Self-management support needs of patients with chronic diseases in a South African township: a qualitative study

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Abstract

Despite the need for chronic disease self-management strategies in developing countries, few studies have aimed to contextually adapt programs; yet culture has a direct impact on the way people view themselves and their environment. This study aimed to explore the knowledge, attitudes and self-management needs and practices of patients with chronic diseases. Four patient focus groups (n=32), two patient interviews, group observations, and key informant interviews (n=12) were conducted. Five themes emerged: health-system and service-provision challenges, healthcare provider attitudes and behavior, adherence challenges related to medication and lifestyle changes, patients' personal and clinic experiences and self-management tool preferences. The findings provide a window of opportunity for the development of contextually adapted self-management programs for community health nursing in developing countries.

Keywords Chronic disease \cdot Self-management support \cdot Patient needs and challenges \cdot Community health nursing \cdot South Africa

Introduction

Non-communicable diseases (NCDs) affect all countries, people, genders and ages, regardless of socioeconomic status; however, they are more devastating in low-and-middle income countries (World Health Organization, 2015a). Albreht, Dyakova, Schellevis, & Van den Broucke, (2016) argue that worldwide the advances in health care systems have transformed previously life-threatening diseases like HIV into chronic conditions requiring on-going care. Because of this transformation, developing countries now face a unique double burden of communicable and non-communicable diseases. As such, NCDs have become an international public health threat and have now been included in global health targets for the first time, for example in the Sustainable Development Goals (SDGs) (World Health Organization, 2015b).

NCDs are grouped into cardiovascular diseases, cancers, diabetes and chronic respiratory diseases, revealing their relationship with common modifiable lifestyle risk factors such as physical inactivity, tobacco use, unhealthy diets and harmful use of alcohol (Maher, Ford, & Unwin, 2012). They are conditions that do not disappear and affected people have to adjust their lifestyles in order to remain healthy (van Olmen et al. 2011). As such, self-management is generally considered a key treatment modality for patients with chronic diseases (Dube, et al. 2015a).

De Silva describes self-management as "the actions that individuals and caregivers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health, meet social and psychological needs, prevent illness or accidents, care for minor ailments and long-term conditions and maintain health and wellbeing after an acute illness or discharge from hospital" (deSilva, 2011).

People with chronic conditions or their caregivers and family perform 80 to 90 per cent of the overall care needed. Taking up this responsibility requires collaborative support from health service providers. Self-management support involves educating patients to maintain greater control through understanding their condition, being involved in monitoring, and taking action. This should be complemented by support in goal setting, decision making, adopting a healthy lifestyle and knowing when to seek help (deSilva, 2011; Lukewich, Mann, VanDenKerkhof, & Tranmer, 2015).

There is evidence that supporting patients to improve their self-management has positive effects on clinical outcomes, quality of life and health service use (Brady, et al. 2013; Franek, 2013; Steinsbekk, Rygg, Lisulo, Rise & Fretheim, 2012; Stoilkova, Janssen, & Wouters, 2013). For this reason, health programs such as Healthy People 2020 include self-management objectives for chronic patients (Healthy People.gov, 2014). However, in developing countries, there is a paucity of literature related to culturally-appropriate chronic disease self-management strategies and tools that would meet both the

surface and deep structural aspects of the societies in which they are offered and that would affect sustainable changes in behavior (Dube, Van den Broucke, Hosiaux, Dhoore & Rendall-Mkosi, 2015b; Choi, Walker, Ralson, & Palermo, 2014). Surface structure refers to matching interventions to observable characteristics of a target population (people, places, language, music), while deep structure refers to an understanding of the culture of the target population and includes an analysis of needs (Dube et al. 2015b).

Culture has a direct impact on the way people view themselves and their environment (Marsiglia & Booth, 2015). While overweight and obesity are major risk factors for NCDs, increasing weight in the South African culture is associated with success (Kirsten & Karch, 2012) and overweight women do not perceive obesity as a health threat (Okop, Mukumbang, Mathole, Levitt & Puoane, 2016). Other studies have found that exposure to Asian cultural cues and identification with black culture in American women was associated with larger ideal body sizes (Yam, 2013). In some cases, chronic illness is attributed to spiritual causes and as a result the individual is perceived as not having control over the disease (de Graft Aikins, Anum, Agyemang, Addo & Ogedegbe, 2012). In South African culture, traditional healers play a significant role in some communities. Sometimes these healers would not refer patients to western-orientated health facilities or they would tell patients to stop taking treatment (Maimela et al. 2015). Although contextually relevant self-management strategies are therefore required, the development and use of such strategies are often challenged by weak health systems and human resource shortages. As such, the adaptation of interventions to the culture and context of the target population is still lacking in many settings (Kirsten & Karch, 2012). Selfmanagement does not replace health services, but complements them by building skills for application at home and in routine health consultations (deSilva, 2011).

Self-management education, coupled with other strategies, can thus contribute to the task of dealing with the burden of chronic diseases in resource-poor settings like South Africa (Dube, et al, 2015a). The South African integrated disease management model highlights "assisted" self-management as a core component of care (Asmall & Mahomed, 2011). In South Africa, primary healthcare (PHC) facilities are the patients' first point of contact with the healthcare system. These facilities focus mainly on disease prevention and assisting and empowering patients, while also diagnosing and treating minor illnesses. In the PHC system professional nurses are the frontline service providers to communities, whereas medical professionals only visit healthcare facilities for rendering services (Mahomed & Asmall, 2015).

According to the World Health Organization (2105c), there is a misunderstanding that chronic diseases cannot be prevented, while, in fact, 80% of premature onset of diseases such as stroke, diabetes and heart diseases are preventable. As PHC nurses form a central part of the multidisciplinary health team,

they are increasingly taking up roles in chronic diseases management, with one systematic review demonstrating the effectiveness of self-management interventions implemented by PHC nurses (Sargent, Forrest, & Parker, 2012). Community health nursing, therefore, provides opportunities for the establishment of fruitful self-management initiatives by patients (Maimela et al. 2015).

Despite the importance of contextually adapted interventions, few studies have aimed to contextually adapt programs to the needs of the target population in developing countries (Dube et al., 2015b). Therefore, the aim of the present study was to explore chronic patients' experiences of self-management and their perceived support needs and the perspectives of key informants on patient self-management, with a view to develop contextually appropriate disease self-management support tools for chronic patients in South Africa.

Methods

A qualitative exploratory design with a content analysis approach was used in order to inductively formulate categories and themes that portray the experiences and perspectives of chronic disease participants in their natural environment (Mayring, 2014).

Study setting

The study was conducted in two public primary healthcare (PHC) facilities in an urban township in the Tshwane metropolitan area in South Africa. One is a community health center (CHC), with a 24-hour casualty and maternity service and five doctors for chronic patients. The second center is a PHC clinic operating on weekdays, with two doctors and no emergency department.

Study participants and sampling

The study had two distinct participant groups: patients with chronic diseases using the two selected clinics for care, and professional key informants working at different levels in the health system. Purposive, convenient and snowball sampling strategies were employed (McKenzie, Neiger, and Smeltzer, 2005). Table 1 gives an overview of participant characteristics, sampling and data collection methods.

Patient inclusion criteria were males and females over the age of 18 years with one or more of the following conditions: diabetes, hypertension, asthma, epilepsy and the human immunodeficiency virus (HIV). Patients were approached for participation on the day of their visit to the facility, while waiting to see a healthcare provider.

Participants	Number	Sampling	Data collection
KEY INFORMANTS:			
Health service providers (at the 2 clinics)	4	Purposive	Semi-structured individual interviews (KI)
Chronic disease program managers / Coordinators	4	Purposive Snowball	
Academics / experts	4	Purposive Snowball	
PATIENTS:			
Male (n= 9) Female (n = 23)	32	Purposive Convenient	Focus group interviews (FG) (n=4)
Male (n=1) Female (n =1)	2	Purposive Convenient	Individual interviews (PI)
Male (n=2) Female (n =4)	6	Convenient	Observations: individual consultations
Groups in waiting area $(= \pm 30-40)$	4	Convenient	Observations: health education group sessions

Table 1 Overview of participant characteristics, sampling and data collection strategies

Key informants (health service providers, managers and experts) were initially sampled purposively because of their involvement with chronic patients, chronic disease treatment or research. Snowball sampling was added to identify additional information-rich participants. Sampling continued until data saturation had been reached.

Data collection

Focus group interviews with patients

Focus group (FG) interviews were chosen as data collection method because of patients' shared experiences of self-management. Two FGs were conducted per facility in the preferred indigenous language. In two instances, individual interviews were conducted, as sufficient patient numbers for a group were not available. All four FGs had eight members each, with roughly three men per FG, except for one all-female group. A female community health worker from the same cultural background had two days of training in being the primary facilitator, with the primary researcher (LD) and a research assistant present at all FGs. The FGs lasted approximately 60 minutes, with individual interviews being slightly shorter. All interviews were audio-recorded and were guided by an interview schedule with open-ended questions.

Observations of patient consultations and group education

Ten systematic observations of the types of education patients received were conducted (6 individual patient consultations and 4 group education sessions). Aspects observed included educational method(s), materials used, assessment of patient needs prior to the education, level of patient participation, recording of information by patients, and duration of educational sessions.

Key-informant interviews

The primary researcher (LD) conducted audio-recorded interviews in English with 12 key informants, which included four health service providers at the study facilities (1 nurse, 1 doctor and 2 health promoters), four chronic disease program managers at district and provincial level (2 at each level), and four academic experts in chronic disease (2 providing active care). Program managers and academic experts were included to provide a better understanding of the context of chronic-disease self-management promotion in the broader health system.

Data management and analysis

The first author (LD) transcribed the key-informant interviews and the fifth author (NGM), with translation experience from indigenous languages to English, transcribed and translated the patient interviews simultaneously. A second person did a peer review of two transcripts to control for accuracy. All direct quotations in this paper were double-checked for translation accuracy.

Inductive qualitative content analysis was used to analyze the interview transcripts by means of Atlas.ti 7 software (Mayring, 2014; Scientific software development, 1999). Data analysis occurred in two phases. Two researchers (LD, NGM) independently analyzed the transcripts to identify manifest content and then reached consensus on codes and categories to be used. In the second phase, two researchers (LD, AMB) confirmed the original interpretations and did a further inductive thematic analysis.

Credibility of data

To ensure trustworthiness of the analysis (Shenton, 2004) several steps were undertaken. Credibility was enhanced through letting the researchers familiarize themselves with the research context, using different methods of data collection and doing frequent member checks during the interviews by summarizing participants' contributions. Confirmability was ensured by involving three different researchers in the data analysis. Transferability was achieved through presenting thick descriptions and direct quotations to allow for possible application in other settings.

Ethical considerations

The study received ethical approval from the Research Ethics Committee of the Faculty of Health Sciences, University of Pretoria (Protocol No. 57/2015) and the Tshwane District Department of Health (Project No. 15/2015). Participants received an information leaflet about the study and all voluntarily gave consent, mostly written, but verbally in the case of participants with limited reading abilities. The patient participants received a small gift equivalent to R30 (±USD2) afterwards as a token of appreciation for their time.

Results

The findings from the content analysis revealed five issues for patients with a chronic disease(s) that could have a profound influence on their ability to achieve self-management: (i) health-system and service-provision challenges, (ii) healthcare provider attitudes and behavior, (iii) adherence to medication and lifestyle, (iv) patients' personal and clinic experiences, and (iv) self-management tool preferences. Table 2 provides more detail on the identified themes and categories. In the quotations below FG refers to focus group and KI to key informant.

Health-system and service-provision challenges

Both patient and key-informant participants referred to challenges related to the health system and service provision. An important challenge was medication stock-outs, which could have a major impact on the self-management options of patients.

"I do take treatment and I also drink my pills, but I have got one problem with one thing. Here at the clinic they are always short of pills for a long time. Like now, since last time they didn't have pills. Even now we are here to collect pills and they only give us those vitamin pills." (Male FG4)

A further concern was the long waiting times for patients. Participants at one clinic indirectly alluded to getting emotionally tired while waiting in the queue and saw this as a possible reason for their high blood pressure when they finally reached the vitals station:

"That is why you find that, in the queues you wait for a long time; sometimes your blood pressure goes up while ... waiting to be assisted and sometimes they [nurses] go for their tea times and meetings." (Female FG4)

Themes	Categories	
Health-system and service- provision challenges	 Medication stock-outs Long waiting times Lack of educational materials and equipment Mind set of providers Lack of structure 	
Healthcare provider attitudes and behavior	 Poor communication Lack of proper check-ups and follow-up Confidentiality breaches Poor relations 	
Adherence to medication and lifestyle changes	 Inconsistency in taking treatment Poverty Different food choices of family Lack of self-monitoring equipment Financial challenges Side-effects of medication Lack of information 	
Patients' personal and clinic experiences	 Health education set-up in clinics Feelings of hopelessness and acceptance of disease Coping mechanisms Substituting medication with herbs 	
Self-management tool preferences	BookletContent	

Table 2 Main themes and categories

Key informants referred to resources and approaches to care provision as challenges to selfmanagement. Resource issues related to lack of educational materials (e.g. pamphlets for patients about their disease) and no dedicated space to implement physical activity interventions or, where there was space, a lack of equipment for patient use: "*Honestly, we are suffering with chronic disease materials* ... *it is difficult to implement awareness interventions when we do not have these things*." (KI-5) Some health workers even ended up photocopying pamphlets for patients.

Another challenge was healthcare providers' approach to the provision of care:

"The framework or mind-set or the model that the people [healthcare providers] are trained here is just to give patients medicine and they hope they will take it and get better ... So, selfmanagement as a co- vital component of care is missing in the mind-set of health practitioners [nurses and doctors]." (KI-7)

As a result, the self-management education given to patients was "... not done in a structured way. It is not planned; it's haphazard, you know; it just happens when it happens." (KI-7) Because the education was not planned, health service providers sometimes gave conflicting messages, and there was no adequate follow-up of patients referred to other health service providers.

Healthcare provider attitudes and behavior

Patient participants reported several issues related to the attitudes of nurses towards them, which had an effect on their self-management. They perceived communication with nurses to be poor, resulting in patients not feeling free to say how they felt. One participant commented:

"We communicate with the nurses but when we try to explain something, they become irritable, saying, 'You are teaching me my job'. We do not have a voice." (Female FG3)

Patients also complained about a lack of proper check-ups and information on their well-being and expressed a desire for a doctor to explain their disease status:

"They [nurses] do ask us about pain and we tell them, but they do not check us. The doctor must check us and inform us of the status of our condition. We need to know what is happening this month." (Female FG3)

In addition, participants reported confidentiality breaches by nurses:

"I once came to the clinic, I fell pregnant while my other baby was still one year. Instead of the sister [nurse] talking to me nicely in the consulting room, she waited for me to leave the room and said in front of other patients: 'Don't you know there is something called family planning?' Just imagine, other patients sitting there. So, it made me angry." (Female FG4)

Poor relations between nurses and patients also resulted in patients not wanting to visit the clinic because of the way they had been treated. In one focus group, it was explained as follows:

"One thing I am not satisfied about is that at the blood pressure side. If they see that your blood pressure is high, they tell you that you are going to die. This is not nice, especially for someone who does not understand blood pressure. They might think this is their last day of life." (Female FG4)

Adherence to medication and lifestyle changes

Patient participants highlighted several challenges regarding adherence to medication and lifestyle changes. One dominant challenge was consistency in the time of the day for taking medication. A major reason for this was poverty:

"Poverty is also the reason you can't take medication, because you can't take medication on an empty stomach, sometimes there is no bread in the house." (Female FG2) Some participants also reported that they forgot to take their medications on time: "*I sometimes forget* to take my medication, like if I'm in hurry, rushing to the mall, I forget and then take it after some time." (Female FG1)

A further challenge was adherence to dietary recommendations hampered by cultural expectations. When visiting other households, patients were expected to eat the food provided and could not choose something else. At functions like weddings, cultural expectations were described as follows:

"But now when you are maybe at a wedding and you don't eat the food there, people will start talking, 'There he goes again, we know this type. He doesn't like eating other people's food.' When you eat that food, because you are now a visitor that is where you make a mistake." (Male FG2)

Diet challenges at home related to participants' different food needs than those of the rest of the family and the unavailability of the right types of food: "*It is difficult to make the children to eat your diet because they want this and that.*" (Male FG2) The problem could even arise at the grocery shop:

"At least at the shops they do have the food that accommodates us. But when you go for groceries, they [other family members] don't buy the food that accommodates you. When you try to buy Tab [sugar-free cola drink], they would rather buy cold drinks with bad acid in them... you end up joining the chosen drink." (Male FG2)

Other lifestyle-change difficulties included a lack of time to exercise and lack of glucose or blood pressure self-monitoring equipment at home. One participant reported that, *"I was supposed to quit smoking but I didn't"* (PI-1), indicating that he knew what was the correct thing to do.

Financial challenges existed when employed patients had to go and collect medication, as this patient reported:

"We work casual jobs. You find that you are only working ten days and on those ten days they give you one day off to come and collect medication and [if] you do not get it, you are given another date [at the clinic] and you still have to take another [day] off for you to collect your medication. And when you check, you see that you could have actually done something with that money you lost on the day you were absent." (Female FG4)

Some patients mentioned not taking their medication because of side-effects: "*I don't even take my medication if I'm going to town because I know I have to go to the toilet in two hours every ten minutes.*" (Female FG1) Other patients reported coming to the clinic to collect the medication but

"... there are some high blood pills that they changed for us and they are not treating us well. We get swollen and dizzy, so as she [other participant] says, she throws them away. We also throw them away." (Female FG3)

Finally, participants referred to a lack of information about the disease and the prescribed medication as a factor influencing self-management. One key informant was of the view, "... that is why our patients do not complete their medication because they don't get information, full information." (KI-5)

Patients' personal and clinic experiences

On arrival at the clinic, patients received their clinic record on which all the previous information about their condition was recorded. They handed the record back to the clerk before leaving the premises. Patients were only allowed to take home a clinic appointment card with the next appointment date. In most instances, patients were passive or only partially active. Individual health education in consultations lasted about two minutes and ad-hoc waiting-area group talks lasted around 30 minutes. Patients had nowhere to record any information conveyed to them and did not prepare questions in advance.

Patient dispositions influenced the participants' adherence to self-management recommendations. Some participants expressed a feeling of hopelessness regarding their condition, with one commenting that "... there is no victory; you must just continue like AIDS; you drink medication throughout." (Female FG2) Others reported learning to accept their disease(s): "Acceptance is what is helping us; it is also what motivates us to be here and to check our conditions and take our medication." (Male FG2)

Participants reported different ways of coping with their condition, which in turn had an effect on the way they managed their condition themselves. Some adopted a religious approach: "*I ask God and whatever they are doing to me I send it to God.*" (Female FG3) Others had learned to manage and control their emotions, so that this should not affect their blood pressure:

"At home I stay with my boys; they are orphans and they are my grandchildren. They are troublesome people, but in most cases I try to stay calm and not to shout when I am with them." (Female FG2)

There were also participants who were scared of taking tablets or who replaced their medication with herbs in order to get better: "*I don't take medication*. *I drink some herbs*. *I can take a week and not drink my medication*." (Female FG3)

Self-management tool preferences

Patients and key informants were also asked about the type of chronic disease self-management tool they believed could make a difference. Most participants mentioned a booklet for those who could read and write: *"I go with a booklet because you can sit and read. Where you don't understand, you read again."* (Male FG2)

Those with limited literacy could be assisted by family members or neighbors in the "spirit of Ubuntu", a South African humanity principle where "... most people run to their neighbors or within the household." (KI-3) Other suggestions included support groups, mobile phone messages, and radio and TV programs.

In terms of content and appearance participants suggested that the booklet "... must be written in different languages so that we can all understand ..." (Male FG1) and it "... must not be too thick because it demotivates [us] to read." (Female FG1) It should have pictures to assist those with low levels of literacy and should be sufficiently motivating to share it with family members. Furthermore, the booklet should contain information about the diseases and their complications and should have clear instructions for patients in cases of emergencies.

Discussion

The sustainability of health interventions depends on the capacity of stakeholders (patients and health professional) to participate (Maimela et al. 2015). This study explored South African chronic patients' experiences and key informants' perspectives of self-management in order to identify perceived support needs. A number of issues were identified concerning self-management education for chronic patients in primary care. These issues relate to the health system as well as to patients.

Several hindrances to self-management by patients originate from the health system and service provision, such as medication stock-outs, long queues and lack of educational materials. These are issues that the patient and the healthcare provider do not have control of, no matter their need for self-management. These results are also reflected in other study results in the South Africa that demonstrated how medication stock-outs at facilities left the patients stranded (Maimela, et al. 2015). Other studies have also reported concerns on the lack of health promotion materials and the use of poor quality photocopies that could discourage patients to read (Parker, Steyn, Levitt, & Lombard, 2012; Rushforth, McCrorie, Glidewell, Midgley & Foy, 2016).

Our study highlighted the treatment-and-drug-dispensing approach of health professionals, with a neglected focus on self-management as a vital core component. The way in which individual consultations and ad-hoc health information sessions were conducted – often in noisy waiting areas –

highlighted the need for better patient support for self-management. Patient health education is haphazard and may result in conflicting or confusing messages received from different providers. Other South African studies report on the lack of training of primary healthcare providers in behavior-change counseling skills and recommend effective training, accompanied by health-system reform that supports health promotion and self-management (Dube et al, 2015a; Malan, Mash, & Everett-Murphy, 2015; Murphy, Chuma, Mathews, Steyn & Levitt, 2015).

In our study, provider attitudes and behaviors in the form of poor communication and relations presented as a concern for patients' motivation for self-management. Because of poor or absent patient-provider relationships, patients felt obliged to collect their medication even if they discarded it afterwards. Primary care is the first contact point of the community with the health system in South Africa. This highlights the imperative of effective health communication by PHC providers to make a major difference in self-management (Maimela et al. 2015). The current absence of patient-centered practice hinders patient self-management, as has also been reported elsewhere (Everett-Murphy, De Villiers, Ketterer, & Steyn, 2015; Fort et al. 2013. Rushforth et al. (2016) argue that, although self-management has been promoted in different settings, PHC providers continue to find it difficult to effectively share responsibility with patients and to support them to change their behavior.

Community health nursing lends itself to lead the integration of self-management into a patient-centered model of care for chronic patients that complements the other components of care. Therefore, in order to make meaningful collaborations with patients in self-management, community health nurses need to be aware of the needs and experiences of the specific target groups of patients they serve. In chronic diseases, unlike in acute conditions, patients themselves are principal caregivers and health professionals only act as consultants in supporting the patients. Although patients may consult with the professionals periodically, much of the time they are at their homes, making everyday choices that affect their chronic condition (van Olmen et al. 2011).

In addition to issues within the health services, other barriers to medication and lifestyle adherence found in our study included poverty, cultural expectations and family dietary preferences. Participants in our study appeared to lack knowledge on how to address immediate side-effects of their prescribed medication, resulting in non-adherence. Patients felt a social obligation to eat whatever was presented and were also forced to eat the available food because of financial constraints and the attitudes of family members. Problems with losing weight as a barrier to active self-management were not raised in our study, possibly because gaining weight is associated with health, affluence and success in South African culture (Kirsten & Karch, 2012). A lack of social support and financial resources has also been reported in previous studies as barriers to self-care (Liddy, Blazkho, & Mill, 2014; Muchiri, Gericke, & Rheeder, 2012).

Study limitations

Our study had a number of limitations. Firstly, patient interviews were not conducted in English, which limited the degree of rapport building between researcher and participants. The trained facilitator was, however, fluent in the local vernaculars. Secondly, more women than men consented to participate. Although we benefited from mixing genders in the focus groups and discussed topics that might not have been raised in separate groups, other issues may have been missed because of the gender mixing. Finally, this study was only conducted in one part of the Tshwane metropolitan area, although the findings may resonate with the situation in other areas in South Africa. Further research on the subject of self-management needs is required in order to add to the knowledge base of culturally adapted interventions in community health and to inform policy development.

Conclusion

The current study raises awareness of self-management needs and experiences of patients and healthcare providers in one cultural context in order to improve community health nurses' knowledge and skills in working with these patients. While adherence to medication and lifestyle changes are recognized as important by patients and providers alike, the two groups have different perspectives and experiences of treatment and self-management of chronic diseases. In this study, patients expressed their willingness to be involved and to learn more about their disease(s), while PHC providers were willing to assist with such an endeavor. However, more training of community health nurses and other healthcare professionals as well as changes in the healthcare system are needed to achieve better self-management support for patients.

The findings of this study provide a window of opportunity for the development and implementation of contextually adapted, structured self-management support interventions for community health nurses in developing countries. Although self-management is now regarded as a pillar in the treatment of chronic diseases like diabetes and hypertension, it is not a panacea for everything.

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