

Chronic Disease Stigma, Skepticism of the Health System, and Socio-economic Fragility: Qualitative Assessment of Factors Impacting Receptiveness to Group Medical Visits and Microfinance for Non-Communicable Disease Care in Rural Kenya

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Research

Keywords: group medical visits, microfinance, hypertension, diabetes, qualitative inquiry

DOI: <https://doi.org/10.21203/rs.3.rs-47902/v1>

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Abstract

Background: Non-communicable diseases (NCDs) are the leading cause of mortality in the world, and innovative approaches to NCD care delivery are being actively developed and evaluated. Combining the group-based experience of microfinance and group medical visits is a novel approach to NCD care delivery that has demonstrated beneficial impact in previous pilot studies. However, the contextual factors, facilitators, and barriers impacting wide-scale implementation of these approaches within a low- and middle-income country setting are not well known.

Methods: Two types of qualitative group discussion were conducted: 1) *mabaraza* (singular, *baraza*), a traditional East African community gathering used to discuss and exchange information in large group settings; and 2) focus group discussions (FGDs) among rural clinicians, community health workers, microfinance group members, and patients with NCDs. Trained research staff members led the discussions using structured question guides. Content analysis was performed with NVivo using deductive and inductive codes that were then grouped into themes.

Results: We conducted 5 *mabaraza* and 16 FGDs. A total of 205 individuals (113 men and 92 women) participated in the *mabaraza*, while 162 individuals (57 men and 105 women) participated in the FGDs. Participants expressed interest in participating in microfinance and group medical visits, but cited several key challenges: 1) stigma of chronic disease, 2) earned skepticism of the health system, and 3) socio-economic fragility.

Conclusions: Our qualitative study revealed and illuminated actionable factors that could impact the success of implementation of group medical visits and microfinance initiatives for NCD care. While several challenges were highlighted, participants also felt that planned interventions could address and mitigate the impact of these dynamic factors. We anticipate that our approach and analysis provides new insights and methodological techniques that will be relevant to other low-resource settings worldwide.

Trial Registration: Clinicaltrials.gov, [NCT02501746](https://clinicaltrials.gov/ct2/show/study/NCT02501746), registration date: July 17, 2015

Contributions To The Literature

1. Combining the group-based experience of microfinance and group medical visits is a novel approach to NCD care delivery.
2. Our qualitative study revealed that stakeholders in western Kenya were interested in microfinance and group medical visits, but cited several key challenges: 1) stigma of chronic disease, 2) skepticism of the health system, and 3) socio-economic fragility.
3. This type of formative work helps to illuminate factors that can positively and negatively impact the remainder of the implementation science study.
4. Our methods included novel qualitative approaches (e.g. *mabaraza*, traditional community gatherings) and involved multiple stakeholder groups, allowing us to triangulate multiple

perspectives.

Background

Non-communicable diseases (NCDs) are the leading cause of mortality in the world, with 80% of this burden occurring in low- and middle-income countries (LMICs) (1). Innovative approaches to NCD care delivery are being actively developed and evaluated. In particular, there is increasing recognition that social determinants of health need to be incorporated into care delivery, in order to simultaneously address socio-economic as well as health issues (2, 3).

One potentially promising approach includes microfinance (MF) initiatives, which are financial services targeted at individuals, groups of individuals, or small businesses, to provide individuals with access to saving mechanisms and loan opportunities (4–7). MF activities have been shown to reduce poverty and improve health outcomes (8). Another innovative care delivery approach is the group medical visit (GMV), which is a clinical encounter involving a group of patients, and has been shown to increase the efficiency of care delivery, quality of care, enhance social support, and encourage self-efficacy (9, 10). Combining the group-based experience of MF with a GMV is a novel approach to NCD care delivery that has demonstrated beneficial impact in a small pilot study in western Kenya (11). However, the contextual factors, facilitators, and barriers impacting wide-scale implementation of these approaches within an LMIC setting are not well studied.

The Bridging Income Generation with Group Integrated Care (BIGPIC) study in western Kenya is evaluating the impact of MF and GMVs on cardiovascular risk reduction among individuals with and at increased risk of diabetes.(12) The formative phase of this study aimed to identify the contextual factors, facilitators, and barriers that may impact the success this approach. In this paper, we report the results of that pre-implementation formative inquiry.

Methods

Setting

The Academic Model Providing Access to Healthcare (AMPATH) is a partnership between Moi University College of Health Sciences, Moi Teaching and Referral Hospital (both in western Kenya), and a consortium of North American academic medical centers (13). AMPATH established a system of care delivery for HIV patients in 2001. Subsequently, in response to the growing burden of chronic disease (particularly diabetes and hypertension) within the population (14), expanded its clinical scope to include primary health care and chronic disease management serving a catchment area of over 4 million people (15). The chronic disease management program primarily provides health facility-based care for patients with diabetes and hypertension.

Participants and procedures

For this qualitative study, community members were invited to join *mabaraza* (singular, *baraza*), a traditional East African community gathering used to discuss and exchange information regarding a variety of topics and issues in large group settings (16). In addition, we conducted focus group discussions (FGDs) of 10–15 participants each, among people with shared characteristics (e.g. rural clinicians, community health workers, microfinance group members, and patients with chronic diseases). Structured question guides were developed to include content related to experience of chronic disease care, perceptions of MF and GMVs, and factors that might impact joining and remaining in groups. These question guides were pilot-tested on community members, patients, and clinicians prior to being used in the qualitative sessions. Trained research staff members led the discussions in English and Kiswahili, as was appropriate for the participants.

Sessions were audio-recorded, transcribed, and translated to English. Content analysis was performed with NVivo using deductive and inductive codes that were then grouped into themes. A kappa score of > 0.90 was established as the threshold to ensure inter-rater reliability among three independent coders (RD, CL, MN). The Standards for Reporting Qualitative Research checklist was completed (Additional File) (17).

Results

In total, 21 qualitative sessions (5 *mabaraza* and 16 FGDs) were conducted in 11 distinct geographic regions in western Kenya. A total of 205 individuals (113 men and 92 women) participated in the *mabaraza*, while 162 individuals (57 men and 105 women) participated in the FGDs. Participants expressed interest in participating in MF/GMV programs, but cited several key challenges. Specifically, participants described stigma of chronic disease, earned skepticism of the health system, and socioeconomic fragility as major barriers to MF and GMVs for NCDs.

Stigma of Chronic Disease

Participants noted that, specific to NCDs, there was the potential for stigma and being considered a distinct 'other,' characterized by undesirable status or negative stereotypes. For example, some participants described patients with hypertension as lacking motivation to improve or get better. With respect to group-based MF or GMV, there was concern that membership in the group would lead to being labeled as "sick" and potentially "inferior."

Maybe the disadvantage can come in the form of stigma where outsiders can christen the group the title 'people with pressure,' the group would be known by such a title.

Conversely, some participants expressed optimism that participation in MF or GMV could increase a sense of "belonging," acceptance, and social cohesion, which could counter the potential for negative stigma.

There is also stigma reduction when they are in groups, someone feels that they are not alone with this condition.

Skepticism of the Health System

Skepticism of the health system was described regarding both the overall quality of care provided, as well as trust in clinical providers. Much of this skepticism was grounded in participants having had previous negative experiences with the health system and clinicians. Participants reported experiencing a lack of respect, verbal abuse, and not getting adequate or comprehensive services.

There was a time I was taken there it's like I saw the devil with my naked eyes! The kind of verbal abuse you get there! And also beating! You will be very surprised ... until I wondered and decided if this was a hospital facility really.

The problem affecting the community, most people are afraid of going to hospital, the way of approach, the way the doctor communicates, the way he starts, let alone serving you, the way he enters and welcomes you contributes for a person to fear the doctor.

There were some notable differences in previous experiences in the public vs. private sector, but neither sector was free from criticism or concern. For instance, participants reported that in the private sector, doctors' actions are felt to be driven by money and commercial interests, and they might not have patients' best interests at heart. In contrast, public-sector health providers who are paid a salary are not incentivized to provide services for the purposes of making more money. These providers were described as being "serious" and "more professional." However, participants also reported the opposite experience, where private-sector providers were seen as providing higher quality care because they are incentivized to treat patients better in order to increase their income, in contrast to public doctors who are not necessarily incentivized to provide quality care in this way. Private sector health facilities were also viewed as being more efficient and clean, but more expensive than the public sector, which was described as being less expensive but of poor quality.

I am not paid according to the patients I serve, if I treat just one or two I will still get my salary.

Some like private [facilities] because of the fast services. When you reach there it does not take time even though it is a bit expensive but your time will be shorter.

GMV, in particular, and MF were felt to have the potential to lead to increased clinician engagement and accountability. Given that a group of patients would be together for a GMV, participants felt that the clinician would be more responsive, more respectful, and more accountable.

I also support a group, is very important because it will make the doctor to work harder, unlike one by one.

In addition, it was felt that MF and GMV would increase both social and instrumental support with respect to access to care. Specifically, the group-based format could serve as an avenue for advocacy

and for increasing the confidence to advocate on behalf of oneself and other group members.

When they are together and they teach each other they also motivate themselves, and the groups will help them if there are other needs. They can get money in the groups [...] or maybe there is a certain drug missing and they can get to work with the doctor and tells them it is this amount so they can go as a group and bargain for the cost to go down.

Socio-Economic Fragility

Study participants described a nearly all-encompassing sense of socioeconomic fragility that adversely impacted the entire care cascade, from being screened to seeking care to affording medications to completing follow-up visits. For example, lack of access to medicines due to cost was considered a major barrier to experiencing positive health outcomes.

When asked, 'Why didn't you come early?' They say, 'I was trying to look for money.'

In addition, poor health and unplanned illness were felt to further exacerbate an individual's and family's economic strain due to the cost of medical care, as well as lost wages.

Diseases don't tell when they come. It can be even at night. Now at night, where will you go to look for money—nowhere. Your work is to wait till morning for you to go and borrow.

That time when you are sick, the time you go to the hospital it means, like if you have the jobs that you do, you will not progress, so when you see you are just at the hospital, your income has stopped because you will not be working.

Socio-economic fragility was felt to worsen the impact of previously described stigma and health system skepticism. Participants reported that challenges with health care access due to affordability would adversely affect both real and perceived quality of care received by patients. In a negatively reinforcing cycle, the poorer quality of care would exacerbate health system skepticism, leading to lower healthcare utilization, delayed care-seeking, and lower adherence to medical advice, resulting in even worse health outcomes.

The combination of GMV and MF were felt to hold promise for addressing this socio-economic fragility. MF was felt to directly increase liquidity and purchasing capacity, and indirectly to improve overall income-earning potential. In addition, GMV was felt to potentially increase social support and thereby increase motivation and capacity for economic improvement.

Group is good because when the money gets to the table we are happy even though you don't own [it] all but we can divide equally and use them for hospital expenses.

When you are together, you will find that your colleague is better off and you give yourself hope. You now get energized. Now, another time you come together, you may find that another colleague has changed a bit and improved. As time goes by, you will find that every member in the group becomes strong.

Discussion

In this qualitative study from western Kenya, we found that chronic disease stigma, skepticism of the health system, and socio-economic fragility were all factors that could impact the potential implementation success of GMV and MF for patients with diabetes and hypertension (Figure). Importantly, all three factors were reported as potential barriers for any NCD program and were based on historical experiences that did not necessarily include previous exposure to GMV or MF. Conversely, participants also felt that GMV and MF could potentially address and mitigate the impact of these dynamic factors.

Stigma has commonly been associated with infectious diseases such as HIV, and HIV-related stigma and discrimination have been well established as barriers to accessing HIV prevention, treatment, and support services (18). Our group has previously reported that co-locating hypertension management in the same facility as HIV care can present challenges due to HIV-related stigma (19). However, in the current study, participants described NCD-specific stigma that could act as a barrier to care. Others have reported that individuals with NCDs feel like they are blamed for their own illness by community members and health care workers (20). In particular, individuals who anticipated greater stigma from health care workers have been found to be less likely to access health care due to the prior negative experiences (21). Specific to the group-based GMV and MF activities proposed in this study, stigma may lead to fear of joining a patient group because being linked to the group may be associated with negative stereotyping, lower social status, and discrimination.

Stigma related to health care workers' attitudes towards patients with NCDs may contribute to the health system skepticism described by participants, as described above. In addition, participants reported instances of verbal abuse and lack of being respectfully treated by health care staff. Perceived low quality of care has been corroborated by empirical data indicating poor quality of care in LMICs (22). The adverse experiences described by our participants led to skepticism, lack of confidence, and lack of trust in the health system, which again has been widely reported in other parts of the world (23). Unfortunately, mistrust in clinical providers can lead to lower adherence to medical advice and subsequent poor health outcomes (24, 25). Skepticism of the health system has also been associated with lower health care utilization, lower rates of adoption of prevention interventions, and higher rates of unhealthy behaviors (26). This self-perpetuating, negatively reinforcing cycle yields adverse outcomes for individuals, populations, and health systems (27). Thus, it is imperative to break this cycle by improving quality of care, re-gaining trust of patients and community members, and disseminating these successes to the broader population.

Socio-economic fragility, in our population, appeared to exacerbate the potential negative sequelae of stigma and health care skepticism. Low socio-economic status is known to be associated with increased morbidity and mortality, although the mechanisms responsible for this are not fully established (28). In Kenya specifically, it has been demonstrated that poorer households in rural areas are more likely to experience catastrophic out-of-pocket expenses, primarily related to payments for outpatient services

(29). At the societal level, socio-economic inequality is associated with disparities in NCD burden (30). In our setting, all of the above dynamics appeared to be relevant. We have previously described substantial levels of material deprivation and lack of health insurance in western Kenya (31), thus lending support to care delivery models, such as BIGPIC, that incorporate social determinants of health into clinical care (11).

Participants in general felt that, despite the barriers presented by stigma, skepticism, and socio-economic fragility, the combination of GMV and MF could potentially address those barriers and be successful despite those factors. Given that this qualitative inquiry was the formative component of a larger implementation research trial (12), we have been vigilant to incorporate the findings from this inquiry into the design of the BIGPIC intervention using a stakeholder-based, human-centered design process (32). At the same time, we recognize that our planned intervention will not be able to fully solve all of the potential issues, such as poverty and lack of health insurance. We are therefore heartened by the rollout and scale-up of universal health coverage programs in Kenya and other LMICs, which will provide much-needed financial risk protection for these populations (33).

We acknowledge the following limitations of our study. First, while we attempted to involve multiple stakeholder groups, it is likely that not all stakeholder perspectives were fully represented in this qualitative study. The overall BIGPIC project has other components that involve stakeholder engagement, such as the human-centered design process, in order to secure broader and deeper stakeholder participation throughout the implementation research project. Second, we recognize the potential for limited generalizability, since we recruited participants from specific geographic areas in western Kenya. Several of the salient themes, however, are consistent with findings from literature arising from other geographies, as discussed above, thus indicating that elements are indeed relevant for similar settings worldwide. Third, we did not record individual-level demographic information for the quotations and transcript. However, we view the themes as arising from a collective discussion, not necessarily from any one specific individual.

Conclusions

NCDs are the leading cause of mortality in the world, and there is increasing recognition of the need to simultaneously address socio-economic as well as health issues in NCD management. Qualitative inquiry, as we have conducted in this study, is helpful to reveal and illuminate factors that may positively and negatively impact implementation success. The factors highlighted in our analysis—chronic disease stigma, skepticism of the health system, and socio-economic fragility—have clearly informed the design, development, and implementation of our group-based GMV and MF strategies for optimizing NCD management in western Kenya. We anticipate that our approach and analysis provides new insights and methodological techniques that may be relevant to other low-resource settings worldwide.

Abbreviations

AMPATH
Academic Model Providing Access to Healthcare
BIGPIC
Bridging Income Generation with Group Integrated Care
FGD
Focus group discussion
GMV
Group medical visit
LMICs
Low- and middle-income countries
MF
Microfinance
NCDs
Non-communicable diseases

Declarations

Ethics approval and consent to participate:

Ethics approval was obtained from NYU Grossman School of Medicine Institutional Review Board, Icahn School of Medicine Institutional Review Board, and Moi University Institutional Research and Ethics Committee. All participants provided verbal informed consent prior to participating in the study.

Consent for publication:

Not applicable

Availability of data and materials:

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request. This study complies with the NIH Public Access Policy, which ensures that the public has access to the published results of NIH funded research, and therefore, all results have been (and will be made) available from final peer-reviewed journal manuscripts (including this one) via the digital archive PubMed Central upon acceptance for publication.

Competing interests:

The authors declare that they have no competing interests

Funding:

Research reported in this publication was supported by the National Heart, Lung, and Blood Institute of the National Institutes of Health under award number R01HL125487. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Contributions

to the literature

Acknowledgements:

The authors wish to thank the BIGPIC research team for incredible work and passion, and for all study participants for devoting their time and energy that led to this manuscript.

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Figures

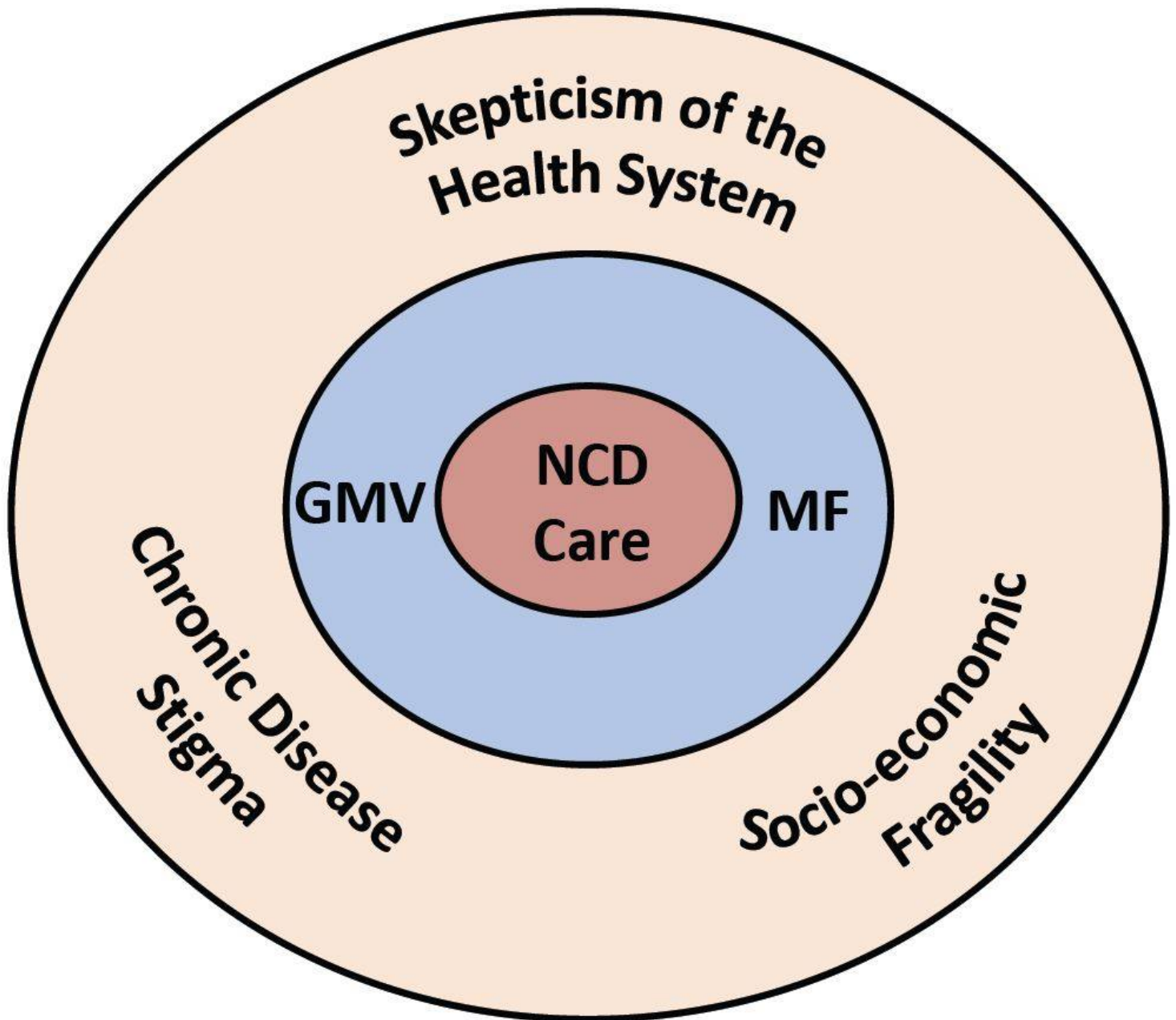


Figure 1

Conceptual representation of challenges to NCD care that can be mitigated by GMV and MF.

Supplementary Files

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