

Research Articles

Frontline community health care workers' intervention for diabetes management in resource limited settings: a qualitative study on perspectives of key stakeholders

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Background

Diabetes mellitus (DM) is a global public health concern, with significant increase in the transitioning low- and middle-income countries (LMICs), such as India, with limited resources and poor health care systems. Recognising the need for innovative, feasible, targeted interventions for diabetes care, a non-randomized, controlled, phase II clinical trial was conducted in a rural revenue block in Tamil Nadu, India. This pilot trial tested the non-inferiority of the trained community health workers (CHWs) in delivering education, screening for diabetes complications using a protocol-based referral for physician consultation for management, assisted by an android application (App) for patient tracking. Understanding the perceptions of key stakeholders including patients and health workers is crucial for upscaling and sustaining these novel interventions for diabetes care. This study explored the perspectives and views of patients with DM and diabetes CHWs who participated in the pilot trial.

Methods

Using qualitative research methodology, individual in-depth interviews were conducted in the local vernacular (Tamil) language among the two diabetes CHWs and purposively chosen 24 patients until the data saturation was reached. Participant information sheets, consent forms and a detailed topic guide were developed. Interviews were transcribed verbatim, translated into English and thematic analysis was conducted.

Results

Five main themes emerged during interviews with diabetes CHWs: deeper understanding of the disease; belonging and strengthening; ease of use of digital technology and a timesaver for patient tracking; cultural sensitivity; stigma and change in attitudes over time. Interviews with patients highlighted four major themes: convenience; cost reduction; improved knowledge and perceptions on health. Benefits were perceived by both patients and diabetes CHWs, in the domains of convenience, access, cost and knowledge. Perceptions of changes in health were mixed with room for improvement in the digital App.

Conclusions

Training CHWs in resource limited settings in supporting community diabetes care, assisted by digital technology for tracking is acceptable to the patients and will help shift the care pathway for Diabetes closer to the patients in a rural setting. This qualitative study identified a number of areas for improvement and potential barriers that will need

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to be addressed prior to scaling up in similar resource constrained settings.

Diabetes Mellitus (DM) is a highly prevalent public health issue globally.¹ In India, major social and economic transitions has resulted in dramatic increase of the disease² where the prevalence of diabetes in adults aged 20 years or older in India increased from 5.5% (4.9–6.1) in 1990 to 7.7% (6.9–8.4) in 2016.³ In remote and rural areas of India, poverty, lack of awareness, lack of access to medical care and additional financial constraints associated with travel and loss of pay when attending hospital appointments^{4,5} prevents patients accessing routine diabetes care.⁶ Consequently, management of diabetes is suboptimal, with patients frequently suffering disease complications^{7,8} calling for innovative ways of managing DM in resource constrained settings.

In a step to address the weaknesses in the health care delivery system for an optimal DM care, a community based care pathway was developed and piloted in the Department of Rural Unit for Health and Social Affairs (RUHSA) of Christian Medical College (CMC), Vellore, Tamil Nadu, India. This pilot project was a nonrandomised, controlled, phase II, non-inferiority trial (Online Supplementary Document, Appendix 1). The design and quantitative results of the study is published elsewhere.⁹ A trained diabetes community health worker (CHW) delivered structured care including screening for diabetes and its complications at the sub-center and a protocol based referral for physician consultation to secondary level care center for management, assisted by android tablet based application (App) for patient follow-up. The aim of this nested qualitative study within the pilot trial was to explore, in-depth, the range of perspectives and views of key stakeholders including the patients and diabetes CHWs on this innovative diabetes care model.

METHODS

This study followed a qualitative research methodology, using Individual face to face in-depth interviews conducted with two trained diabetes CHWs and 24 purposively chosen patients from the intervention arm. Ethical approval was obtained from the Institutional Review Board of Christian Medical College, Vellore, India. Individual patient interviews were conducted rather than focus groups, due to logistics of reaching participants living in widespread rural areas who may also have multiple demands on their time such as work, and financial constraints associated with travel. Individual interviews in the participants' own homes were therefore deemed more practical in order to maximise participation in the study. In addition to this, individual interviews were conducted at their own homes to allow greater honesty and expression of participants, without being influenced by other participants present.¹⁰ Investigators made sure that diabetes CHWs were not present at the time of patient interviews as this was deemed likely to influence the answers given.

SAMPLE AND RECRUITMENT

Participants were patients who were purposively chosen from the patients with diabetes enrolled in the intervention arm and the two trained diabetes CHWs who consented to participate. There were no exclusion criteria. Potential participants were identified based on their existing enrolment in the larger study. Using the list of patients in the intervention group, purposive sampling was carried out based on the criteria that will capture the unique and diverse variations within the population to capture the maximum variation to document the phenomenon of interest. To represent the views of specific groups of stakeholders, a range of ages, sex, and localities were included. Participant information sheet (Online Supplementary Document, Appendix 2) was developed and distributed to potential participants, before asking for written consent to participate (Online Supplementary Document, Appendix 3). Participant information sheets (PIS) and consent forms were created by the lead researcher in English (AP and EW), then checked by a local Tamil speaker, in order to make sure they were culturally congruent and conveyed information effectively for any participant. They were checked again following translation into Tamil to make sure translation was accurate and understandable to participants and using the same form of carefully selected lay vocabulary as initially planned. PIS and consent forms were explained again verbally at the time of interviews, due to variable literacy levels of participants.

DATA COLLECTION

A topic guide was developed (Online Supplementary Document, Appendix 4) and followed to conduct interviews with two diabetes CHWs (there were only two diabetes CHWs in the intervention therefore both were interviewed) and 24 patients with diabetes. Interviews were conducted in the patients' own homes in order to maximise participation. Private rooms at RUHSA campus were used as the location for the two CHWs interviews, for convenience and in lieu of time constraints. The Interviews were conducted in Tamil language by a fluent Tamil speaker with a background in healthcare but was not part of the diabetes healthcare team or wider pilot project. This was in order to minimise influencing the answers of the participants, and to encourage honest opinions and experiences. Field notes were also taken during interviews by EW, based on facial expressions and body language reactions exhibited by participants. All interviews were audio-recorded using digital recording devices. The recordings were transcribed verbatim from Tamil into English by a trained transcriber fluent in both languages and a random sample was checked by an independent person for accuracy.

DATA ANALYSIS

Thematic analysis was used to analyse the data. English-translated transcripts were read repeatedly to immerse in the data. Following this, phrases in the transcripts relevant

to the research question were coded manually. A coding tree was developed with relevant phrases and those similar were categorised further (Online Supplementary Document, Appendix 5). The themes were identified from the data inductively and quotes were used to reflect the emerging themes. To protect the anonymity, codes were allocated to all participants to protect the identity of the individuals. Quotes for the diabetes CHWs were not presented using demographic codes in an attempt to maintain some confidentiality, as there were only two CHWs in the pilot project.

RESULTS

A total of 26 interviews were conducted. Both the CHWs were Females; and among the patients who participated 17 were females and 7 were males. The age range of the participants was from 35- 58 years. Data saturation was obtained from the 24 interviews conducted with patients. Selected relevant quotes are presented in the main text and some additional quotes are presented in Online Supplementary Document, Appendix 6.

PERCEPTIONS OF PEOPLE WITH DIABETES

Interviews with patients' highlighted four major themes: convenience; cost reduction; improved knowledge and perceptions on health.

CONVENIENCE

Patients described being seen in their own homes by the CHWs as convenient. CHWs also provided reminders for appointments, both over the phone and in person, which was perceived as very helpful by patients:

"If I don't go today, she will call and remind me once or send someone to remind me" (F, 48)

"Two days before the follow up date she (CHW) used to come home and remind me. Same way after I visit RUHSA also she informed me when I should give blood for investigation" (M, 48)

The majority of patients felt that they did not have to attend RUHSA (secondary level care centre) as frequently as before since joining the pilot study, as visiting a health center far from home can be stressful with long waiting times. Some patients described that they would need to dedicate a day to a RUHSA visit, due to these waiting times:

..."before joining in the scheme, if I went to RUHSA, I have to make an appointment and wait for a long time to see doctor. Now it's not like that. If we go to RUHSA at 3 o'clock also we can get medicine easily. This scheme is very good scheme, it is helpful for us." (M, 58)

"Now getting medicine in [local mobile clinic it will [be] easy for me...If I go to RUHSA, I have to spend one day, that is from morning to evening 4 o'clock or 5 o'clock." (F, 54)

REDUCTION IN COSTS

Several patients perceived that receiving concession for treatments and investigations was of huge benefit to them:

"change is that they have exempted my consulting cost and I got medication free of cost..... Expenses are low now after being part of this plan" (F, 43)

Visiting RUHSA was perceived as expensive. One patient described that she could not afford treatment prior to the project concession rate, and was only taking treatment now due to the lower cost:

"[Before project] I paid, my husband used to scold me, we will go to government hospital, RUHSA is not suitable place to us, like that he told. So we got discharged and came home.....at first, I am unable to spend money for treatment so I stopped treatment. Now I am taking treatment because of this scheme." (F, 36)

IMPROVED KNOWLEDGE

Patients perceived that they have better understanding of the condition after participating in the project. This took the form of improved knowledge about diet, followed by exercise, taking medications, better control of blood sugars leading to fewer complications. Some patients appreciated the educational pamphlets as they were pictorial and easy to understand:

"now I know about my disease and treatment"...after joining in the scheme I got awareness. So, I prepare healthy diet for me now. Previously I never used to prepare anything particular to me. I used to make common food for all at home" (F, 52)

"it was very useful to me sir, those pictures gave information regarding food habits. It was very useful sir." (F, 36)

However, some patients were unable to understand the posters due to their level of education and some described remembering the education received from the health aide, but not retaining this information, as was reiterated by the health aides (as mentioned above):

[in regard to posters:] "what can I know sir, educated peoples will know about it" (F, 54)

[understanding the posters pictures] "No sir"... "I studied only 5th std." (M, 58) "They explained many things but I forgot most of them" (F, 43)

PERCEPTIONS ABOUT HEALTH

Most patients perceived being a part of this pilot project as beneficial in regard to treatment and health in general and had positive changes to report. Several patients specifically described that they had better control of sugar levels:

"I have lot of changes after joining in the scheme...Maintaining my diet, walking, exercise and taking regular medication will help me to maintain good health" (F, 54)

"After joining the scheme my sugar level is under control"... "Previously my sugar level was so high I was admitted in the hospital twice. Now it is under control because of this scheme" (F, 35)

One patient felt he did not feel any different with the different intervention model:

“I don't find any difference I feel as usual” (M, 54)

PERCEPTIONS OF COMMUNITY HEALTH WORKERS

Interviews with diabetes CHWs revealed perceptions on aspects of diabetes training, use of digital technology and care management in the community. Five main themes emerged were: deeper understanding of the disease; belonging and strengthening; ease of use of digital tablet-based App and timesaver; cultural sensitivity; and stigma and change in attitudes over time.

DEEPER UNDERSTANDING OF THE DISEASE

The diabetes CHWs had positive training experience with plenty of opportunity to clarify understanding and seek support when needed. They felt that they have in-depth understanding of the disease after the training they received, and the educational resources obtained like option grid with structured responses to frequently asked questions by the patients and pamphlets. This was in contrast to knowing relatively little about diabetes prior to the training:

“Initially, we didn't know much about the diabetes disease, during the training came to know about the disease more deeply”

“equally I was trained well to do basic tests..... Nothing was difficult”

BELONGING AND STRENGTHENING

By being more knowledgeable, the diabetes CHWs felt it carried more weight and they gained respect in the community. By interacting with the community with improved knowledge, the CHWs felt they appreciated their roles and responsibilities better and were able to communicate their knowledge with confidence, even with those who were not part of this intervention. This strengthened their relationship and built trust with the patients and their families. Patients supported each other by passing on the knowledge received from the CHWs and this created a sense of belonging between CHWs and the patients:

“...After providing education in group, patient's wife came and requested us to talk to him in person”

“I am able to clarify their doubts and refer them to RUHSA to do the blood test. I gained some respect in the community”

“after me providing training to the patients, those patients are providing education to other patients about medications”

EASE OF USE OF DIGITAL APPLICATION AND TIME SAVER

When asked about the training they received, in using the digital application and the mode of data collection using a Tablet, the CHWs expressed positive views in terms of time saved and easiness to use the application. The mixture of theoretical and practical training was discussed by both CHWs as a positive aspect:

“Writing reduced. Before, we used to write the patients' details in the note. With this, it's easy to type and we can also search patients' details. Time saving.”

“after recruitment, only a limited number of questions were there in the app to understand the patients details. That was very useful”

“I am 100% confident in using the app. It's easy for me to use it.”

CULTURAL SENSITIVITY

CHWs highlighted some of the culturally sensitive components of the questionnaire, when collecting data on the lifestyle of patients. While asking men about drinking was acceptable, they thought that asking women the same question was culturally inappropriate:

“Only that alcohol related question was very difficult to ask. But this question is useful but to women in this part is difficult.”

“won't agree with few questions that we need to ask the patients... such as 'do you drink?'. The patients get angry with usbut we asked them, men used to say yes we do drink but for women the question was embarrassing for us to ask.”

STIGMA AND CHANGE IN ATTITUDES

Diabetes CHWs also highlighted the fact that some of the participants initially were reluctant to come for screening due to worry of being diagnosed with diabetes or they were afraid that neighbours will know that they have Diabetes. However, they felt that more education will change their attitudes and over a period of time, they were able to convince quite a few patients to engage with the programme:

“.....Only few fear that they might have the disease and don't want to be screened.”

“If we give them more education they will come and get screened.”...“If we educate them, they will change”

“Initially he refused to listen, but we repeatedly went and spoke to him in the field, his work place or in his home, nowgoes regularly for treatment”

Diabetes CHWs were sometimes frustrated that a few patients were keen to listen to Diabetes health education but reluctant to come for screening and also some patients forgot about the education provided on the condition and screening for complications:

“.....But a few forget what I have educated. They forgot what have to be eaten and don't follow it at all saying that I can't follow-it.”

“more interested in listening to the education but some do not show interest to come for screening”

DISCUSSION

Diabetes care management delivered in the community through an innovative model using diabetes CHWs trained in routine and essential diabetes care supported by a mobile care application was considered more convenient for patients. Patients found visiting the main hospital stressful, time-consuming or distant and therefore they valued the

input from the diabetes CHWs close to their home including appointment reminders and visits. Cost was perceived to be reduced with this project, which was very important to patients and allowed more patients to access treatment. Education was a strong theme with both patients and CHWs feeling they had benefited from diabetes education received from this project. Further education was felt to be beneficial, as some patients still lacked knowledge and understanding, could not recall the education received, or were fearful of screening. Some patients felt their health was better, although not all perceived a difference. The CHWs valued the structure and input from the research team including the training, support, the App and educational materials.

STRENGTHS, LIMITATIONS AND REFLEXIVITY

In resource constrained settings in rural India, training grass root workers in basic knowledge of diabetes, to conduct basic screening prompted by digital technology in order to help the patients navigate their care pathway in diabetes within the community is the major strength of this study. Interviews were conducted by a researcher from out-with the care provision team in patients' homes, minimising the potential influencing of participants' answers. For diabetes CHWs, however, as there were only two, it would be possible that concerns regarding anonymity could have influenced answers. In addition, these interviews were conducted at RUHSA, and although no members of the research team were present for the interviews, it is possible that the setting could have influenced answers. Some patients did not volunteer much information when asked open questions, therefore a lot of answers were prompted by the topic guide, which could be a limitation as being too prescriptive. However, without the prompting, there is a possibility that sufficient data would not be generated. This reserved attitude could be cultural and/or due to inexperience of rural population participating in interviews.¹¹

Interviews in this study was conducted in Tamil and translated to English by researchers fluent in both languages. While random sample of transcripts were checked for accuracy, back translation was not conducted to check all the data. Consequently, there may have been some meaning lost through translation, which may have affected data richness and data quality.

INTERPRETATION OF THE RESULTS

A recent systematic review indicated that patient navigator systems using CHWs such as this one improves the process of care.¹² However, this same review indicated that little research has been done evaluating clinical outcomes, economic considerations, or clinical markers and outcomes. Therefore, this qualitative study provides some relatively novel insights highlighting the room for improvements. The results of this qualitative study should be interpreted in conjunction with the quantitative results of the wider pilot study.⁹ Regardless of quantitative results however, this qualitative study has shown some benefits of this model of care provision. The themes which emerged suggested that

stakeholders commonly perceived benefit from this project in the domains of knowledge, convenience, and cost, and health (less consistently), as well as resources used to conduct these changes. Results from this project addresses some of the barriers for patients in engaging with health-care services, not only for diabetes but for other chronic conditions such as HIV and Hypertension.^{13,14} Studies have shown that knowledge about their condition alone is not enough to improve health but need improved engaging with healthcare services.⁶ Using people from their own community with enhanced knowledge of the condition and use of technological devices will enable patients to engage with health care services.¹⁵

One of the difficulties that may arise with this model is the concession rate patients received for their care and medications as part of this project, which was perceived as one of the key elements of the benefit. While this was provided in order to eliminate bias due to financial constraints of participants, large scale cost reduction may be out-with the means of an extended project and was not intended as the main intervention. Nevertheless, as other benefits to the patients were identified (education, health and convenience), it is indicated that there is perceived benefit to stakeholders beyond financial considerations. In addition, task shifting (the shifting of tasks from one cadre of healthcare worker to another, in this case from physicians to CHWs) such as is used in this project, is an approach gaining attention and use in low-income and high patient density contexts such as this one, with the ability to boost health system capacity without major investment.¹⁶ Low doctor to patient ratio which in low resource settings and a poor patient centered approach to management of diabetes by providers can be alleviated using CHWs trained adequately as in this study.^{17,18} Therefore, there may be economic arguments made in favour of pilot studies such as this. This should be evaluated alongside the quantitative results.

To continue to develop this innovative project, which focussed on task shifting and digital technology, issues that were identified by this study should be addressed and incorporated into the next stage following the pilot. These included lack of behaviour changes despite education, lack of knowledge retention by patients, lack of understanding of educational materials by those of low educational levels, stigma surrounding diabetes treatment, and discomfort of patients and health aides asking questions about socioeconomic status and alcohol intake. Once the improvements have been made and gaps addressed, this project would be supportive of a recommendation for this model to be scaled up to be tested in a well conducted randomised controlled trial. If proven successful, it is feasible that this approach could be applied in similar contexts in rural India, but also to other areas of rurality, low income, or low levels of education. Depending on quantitative results and measures of change in behaviour, behaviour change interventions may be of benefit in addition to the content of the project. Interventions reducing stigma surrounding diabetes care may also be considered, which may take the form of further education on this issue. In spite of the limitations, this project is the first step of realising the multi-pronged approach and integrated nature of community-based DM care in a re-

source limited setting to prevent long-term complications and strengthen health system in India.¹⁹

CONCLUSIONS

In conclusion, the results of this qualitative study indicate perceived benefit by key stakeholders (people with diabetes and CHWs), in the domains of convenience, cost, knowledge, and health, as well as positive perceptions of resources used within this project (option grid, health promotion materials). These results should be interpreted alongside the quantitative results of this pilot study to inform further development of this project.

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ETHICAL APPROVAL AND CONSENT TO PARTICIPATE

Approval from the institutional review board of Christian

Medical College, Vellore, India was obtained. All study subjects provided written informed consent.

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AUTHORSHIP CONTRIBUTIONS

AP and RI conceptualised the study, drafted and revised the manuscript; BB, SP, PA contributed to the development of the protocol and are co-investigators of the project; EW lead the data collection and contributed to drafting the manuscript; PJ, V and B contributed to the data collection; NT developed the education and training materials for the diabetes CHW training; OJ is the co-lead in developing the App. All the authors contributed in revising the manuscript.

COMPETING INTERESTS

The authors completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available upon request from the corresponding author), and declare no conflicts of interest.

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SUPPLEMENTARY MATERIALS

Online Supplementary Document

Download: <https://www.joghr.org/article/24169-frontline-community-health-care-workers-intervention-for-diabetes-management-in-resource-limited-settings-a-qualitative-study-on-perspectives-of-key/attachment/61154.docx>
