

Brief Research Article

Reasons for Default from Treatment of Chronic Illnesses in a Primary Healthcare Program in Rural Tamil Nadu

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Summary

Chronic illnesses are an increasing cause of morbidity and mortality in rural India. Many patients default from treatment, and exploring their reasons for the same may suggest strategies to improve service accessibility and acceptability. A qualitative study was conducted of 22 patient interviews, six key informant interviews, and two patient focus group discussions for investigating the reasons for default at the KC Patty Primary Health Centre and surrounding villages in Kodaikanal Taluk, Dindigul district, Tamil Nadu. The reasons included money or transport difficulties, frequent travel, feeling healthy, focus on work, fear of scolding from clinic staff, medication side effects, preference for alternative therapy, and depression. Some reasons were only divulged after an extended discussion. Support from families and village-level health workers (VLHWs) were also identified as important. Recommendations include more open and patient communication between health workers and defaulting patients, in addition to recruitment of more VLHWs.

Keywords: Chronic disease, Patient dropouts, Patient non-compliance, Primary healthcare, Village health worker

Introduction

Chronic illnesses are being increasingly recognized as major threats to health in rural India.¹ More research is required to inform about effective and acceptable strategies for rural primary healthcare. Investigating patients' reasons for default from treatment can highlight areas for service improvement. Studies in developed settings have identified reasons such as patient motivation and time, side effects, and frustrations with clinic administration and doctors' attitudes.² Studies in India have investigated factors associated with default in tuberculosis,³⁻⁶ but did not ask patients for their own

reasons; moreover, most studies have been conducted in urban populations. Therefore, the present study aimed to investigate reasons for default from treatment of chronic illnesses in a rural primary healthcare program.

A qualitative study was conducted with patients, health staff, and other key informants at the KC Patty Primary Health Centre and surrounding villages in Kodaikanal Taluk, Dindigul district, Tamil Nadu, in January and February 2011. The study was approved by the Nossal Institute for Global Health Human Ethics Advisory Group at the University of Melbourne, and by a local committee of community leaders. The Centre is a non-governmental organization (NGO) serving a local population of 17,000 that was selected because of its comprehensive registry and follow-up programs. Patients who miss collecting medication for three consecutive months are visited by health workers and assisted with information, transport, and subsidies according to their apparent means.

Prior studies have used various definitions of "default" or "drop out".³⁻¹⁰ In keeping with local practice, patients in this study were considered "defaulters" if they had missed collecting medication for three consecutive months in the previous year and "regulars" otherwise. Participants were non-randomly selected from the

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clinic register to provide a sample varying in age, gender, location, socioeconomic status, illness, and pattern of default. Of the 24 patients approached, 22 (15 defaulters; seven regulars) agreed to confidential interviews. One focus group was run for regulars (11 attendees) and one for defaulters (four attendees). Six key informants who worked with patients with chronic illnesses were also non-randomly selected: two clinic health workers (CHWs), two village-level health workers (VLHWs), one nun, and one officer of another local NGO. All interviews and focus group discussions employed an English-Tamil interpreter. Interviews with defaulters explored their own reasons for default; other interviews and discussions explored reasons for default in general. These multiple sources allowed triangulation of reasons and identification of other underlying factors. Data were audio recorded, transcribed, and manually coded into emerging themes for qualitative analysis.

Of the seven regular patients, four had hypertension; one, asthma; one, insulin-dependent diabetes mellitus; and one had epilepsy. Five patients were male and two, female. Of the 15 defaulters, 10 had hypertension; one, iron-deficiency anemia; one, ischemic heart disease; one, rheumatoid arthritis; one, leprosy; and one had tuberculosis. Nine patients were male and six, female. The regulars' focus group comprised four male and seven female patients, and the defaulters' had one male and three female patients. Key informants included one male and five female patients.

Defaulters' reasons are presented in Figure 1. Some were stated upon initial questioning and some only later in interviews.

Money issues: While these were commonly reported, subsidies were individually tailored, underpayments occasionally accepted, and all defaulters who initially cited money problems later admitted other reasons.

Most regular patients made assertions such as:

"It is difficult for me to pay the 200 rupees, but I am happy to pay because I need good health."

Side effects: These included menstrual irregularities, loss of appetite, and cramps. Some regular patients and key informants suggested that defaulters' concerns might be more general:

"They feel uneasy... thinking, 'What is this medicine, always taking medicines, why should we take?'..."

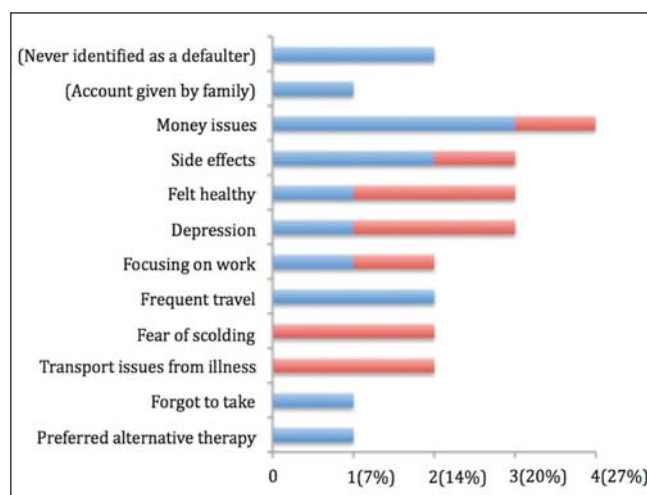


Figure 1: Showing reasons for being default for chronic illnesses Blue: Number of defaulters citing initially (percentage of total defaulters); Red: Number of defaulters citing later (percentage of total defaulters)

Felt healthy: Two defaulters with hypertension and one with leprosy each gave this reason:

"I was able to work, and climb trees and everything. So I thought I am OK, I have no need to take medicines."

Depression: Some defaulters felt depressed after deaths of friends or relatives:

"After seeing everybody else go like this, what I will do? Why take medicines, why do I have to live?"

Key informants and focus groups acknowledged:

"They are thinking, 'Do we have land or anything? There is nothing. Why stay here? When fate comes we will die.'"

Focusing on work: One defaulter explained:

"I am going for work, no? That is very important, so in that mood I went off and did not come to get the medicines"

Frequent travel: Both defaulters who initially cited this later admitted that they feared scolding (see below).

Fear of scolding:

"For a long time I did not go and get medicines, no? So Doctor may scold me. He may shout at me, 'why did you not come?'"

Most patients felt comfortable coming to the clinic. Some patients and key informants felt that scolding was justified for patients' health or program cost-effectiveness.

Transport: Despite some patients residing at two hours' bus ride from the clinic, this reason was cited by only two defaulters with mobility impairments. Health workers and family members offered to deliver medications, if necessary.

Preferred alternative therapy: The defaulter with rheumatoid arthritis preferred siddha because she perceived it as effective, more convenient, lacking side effects, and potentially curative.

Some underlying factors included:

Knowledge about disease: Defaulters identified less serious consequences of untreated disease than did regulars. Of the patients with hypertension, all four regulars but only four of nine defaulters identified disability or death as potential complications. Key informants and regular patients agreed that information was provided but added:

"Firstly they did not know, and secondly they did not take it seriously..."

Family support: Nearly all regulars had supportive families, while three of the 15 defaulters were widowed or abandoned.

Focus groups and key informants agreed that isolation could impact on transport, money, lack of knowledge, or depression:

"The main reason is, a human being is not there. That will lead to the other reasons."

Village-level health workers: VLHWs could check patients' adherence, advise them of the importance of treatment, and deliver medications. Patients and key informants recommended recruiting more VLHWs.

Patients' decisions depend on a balance of perceived benefits against perceived costs and inconveniences.¹¹ Not all factors may be consciously acknowledged or readily disclosed. Some defaulters may cite reasons outside their control (eg, cost), or deny defaulting to avoid discussing embarrassing reasons (eg, fear of scolding).

Triangulation was achieved regarding all themes except money. However, the size of subsidies, individual tailoring, acceptance of underpayments, and admission of other reasons suggest that cost is not an absolute barrier for this population. Transport difficulties, similarly, can usually be overcome with assistance. Apprehensions

of side effects or preference for alternative therapies may require extended discussion informed by patients' understandings and culture.

Reasons such as "Felt healthy", "forgot to take", and "focused on work" suggest a lack of either understanding about the disease or appreciation of its import. Defaulters' limited identification of long-term risks may reflect either a lack of knowledge or a dread of acknowledgement. In either case, information must be delivered comprehensibly, patiently, and founded on a genuine rapport. The latter is critical to convey that the staff are fundamentally concerned for patients' health and to allow patients to articulate any apprehensions.

Depression in this context has profound social and economic determinants, but it may be possible to train CHWs and VLHWs in basic counseling techniques.^{12,13}

"Fear of scolding" can be self-fulfilling: If defaulters give alternative explanations that are met with skepticism, they may become yet more afraid of reproach and aversive of clinical contact.¹⁴ Health workers may need to anticipate fear of scolding among defaulters and offer reassurance as appropriate.

Adult family members can assist with money or transport and should also be integral in persuading, reminding, and motivating patients to take medications. They should be utilized as partners in management, with additional follow-up where possible for isolated defaulters. VLHWs are also ideally placed to understand defaulters' perspectives, build rapport, and supply medications.

Transport difficulties, lack of social support,² depression, work commitments, and side effects have all been reported as reasons for default in developed settings.^{2,15} "Feeling healthy" and a preference for alternative therapy seem dependent on cultural health beliefs,⁹ while fear of scolding may be more common in low-income settings.¹⁰ Lack of knowledge has also been found to be relevant in other Indian studies.⁴

Limitations included language interpretation complicating qualitative analysis, social desirability biases, and selection biases in non-random sampling. The sample was small and included no mental illnesses. Being a qualitative study, the findings cannot be generalized freely to other settings. However, given the predominance

of private health spending in India,¹⁶ it is hoped that these will nevertheless prove useful to other providers of primary healthcare in rural areas.

Reasons given by defaulters ranged from logistical (e.g., cost, transport) to knowledge (e.g., “felt healthy”) and personal/interpersonal (e.g., depression, fear of scolding). The latter factors were less readily admitted. For this reason, more sympathetic and open discussion between health workers and defaulters, in addition to recruitment of local support (such as VLHWs and family members) are recommended.

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- Last Date of submission of Nomination for Honorary Fellowship has been extended for 30 days i.e. dt. 30.10.13.
- Last date of submission for nomination for Fellowship has been extended for 15 days. i.e. dt. 15.10.13.



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