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Patient-Provider Perspectives on Self-Management Support and Patient Empowerment in Chronic Care: A Mixed-Methods Study in a Rural sub-Saharan Setting

Running head

Self-management support and patient empowerment

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Conflict of Interest

The authors declare they have no competing interests.

Author Contribution

Criteria	Author Initials
Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data;	VA, BC, CA
Involved in drafting the manuscript or revising it critically for important intellectual content;	VA, BC, CA, JBA, JVL
Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content;	VA, BC, CA, JBA, JVL
Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.	VA, BC, CA, JBA, JVL

ABSTRACT

Aim: To explore how provision of self-management support to chronically-ill patients in resource-limited settings contributes to patient empowerment in chronic care.

Design: Concurrent descriptive mixed methods research.

Methods: A survey of 140 patients with chronic conditions administered at four time-points within 12 months. We conducted 14 interviews and four focus-group discussions with patients (N=31); 13 healthcare provider interviews; and observations of four patient-support group meetings. Data were collected between April 2016 - May 2017 in rural Malawi. Qualitative data were analysed using a thematic approach and descriptive statistical analysis performed on survey data.

Results: Healthcare professionals facilitated patient empowerment through health education, although literacy levels and environmental factors affected self-management guidance. Information exchanged during patient-provider interactions varied and discussions centred around medical aspects and health promoting behaviour. Less than 40% of survey patients prepared questions prior to clinic consultations. Health education was often unstructured and delegated to non-physician providers, mostly untrained in chronic care. Patients accessed psychosocial support from volunteer-led community home-based care programmes. HIV support-groups regularly interacted with peers and practical skills exchanged in a supportive environment, reinforcing patient's self-management competence and proactiveness in healthcare.

Conclusion: For optimal self-management, reforms at inter-personal and organisational level are needed including; mutual patient-provider collaboration, diversifying access to self-management support resources and restructuring patient support-groups to cater to diverse chronic conditions.

Impact: Our study provides insights and framing of self-management support and empowerment for patients in long-term care in sub-Saharan Africa. Lessons drawn could feed into designing and delivering responsive chronic care interventions.

KEY WORDS

chronic care; hiv; non-communicable diseases; mixed methods; nursing care; nurse practitioners; patient empowerment; sub-saharan africa; self-management support

ABBREVIATIONS

AIDS: acquired immunodeficiency syndrome; CBO: community-based organisation; CHBC: community home-based care; FBO: faith-based organisation; FGD: focus group discussion; IDI: in-depth interview; HIV: human immunodeficiency virus; HSA: health surveillance assistant; NCD: non-communicable disease; PHC: primary healthcare.

INTRODUCTION

Patients living with chronic conditions require support to self-manage their conditions and make the necessary lifestyle adjustments to maintain good health and minimise complications (Bodenheimer et al., 2002). The long-term nature of chronic conditions requires patients to

take up a more central and active role in their day-to-day self-management activities (Holman & Lorig, 2000), while changing how patients have traditionally been engaged in healthcare (Bodenheimer et al., 2002). Conceptual frameworks, such as Wagner's chronic care model, posit that patients need to be informed and activated in health, whilst interacting with a prepared and proactive healthcare team, to attain an optimal level of care (Wagner et al., 2001). The concept of patient empowerment has gained prominence in the health discourse and clinical practice (Ellis-Stoll & Popkess-Vawter, 1998; Small et al., 2013). It is viewed as the process or outcome of collaborative relations between patients and care providers and occurs when patients' capacity for making autonomous informed decisions regarding their health is increased as part of this collaboration (Bodenheimer et al., 2002; Pulvirenti et al., 2014). Empowerment further extends to patients' responsibility for managing their own conditions, which in some instances may involve the patient's choice to relinquish this responsibility to caregivers (Collins & Rochfort, 2016). During patient-provider encounters, the emphasis is on assimilating patient's views and taking account of their socio-environmental contexts in the provision of holistic care that is responsive to patient needs (Bodenheimer et al., 2002; Collins & Rochfort, 2016; Holman & Lorig, 2000; Pulvirenti et al., 2014). Hence, there is a need to activate the principles advocated in delivering patient-centred care (Aujoulat et al., 2007; De Man et al., 2016).

Chronic disease self-management has been conceptualised as a fluid iterative process, during which patients incorporate multidimensional strategies to meet their self-identified needs (Auduly et al., 2016; Miller et al., 2015) and gain confidence in managing their health (Bodenheimer et al., 2002; Wagner et al., 2001). During this process, multiple providers within and beyond clinic settings engage with patients. The practice and provision of self-management interventions have been widely documented in high-income settings, where

health systems, to a large extent, have been adjusted to accommodate specific programmes for patients with chronic conditions (Barlow et al., 2002; Elissen et al., 2013). Evidence from self-management interventions has demonstrated improvements in patient self-efficacy and patients' preparedness for self-management (Elissen et al., 2013; Lorig KR et al., 2001).

The growing global burden of chronic illnesses fuelled by changing demographics and lifestyles, calls for urgent reforms to reverse these trends (Defo, 2014). In sub-Saharan Africa (sSA), non-communicable diseases (NCDs) such as cardiovascular diseases, diabetes and cancer will account for 70% of deaths by 2030 (Dalal et al., 2011; Mathers & Loncar, 2006) and costs associated with chronic care will exert pressure on government health spending (Geldsetzer et al., 2016). sub-Saharan African health systems face numerous challenges, including critical health workforce shortages, fragmented health services and mismatched funding/resource allocation which hampers their capacity to serve this growing patient population (Atun et al., 2013; Criel et al., 2004). Whilst chronic care services are still in a developmental phase in most parts of Africa, there is evidence of local innovation and experimentation, which slowly diffuse into health service delivery structures (Aantjes et al., 2014; Bekker et al., 2018). Most examples stem from HIV-focused services, whereby non-clinical staff and lay caregivers are drawn into the provision of self-management support (Levitt et al., 2011; Rabkin & El-Sadr, 2011). The extensive attention for HIV services in the region, has facilitated the deployment of trained expert patients in facilities, establishment of treatment adherence clubs and peer-led support groups, or engagement of volunteers in community and home-based care (Decroo et al., 2012; Luque-Fernandez et al., 2013; Tenthani et al., 2012). A growing body of literature describes the transfer of such approaches to patients with other chronic conditions, including HIV co-morbidities (Khabala et al., 2015; van Deventer, 2015; Van Olmen et al., 2015). However, there is still limited insight into how

the diffusion of chronic care approaches facilitates patient self-management and, within it, the empowerment of chronic patients in sub-Saharan Africa.

Conceptual background

Self-management support is an essential component of the chronic care model (Wagner et al., 2001). In this model, emphasis is placed on creating awareness and mobilizing resources to ensure patients' access the necessary support for self-management. This requires prepared and proactive healthcare teams. In the African context, healthcare teams extend to family, peer patients and lay/informal community caregivers who play a central role in supporting patients. Although they provide complementary services in communities and home settings, community-based providers' capacity to support patient self-management varies and is limited by, for instance, the level of training, knowledge and skills and available resources (Dube et al., 2017; Murphy et al., 2015; Mwangome et al., 2016; Russell et al., 2016).

Patient empowerment in chronic disease management, involves the transfer of power and control from care providers to patients, facilitated through an enabling environment (Aujoulat et al., 2007; Miller et al., 2015). Literature delineating the concept of patient empowerment propose the importance of mutual participation during patient-provider encounters; patient-centred education (e.g. drawing on patients' experiential knowledge); and empowering attitudes and communication styles (Aujoulat et al., 2007; Bodenheimer et al., 2002; Ellis-Stoll & Popkess-Vawter, 1998; Gibson, 1991). The outcome of these processes, in most instances, leads to enhancing self-determination, independent health promoting behaviour, activated patients and improved self-management competence (Aujoulat et al., 2007; Gibson, 1991; Wagner et al., 2001). In the African setting, the presence of an extended healthcare

team requires broadening perspectives and critically examining the role of health professionals and other community-based providers in promoting patient empowerment.

Validated instruments such as the Patient Activation Measure, Patient Enablement Instrument and Patient Empowerment Scale have been widely used (especially in high-income settings), to measure patient empowerment dimensions in healthcare (Barr et al., 2015). Other studies have applied data-driven approaches drawn from patient perspectives to develop contextually adapted scales (Small et al., 2013), or interrogate the operationalisation of patient empowerment for long-term conditions (Aujoulat et al., 2008). Our paper draws on perspectives from patients and care providers and applies patient empowerment as a lens to explore how and to what extent this concept is promoted in chronic care in rural sub-Saharan Africa.

THE STUDY

Aim

This paper explores how provision of self-management support to chronically-ill patients in rural Malawi could contribute to patient empowerment in chronic care. The research questions were: 1) What are care providers' perceptions of chronic disease self-management and how do they facilitate patient empowerment in chronic care; 2) What forms of self-management support exist in community and clinic settings for chronic patients; and 3) Are there differences in self-management outcomes by patient groups and if so why?

Design

A concurrent descriptive mixed methods study was used (Creswell, 2014). This included repeated surveys with patients to evaluate self-management outcomes and qualitative data approaches comprising of interviews, focus group discussions (FGDs) and structured-observations. Data are drawn from a larger study examining local models for chronic care and self-management support initiatives in southern Malawi (2015 – 2018).

Setting

This study was conducted in Phalombe, a rural district located south-east of Malawi near the border with Mozambique. Phalombe's population is 390,000, with high poverty and unemployment levels, while farming and small-scale trading are the main economic activities (Malawi Ministry of Health, 2013). Phalombe accounts for 16.5% of the national HIV prevalence and experiences a growing NCD burden (cancers and cardiovascular diseases). The district has 13 primary healthcare (PHC) facilities, mainly served by nurses, medical assistants and health surveillance assistants. With the absence of a government-owned hospital, some secondary care is provided in a district government health centre, but referrals from PHC facilities are largely directed to a mission hospital. In communities, community health volunteers (CHVs) provide support and care to chronically ill patients. Typically, CHVs function in community and home-based care (CHBC) programmes led by community/faith-based organisations (CBO/FBOs) and undergo training based on nationally approved guidelines (Government of Malawi, 2011).

Participants, sampling and recruitment

Given the prominence of CHBC programmes in Malawi, we enrolled chronic patients into the study from existing CBO/FBO-led programmes. We collaborated with five CBO/FBOs in Phalombe district, selected purposively, based on previous involvement in a pilot-project on capacity-building CHVs in chronic care between 2013 and 2015 (Angwenyi et al., 2018). For the survey, we targetted newly enrolled patients into CHBC programmes, since no other intervention was administered, besides home care patients receive from these CBO/FBOs. Hypothetically, we wanted to establish if exposure or receipt of CHBC made any difference over time in how patients managed their conditions. Study outcomes were changes in health status, self-efficacy and self-management behaviour; the latter being the primary focus of this paper. Survey inclusion criteria were patients aged 18 years and above, with one/more chronic condition(s) and newly registered in one of the CHBC programmes.

Survey sample size estimation was based on the ability to detect a 12-month mean change of at least 0.5 (SD 2.4) in self-efficacy scores (Lorig KR et al., 2001), a significance level of 5%, at 95% power after accounting for 30% attrition. The estimated sample to recruit was 140 patients at baseline, with four-repeated measures within 12 months. Patients meeting eligibility criteria were identified from CBO/FBO registers, with recruitment happening concurrently. CBO/FBO volunteers visited eligible patients to book appointments, followed by a research team visit to provide detailed study information and administer consent.

Selection of interview and focus group respondents was carried out through purposive and snowballing techniques (Green & Thorogood, 2004). Patients were identified from the same CBO/FBO registers, with selection aimed at ensuring representativeness in gender, diversity

of chronic conditions/comorbidities and residency. Fourteen patient interviews and four focus-group discussions (N=31 participants) were organised. Thirteen healthcare professional interviewees were identified from five of the fifteen district health facilities, situated in the same CBO/FBO catchment areas. Selection aimed for representation by gender, health worker cadre (clinical, non-clinical and health managers; with varying responsibilities in chronic care) and facility type. Researchers also attended four HIV support-group meetings to observe activities performed. Study participant's characteristics are summarized in Table 1.

Data collection and instruments

Data were collected between April 2016 and May 2017. The survey adapted validated scales from the chronic disease self-management programme (Lorig K & Laurent, 2007; Self Management Resource Centre), behavioural risk-factor questions from a Malawian study (Msyamboza et al., 2011) and modified questions from other literature (Modeste et al., 2014). The survey included semi-structured questions and Likert-scales to capture patient responses – see Supplementary File 1. Prior to the survey, tool pretesting was conducted among a small patient population (N=20 from the same setting) to check the accuracy of translation of adapted validated scales and pre-test new items added into the questionnaire. The survey was conducted at baseline (T1) and after months three (T2), six (T3) and twelve (T4) and administered by three interviewers (two females and one male).

Interview guides were developed iteratively and based on emerging issues from patient survey. Healthcare professional interviews explored care provision, perceptions of self-management, patient-provider communication and relations. Patient interviews explored clinical and community resources for self-management support and their influence on self-

management practices. A sample of topic guide themes are presented in Supplementary File 2.

Ethical considerations

Ethical approval for this study was obtained from two institutions (EMGO⁺ WC2015-080, 27-Oct-2015; NCHRS P.11/15/64, 10-Dec-2015). Written informed consent was obtained from all respondents.

Data analysis

Survey data were analysed in STATA (Version 13; StataCorp, College Station, TX, USA), using descriptive statistics including medians, means, standard deviations and percentages. Chi-square test for association were performed to establish relationships between categorical variables (e.g. HIV/non-HIV patient groups) and study outcomes (e.g. self-management support). To compare changes in outcomes (e.g. self-management behaviour) across time-points and using baseline scores as reference, we performed either paired student T-test or Wilcoxon signed-rank test, depending on data distribution. Due to multiple comparisons, we used statistical significance levels at Bonferroni-corrected p-value thresholds, adjusted by number of comparisons. All statistical tests were two-sided.

Audio files from interviews were transcribed and later translated to English, where necessary. All qualitative data were managed using NVivo (Version 11, QSR international), applying a thematic analytical approach (Green & Thorogood, 2004). A coding framework was developed inductively, based on initial codes emerging from interviews and deductively from topic guides. Once coding was completed, categories were developed based on overarching

themes. Charting was done in Microsoft Word[®] to explore emerging patterns and refine interpretation of findings.

Validity and rigour

First, the iterative data collection process allowed for incorporating emerging issues from patient survey in interview topic guides. Second, the diversity in respondents and multiple data sources across different time points allowed for triangulation. Data collection was carried out by three trained Malawi research assistants, together with and under close supervision of the first author (VA). Daily feedback meetings permitted the research team to improve data collection procedures, reflect on researchers' position and emerging issues, which were continuously documented in a research journal.

RESULTS

Characteristics of respondents

Patients median age was above 40 (range; 20–84) and over 70% of all patients were females (Table 1). Patients enrolled in the baseline survey (T1) were 140, while those interviewed in subsequent rounds were 128 (T2), 129 (T3) and 126 (T4). Among the 140 survey patients, 72.9% had HIV, 16.7% had HIV and comorbidities and 27.1% had a NCD. Common NCDs among survey patients were hypertension (22.9%), epilepsy (7.1%) and asthma (5%), while a few patients had cancer, diabetes or a cardiovascular condition other than hypertension. Among interviewees and focus group participants, 29 patients had HIV (of which 11 had a NCD comorbidity) and 16 patients had a NCD.

Healthcare providers' perceptions of patient self-management

To understand how self-management is perceived and practiced by healthcare providers, we interviewed 13 providers from different healthcare facilities. A common understanding was self-management referred to a patient's ability to manage conditions on their own, with support from family and other community caregivers. Providers emphasized the active role of family caregivers and community-based support to facilitate management and restore patients' health:

R: ...it is empowering the patient...together with their caregivers at home or close relatives, to manage that particular condition right in their community...it is not managing that patient at the health facility but taking that patient from the hospital back to the community, where they [caregivers] can attend to that patient.

KII03_Male_Nurse_Public-PHC

Some healthcare providers explained their role was to impart patients with knowledge for symptom identification, increase their understanding that conditions are 'incurable', recognise the importance of adhering to medication and clinic appointments and modifying behaviour that negatively affects their health:

...they [patients] should know the danger signs of their chronic condition...when to get drugs and when to take them. They should not stay without drugs and they should know what to eat and how to manage themselves ...

KII01_Female_Nurse_Private-PHC

One provider highlighted levels of self-management and efficacy varied across conditions, with some conditions (e.g. cancer) being more difficult for patients to manage on their own.

Another provider emphasised patient counselling, particularly during treatment initiation, should strive to cover patient expectations, guidance towards acceptance and dealing with grief, as well as identification of gaps in patient comprehension of their condition(s).

Healthcare providers recognised the need for patient support with other daily needs like proper and balanced diet, good shelter and livelihood support. However, as a result of very challenging socio-economic circumstances and low literacy levels among patients and family caregivers, providers acknowledged these interfered with proper guidance and patient's self-management.

Patient-provider interactions: facilitators and barriers to engagement in care

To further explore how chronically-ill patients interact with healthcare providers and extent of engagement in care, our survey explored information exchanged during clinic consultations. Questions were asked in three consecutive survey rounds (T2, T3, T4) as illustrated in Figure 1. Less than 40% of patients reported preparing questions prior to consultations (i.e. T2-40%; T3-38%; T4-32%). Over 50% of patients asked providers information related to their treatment (T2-60%; T3-52%; T4-60%). The regularity with which patients discussed personal problems affecting their condition and wellbeing varied (T2-74%; T3-53%; T4-65%). Patients reported healthcare providers often provided general advice related to behaviour modification such as healthy diets, exercise and moderating habits (e.g. smoking and alcohol). However, over 30% of patients reported they never discussed or sought clarification on information written in patient-held records. Over 50% of the patients

reported they never received information/guidance on alternative places where they could access services unavailable at their primary point of care. We found significant differences between HIV and non-HIV patients on the frequency of advice given on moderating habits (T2; $p=0.002$) and alternative places to seek care (T2; $p=0.012$).

During patient interviews and group discussions, several factors were identified that hindered patient's active engagement during clinic consultations (see Supplementary File 3). One factor was the structural set-up of clinics where crowded consultation rooms or 'thin walls' compromised privacy of discussions. The high workload and long queues, especially in public health facilities, impeded on available consultation time and opportunities for extended discussions. Patients reported healthcare providers' attitudes and communication approaches limited their openness towards them, whereby they felt less inclined to ask questions, seek clarification, or actively engage with their providers. In most facilities, group-based health education sessions were offered to compensate for lack of individualised consultation time, but these were reportedly irregular and depended on staff availability.

On the other hand, there were some patients who discussed of how good interpersonal relations and healthcare provider attitudes facilitated positive interactions. This enabling environment made patients feel comfortable to discuss challenges experienced at home (e.g. financial challenges, food shortages), which deterred them from adhering to health advice. In few instances, patients spoke of capitalising on the good rapport with healthcare providers e.g. making personal requests through calls to have drugs sent to them, if patients were unable to attend clinic appointments.

Healthcare providers reported factors in clinic settings that affected their ability to engage patients in care. A common barrier mentioned was absence of training in specific aspects of chronic care, which made providers rely on their pre-service training knowledge, with limited access to informational aides/resources in clinics. Second, the unprepared delegation of health education tasks to non-clinical staff such as health surveillance assistants (HSAs), who in most cases were untrained in NCDs and mental health. Providers' inability to follow-up patients post-consultation (when they failed to show up for appointments) was a barrier identified for close monitoring of patients. Healthcare providers acknowledged their limited capacity to instill requisite skills and knowledge to those surrounding their patients, such as spouses and relatives and who often played an active role in treatment adherence monitoring at home:

...even if we [HSAs] conduct home follow-up visits, some information is hidden away in fear that we [HSAs] told them [patient] to go to the hospital to receive proper treatment and if...they [family caregivers] are not giving the patient medication, it then becomes an issue... [KII07_Female_HSA_Public-PHC]

Taking action in health: patient's self-management practices

The survey examined the extent to which patients incorporated information/advice received during patient-provider interactions in daily practices and control over their health. Survey patients were asked how frequently they engaged in physical exercise or activities – (Table 2). The average time spent walking at baseline (T1) was 57.9 minutes/week, which significantly increased at T2 (86.6 minutes/week, $p=0.001$) and T3 (91.3 minutes/week, $p<0.001$). Time spent stretching and running increased modestly in subsequent rounds ($p<0.013$).

During interviews and discussions, patients reported that although healthcare providers advised on the importance of exercise, they were not necessarily taught what to do. Furthermore, those with physical impairments reported lacking specific instructions on exercise they could still engage in. Patients further reported walking long distances or preferred cycling due to the poor road network and irregular public transport services in the rural district.

With dietary practices, survey respondents indicated consuming vegetables on average 4 times a week and at least had one fruit weekly (Table 3). However, the dependency on rain-fed farming affected seasonality and availability of farm produce, especially fruits and patients could not afford to purchase these from local markets. Patients expressed a desire to gain lessons in food-preparation, as part of nutritional advice. Patients mostly used vegetable oil in their meal preparation, with less than 10% of survey patients reported restricting oil use as advised by healthcare providers.

The proportion of survey patients smoking and drinking alcohol were relatively low, though nearly 20% of patients reported presence of a smoker in their household (Table 3). Our survey assessed whether patients had vital measurements such as blood pressure and blood sugar taken as part of routine health checks. Nearly 50% of patients reported to have regular blood pressure checked but only 10% had their blood-sugar levels checked, hence in general, active routine screening was a challenge for these patients.

Perceptions of support provision by other community-based providers

In this section, we discuss forms of self-management support by other providers, within and outside clinic settings. At household level, patients indicated family caregivers (spouses, children and other relatives) supported in a range of tasks, as discussed in preceding sections. Patients appreciated family caregivers support with household chores such as food preparation, cleaning, finances to meet medical and living costs, emotional and spiritual encouragement, assistance with medication and clinic visits. Overall, survey patients were satisfied with family caregivers support (T1-88.6%; T2-89.1%; T3-77%; T4-94.4%) as demonstrated in Table 4.

The role of community-based organisations

Patients received support in home settings from CBO/FBO volunteers. All patients appreciated home visits by these volunteers, who assisted with domestic chores like fetching water, house cleaning and laundry, food preparation, or bathing patients needing assistance. Volunteers chatted with patients and their family caregivers and provided them with emotional and spiritual encouragement. They exchanged information on general health and well-being, referred sick patients to facility care and encouraged patients to join peer-support groups. Occasionally, they brought along some household items for patients.

The regularity of CBO/FBO support to chronic patients was however constrained by resource challenges; that is, most CBO/FBOs were once recipients of direct funding from national level to support community-based HIV/AIDS activities which ceased in 2015. Hence, they relied on irregular external support from donors/charitable organisations and often worked on a voluntary basis. The increasing absence of ‘tangible’ forms of support and capacity to

provide other support (e.g. psychosocial care) had an impact on patients general perceptions and satisfaction with CBO/FBO services (T1-70.7%; T2-52%; T3-57.5%; T4-69.8%) as shown in Table 4.

The role of peer-to-peer support

HIV expert patients in Malawi, are patients on antiretroviral treatment for several years with high adherence profiles, recruited to assist with HIV services in health facilities, communities and patients homes. Discussions with HIV patients revealed a sense of appreciation of home visits by expert patients, who checked on their wellbeing, provided additional education, encouragement and emotional support. HIV expert patients interviewed mentioned their ability to encourage fellow patients to adhere to treatment by drawing from their own life experiences. They further indicated that through their position, they were better placed to link patients to health facilities and patient-support groups (where they often served in leadership posts) and this contributed to continuity of care for their peers.

In Malawi, patient support-groups are self-formed community-based groups, mostly set-up by patients themselves to provide care and support and mostly focus on HIV patients. Our discussions with patients enrolled in support-groups and observations during HIV patient support-group meetings, pointed to the beneficial role of these groups in patient self-management. Through group interactions, patients gained knowledge and skills on nutrition, living a healthy lifestyle and the “do’s” and “don’ts” on treatment adherence. Group meetings included educational sessions on HIV transmission, viral load suppression and prevention approaches including prevention of mother-to-child transmission and safe sex practices. The educational component was a regular feature since group meetings were organised weekly or

bi-monthly, whereas the provision of information by healthcare providers tended to be constrained, as earlier discussed:

Female: ...we [group members] teach one another...stopping medication or even absconding deliberately is not good...because if we stop taking our medication, may be for 10 days, that is very dangerous, it makes the virus to wake up. When we have received our medication, let us take them as advised... (Support-group meeting_B)

Patient-support groups also adopted innovative approaches to patient problem-solving and stress management. As observed in support-group meetings, these included therapeutic singing with encouraging and educational messages, scripture reading and prayers. Experience sharing through patient testimonials was highly encouraged and in some cases, patients held same-sex brainstorm sessions to discuss intimate issues, proposed strategies to identified problems, which were later presented in joint group sessions for further deliberations. Group members engaged in income-generating activities such as cash-crop farming and members' contribution to savings and loans schemes, to uplift each other financially. Furthermore, HIV support groups networked and linked with other community-based groups like CBO/FBOs and were members of regional patient organisations such as the National Association of People Living with HIV/AIDS in Malawi (NAPHAM).

Despite low membership witnessed in patient-support groups (one-fifth of survey patients), there were high levels of satisfaction with support provided (over 80%) as shown in Table 4. We observed a slow increase in patients joining support groups, which may suggest patients were taking up referral advice or gained interest to join these groups. Common reasons for patients not becoming a member included: the absence of groups for patients with chronic

conditions other than HIV; the lack of awareness/information on requirements for membership; an inability to pay membership contribution; or inability to join due to the physical distance and location of groups. A few patients mentioned they lacked motivation to join, were concerned with disclosure of their disease status, or were too busy to participate in group-based activities (Supplementary File 3).

Considerations for improving self-management support

Diversifying informational channels

Patient education is critical in self-management to improve health-related knowledge and competencies. In this rural context, we explored sources through which patients acquired information about their health/condition, as shown in Table 5. Healthcare providers ranked highly as an information source (T4-85%), followed by self-taught (T4-76%) and family caregivers (T4-65%). HIV patients compared with non-HIV patients relied more on self-taught knowledge ($p=0.01$). Nearly 50% of patients reported learning from individuals in their personal network including religious leaders, CBO/FBO volunteers, friends and from radio/television programmes. However, less than 20% of patients reported learning through patient-support groups, partly explained by the fact these were mainly accessible to HIV patients (one-fifth were members).

Restructuring patient-support groups

In month 12/T4, we explored in FGDs and survey (open-ended questions), patients' perceptions of the value of support groups in self-management and appropriate approaches for establishing support groups to cater for a diverse patient population. Patients gave various recommendations of how support groups could be established or modified. There was

consensus among members and non-members of the potential value of these groups such as positive reinforcement of health advice and instructions, promotion of collective problem-solving approaches and an enabling environment to deal with stress. Furthermore, support groups were perceived to reinforce self-identity, self-esteem, positive living and promote acceptance especially for those dealing with initial disease disclosure challenges. Most patients strongly desired to have these groups provide access to financial support and links to developmental assistance. However, there were mixed responses regarding inclusivity and set-up of patient-support groups. Three of the four patient FGDs mentioned they were in favour of having a common group for patients with multiple conditions, while one group preferred having disease-specific groups (HIV separated from other NCDs). Reasons given for separating groups were linked to minimizing distortion of health messages and the differences in patient treatment regimens and how these conditions manifest would necessitate separate discussions (Supplementary File 3).

DISCUSSION

Our study examined self-management support practices and the facilitation of patient empowerment in patient-provider interactions in both clinical and non-clinical settings, in a rural district in Malawi. While patient empowerment is a lauded practice in chronic disease management (Bodenheimer et al., 2002; Wagner et al., 2001), the implementation of activities promoting such practices in resource-constrained setting, is profoundly challenging but nevertheless undertaken as our findings revealed.

Accepted Article

Patient empowerment is facilitated through appropriate education and productive patient-provider communication (Aujoulat et al., 2007). Our survey highlights mixed practices in information exchange during clinic consultations. Discussions centred around medical aspects and behaviour modification and least on activating patient's role in care; that is the ability to participate in shared decision making and take independent actions to manage their health (Murphy et al., 2015). If patient-centered care values in chronic care are to be realistically promoted in our setting, further adjustments would be required at both interpersonal and organisational levels (Mead & Bower, 2000). Next steps could include increasing health literacy through comprehensive patient education, which takes into account patient's literacy needs and customised messages for a diverse patient population. Second, promoting family caregivers' engagement during consultations to strengthen their agency in healthcare and capacity to closely monitor patients at home. Multiple factors currently influence the inconsistent and unstructured nature of healthcare professionals communication with patients in rural Malawi; that is, to a large extent poor working conditions (absence of educational resources, staffing levels) and providers technical competence. Addressing these challenges, in part, requires more systematised education in chronic care aspects with regular supportive supervision to healthcare professionals, but more importantly, instilling a culture that promotes mutual participation in patient-provider encounters.

Addressing the needs of a growing population with chronic conditions in resource-limited settings like ours requires further strategic emphasis on and investment at primary care level. For instance, through provision and access to routine services such as diagnostics to regularly monitor and take control of patient's health. Chronic disease management requires patient's competency in controlling risk-factors and behavioural modification. This requires improving health promotion efforts that target patients with different informational needs, while

diversifying dissemination channels in community settings. Our study suggests that in this rural setting, patients access and obtain health education through a variety of channels, both formal and informal. Intensifying access to and linkages to community-based self-management resources is of importance. Volunteer-operated CHBC programmes in our setting offered monthly home visits and primarily focused on psychosocial dimensions of care. However, the lack of adequate resources (financial and material) affected the regularity and sustainable provision of such care.

Finally, peer-driven interventions have shown to be effective due to their social embeddedness and capacity to provide emotional, appraisal and information assistance, which is pivotal in patient self-management (Dennis, 2003). Expert patients and patient-support group initiatives in our setting are ‘offsprings’ of HIV programme investments catering to a homogenous patient population. Regular interaction with peers and practical skills, exchanged in a supportive environment, reinforced patient’s self-management competence and their proactiveness in health matters. Although patients expressed desire to join these groups, patient-level factors (such as motivation, awareness) and group composition (membership fee, condition-bound), inhibited patients from benefiting from these resources. While patients valued and gave recommendations to restructure peer-support groups to cater for other chronic conditions, studies elsewhere (Khabala et al., 2015; Stockton et al., 2018; Venables et al., 2016), caution that efforts towards consolidation of peer-support groups should take care of potentially sensitive issues; such as dealing with stigma and disclosure, or unintentional divisions that may emerge due to preferential treatment for certain patient groups (Men et al., 2012).

Limitations

Limitations inherent to our design requires caution in the transferability and interpretation of findings to other contexts. By sampling chronically-ill patients from CHBC programmes, our study may have missed perspectives of patients in community settings receiving standard care. Although our sub-group analysis by patient groups (102 HIV vs 38 non-HIV) was not equally matched, evidence from our descriptive analysis points to the stark contrast in the absence of fully-functional general health services compared with well-resourced disease-specific interventions such as the HIV programme. Whilst our descriptive analysis may have restricted reporting of possible confounders, this analysis enabled us to describe patterns in our dataset. Through triangulation with qualitative data, we were able to provide a detailed description of self-management support practices and their influence on self-management behaviour in a resource-constrained setting. The availability of validated tools to assess patient empowerment and more broadly self-management outcomes, from western settings, requires further cross-cultural studies to validate these tools in non-western settings.

CONCLUSION

This study contributes to a better understanding of self-management support and patient empowerment for chronic conditions in a rural African setting. The interplay between patient-level factors, care providers competence and exposure to and receipt of self-management support resources were key determinants to realising patient empowerment in chronic care. Further research is needed on reconceptualising patient empowerment dimensions, particularly in contexts of resource-constrained public health systems with an increasing chronic disease burden, which could contribute to shaping better clinical care and practices.

CONFLICT OF INTEREST

The authors declare they have no competing interests.

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TABLES

Table 1: Characteristics of respondents

DEMOGRAPHIC CHARACTERISTICS	Baseline survey	Patient IDI	HIV expert patient IDI	Patient FGD	Healthcare providers IDI
TOTAL	140	10	4	4 (n=31)	13
Gender	38 (27.1) males	5 males	3 males	11 males	7 males
	102 (72.9) females	5 females	1 females	20 females	6 females
Median age (range)	42 (20-84)	42 (35-70)	43 (33-47)	54 (29-73)	42 (26-55)
Patient conditions n (%)					
<i>HIV (all)</i>	102 (72.9)	6	4	19	
1) <i>HIV only</i>	85 (83.3)	5	2	11	
2) <i>HIV with comorbidities</i>	17 (16.7)	1	2	8	
<i>Hypertension</i>	32 (22.9)	1	0	5	
<i>Epilepsy & other mental health conditions</i>	10 (7.1)	1	0	2	
<i>Asthma</i>	7 (5)	0	0	4	
<i>Stroke</i>	4 (2.9)	1	0	0	
<i>Cancer</i>	3 (2.1)	0	0	1	
<i>Diabetes</i>	2 (1.4)	1	0	0	
<i>Heart condition</i>	1 (0.7)	0	0	0	
Chronic conditions n (%)					
1 condition	120 (85.7)	6	2	22	
2 conditions	15 (10.7)	4	2	8	
3 conditions	5 (3.6)	0	0	1	
Education n (%)					
<i>No schooling</i>	17 (12.1)	2	0	3	
<i>1-5 years primary school</i>	74 (52.9)	2	0	20	
<i>6-8 years primary school</i>	39 (27.9)	4	2	8	
<i>Secondary (in)complete</i>	9 (6.4)	1	2	0	1
<i>College/tertiary and above</i>	1 (0.7)	1	0	0	12
Occupation n (%)					
<i>Farming</i>	71 (50.7)	5	0	9	
<i>Casual labourer/trader</i>	43 (30.7)	2	0	15	

DEMOGRAPHIC CHARACTERISTICS	Baseline survey	Patient IDI	HIV expert patient IDI	Patient FGD	Healthcare providers IDI
<i>Unemployed (unable to work)</i>	13 (9.3)	2	0	0	
<i>Other (e.g. domestic worker)</i>	10 (7.1)	1	0	7	
<i>Public/private sector worker</i>	3 (2.1)	0	4	0	
<i>Health worker (e.g. nurses)</i>	-	-	-	-	6
<i>Health manager (senior staff)</i>	-	-	-	-	7
CBO/FBO site and participants n (%)					
FBO A	61 (43.6)	2	1	2 (n=14)	
CBO B	28 (20)	2	1	1 (n=7)	
CBO C	27 (19.3)	2	0	-	
CBO D	24 (17.1)	2	1	1 (n=10)	
FBO E	-	2	1	-	

NOTES

CBO: community-based organisation; FBO: faith-based organisation; FGD: focus-group discussion; IDI: in-depth interview

Table 2: Patient self-reported exercise

Physical activity (minutes/week)	Range	Score	Baseline	Month 3	<i>p-value</i>	Month 6	<i>p-value</i>	Month 12	<i>p-value</i>
			T1 (n=140)	T2 (n=128)	(T1-T2)	T3 (n=129)	(T1-T3)	T4 (n=126)	(T1-T4)
Walking	0 – 180	Mean	57.94	86.6		91.28		72.82	
		(SD)	(56.9)	(63.5)	0.0001*	(52.7)	0.000*	(48.5)	0.045
		Median	45	15		120		45	
Cycling	0 – 180	Mean	24.28	41.37		33.26		27.38	
		(SD)	(51.6)	(63.8)	0.014	(54.8)	0.235	(50.2)	0.423
		Median	0	0		0		0	
Stretching	0 – 180	Mean	9.07	15.82		23.14		14.29	
		(SD)	(19.2)	(15.7)	0.000*	(25.3)	0.000*	(13.5)	0.000*
		Median	0	15		15		15	
Running	0 – 180	Mean	1.29	8.91		12.09		9.24	
		(SD)	(5.2)	(25.0)	0.0004*	(28.4)	0.000*	(19.4)	0.000*
		Median	0	0		0		0	
Ball games	0 – 180	Mean	3.64	4.92		5.04		7.86	
		(SD)	(21.4)	(21.9)	0.539	(25.5)	0.375	(27.6)	0.031
		Median	0	0		0		0	
Swimming	0 – 180	Mean	1.19	1.99		1.74		3.1	
		(SD)	(6.8)	(14.9)	0.492	(6.7)	0.081	(10.1)	0.060
		Median	0	0		0		0	
Dancing	0 – 180	Mean	2.46	7.85		11.05		8.4	
		(SD)	(7.8)	(29.6)	0.845	(24.8)	0.000*	(21.7)	0.011*
		Median	0	0		0		0	

NOTES

Wilcoxon signed rank test performed due to asymmetrical data distribution

**Statistical significance level at Bonferroni-adjusted p-value ($p < 0.0125$)*

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Table 3: Patient self-reported diet, habits and routine health checks

Dietary status		T1 (n=140, %)	T2 (n=128, %)	T3 (n=129, %)	T4 (n=126, %)
<i>Days of vegetable intake per week</i>	<i>Mean (SD)</i>	4.25 (1.9)	4.35 (1.8)	4.1 (1.7)	4.85 (1.7)
<i>Days of fruit consumption per week</i>	<i>Mean (SD)</i>	1.89 (2.1)	1.46 (1.8)	2.05 (2.1)	2.83 (2.3)
Oil used in meal preparation		T1 (n=140, %)	T2 (n=128, %)	T3 (n=129, %)	T4 (n=126, %)
<i>Vegetable oil</i>		136 (97.1)	109 (85.2)	119 (92.2)	117 (92.9)
<i>None (medical advice)</i>		4 (2.9)	15 (11.7)	10 (7.8)	9 (7.1)
<i>None (cannot afford)</i>		0	3 (2.3)	0	0
<i>Animal fat</i>		0	1 (0.8)	0	0
Tobacco and alcohol use (Yes response)		T1 (n=140, %)	T2 (n=128, %)	T3 (n=129, %)	T4 (n=126, %)
<i>Does anyone in the household smoke?</i>		28 (20)	30 (23.4)	17 (13.2)	22 (17.5)
<i>Do you currently smoke?</i>		11 (7.9)	7 (5.5)	6 (4.7)	7 (5.6)
<i>Do you currently drink alcohol?</i>		16 (11.4)	5 (4)	11 (8.5)	7 (5.6)
Routine health checks (Yes response)		T1 (n=140, %)	T2 (n=128, %)	T3 (n=129, %)	T4 (n=126, %)
<i>Have you had your blood pressure measured in the past 3 months?</i>		82 (58.6)	63 (49.2)	62 (48.1)	64 (50.8)
<i>Have you had your blood sugar measured in the past 3 months?</i>		14 (11)	9 (7.14)	14 (10.9)	13 (10.4)

Table 4: Perceptions of support from community-based providers

	T1 (102 HIV, 38 non-HIV)			T2 (90 HIV, 38 non-HIV)			T3 (91 HIV, 38 non-HIV)			T4 (88 HIV, 38 non-HIV)		
	HIV	Non-HIV	Total (%)	HIV	Non-HIV	Total (%)	HIV	Non-HIV	Total (%)	HIV	Non-HIV	Total (%)
How would you rate the level of care/support from family?												
1. Good	87.4%	91.9%	88.6	89%	89.2%	89.1	73.7%	83.8%	77	94.3%	94.7%	94.4
2. Indifferent/not good	12.6%	8.1%	11.4	11%	10.8%	10.9	26.3%	16.2%	6.5	5.7%	5.3%	5.6
			<i>p=0.6</i>			<i>p=0.6</i>			<i>p=0.2</i>			<i>p=1</i>
CBO home visits in <30 days at time of survey **												
None (0)	1%	5.4%	2.1	9.9%	18.9%	12.5	40.7%	47.4%	42.6	37.5%	36.8%	37.3
1 – 2 visits	89.3%	89.2%	89.3	64.8%	56.8%	62.5	41.8%	34.2%	39.5	39.8%	57.9%	45.2
3 or more visits	9.7%	5.4%	8.6	25.3%	24.3%	25.0	17.6%	18.4%	17.8	22.7%	5.3%	17.4
			<i>p=0.2</i>			<i>p=0.4</i>			<i>p=0.7</i>			<i>p=0.04</i>
Overall satisfaction with CBO support												
1. Satisfied	68.9%	75.7%	70.7	53.9%	40.5%	50	55.6%	62.2%	57.48	71.6%	65.8%	69.84
2. Indifferent/not satisfied	31.1%	24.3%	29.3	46.2%	59.5%	50	44.4%	37.8%	42.52	28.4%	34.2%	30.16
			<i>p=0.4</i>			<i>p=0.2</i>			<i>p=0.5</i>			<i>p=0.5</i>
In a patient support group (HIV patients)	18 (12.9%)			21 (16.4%)			31 (24.0%)			30 (23.8%)		

Overall satisfaction with patient support group (members only)					
1. Satisfied	17 (94%)		17 (81%)		26 (94%)
2. Indifferent/not satisfied	1 (6%)		4 (19%)		2 (6%)
					28 (93%)
					2 (7%)

NOTES:

***At baseline visit (T1), number of CBO/FBO home visits was calculated as period between initial enrolment and baseline survey date.*

Chi-square test statistical significance level at Bonferroni-adjusted p-value ($p < 0.0125$).

There was weak evidence to support any differences between the provision of support and perceived satisfaction among HIV and non-HIV patients.

Table 5: Sources of knowledge/information in order of most commonly mentioned*

Information source	Most times			Sometimes			No/never			Fischer's exact (p<0.05)*
	HIV (%)	Non-HIV (%)	Total (%)	HIV (%)	Non-HIV (%)	Total (%)	HIV (%)	Non-HIV (%)	Total (%)	
1. Healthcare providers	51.1	42.1	48.4	37.1	36.8	37.3	11.4	21.1	14.3	0.33
2. Self/self-taught	23	15.8	20.8	60.9	42.1	55.2	16.1	42.1	24	0.01*
3. Family members	12.5	18.4	14.3	47.7	57.9	50.8	39.8	23.7	34.3	0.2
4. Radio/TV	12.6	13.2	12.8	48.3	36.8	44.8	39.1	50	42.4	0.5
5. Religious leaders	14.9	15.8	15.2	35.6	36.8	36	43.9	47.4	48.8	1.0
6. CBO/FBO	9.1	10.5	9.5	48.9	47.4	48.4	42.1	42.1	42.1	0.96
7. Peers/ friends	4.56	10.8	6.4	43.2	43.2	43.2	52.3	46	50.4	0.4
8. Neighbours	0	5.3	1.6	35.2	39.5	36.5	64.8	55.3	61.9	0.11
9. Support groups	13.8	2.6	10.4	12.6	2.6	9.6	73.6	94.7	80	0.03*
10. NGOs	4.6	5.3	4.8	17.1	5.3	13.5	78.4	89.5	81.8	0.2
11. Community leaders	2.3	2.6	2.4	25	21.1	23.8	72.7	76.3	73.8	0.92

NOTES:

*Data derived from month 12/T4 survey with 126 respondents (88 HIV and 38 non-HIV)

Figure 1: Information healthcare providers discuss with patients

