

Public and Patients involvement in chronic illness care, a way to provide universal health coverage in poor resource setting - A case study

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Abstract

Lack of active community participation and inadequate human resources are challenges in caring chronic illness. Involving patients and publics in health care is an evidence-based strategy to overcome the above challenges. Department of Community and Family Medicine University of Jaffna has designed and evaluated a strategy. Three females were selected, trained and designated as Community Health Assistants (CHA) and financially supported by an NGO. Their performance was evaluated with mixed methods. CHAs supported clinics, education programs, home visits and some community-based NCD screening. CHAs found difficulties in working with some socio-economic groups and some categories of health care providers. They were interested in working in an institution-based setup. There were some problems in maintaining medical records. Satisfaction with each CHAs varied. The program could be improved by training the CHAs and a mechanism needs to be established to provide ongoing financial support.

(Key words: Public, Patients, Chronic illness, PPIE)

Background

Ensuring universal health coverage for the management of non-communicable diseases is a daunting task in rural areas of Sri-Lanka. This is primarily due to inadequate community participation and lack of human resources. (1) Involving patients and publics in health care is an evidence-based strategy to overcome the above challenges. (2) Furthermore this strategy has recently been endorsed by the Ministry of Health in Sri-Lanka.

However, scaling up and sustaining such a strategy requires effective program design and evaluation. In order to develop public involvement, the

Department of Community and Family Medicine (DCFM), University of Jaffna (UOJ), has designed and evaluated the strategy in the context of the University project area. The University project area is a geographically-defined target population cared for by the DCFM, with the support and collaboration of the local health authority; it has been established as a means of facilitating population-based medical education and research.

Before pioneering the strategy, the DCFM modified the health system in the University project area so that it was suitable for involving members of the public. The key modification was to establish an extended arm in the project area called the Family Health Centre (FHC). The FHC functions as the focal point and coordinating centre of the health care and medical education programs related to non-communicable diseases. An academic from the DCFM coordinates the activities in the Family Health Centre. The FHC has played a key role in implementing and evaluating the program to involve patient and public in health care delivery.

Objective:

The objective is to design a program to involve public and patients in chronic illness care and evaluate its effectiveness.

Methods

Program design: Three females were selected from the local community based on their commitment and interest in working as a health care support worker. They were trained to support in providing health care delivery (preventive, rehabilitative and palliative care), organizing medical educational programs (undergraduate teaching and continuous medical education program), and maintaining paper-based medical records. Training was provided on-the-job. The selection of Community Health Assistants (CHAs) was carried out by the FHC coordinator and the training, supervision, motivation and evaluation were carried out by a



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panel of experts comprised of the FHC coordinator, a family physician, a clinical psychologist, a community physician, and two nursing officers. (3,4)

Program implementation: The trainees were designated as Community Health Assistants (CHA) and financially supported by an NGO. They were provided with an official identity card and strictly instructed to wear it during their duty time. CHAs were allowed to work only in the Jaffna University project area, University Family Health Centre and Department of Community and Family Medicine. CHAs supported health care providers to conduct community-based screening, rehabilitation and palliation in the University project area, healthy lifestyle clinics (HLC), and NCD clinics conducted in the Family Health Centre. In addition, CHAs supported academics in organizing monthly education programs for continuous medical and undergraduate students and helped health care providers to maintain and retrieve medical records. (4,5)

Evaluation: The performance of those three community health assistance were evaluated under two headings firstly adherence to the duty list and secondly ability to work as team player. This was carried out by the same expert panel using mixed methods. Quantitative methodology was used to quantify the number of supported health care activities and educational programs against the total number of conducted programs. Qualitative methodology was utilised to describe the interactions between the multiple stakeholders. Data were collected through semi-structured interviews with selected health care providers (HCP), medical students, and with all three CHAs, as well as group discussion with representatives of all stakeholders, CCTV camera footage and overt participatory observation notes prepared by the coordinator FHC.

Results

CHAs supported the conduct 100% of HLC, NCD clinics, and education programs, 80% of community-based rehabilitation and palliative care and 40% of community-based NCD screening.

CHAs found difficulties in working with some socio-economic groups within the community and some categories of HCPs. They were interested

in working in an institution-based setup but not in a community-based one. CHAs maintained the medical records as expected. However, there were some problems identified in retrieving the medical records: delay in retrieving, inappropriate retrieval of medical records (incorrectly identified patients).

Most of the healthcare providers and academics were satisfied with CHAs. 'However, satisfaction with individual CHAs varied, with most HCPs and academics expressing satisfaction with one CHA in particular'. (3,4)

Conclusion and recommendation

The program illustrated the usefulness and sustainability of the strategy. It could be further improved by training the CHAs to work harmoniously with all categories of HCPs and socio-economic classes. Further training is needed to enable CHAs to work efficiently in the community and effectively in the retrieval medical records. 'A resource or mechanism needs to be established in order to provide ongoing financial support'

Reference

1. Wilsher SH, Brainard J, Loke Y, Salter C. Patient and public involvement in health literacy interventions: a mapping review. *Research involvement and engagement*. 2017 Dec;3(1):31.
2. Pallas SW, Minhas D, Pérez-Escamilla R, Taylor L, Curry L, Bradley EH. Community health workers in low-and middle-income countries: what do we know about scaling up and sustainability?. *American journal of public health*. 2013 Jul;103(7):e74-82.
3. Singh P, Chokshi DA. Community health workers-a local solution to a global problem. *New England Journal of Medicine*. 2013 Sep 5;369(10):894-6.
4. Ingram M, Reinschmidt KM, Schachter KA, Davidson CL, Sabo SJ, De Zapien JG, Carvajal SC. Establishing a professional profile of community health workers: results from a national study of roles, activities, and training. *Journal of community health*. 2012 Apr 1;37(2):529-37.
5. Gilkey M, Garcia CC, Rush C. Profession-alization and the experience-based expert: Strengthening partnerships between health educators and community health workers. *Health promotion practice*. 2011 Mar;12(2):178-82.