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Empowerment and involvement of tuberculosis patients in tuberculosis control:

Documented experiences and interventions

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Empowerment and involvement of tuberculosis patients in tuberculosis control:

Documented experiences and interventions

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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.

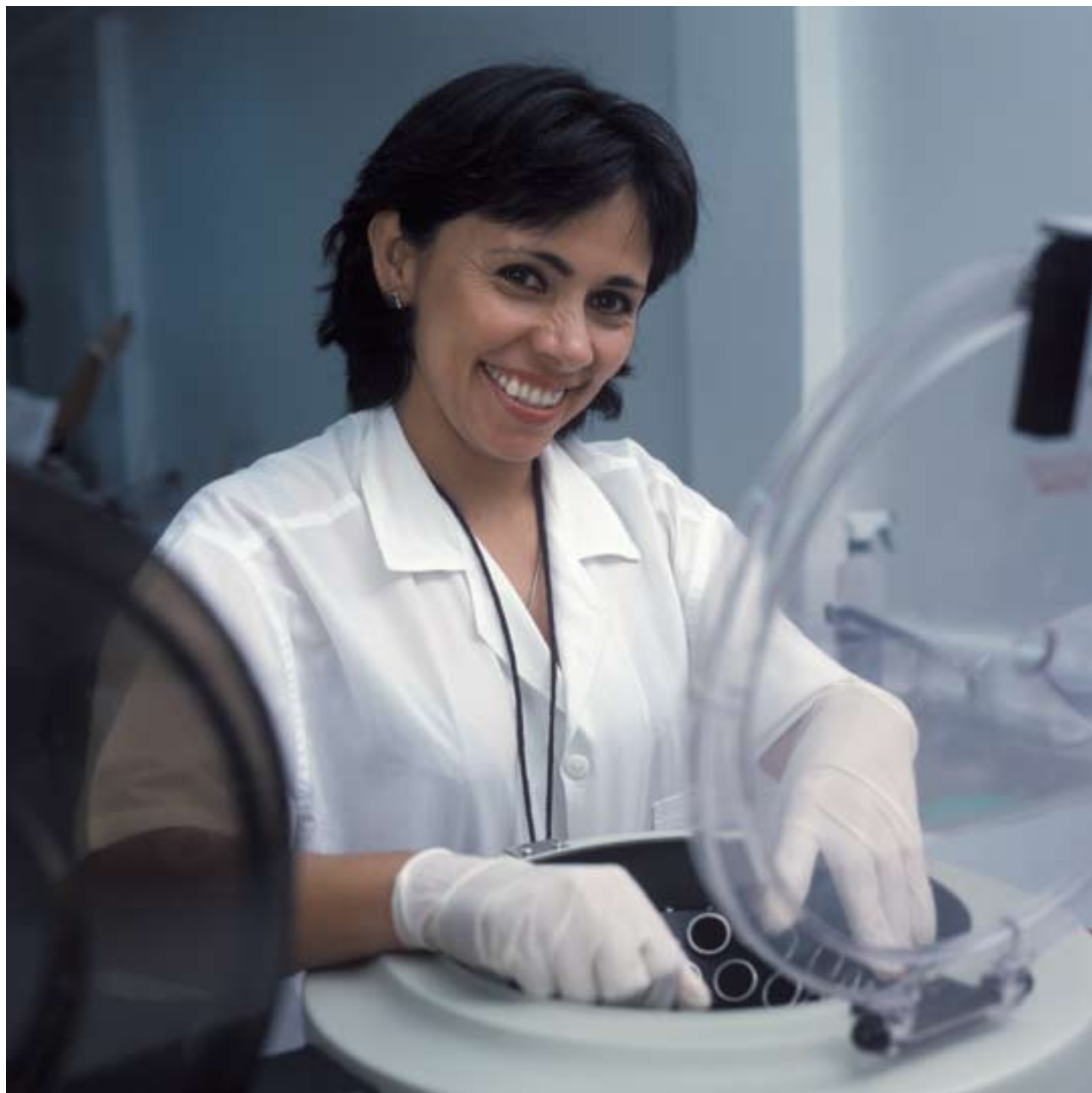
Empowerment and involvement of the patient and patient-centred care in the context of TB control are the central themes of this document. Several reviews on the organization and management of chronic care have explored these relatively vague concepts (Feste & Anderson, 1995; WHO, 2002b; WHO, 2003; Michie, 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.



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Operational definitions of empowerment

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