the study.

Table 1: Description of study coverage and sample

Province	Area	KI sample	FGD sample	Survey sample		Data collection method
				Service users	Primary care givers	
Harare (Urban)	Mabvuku High Density Area, Harare	3	8	10	6	FGD and structured questionnaire
	Kuwadzana Ward 37 Harare	4	6	20	5	FGD and structured questionnaire
	Mbare High Density Area	5	11	22	5	FGD and structured questionnaire
	Tafara High Density Area	0	18	10	12	FGD and structured questionnaire
	Dzivarasekwa H/Density Area	2	26	19	14	FGD and structured questionnaire
	Harare Urban	3	-	-	-	In-depth interviews
Marondera District (Rural)	Marondera/Rusike High Density Area	3	10	15	4	FGD and structured questionnaire
	Wenimbi East- Ward 6 Marondera	5	16	29	8	FGD and structured questionnaire
	Garikayi- Ward 10 Marondera	3	8	16	7	FGD and structured questionnaire
	Ruwari Resettlement- Ward 23	1	0	4	0	Structured questionnaire
	Marondera Rural and Urban	5	-	-	-	In-depth Interviews
TOTAL		34	110	145	61	Mixed Methods

Key: KI = Key Informants; FGD = Focus Group Discussions

Data collection

The sources of evidence used in this study were diverse. They consisted of 34 individual interviews, 110 participants who took part in 10 focus group discussions; 61 caregivers

who completed questionnaires and 145 service users who completed questionnaires making a total of 206 participants. The questionnaire comprising both open-and closed ended was pre-tested with 20 clients and 5 caregivers who did not participate in the main study. Feedback from these persons was incorporated in the revised version of the instrument following intense discussions with researchers. The first author collected data from 1st February to 30th March 2012 with the assistance of three research assistants who were nurses with Master's degrees and who had been trained in data collection.

Data processing and analysis

Quantitative data

Data collected were verified for completeness and accuracy during the fieldwork and during the data cleaning after the completion of the field work. Quantitative data were collated and entered into a CSPro data entry template, before being exported to MSExcel and to the Statistical Package for the Social Sciences (SPSS version 20.0). A code book was developed to enter themes and categories for the management of the coding system, using latent and manifest codes. 'Manifest codes' are terms that recur within the data collected, whereas 'latent codes' are those themes that are implied in the text and are identified by the researcher (David & Sutton, 2007:204). The code book for this study lists all the codes generated and applied to the data for establishing patterns and themes.

The quantitative questions were pre-coded before data collection and analysis. Quantitative data analysis was presented as descriptive statistics, showing frequencies, and cross tabulations. As part of data analysis, comparisons were made to search for patterns, themes and trends between the different groups of respondents sampled from various settings.

Reliability and Validity of Quantitative Data

Validity of the tool was determined by the extent to which it addresses the research questions and objectives of the study. The reliability was determined by the consistency with which respondents understood and responded to all questions. A thorough literature search for the concepts used in the questionnaires was done.

Qualitative Data

For the qualitative data (FGD and key informant interviews), specific data entry templates were developed for the purpose of entry and analysis, using the NVivo computer program. Data were synthesised and analysed by thematic areas. NVivo

analyses detailed textual and/or multimedia data. The NVivo software performs tasks such as classifying, sorting and arranging information. The NVivo analysis software helped to clarify the researchers' understanding of the data, to discover meanings and patterns and to identify themes to answer the research question and to reach conclusions about the research findings.

ETHICAL CONSIDERATIONS

The study was approved by the Research Ethics Committee of the Department of Health Studies, University of South Africa. The Medical Research Council of Zimbabwe also granted ethical clearance. Permission and approval was also granted by organisations with direct contact with communities that participated in this study. Ethical considerations included autonomy, informed consent and confidentiality.

To ensure autonomy in this study, a written statement explaining the purpose of the study and procedure for data collection, and the nature of voluntary consent was read to every participant. This was done to ensure consistency in information provided to all potential participants. They were informed about the purpose of the study and its implications for the C&HBC programme. Participants could choose whether or not they wanted to participate in the study.

Participants who agreed to participate in the study provided written informed consent. Consent forms were translated into Shona (the local language), for those participants unable to read English. Study information and consent forms were read to those who were unable to read.

Confidentiality and the protection from invasion of privacy were prioritised throughout the study. The interview sessions were carried out in secluded settings to ensure privacy and confidentiality. Emphasis was placed on information being shared between the interviewee and interviewer privately and confidentially. Participants' names were not entered on the questionnaires and no names were used during the focus group discussions. Numbers were assigned to the completed questionnaires. The names of organisations and of key informants were recorded opposite specific numbers to enable follow-up interviews, if necessary.

TRUSTWORTHINESS

The following list shows how threats to trustworthiness were managed in this study:

- The sample of study participants was selected from individuals who had experienced chronic illnesses. This strategy ensured effective attainment of the research goal and objectives and a reflection of relevant experiences of the participants.

- The purposive sample, comprising 145 clients and 61 caregivers, was considered adequate to generate sufficient data for valid conclusions and generalisations to similar populations and settings.
- Use of research assistants for the collection of data and meetings to discuss and confirm findings each day following field work reduced the principal investigator's bias and reliance on her personal perceptions. This peer debriefing also ensured triangulation of findings between the researchers.
- Some respondents participated in both the qualitative and quantitative aspects of the study as shown in table 1. This increased the credibility of data obtained from both sources and achieved triangulation.
- Triangulation was established in this study through the use of different data collection methods. These included in-depth interviews, focus group discussions and self-completion questionnaires. The in-depth interviews were conducted with key informants (secondary population) that consisted of health institution managers, managers of non-governmental organisations, community health workers and local leaders.
- The use of qualitative data software, Nvivo, for data management and its analysis authenticated the findings and increased the integrity of the conclusions (Sinkovics, Penz & Ghauri, 2008:694).

RESULTS

Demographics

Of the 145 clients, 107 (73.8%) were females and out of the 61 caregivers 50 (82.0%) were females. Primary school education implies seven years of basic literacy and numeracy education in Zimbabwe. As many as 84.8% (n=123) of the clients and 82.0% (n=50) of the caregivers had completed primary school.

Health experiences and expectations of chronically ill patients

Many clients suffered from HIV or AIDS (62.1%; n=90) and some (20.0%; n=29) suffered from Tuberculosis (TB) which is a common opportunistic infection. Medical conditions such as mental illnesses (10.3%; n=15), asthma (6.2%; n=9), neuropathy (4.8%; n=7) and cancers associated with HIV and AIDS (3.4%; n=5) were also reported.

Clients' expectations

All clients (100%; n=145), reported that their expectations were due to their chronic illnesses and home-based care. Table 2 shows the clients' expectations and what they

considered could be done to assist them to meet their health goals. Clients were allowed to choose more than one option.

Table 2: Clients' expectations of C&HBC programme (n=206)

Clients' expectations	Frequency	Percentage
To receive financial assistance	78	37.8
To eat	78	37.8
To improve symptoms of pain, nausea and insomnia	61	29.6
To receive information about my condition	26	12.6
To feel more useful within my family	11	5.3
To afford school fees, accommodation, exercise	9	4.3
To receive assistance with eating and going to the bathroom	8	3.8
To access certain types of medication	6	2.9
To have better dialogue with care providers	5	2.4
To find counselling	3	1.4
To want respect for my privacy	2	0.9
To speak with spiritual advisor	1	0.4

In focus group discussions, expectations similar to the ones listed table 2 were identified by clients and their caregivers. The need for food was also cited as a priority. A key informant had this to say about the need for food in C&HBC:

“People who are ill only think of food and their treatment.”

Meeting clients' expectations

Clients indicated that their health expectations were generally met, with 30.3% (n=44) of respondents reporting their expectations being met all the time; 30.3% (n=44) having their expectations met sometimes and 40.0% (n=58) indicating that their expectations were not met by their family members nor by the health delivery system. Families were generally responsible for meeting the expectations of their sick relatives.

Clients' expectations were also explored from the caregivers' perspectives, revealing that food insecurity emerged as the priority need (49.2%; n=30). Medication was rated as the second need (13.1%; n=8) and other financial expectations (9.8%: n=6) were

reported. Caregivers also believed that 62.3% (n=38) of clients' expectations were met largely through the extended family. However, welfare organisations made significant contributions (19.7%; n=12) to meet the expectations of the clients and also to the overall implementation of C&HBC within the communities.

Perceptions from health institution managers, local leaders and managers of HBC who were the key informants of the study (in particular the health professionals) indicated that their expectations were not met. They cited shortages of medicines, lack of transport to visit patients in need of health professionals' assistance, and lack of medical supplies (such as disinfectants, analgesics, wound dressings and gloves). These shortages of C&HBC requirements posed barriers to meeting clients' expectations. The following quotations summarise the challenges and failures encountered by the health care professionals to meet the patients' expectations and to attain the health goals:

"We can do so much to reach the goals and meet the expectations of clients as health personnel, but due to the poor social standing of clients, there are many things we are not in control of".

"We are not completely meeting expectations because resources are scant"

"Government HBC is not holistic because it's about health care only and neglects orphans and food provisions".

Key informants' perspectives of clients' expectations

Data from health professionals interviewed and other key informants revealed their own perceptions of clients' expectations, based on interactions and experience in community health services as indicated below. Pain management posed a challenge and the required medicines were not always available depriving patients of pain relief.

A safe and welcoming home environment after discharge from the hospital posed challenges as caregivers were inadequately prepared to help family members prepare for their relatives' discharge from hospital.

Financial assistance to cover medical expenses, transport and food were dire needs as most clients were breadwinners, who had lost their income as a result of their illness, and their caregivers were unemployed. The burden of financing medical expenses aggravated their poverty situation making it impossible for them to purchase supplies. Food is necessary for those on ARVs as these medications affect the gastric system. Their diets should have balanced nutrients which most patients could not afford.

The quantitative survey also showed some significant variations and similarities in the expectations of urban and rural clients, as displayed in table 3.

Table 3: Comparisons of urban and rural patients' expectations (n=145)

Client expectations	Urban(n=96)		Rural (n=49)	
	Frequency	%	Frequency	%
Financial assistance	57	59.3	22	44.9
Improve symptoms of pain, nausea and insomnia	43	44.8	26	53.0
Receive education about patient condition	21	21.9	5	10.2
Feel more useful within my family	10	10.4	1	2.0
Assistance with eating, dressing, and going to the bathroom	8	8.3	0	0
School fees, accommodation, exercise, weight gain and clothing	7	7.3	2	1.0
Better dialogue with health providers	5	5.2	0	0
Counselling	3	3.1	0	0
Respect privacy	2	2.0	0	0
Speak to a spiritual advisor	1	1.0	0	0

Urban communities' quest for financial security was greater than of those in rural areas. Rural clients were less concerned with comforts or interventions such as being assisted with eating, dressing, and going to the bathroom; receiving information regarding their condition and feeling more useful within their families, than their urban counterparts.

Furthermore, 24.1% (n=35) of clients from all areas mentioned the lack of support from their families. Of these, 71.7% (n=104) were from urban areas and 27.5 % (n=40) from rural areas. The support rendered was either largely financial or food (both urban and rural settings), and assistance with household chores and counselling in urban areas. The above pattern could be the result of the ability of rural communities to cope more collectively through difficult circumstances than urban dwellers. The social support network might be stronger in rural than in urban areas despite documented disintegration of social support systems within rural settings in general (Caring from within, 2008:15).

DISCUSSION

The Zimbabwean government-designed C&HBC programme addressed some of the clients' expectations. However, economic well-being, and appropriate interventions for pain and symptom management, posed challenges to clients and their families and to health service providers.

Clients did not separate their social expectations from their health expectations. This supported the generally-assumed interconnectedness “in the real world” between health issues and the expectations expressed by respondents (Bowling, 2009:65; WHO-2008b:10). Clients’ expectations tended to be subjective and were bound to change over time in relation to the influence of social, cultural and economic factors. The socioeconomic situation in Zimbabwe constrained patients and limited their caregivers’ abilities for providing adequate healthcare and other types of support.

Emotional Expectations

The emotional state of patients was affected by their socio-economic environment and, thus playing a big role in the overall well-being of chronically-ill persons and their families. The need for “peace of mind” was referred to by clients throughout the study. The expectations identified in this research appeared to corroborate with findings from studies from other countries (Boryc et al., 2010:488; Jooste et al., 2009:4; & Thorne et al., 2003:1344). Other critical expectations expressed in this study and other studies included care for orphaned children, ameliorating the fear of death, regular supplies of medications, and transport for accessing health services by clients and for accessing clients by home care providers (Goudge et al., 2009; Jeon, Essue, Jan, Wells & Whitworth, 2009). These expectations were essential for a functional health system which could meet the goals of both parties of C&HBC.

Nutritional Expectations

The nutritional and financial expectations of clients were the most important needs. Other studies assessing the expectations of C&HBC studies in Africa also showed similar results (Boryc et al., 2010:488). Those with high incomes enjoyed good nutrition and relatively unrestricted access to healthcare. The findings in this study showed that poverty and lack of income and access to food were the main barriers to meeting the expectations of the clients. This occurrence is also similar to findings from a study carried out on “met and unmet palliative care expectations of people living with HIV/AIDS in Rwanda” (Uwimana & Struthers, 2007:580-581).

Physical Expectations

Chronically ill people have diverse medical care expectations. The need for pain and symptom management is a critical component of care in chronic illness, rated second most important in this study. Other studies (Grant, Brown, Leng, Bettega & Murray, 2011:9; Uwimana & Struthers., 2007:581) also revealed the unmet need for pain relief in clients with HIV and AIDS. Bodibe (2012:16) reported that South Africans, living with HIV in the Limpopo Province, experienced varied degrees of pain which remained

unreported, and health workers did not have the skill and capacity to assess pain and treat it appropriately.

Focus group discussions conducted during this study revealed that C&HBC clients usually experienced neuropathic pain and other body pains without receiving adequate pain relief. Inadequate symptom and pain management suggested that comprehensive palliative care was ineffective in HBC.

CONCLUSIONS

The study explored and described the expectations of chronically ill patients enrolled in the C&HBC programme and their caregivers. There were slight variations in the ranking of priorities for rural and urban participants. Urban participants ranked financial assistance as the first priority, whilst the rural participants ranked food as their immediate need. Access to medication for symptom management and pain control were espoused by all participants of both rural and urban communities. It is evident from previous studies that people are generally aware of C&HBC services. This study reveals an opposite view, as its outcomes indicate that people are not aware of these services and therefore need such information.

RECOMMENDATIONS

Resources should be channelled towards C&HBC in order to meet the expectations of clients enrolled in the programme. Noting the lack of knowledge of and/or limited information about homecare expressed by clients, it is critical that they should be offered health education in this area of community care. Doing so would enhance clients' adherence to treatment programmes, including medication. The creation of some finance generating programmes, such as development of "backyard gardens" should be established for C&HBC clients. These programmes would not only enhance clients' self-esteem and engagement in physical activities, but could lead to financial gains if these products are sold. Even if produce is not sold but eaten by the family members, including the clients, their nutritional status would improve.

LIMITATIONS

This study was conducted in the Shonaland province of Zimbabwe, which means other areas of the country were excluded. This has implications for the generalisability of the findings even though the study utilised a large sample size. This assertion is a function of the view that clients in one region might have different characteristics and views about C&HBC of another region. Despite this limitation, the study generated

new insights into the expectations of clients about C&HBC. However, more studies are needed to further explore this area of healthcare.

REFERENCES

- Aikins, A., Unwin, N., Agyemang, C., Allotey, P., Campbell, C. & Arhinful, D. 2010. Tackling Africa's chronic disease burden: from the local to the global. Available at: <http://www.globalizationandhealth.com/content/6/1/5> (accessed on 25 November 2012).
- Beaglehole, B., Ebrahim, S., Reddy, S., Voute, J. & Leeder, S. 2007. Prevention of chronic diseases: a call to action. *Lancet*, 370:2152-2157.
- Bodibe, K. 2012. Pain: a neglected complication of HIV living with AIDS #505 Health eNews Service, SA Available at: <http://www.health-e.org.za/news/article.php?uid=20033458> (accessed on 8 March 2012).
- Boryc, K., Anastario, P.M., Dann, G., Chi, B., Cicatelli, B., Steillen, M., Gordon-Boyle, K., Singh, S. & Morris, M. 2010. A needs assessment of clients with HIV in a home-based care program in Guyana. *Public Health Nursing*, 27(6):482-491.
- Bowling, A. 2009. *Research methods in health: investigating health and health services*. London: Open University Press.
- Caring from within. 2008. Key findings and policy recommendations on home based care in Zimbabwe. Harare: Health and Development Networks, Southern Africa HIV and AIDS Information Dissemination Service & Irish Aid..
- David, M. & Sutton, C.D. 2007. *Social research: the basics*. Oxford: Sage. Zimbabwe Demographic and Health Survey.
- Goudge, J., Gilson, L., Russell, S., Gumded, T. & Mills, A. 2009. Affordability, availability and acceptability barriers to health care for the chronically ill: longitudinal case studies from South Africa. *Biomed Central Health Services Research*, 9:75.
- Grant, L., Brown, J., Leng, M., Bettega, N. & Murray, S.A. 2011. Palliative care making a difference in rural Uganda, Kenya and Malawi: three rapid evaluation field studies. *Biomed Central Palliative Care*, 10:8.
- Hasson, H. & Arnetz, J.E. 2011. Care recipients' and family members' perceptions of quality of older people care: a comparison of home-based care and nursing homes. *Journal of Clinical Nursing*, 20:1423-1435.
- Jeon, Y.H., Essue, B., Jan, S., Wells, R. & Whitworth, J.A. 2009. Economic hardship associated with managing chronic illness: a qualitative inquiry. *Biomed Central Health Services Research*, 9:182.
- Jooste, K., Chabeli, M. & Springer, M. 2009. The health care needs of the physically disabled patient in a home-based care environment: Implications for the training of ancillary health care workers. *Health SA Gesondheid*, 15(1):480-486.
- Little Oxford Dictionary 2005. *The world most trusted dictionaries*. Philadelphia: Oxford Press.
- Mahillal, R. 2009. The integral role of HBC in the fight against HIV/AIDS. Unpublished Masters Dissertation. Pretoria: University of South Africa.
- Shimeles, A. 2010. Community based health insurance schemes in Africa. *African Development Bank*, 10:1-29.
- Sinkovics, R.R., Penz, E. & Ghauri, P.N. 2008. Enhancing the trustworthiness of qualitative research in international business. *Management International Review*, 48(6):689-714.
- Thorne, S., Paterson, B. & Russel, C. 2003. The structure of everyday self-care decision making in chronic illness. *Qualitative Health Research*, 13(10):1337-1352.

- UNAIDS. 2012. UNAIDS report on the global AIDS epidemic. Global report. Washington DC.
- Uwimama, J. & Struthers, P. 2007. Met and unmet palliative care expectations of people living with HIV/AIDS in Rwanda. *Journal of Social Aspects of HIV/AIDS*, 4(1):575-585.
- World Health Organization. 2008a. The world health report 2008: primary health care now more than ever. Geneva.
- World Health Organization. 2008b. Social determinants of health: the solid facts. Copenhagen: WHO Regional Office of Europe.
- Zimbabwe Demographic and Health Survey, 2010. *Zimbabwe statistics report*. Harare.