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SOCIOLOGY | RESEARCH ARTICLE

“This book is my life...”: A qualitative feasibility study on the use of a self-management support tool

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Abstract: As self-management support is a cost-effective way to enable patients to take an active role in managing their own condition and to address the chronic disease burden, there is a need for contextually appropriate self-management support tools. This study explored the feasibility of using a contextually adapted self-management care-plan booklet for diabetes and hypertension for use in medical consultations in a middle-income country. Focus groups and individual interviews with patients and health care providers were conducted in three primary health care facilities. Four relevant focus areas for feasibility studies were used as the lens for data analysis: acceptability, demand, implementation, practicality. The study revealed a high acceptance of the care-plan booklet by both patients and providers. Patients reported that the booklet increased their knowledge of their conditions. They also indicated that they would share the booklet with friends and families and expressed the need to use it with their providers. Providers mentioned that community health workers and health promoters could play an important role

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The work reported in this paper is part of the wider and phased Ph.D. project for Dube that focused on educational approaches and conditions for the implementation of self-management education for patients with chronic diseases in South Africa. Three other peer-reviewed papers on self-management support in developing countries have been published in international journals.

PUBLIC INTEREST STATEMENT

Diabetes and hypertension are chronic diseases increasingly affecting people in developing countries. Self-management and education support can lead to an improvement in the way patients manage their conditions and to improved health outcomes. Despite this evidence, self-management support programmes are rare or non-existent in developing countries. Where they do exist, they often lack contextual integration. This study sought to develop a contextually adapted self-management support tool to be used in medical consultations and to assess the feasibility of integrating it into the health system of a developing country. Data was collected from patients and health care providers by means of focus groups and individual interviews. Both participant groups accepted the booklet. Patients referred to the interaction it enabled with providers and an increase in their own knowledge. The findings of this study contribute to the knowledge base of self-management support tools in South Africa.

in implementing the tool. The findings of this study contribute to the knowledge base needed for the development and adoption of the self-management component of the South African integrated chronic diseases model. The care-plan booklet can be used to stimulate the interaction between patients, providers and/or family and friends.

Subjects: Health Promotion; Education; Behavioural Sciences; Social Sciences

Keywords: cultural adaptation; self-management; diabetes; hypertension; feasibility study; South Africa

1. Introduction

As non-communicable diseases (NCDs) continue to rise globally, it is crucial for health care systems to shift to partnership models of care, with a focus on patient self-management in which patients take up active roles in the management of their disease(s) (Bodenheimer, Lorig, Holman, & Grumbach, 2002; de Silva, 2011; Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997). An extensive literature shows that chronic disease self-management education and support by health providers is cost effective and improves the way patients manage their conditions, which helps to improve population health (Cunningham, 2016; de Silva, 2011; Mills, Brady, Jayanthan, Ziabakhsh, & Sargious, 2016). However, one of the challenges for self-management support programmes is their implementation in underserved communities, where such programmes are often non-existent or less well organized. Even when programmes are available through health centres, the specific individual needs of chronic patients related to their social environment and cultural background are often neglected (Mills et al., 2016).

This is also the case in developing countries, where the burden of disease is shifting from infectious to chronic disease because of the transition from traditional to western lifestyles (Levin-Zamir et al., 2016). However, chronic disease self-management has not kept up pace with this trend (Puoane, Tsolekile, Sanders, & Parker, 2008). Most existing self-management education programmes and materials have been developed in western countries, and are not necessarily sensitive to the needs of communities in developing countries. Systematic reviews on self-management education in high- and low-mortality developing countries suggest that self-management education can be effective in changing behaviour and improving glycated haemoglobin (HbA1c) and fasting blood glucose (Baradaran, Shams-Hosseini, Noori-Hekmat, Tehrani-Banihashemi, & Khamseh, 2010; Dube, Van Den Broucke, Housiaux, Dhoore, & Rendall-Mkosi, 2015; Lou, Wu, Dai, Cao, & Ruan, 2011; Rawal et al., 2012). Western self-management programmes need to be adapted to the socio-economic and cultural contexts and materials must be tailored to conform to the cultural aspects of the target population.

To find out if adaptations of programmes take the cultural context into account sufficiently, feasibility studies can be undertaken. Knowledge about the feasibility and acceptability of an intervention does not guarantee its effectiveness, but can increase the possibility of an intervention being liked, comprehended, credible, accepted, and remembered by the users, thereby enhancing the probability of effectiveness. The aim of this study was to explore the feasibility of using a contextually adapted individual care-plan booklet as a self-management support tool for diabetes and hypertension during medical consultations in a South African community. The experiences and views of patients and health care providers were elicited to assess the feasibility of the tool's implementation. In our literature search, we could not find another study that has systematically evaluated the feasibility of the use of a self-management support tool for chronic patients in a developing country.

1.1. The intervention

The intervention involved a prototype care-plan booklet in A5 format for use by health care providers and diabetic and/or hypertensive patients during medical consultations. The contents

Table 1. Contents of the prototype booklet

- How to use the booklet
- Glossary of terms (with translations in Zulu and Sepedi)
- Making most of the medical consultation (tips for patients)
- Information on diabetes and hypertension
 - definition
 - physiology
 - signs and symptoms
 - complications
 - health education messages
- Lifestyle change messages
- Body mass index table
- Preparing for the consultation
 - tables for recording vital signs by health care providers
 - tables for use in provider-patient consultation
- Spaces for referral notes
- General notes by health care provider
- Pocket for appointment card at the inside back cover
- Emergency telephone numbers on outside back cover

of the booklet (Table 1) was informed by several already existing pamphlets on specific disease conditions (Curohealth, 2015; Department of Health South Africa, n.d. a, n.d.b) and by the results of a previous study among the same target population (Dube, Van Den Broucke, Bergh, Mafutha, & Rendall-Mkosi, 2017). The latter study showed that patients did not have an opportunity to prepare questions for a consultation with the provider, had no means to record the advice of the physician, and did not have a take-home individual care plan. Providers did not have enough educational materials to support patients in the self-management of their disease (Dube et al., 2017). A first draft of the booklet was circulated to different stakeholders for inputs, after which the prototype booklet was finalised in English, one of the official South African languages and the language of schooling. Figure 1 is an example of the page describing what the booklet is for and how to use it.

2. Materials and methods

A qualitative study design was used to explore the views and perspectives of the participants on the feasibility of using an individual care-plan booklet integrated in the consultations with providers. The study aimed to answer the question if the instrument could work, and more particularly to understand how the use of the booklet could fit with the daily-life activities of providers and patients (Bowen et al., 2009).

2.1. Sampling and recruitment

The study was conducted in three community health care facilities and had two distinct groups of participants: an intervention group and a “comments-only” group that did not use the booklet in consultations. The intervention group consisted of diabetic and hypertensive patients and health care providers (nurses and doctors) recruited from an urban community health centre (CHC). Providers in this group were trained on using the booklet with patients in existing consultations. The comments-only group was comprised of diabetic and hypertensive patients and providers (doctors, nurses, dieticians and health promoters) in a CHC in a rural setting and an urban primary health care clinic. They were asked to comment on the content and possible use of the booklet. The reason for including a comments-only group was to elicit a wider variety of views, as it was not practically possible to include more sites and participants in the intervention group.

Figure 1. Example of a page from the prototype booklet.

DRAFT PROTOTYPE

What is this booklet about?

This booklet is for people with type 2 diabetes and / or hypertension (high blood pressure).

Diabetes and hypertension are chronic diseases or conditions.

Why this booklet?

- A chronic disease advances slowly.
- You need on-going care throughout your life.
- If you have diabetes or hypertension you must also take care of yourself.
- Your family can help you to take care of yourself.

How do I use the booklet?

The first part of the booklet has health messages for diabetes and hypertension.

The information can help you to understand your disease.

At the end of the booklet there are tables with spaces for you to write in.

Use the tables to prepare for your next visit to the clinic.

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The patients participating in both the intervention and comments-only groups received primary care services at the three study facilities. To be included, patients had to be diagnosed with diabetes and/or hypertension, be 18 years or older and be able to read and write or have assistance with reading and writing at home. Health providers were included because of their crucial role of integrating interventions in consultations (Lake & Staiger, 2010). At the intervention CHC, patients were purposively selected to only include diabetic and/or hypertensive patients with uncontrolled values (for blood sugar and/or blood pressure) and who would return for follow-up within one month. Doctors and nurses identified qualifying patients and,

Table 2. Breakdown of participants

	Intervention group					Comments-only group				
	Method		Participants			Method		Participants		
	FG (n)	II (n)	Total (n)	M (n)	F (n)	FG (n)	II (n)	Total (n)	M (n)	F (n)
Patients	2	1	16	3	13	4	0	32	13	19
Providers	2	2	8	*	*	2	4	9	*	*
Total	4	3	24			6	4	41		

FG = focus group; II = individual interview, M = male; F = Female

* Not documented

after issuing the booklet, referred the patients to the researchers who then explained the purpose of the study and sought written informed consent.

More females than males participated in both study groups (see Table 2). Participants' ages ranged between 29 and 98 years (see supplementary file).

2.2. Data collection strategy

Focus group and individual interviews were held with patients and providers using interview guides. Availability of participants determined the choice of method. Focus groups are considered an appropriate method to collect evidence for the acceptability of an intervention (Bowen et al., 2009). All focus groups were conducted by two researchers, one acting as facilitator and the other as moderator.

The interviews took place after one month and after patients and providers had used the booklet in consultations. Questions focused on content and experiences of using the booklet. In the comments-only group, the focus was on content and potential use of the booklet.

Ten focus groups and seven individual interviews were conducted. Table 2 gives a breakdown of participants.

Audio-recordings of the interviews were transcribed and, where needed, translated and cross-checked by researchers fluent in the vernacular languages.

2.3. Data analysis

Data analysis was organised along four of the areas of feasibility identified by Bowen et al. (2009): **acceptability** (reaction of target population), **demand** (likelihood of using the intervention or instrument), **implementation** (applicability of the intervention or instrument) and **practicality** (execution of intervention with limited resources). For each area, a reiterative thematic analysis was performed to explore salient topics, and codes were developed within each theme. Two authors (LD & AMB) analysed the data independently, with regular discussions on interpretations and provisional findings. Codes were continuously refined and the data re-analysed until consensus was reached. The following reference codes are used for direct quotations: Prv = provider; Pat = Patients; IG = intervention group; CO = comments-only group.

2.4. Ethical approval

The Research Ethics Committee of the Faculty of Health Sciences, University of Pretoria (Protocol 57/2016) and the Tshwane District Research Ethics Committee (Project 15/2016) approved the study. All participants gave written informed consent before participating in the study.

Table 3. Topics in each of the four feasibility areas

Feasibility area:	1. Acceptability	2. Demand	3. Implementation	4. Practicality
Topics	• Satisfaction • Appropriateness • Organisational culture	• Intention to use/ Continuation of use • Perceived demand	• Successes and failures • Resources • Ease/Difficulty of implementation • Efficiency and speed	• Positive/ Expected positive effects • Patients' ability to use booklet effectively

3. Results

Table 3 provides a summary of the topics developed for each of the four feasibility areas that are discussed.

3.1. Acceptability

Both patients and providers expressed **satisfaction** with the content and the approach of the booklet. One provider commented specifically on the holistic approach: *"Most of the time when we treat the chronic illnesses, we emphasise pharmacology, but this one is non-pharmacological"* (Prv-IG). Patients reported that the booklet improved their knowledge of their condition: *"This booklet ... opens our knowledge, because we are sick and we don't know how to cure ourselves"* (Pat-IG).

Providers perceived the booklet as **appropriate** in encouraging patients to self-manage their care and enforcing patients to get what they are actually supposed to get: *"[We] don't always have time to discuss everything with them [patients]; so things that we may have left out will be in here [in the booklet]"* (Prv-CO). The providers also remarked that the booklet might make it easy for junior doctors when doing routine check-ups for chronic patients, which fits in with the demands of the **organisational culture**. The booklet was also seen as *"a monitoring tool"*. From a patient perspective, members of the intervention group mentioned that writing down questions for the next consultation was an effective reminder mechanism. One patient mentioned: *"The booklet gives us access to the doctors, so you can ask questions concerning this book and you get a good relationship with the doctor"* (Pat-IG). Others also found the more holistic and patient-centred approach appealing as one patient reported: *"Last time we would get inside, they just write and say, 'Go and take the pills.' And we follow drinking those pills just like that. This ... book is better than that"* (Pat-IG).

3.2. Demand

Patients expressed themselves strongly on their **intention to use or to continue to use the booklet**. Some patients mentioned: *"Nothing will stop me from using this book"* (Pat-IG) and *"My children will read for me and I will know what to eat, what not"* (Pat-CO). Others viewed the booklet as a facilitator for self-managing their own care: *"This book is my life, that's why I am going to use it"* (Pat-IG). Patients in the intervention group used the booklet for reading and preparing their questions for the providers, whereas providers used the booklet for communication and answering patient questions. One patient reported:

"Today I did ask the doctor that I wanted to chat to him and I gave him this booklet and he asked if I was drinking or smoking ... eating correctly ... if I was sleeping okay ... So you understand that you talk with your doctor about what is bothering you." (Pat-IG)

Patients in the comments-only group expressed their intention to use the booklet as a *"passport"*, but with reservations: *"If the doctors would give us that chance, we would use it"* (Pat-CO). Reasons for wanting to use the booklet included improved knowledge and the benefit of sharing information with family and offspring: *"Even kids at home will see it and read it. A book is like a history; it has things that will not disappear. It's like a candle that lights for them to be clever"* (Pat-CO).

Both patients and providers reported a **perceived demand** for the booklet. From the patient's perspective, the emphasis was on the demand for information, on the condition itself and on lifestyle changes, especially dietary guidelines: *"We will hear what is the disease, what we should eat and what are the mistakes"* (Pat-CO). The demand for the booklet was perceived to go beyond the patients themselves: *"Everyone in this world who is alive will benefit from this booklet"* (Pat-CO) and *"Since diabetes runs in the family ... even if I pass away, they [family members] will know how to treat themselves"* (Pat-CO).

The study also had a ripple effect on other providers who were not involved in the study, but who enquired about the possibility of photocopying the booklet or making recommendations for using it with community health workers.

3.3. Implementation

Successes and failures in using the booklet were related to the way patients in the intervention group read and wrote in the booklet: *"I wrote whatever was my concern and then I asked my doctor about it; so, in case I forgot ... I wrote whatever complains that"* (Pat-IG). Participant feedback was varied, with comments like: *"We have taken time to read it"* (Pat-IG) and *"I did write where I understand; where I did not understand, I did not write"* (Pat-IG). Other reasons for not writing included being *"lazy to write"*, and *"problems of funerals"*. On the other hand, the providers' use of the booklet was influenced by their assessment of the patients' literacy levels and of their ability to understand English, and by the availability of family members to read for them: *"We [providers] find ourselves having this book, but patients not understanding how to use it"* (Prv-IG).

There was not much information revealed in terms of the **resources** that were needed to use the booklet. However, some providers referred to the importance of including frontline community health workers, *"the ones that go into the families"*, in using the booklet. Others saw health promoters as key implementers, as *"they will be able to unpack the book properly for patients while they are waiting [to see the doctors]"*. The potential of using the booklet in support groups was also mentioned.

"I think as a tool to educate the patients this book it's out of this world. Actually, I was thinking of coming back to you [researcher] to ask, 'Do you mind if I can use this book when I have support groups?' It's very good." (Prv-IG)

Factors mentioned that affected the **difficulty of implementation** included the size of the booklet.

"Some of them [patients] ... might look at it and say, 'A book'. You know, most people are lazy out there. These are practical ways on how people may react to this like 'Oh, why did they give me such a huge book with lots of tables? I don't have time for that.'" (Prv-IG)

Other factors were the patients' functional literacy and proficiency in English, with some patient participants finding *"the English is very understandable"* and the glossary with the translation of key words in Zulu and Sepedi helpful: *"They explain the words that they thought will be difficult for us to understand in English"* (Pat-IG). Cooperation of health care providers in the use of the booklet was also a concern: *"Maybe if you [researcher] haven't talked to them [nurses]... it will be difficult"* (Pat-CO).

Providers referred to rural patients who never read or write, and to the fact that most of the diabetic patients are older patients who cannot read and write. They also had concerns about privacy: *"Some people, they don't want other relatives or family members to know what they are suffering from"* (Prv-IG). One provider from the rural CHC in the comments-only group also expected that difficult patients would not want to bring their booklets along for consultations: *"Some patients are lazy, and ... stubborn ... harsh. You will ask them, 'Where is that book?' And they will start complaining"* (Prv-CO).

3.4. Practicality

Patients in the intervention group reported several **positive and expected positive effects** of the use of the booklet. In terms of interaction with health care providers, they mentioned the reciprocity of asking questions: *"I don't think there was a time when the doctor asked me questions like that, but now I am happy"* (Pat-IG). Some participants found the booklet helpful in making decisions about lifestyle changes: *"I got the information from the book about my diet, so I decided to start with my diet and if I get that right I will start to exercise"* (Pat-IG). Others reported on the improvement of perceived or expected health outcomes: *"I am better than before because I read this book"* (Pat-IG) and *"My blood pressure is still high, but I believe this book is going to help me"* (Pat-IG).

Providers saw the booklet as an empowerment tool that led to patients taking up more responsibility, but a few doubted if the patients would be **able to use the booklet effectively**, as they perceived some of them to be lazy and stubborn. On the other hand, some providers also felt that parts of the booklet would have more value for use: *"I think one should stress that a patient ... should be able to look on the first few pages just to get information on what is diabetes ... I think that's really good and the health messages"* (Prv-CO).

4. Discussion

Feasibility studies aim to assess whether an intervention or instrument is suitable for further testing and provide information on whether it is relevant and sustainable (Bowen et al. 2009). This study tried to answer the question regarding the feasibility of a self-management care-plan booklet that was adapted for patients with diabetes and/or hypertension in South-African communities to facilitate collaboration.

The results indicated that there was a high level of acceptability of the booklet by both patients and providers. This is probably motivated by the current absence of culture- and context-specific health education material to answer the patients' **need for information** about their condition(s) (Dube et al., 2017; Parker, Steyn, Levitt, & Lombard, 2012). Some comments relating to organisational culture fit in well with the emphasis on "assisted self-management support" in the integrated chronic diseases model (ICDM) as adopted for South Africa (Mahomed & Asmall, 2015).

The study also highlighted the value of the individual care-plan booklet in **improving the communication between patients and their health care providers**. This is in line with the findings from a previous study showing that South African providers have a predominant treatment-and-drug-dispensing approach, while neglecting the self-management component of care (Dube et al., 2017). The current shift from paternalistic to partnership models in care provision requires patients to participate in the treatment process (Bodenheimer et al., 2002; Von Korff et al., 1997), with their voices heard and their needs attended to in a more holistic manner.

The demand for a care-plan booklet was illustrated by patients' desire to **share the booklet with family members** and even neighbours. This demonstrates how the booklet can be used as a vehicle for communication, not only with providers but also with family and friends. It reflects the findings from a study on maternal handbooks in Cambodia, showing that women were willing to share manuals with family members and saw records as a valuable source of health information (Yanagisawa, Soyano, Igarashi, Ura, M., & Nakamura, 2015).

Although the patients in our study were keen to use the care-plan booklet, most of them would not do so alone, but expressed the wish for health service providers to cooperate with them. This highlights the **need for partnership** in the treatment of chronic diseases. Having a care-plan booklet could be a good start for many developing countries, as patients need to understand their changing role from being dependent on health care providers to becoming active agents of their own (Bodenheimer et al., 2002; Von Korff et al., 1997).

The booklet was regarded as **easy to implement in the existing health care system**, as the people who could be instrumental for a rollout were already available. Community health workers (CHWs), who are the link between community and health facilities, and health promoters engaging with patients in health facility waiting areas were seen as the key implementers. In many low- to middle-income countries like South Africa, the involvement of CHWs to take over some tasks of health service professionals has been accelerated (Mishra, Neupane, Preen, Kallestrup, & Perry, 2015). For instance, research in Iran showed that trained CHWs were effective in ensuring control of diabetes and hypertension (Farzadfar et al., 2012). However, while involving CHWs might seem an efficient way to relieve the tasks of health care workers in resource-limited settings, it should be approached with caution. There is a danger of overburdening CHWs, thereby reducing the quality of their work. CHWs will also need proper training, adequate provision of equipment and support, if they are to be involved in NCD care (Mishra et al., 2015).

In general, the care-plan booklet was perceived as a **practical instrument** that could easily be integrated in treatment plans. This aligns with South Africa's current drive to re-engineer primary health care and to move towards a chronic care model that includes self-management as an equal component of care (Mahomed & Asmall, 2015; Wagner, 1998).

4.1. Limitations of the study

The prototype booklet was only available in English and the impact of existing knowledge about the disease and of the patients' level of health literacy was not explored in depth. To address these limitations, more research on the use of the care-plan booklet and its effects on self-management behaviour and on disease outcomes is necessary.

5. Conclusion

This study provides relevant information for the development and adoption of the self-management component of the ICDM that is currently being implemented in South Africa. The care-plan booklet can be used as a vehicle to improve the interaction between patients and their providers and/or family and friends. However, more studies are needed to further validate the booklet as a self-management support tool.

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Supplementary material

The supplementary material for this article can be accessed [here](#).

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