



© WHIB/Pierre Viot



Empowerment and involvement of tuberculosis patients in tuberculosis control:

Documented experiences and interventions

© World Health Organization 2007

All rights reserved. Publications of the World Health Organization can be obtained from WHO Press, World Health Organization, 20 Avenue Appia, 1211 Geneva 27, Switzerland (tel.: +41 22 791 3264; fax: +41 22 791 4857; e-mail: bookorders@who.int). Requests for permission to reproduce or translate WHO publications – whether for sale or for noncommercial distribution – should be addressed to WHO Press, at the above address (fax: +41 22 791 4806; e-mail: permissions@who.int).

The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by the World Health Organization in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by the World Health Organization to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either expressed or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall the World Health Organization be liable for damages arising from its use.

Printed in France

WHO/HTM/STB/2007.39

Empowerment and involvement of tuberculosis patients in tuberculosis control: Documented experiences and interventions

Jean Macq

Health Programmes and Policies in Developing Countries Unit, Department of Policy and Health Systems, School of Public Health, Université Libre de Bruxelles, Brussels, Belgium

This publication was commissioned by the Stop TB Partnership and the World Health Organization

February 2007

Contents

Executive summary	3
Introduction	4
Methods	5
Operational definitions of empowerment and involvement of TB patients	6
Better control by patients of their health and life	6
Peer support	6
Assisting TB control services	7
Barriers to empowering TB patients	8
Barriers to accessing health services	8
Stigmatization and isolation of and discrimination against TB patients	8
'Patient control' in TB programmes	9
Belonging to vulnerable groups	9
Experience with empowerment of TB patients	10
Enabling TB patients to take more responsibility for their health	10
Organization of TB patient groups and clubs	11
Instituting more patient-centred TB and general health care	11
Improving the advocacy skills of TB patients	12
Operationalizing TB patient empowerment: lessons learnt	14
Stakeholders	14
Incentives and enablers	15
Performance of TB control programmes	15
Burden of TB	16
Resource availability and sustainability	16
Scaling-up an experience or intervention	17
Evaluation of the process	19
Outcome evaluation: TB control	19
Outcome evaluation: patient well-being	22
Outcome evaluation: equity	23
Conclusions	24
Recommendations	25
Meaning and purpose of the empowerment of TB patients	25
Barriers to the empowerment of TB patients	25
Design and choice of strategies to enhance the empowerment of TB patients	25
Stakeholders	25
Evaluation and scaling-up	25
Acknowledgements	27
References	28

Executive summary

Empowering and involving patients with tuberculosis (TB) in the management of their disease is of increasing interest for policy-makers, managers and health care providers involved in TB control. It is clearly connected to other priorities in TB, such as equitable access to services by vulnerable and poor populations, the interaction between TB and HIV, and human rights. It is, however, a complex issue.

This document presents the results of a review of the available published and grey literature on the empowerment and involvement of patients and former patients in TB control. It identifies possible trends and conclusions and suggests ways of informing policy-makers and further research. Multiple strategies were used to ensure that relevant information was used in the review, including key words for the MEDLINE and PSYCINFO databases and use of worldwide web research engines, conference abstracts and project reports.

The review of documented experience covers the means used to enable patients to take more responsibility for their health and, in particular, for adherence to treatment; organizing TB patients into groups and clubs; ensuring patient-centred TB and general health care; and helping TB patients to use advocacy to improve TB control. It describes the operational definitions of and potential barriers to empowerment and the importance of context, including the characteristics of stakeholders, incentives, the performance of TB programmes and the burden of TB. These issues must be explored carefully in evaluating and planning the scaling-up process.

Introduction

The empowerment of patients in the fight against TB is still an underdeveloped area, although it is not a new concept. For example, in 1992, the United States Centers for Disease Control and Prevention recommended that “Empowerment of at-risk groups in the community is a crucial element in TB control. This step begins with the public awareness campaigns because it is vitally important for members of at-risk populations to understand TB, its impact on the community, how it is diagnosed, treated, and prevented, and what services are available. These populations also should be able to influence TB programs directed toward their communities.” (Centers for Disease Control and Prevention, 1992). In the late 1990s and early 2000s, on the basis of experience with community-based care in Africa and elsewhere, the framework for expansion of the direct observation of treatment strategy (DOTS) included the need for patient-centred care for TB patients (WHO, 2002a). The current Stop TB strategy, which is based largely on DOTS, recognizes empowerment of patients and communities as a key component (Stop TB Partnership & WHO, 2006).

This document presents a review of experiences in empowering patients. Available scientific and descriptive studies on the empowerment of TB patients have been summarized in order to identify and explore possible trends, examine the evidence gap and inform further research. Conclusions have been formulated to assist implementation of this key component of the Stop TB strategy. The document describes successful experiences in empowering and involving TB patients or affected communities in TB control and the delivery of services. The first task was to determine what information was available in the literature on empowering and involving TB patients and former patients in TB control, in particular to analyse any effects on TB programmes and on patient-centred care. The second task was to summarize the available scientific and descriptive studies on the empowerment and involvement of TB patients and former patients in TB control, to identify trends and conclusions and to suggest means for informing policy-makers and further research.

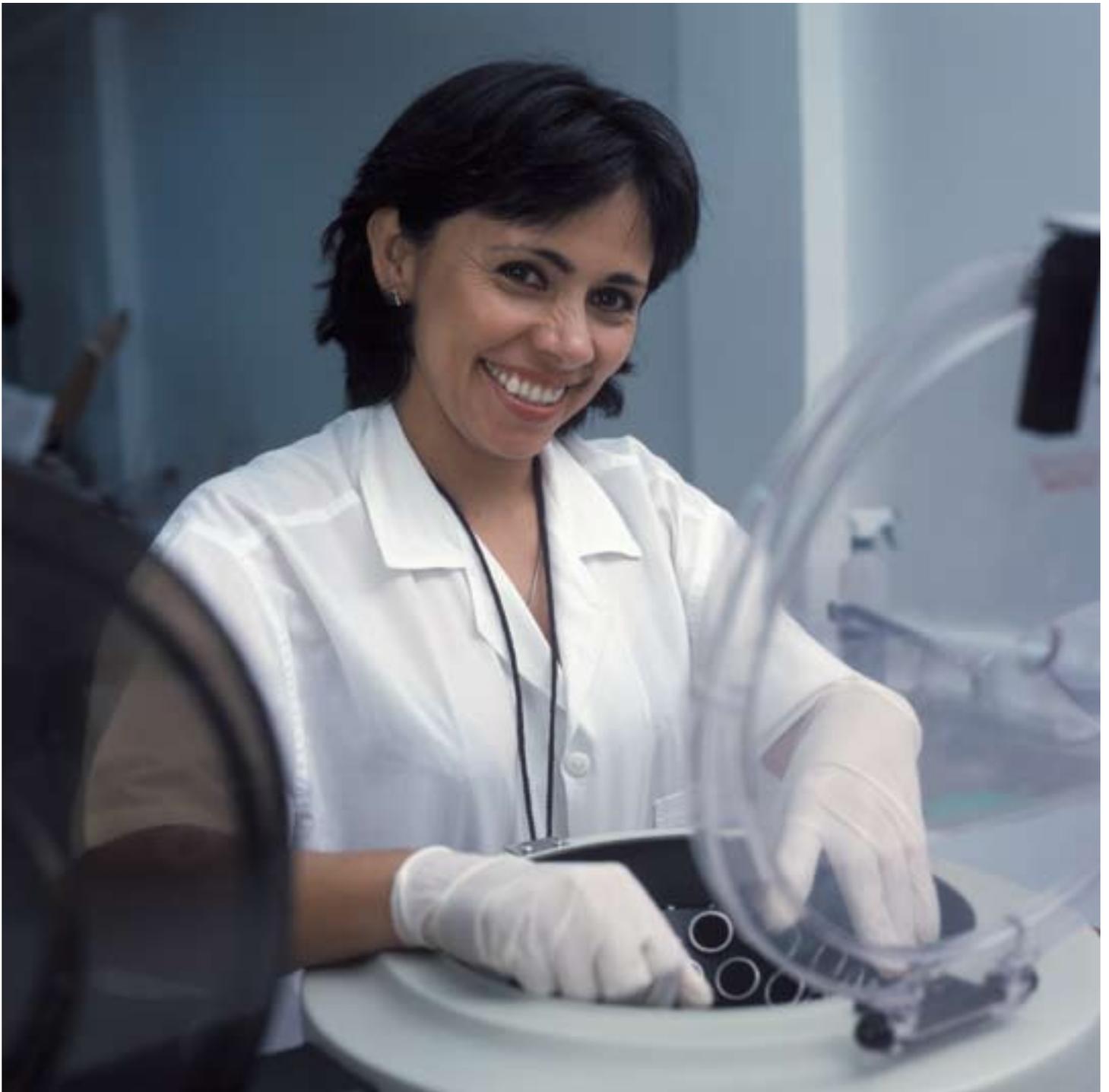
Empowerment and involvement of the patient and patient-centred care in the context of TB control are the central themes of this document. Several reviews on the organization and management of chronic care have explored these relatively vague concepts (Feste & Anderson, 1995; WHO, 2002b; WHO, 2003; Michie, Miles & Weinman, 2003; Hibbard et al, 2004; Mc Gregor, 2006;). The meanings of empowerment and involvement are analysed from the point of view of the conditions necessary for patient empowerment (self-esteem, motivation, information, capacity, communication, patient-provider interaction, social support); threats and barriers to empowerment (human rights, DOTS typology, poverty, patient-centred care); and lessons to be learnt from empowerment and involvement (autonomy, acting for others, acting in collaboration with health care providers and TB programmes).

Methods

The evidence and conclusions of this paper are derived from the published literature, reports, conference abstracts and information on the internet. The published literature in the MEDLINE and PSYCINFO databases was searched with the key words 'tuberculosis', 'patient' and '(participation or behaviour or incentive or empowerment or poverty or human right or patient right or community care)'. Each of the 314 articles initially retrieved was screened by reading the abstract. Only articles in which interventions or issues related to changing TB patients' behaviour or involving them in their own care or in TB control were mentioned were finally included in this review.

Abstracts were retrieved from abstract books distributed at conferences organized by the International Union against Tuberculosis and Lung Disease between 2003 and 2005, and the authors were contacted to obtain additional information when needed. Other conference abstracts and the 'grey literature' on TB patient empowerment or involvement were obtained through e-mail contacts and internet searches with the Google engine.

To make the review useful for operational decisions, practical experiences and interventions for empowering patients in TB care and control were sought. For each experience or intervention identified, the following information was systematically recorded: (1) description of the intervention (components, level of complexity) or experience and period of implementation; (2) the evaluation method (quantitative or qualitative, design); (3) implementation (challenges, useful ingredients, leaders or initiators); (4) the context (burden of TB, co-infection with HIV, other interventions, community role, first-line health services, nongovernmental organizations, TB control programmes); (5) measures or indicators of TB used and the results; and (6) the empowerment area explored, measurement indicators and results.



© IFRC/Chris Black

Operational definitions of empowerment

预览已结束，完整报告链接和二维码如下：

https://www.yunbaogao.cn/report/index/report?reportId=5_29576



云报告
<https://www.yunbaogao.cn>

云报告
<https://www.yunbaogao.cn>

云报告
<https://www.yunbaogao.cn>