An Exploration of Patient Perceptions of Adherence to Tuberculosis Treatment in Tanzania

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Abstract

In this study, we aimed to explore patient perceptions of adherence to tuberculosis (TB) treatment and construct a theoretical model of treatment adherence behavior. We conducted semistructured interviews with 11 adherent patients from Tanzania whom we recruited by purposive sampling. The interview data were analyzed by content analysis. We found that the patient's intention to adhere is the most important determinant of adherence behavior. This intention is preceded by the decision to seek biomedical health care, and based on knowledge and beliefs about TB treatment and the motivation to be cured. The intention to adhere helps patients to cope with perceived barriers to adherence, such as socioeconomic difficulties, and to create an adherence-enabling environment in which the presence of social support plays an important role. Our preliminary adherence behavior model should be validated in larger, nonadherent patient populations and evaluated for its applicability to the development of adherence-promoting strategies.

Keywords

Despite the availability of effective treatment, tuberculosis (TB) remains one of the main infectious diseases worldwide that is associated with severe morbidity and mortality. Every year, more than 9 million people are diagnosed with TB, and 1.6 million people die of the disease (World Health Organization [WHO], 2010). A major challenge to global TB control is nonadherence to treatment. The extent of nonadherence to TB treatment is difficult to assess, but it is estimated that up to one fourth of TB patients fail to complete the 6-month treatment course (Sumartojo, 1993). Nonadherence increases the risk of treatment failure and relapse, and is considered to be the most important cause of drug-resistant TB (WHO, 2008). In particular, multidrug resistant (MDR) and extensively drug resistant (XDR) TB constitute serious threats to public health. According to recent estimates of the WHO, almost half a million people were diagnosed with MDR TB in 2008 (WHO, 2010). To improve adherence to TB treatment, the WHO recommends the direct observation of treatment (DOT) by a trained person who monitors the patient's medication intake (WHO, 2002). However, DOT is labor intensive when provided in health care facilities (facility-based DOT), and might not be applied strictly when provided by a member of the patient's community (community-based DOT; Frieden & Sbarbaro, 2006).

An in-depth understanding of the factors that affect adherence to TB treatment could facilitate the development of complementary adherence-promoting strategies. Several mainly quantitative studies have been conducted for this purpose, and more than 200 determinants of adherence have been described, including social, demographic, and other patient factors. However, the relationship between these factors and adherence is not very consistent, and reveals little about causality (WHO, 2003). In a few studies, attempts were made to evaluate theoretical models that could be applicable to adherence behavior, but none of the existing health behavior theories sufficiently explained adherence behavior to TB treatment (Munro, Lewin, Swart & Volmink, 2007; Van Dulmen et al., 2007). Most theories

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do not address the context-specific sociocultural aspects of adherence behavior, and are not applicable to long-term medication adherence (Munro et al.).

In this qualitative research study, we conducted semistructured interviews with patients with TB from Tanzania's northern Kilimanjaro region to analyze factors that influence adherence to TB treatment as perceived by these patients. Our aim was to construct a theoretical treatment-adherence behavior model based on content analysis of the interview data.

Study Setting

Tanzania is one of the 22 countries with the highest burden of TB. The country's TB incidence is estimated at 183 per 100,000 people. The annual treatment success rate of new TB cases is reaching the WHO target of 85% (WHO, 2010). However, among those with an unsuccessful treatment outcome, almost one third are defaulters, meaning that they terminate treatment prematurely (WHO, 2010). Except for default rates, no data are available on the levels and patterns of nonadherence to TB treatment by Tanzanian patients.

The standard Tanzanian treatment regimen for newly diagnosed, drug-susceptible TB in adult patients consists of a 2-month intensive phase of rifampicin, isoniazid, pyrazinamide, and ethambutol administered in three or four fixed-dose combination (FDC) tablets taken once daily, followed by a 4-month continuation phase of rifampicin and isoniazid in three or four FDC tablets. The National TB and Leprosy Program (NTLP) empowers patients to decide whether their daily medication intake is supervised by health care staff at the health care facility or by a treatment supporter from the patient's community (usually a family member or spouse). Facility-based DOT is mainly provided to patients whose medical condition requires hospital admission; more than 80% of outpatients opt for community-based DOT (Van den Boogaard et al., 2009). Patients on community-based DOT are supposed to collect their medication from the health care facility once weekly during the first 2 months of treatment and once every 2 weeks during the remaining 4 months (Ministry of Health and Social Welfare, 2006).

Methods

Study Participants

We recruited the study participants from a cohort of 50 adult patients with TB on community-based DOT, who participated in a longitudinal treatment adherence study. In this study, the levels and patterns of the patients' adherence to treatment were assessed by using a combination of methods including the Medication Event Monitoring

System[1] (MEMS), a medication container with an electronic microchip that records every opening of the container. Other adherence measures used in this study were a urine test to detect rifampicin and isoniazid, pill counts at medication refill visits, registration of the regularity with which patients attended the health care facility for medication refills, and standardized questionnaires. Participants in the longitudinal study were recruited between February and April 2010 from one rural and three urban health care facilities in the Kilimanjaro region.

We selected the participants for the present study from the group of patients in the longitudinal study who had completed at least the first 2 months of treatment. We used the technique of purposive sampling to obtain a maximum variation sample with respect to age, sex, residency, and concomitant diseases that helped us to understand the processes underlying adherence behavior, and enabled us to confirm or disconfirm tentative connections between themes that started to evolve from interim data analyses (Marshall, 1996; Mason, 2007). We continued with the sampling process until themes started to recur in the interviews and no new themes arose (saturation; Guest, Bunce, & Johnson, 2006); this point was reached after 11 patients from the longitudinal study had been interviewed.

The Semistructured Interview

In the preparatory phase of the study, we conducted a review of the literature on the determinants of adherence to TB treatment to define key concepts that provided starting points for the process of data collection (Bowen, 2006; Mason, 2007). The literature review indicated that adherence is a form of health behavior that relates to the presence (or absence) of barriers and facilitators. These key concepts (adherence behavior, facilitators of adherence, and barriers to adherence) helped us to set the context for our study. We used the key concepts to design a topic list with a set of four open-ended core questions that served as a backbone in the interviews: (a) Could you describe your daily medication intake ritual? (b) How would you describe your level of adherence to the prescribed medication? (c) What makes adherence to the prescribed medication difficult for you? and (d) What helps you to adhere to the prescribed medication? The wording of these questions was not fixed, but was adjusted to the level of comprehension of the participants. Additional questioning followed the flow of the participants' answers and was directed by themes evolving from interim analyses of the interviews.

The participants were interviewed in a private room in the clinic from which they were recruited. The interviews were conducted by an English-speaking researcher (first author van den Boogaard, hereafter referred to as the researcher) with a fair understanding of Tanzania's national language, Kiswahili, and a Tanzanian research assistant

(second author Msoka), who translated the researcher's questions from English to Kiswahili and the participants' answers from Kiswahili to English. The interviews were tape-recorded and lasted between 1 and 1.5 hours each. The researcher and research assistant made notes of their observations of the verbal and nonverbal communication during the interviews. The English-spoken parts of the interviews were transcribed, and these transcripts were used for data analysis, together with the original tape-recordings.

Data Analysis

We conducted the data analysis parallel to data collection, and started with the construction of a coding scheme that we developed during the interim analyses of the interviews. For the development of the coding scheme, the three key concepts that were derived from the initial literature review (i.e., adherence behavior, facilitators of adherence, and barriers to adherence) served as initial "master codes" from which second- and third-level codes followed to capture themes and subthemes, respectively (Woods, Priest, & Roberts, 2002). We grouped connected themes and subthemes into categories (that reflected, to a large extent, the initial key concepts) and incorporated them as such in the coding scheme. The final coding scheme was used to code the transcripts of all interviews. This was done by the researcher and the research assistant independently. We compared the coding results and the initial agreement between the two coders was "substantial" (kappa value of 0.74; Landis & Koch, 1977). For each interview, we discussed the coding differences and reached consensus.

The final step involved the generation of a theoretical model in which the categories, themes, and subthemes were interconnected. The largest part of this process had already taken place during data collection; we had confirmed the relationships between themes that emerged from the interim analyses of interviews with participants in consecutive interviews. We constructed the ultimate model with our team of researchers (all authors) after we had reached consensus about the relationships between themes. The process of data analysis is best summarized as content analysis (Priest, Roberts, & Woods, 2002), and resulted in the generation of a theoretical model that was directed by but not restricted to our initial key concepts (Bowen, 2006; Mason, 2007).

Standards for Qualitative Inquiry

The researcher and research assistant discussed the challenges of conducting cross-cultural and cross-language qualitative research extensively in the preparatory phase of the study. The researcher, a Dutch medical doctor, has a fair understanding of Kiswahili, but does not speak the language fluently. The research assistant, a Tanzanian research

nurse, is a native Kiswahili speaker who is also fluent in English. She has a wide experience in translating between English and Kiswahili in in-depth interviews for clinical and research purposes. With respect to the translations during interviews, the key concepts "adherence behavior," "barriers," and "facilitators," and frequently used keywords such as "treatment adherence," "nonadherence," and "treatment supporter" were explored and translated beforehand. To verify the accuracy of translation in the interviews, the Kiswahili-spoken parts of the first interview were transcribed and consecutively translated into English by an independent Tanzanian translator who did not have access to the English-spoken parts of the interview. We compared this translation with the transcript of the English-spoken parts of the interview and did not find inconsistencies between the two documents. Therefore, we used the transcripts of the English-spoken parts of the interviews as the primary data source and referred to the Kiswahili-spoken parts only in case of doubt.

As Squires (2009) pointed out, in cross-language qualitative research the interpreter should be regarded as a social actor and not merely as a technical translator. The complexity of the social interplay in the interviews and the effect on the generation of data was dwelled on by the researcher and the research assistant in the preparatory phase. In particular, they took note of the fact that their different socioeconomic and cultural backgrounds might influence the responses of participants (Temple, 2002). For example, local norms could make it difficult for participants to answer openly and honestly to a foreign visitor or, more generally, to people whom they associate with their local health care providers (Marvasti, 2004, as cited in Silverman, 2006). To reduce this risk, the researcher and research assistant regarded participants as "experts by experience." The researcher and research assistant were not involved in the provision of health care to the participants, and presented themselves as researchers who wanted to learn from the participants' experiences. In addition, participants were approached both as respondents, who would talk about their own perceptions and experiences, and as informants, who would base their answers on what they knew from others. We expected that the latter strategy would help participants talk freely about what is generally considered as deviant health behavior.

We optimized the accuracy of data collection and analysis by an exploration of the key concepts prior to the actual data collection, to capture their broad spectrum of possible meanings. We addressed the validity of data collection in interim interview analyses by evaluating whether the interviewer and the participants appeared to have a similar understanding of the meaning of the key concepts (Mason, 2007). Furthermore, we evaluated the validity of the analyses of the participants' accounts by verification of emerging themes in consecutive interviews, and by a brief evaluation of the constructed model

Table 1. Content Analysis: Overview of Categories, Themes, and Subthemes

Category	Themes and Subthemes	*n / 11**
Intention to adhere to TB treatment	Knowledge and beliefs about TB treatment	11
	General beliefs and perceptions of TB disease	9
	Belief that TB is curable	11
	Belief that the doctor's instructions need to be followed to be cured	9
	Motivation to be cured	10
	Long history of suffering	5
	Responsibility toward family / financial need to start working again	5
Perceived facilitators of and barriers to adherence to TB treatment	Social support	11
	Financial support	8
	Emotional support	4
	Social support as a reminder to take the medication	8
	Cues: reminders to take the medication	6
	Health care service factors	6
	Socioeconomic factors	7
	Substance-abuse factors	11

*Theme/subtheme identified in the accounts of *n* (out of 11) participants

with individual participants after the interviews (respondent validation; Silverman, 2006; Whittemore, Chase, & Mandle, 2001).

Ethical Considerations

We obtained ethical approval from the Institutional Review Board of the Kilimanjaro Christian Medical Centre and the Tanzanian National Institute for Medical Research. Prior to the interviews, participants received verbal and written information about the purpose and structure of the interview, and signed an informed consent form. We informed them that confidentiality was guaranteed.

Results

Characteristics of Study Participants

We interviewed 11 patients, 6 men and 5 women. Their median age was 36 years (range 22 to 71 years). Five participants were married; 3 were single, 2 were widowed, and 1 was divorced. The majority (7 participants) had attended primary education only; 3 had completed secondary school, and 1 had no formal education. Four participants were coinfected with HIV, 2 of whom were using antiretroviral medication. The study sample was a fair representation of the general TB patient population in the Kilimanjaro region with respect to gender distribution (55% men in the study sample vs. 63% in the general TB patient population), median age (36 vs. 37 years), and proportion of HIV-infected patients (36% vs. 37%; Van den Boogaard et al., 2009; WHO, 2010).

All participants were in their third month of TB treatment when they were interviewed, and were on community-based DOT. Most participants were adherent to treatment at the time of the interview. Six participants had not missed a single dose during the first 2 months of treatment, according to MEMS results; 4 had missed less than 5 doses, and 1 had missed 10 doses shortly after the onset of treatment. At the time this writing, all participants had successfully completed treatment.

Content Analysis

Two categories of themes were identified: themes that related to the patient's intention to adhere to TB treatment, and themes that reflected perceived facilitators of and barriers to adherence once the intention to adhere was present. An overview of the themes and subthemes is provided in Table 1. In the following, themes are presented as separate entities and in relation to one another. The quotations in the text do not always follow the technical rules of the English language; rather, they represent as accurately as possible a literal translation of what participants said. In Figure 1, the theoretical adherence behavior model that we constructed is presented. The connections between themes and subthemes are depicted with numbered arrows in the Figure.

Category 1. Intention to Adhere to TB Treatment

The participants all expressed a strong determination to adhere to TB treatment. The main themes underlying this
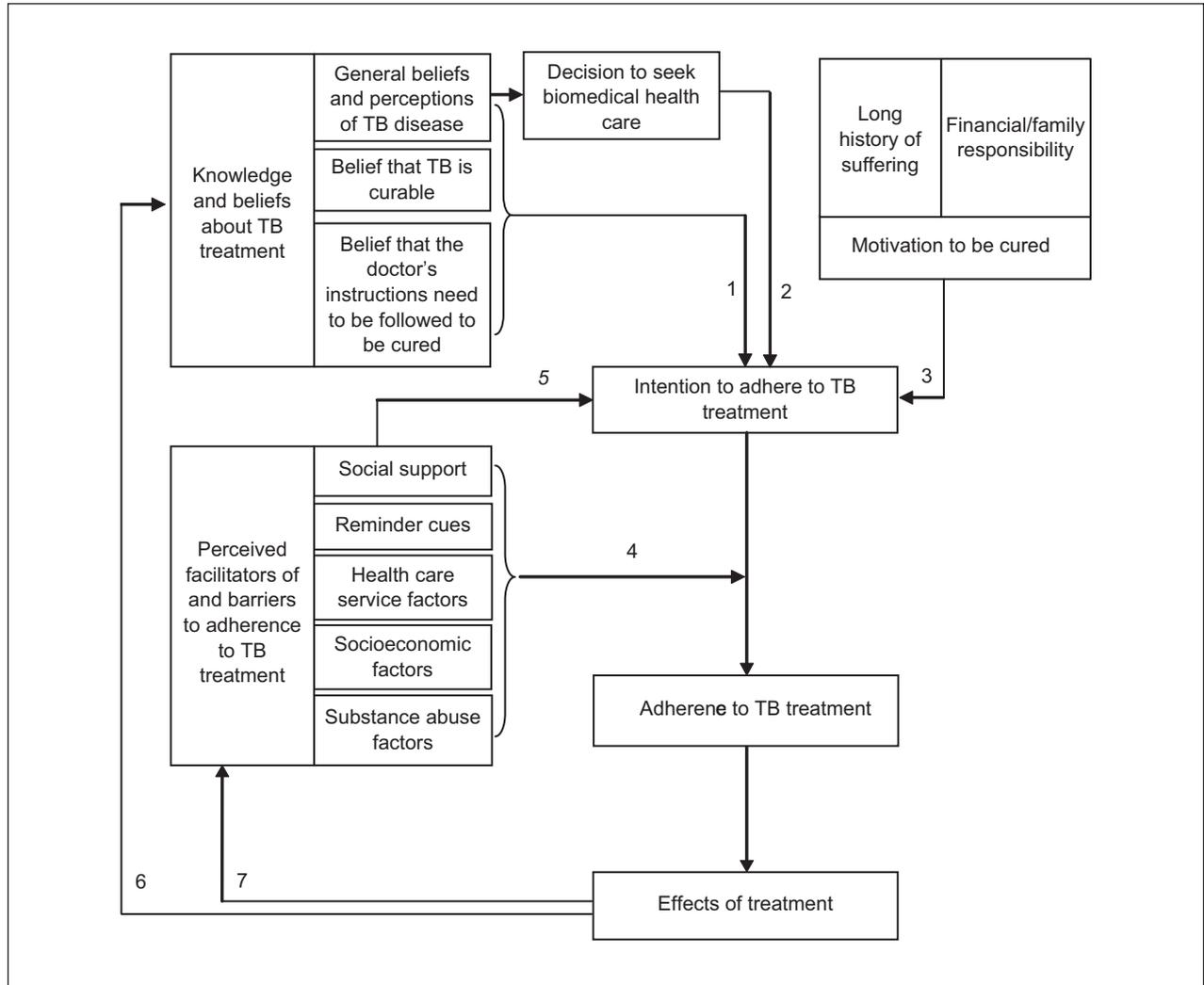
Figure 1. A preliminary theoretical model of treatment adherence behavior

intention to adhere were knowledge and beliefs about TB treatment and the motivation to be cured (see Figure 1, arrows 1 and 3).

Theme 1: Knowledge and beliefs about TB treatment. This theme consisted of three interrelated subthemes: (a) general beliefs and perceptions of TB disease, (b) the belief that TB is curable, and (c) the belief that the doctor's instructions need to be followed to be cured. The participants' confidence in biomedical health care—i.e., biomedicine as opposed to traditional medicine such as witchcraft and herbal medicine, which are widely available in Tanzania (Savage, 2002)—recurred within all subthemes. Five participants contrasted biomedicine directly to traditional medicine. The others referred to their reliance on biomedicine in a more subtle way; for example, by stating, "The disease has come to my body and the doctors in the hospital have identified what it is. So I have to take the medication" (59-year-old woman [59, W]).

With regard to the first subtheme, general beliefs and perceptions of TB disease, the reliance of participants on biomedicine determined their health-care-seeking behavior (see Figure 1, arrow 2). A 56-year-old man from a rural area stated that unlike himself, many older people from rural areas tend to stay away from hospitals, and use traditional medicine instead:

> We have those elders, to date they still have their medication. They won't go to the hospital. Those people, even if they have a headache, they will just go to the field and pick their medication. This disease [TB], especially in this rural area, is said to be a disease of long time [a chronic disease], so people don't bother to go to the hospital to check. They just take the traditional medicine. People in the village, they say this is a traditional disease; it never cures, it never ends. For myself, I went to the

hospital, because I have been out of the village, in towns. I have been to the hospital. I understand.

In the perception of others, traditional medicine and bio-medicine do not automatically exclude one another. A 22-year-old female community worker said, "I think one month before coming here [the hospital], I was taking one traditional medicine, Maasai medicine. They said that this medicine cures TB. It cures every kind of chest [problem]."

Other beliefs about TB also influenced the health-care-seeking behavior of the participants. Some participants believed that all patients with TB have blood-stained sputum. A 56-year-old man delayed going to the hospital to be diagnosed because his sputum was not blood stained, and therefore he did not think he might have TB. A 22-year-old HIV-negative woman believed that people with TB are always coinfected with HIV. Because she feared being diagnosed with HIV, she delayed seeking health care for several months:

> First of all, I was told that the person who is having TB must also have HIV/AIDS. That was my pressure [made me feel anxious]. One day I went to the hospital. They checked me the X-ray and told me that they had to take a sample of my sputum. But I was scared! I told the doctor, just give me the medicine that can make my chest okay, but don't test that thing. Most of the time, I was so concentrated in my brain, I was told that if you have this thing [TB], you must also have something like this [HIV]. That made me sick even more! But the day I decided to go, I said, 'I'd better go and check everything.'

The beliefs of patients and communities about TB also resulted in feared or perceived stigmatization. Community beliefs from which TB stigma originated included the belief that all patients with TB also have HIV, the belief that patients with TB are highly infectious and should be isolated, and the belief that TB is a "bad" disease. Feared or perceived stigma discouraged patients from sharing their experiences with others.

All participants believed that TB is curable, the second subtheme of the theme knowledge and beliefs about TB treatment. Participants reported on several sources of information that helped them to believe that TB is curable. Some participants had read about TB treatment on health education posters in health care facilities. Most participants believed that TB is curable because they had heard from others who were cured after using the medication as prescribed. In addition, the participants had experienced a substantial improvement in their health after they started TB treatment, and this strengthened their belief that TB is curable (see Figure 1, arrow 6). Whereas the participants understood that they had to continue

treatment despite their feeling better, they attributed non-adherence by others to a lack of knowledge about the necessity of continuing treatment: "For those people who feel improved like me, they may stop the medication because they don't know" (36, W).

The belief that to be cured the doctor's instructions should be followed (the third subtheme of the theme knowledge and beliefs about TB treatment) was expressed by all participants. In simplified terms, most participants reasoned that (a) they were sick, so (b) they had to be cured, and thus (c) they had to follow their doctor's instructions. The belief was influenced by examples from others who did not adhere to treatment and had an unfavorable treatment outcome. A 25-year-old man referred to the example of his brother:

> I remember my own brother, who was working in the bush. He got tuberculosis and he stayed in the hospital for almost two years, and thereafter he was discharged. But he was not following the instructions [of the doctor]. He was drinking and sometimes smoking, so the tuberculosis, again he got it. So when he was returned to the hospital, it was in vain. He died. So I decided to take it strongly, because I was remembering my brother and I did not want the same to happen to me.

The participants mentioned several instructions they had received and that they were following strictly, including the necessity of continuing treatment for 6 months, even though clinical improvement had already occurred. They also referred to instructions that they might have taken more literally than meant by the health care provider, such as no alcohol consumption, no smoking, no heavy work, and no sexual intercourse during TB treatment. According to the participants, most patients with TB who fail to adhere to the prescribed treatment either do not know or cannot comply with these instructions.

Theme 2: Motivation to be cured. To the question why the participants were managing so well at taking their medication every day, many participants responded that they wanted to be cured (see Figure 1, arrow 3). The subthemes that were found to underlie this motivation were a long history of suffering, responsibility toward the family, and the financial need to start working again. A 28-year-old woman had attended several health care facilities before it was discovered that her backache was caused by spinal TB. She stated, "For sure, the pain that I had, the way it has been relieved, I need to continue taking the medication." Other participants felt a strong responsibility toward their family, which motivated them to be cured, as illustrated by the following comments made by a 56-year-old man:

There is one thing which is pushing me so much: my kids. Because the first children, when I was not having this disease, I was able to educate them, and that's why they are now in university. But the second range of children, now I am sick, I cannot get the money which I used to get from my job. Because I cannot do that job due to my health. So there is a pushing to me that I need to go back to that job. But how can I go? I need to ensure that I take my medication so that I can get to work.

Category 2. Perceived Facilitators of and Barriers to Adherence to TB Treatment

Several factors were mentioned that could facilitate or hamper adherence to TB treatment. The participants perceived the presence of support from family members and friends, the use of reminder cues, and the presence of helpful health care staff as facilitators of adherence. Socioeconomic difficulties and substance-abuse factors were regarded as the main barriers to adherence. Because the absence of any of these factors could have an opposite effect on adherence (e.g., the absence of social support was regarded as a barrier to adherence by some participants), the facilitators of and barriers to adherence are grouped together in Figure 1 (see arrow 4).

Theme 1: Social support. The presence of social support was a recurrent theme in all interviews. Participants perceived that social support was a means of financial or material assistance, a means of emotional support, or a means to remind them to take the medication. A 65-year-old man referred to material assistance when he was asked how church members helped him adhere to treatment: "It is only one day. They brought me a kilogram of sugar." A 33-year-old man coinfected with HIV received emotional support from his relatives: "So they help me in giving ideas that don't feel lonely, don't feel that you are the only one because you are infected. Just feel like other people." The man who was motivated to be cured because of his responsibility toward his children was reminded to take the medication by his children: "So they actually tell me that, if I am taking my medication at eight a.m., they come and tell me, 'Dad, have you taken your medication?' So they help me with the time."

Apart from being a facilitator of adherence, social support also served as an initiator of perceived social pressure: the expectations of the participants' family members with regard to adherence were important motivators for some participants to adhere to treatment. A 71-year-old man expressed this strikingly: "I need to make sure that I take the medication properly, because if I won't continue well, my family will see me as a meaningless person." Thus, social support was not only perceived as a facilitator of adherence by being a means of financial, emotional,

or practical help; it also influenced the participants' intentions to adhere (see Figure 1, arrow 5).

Almost all participants had informed their close relatives about the disease, and social support was primarily received from family members. Feared or perceived stigma prevented most patients from informing friends or colleagues. A 35-year-old woman from a rural area, for example, stated,

People are just pointing fingers. Even for TB. So when you go there, they [the neighbors] will just say, "That one is now sick, is taking the medication." They cannot help me anything. Instead, they will point fingers along the road.

Although 2 participants received social support from peer patients, others stated that patients with TB are reluctant to share their experience with other patients. A 65-year-old man said, "You know, when we sit here, everyone with the bottle [medication container] just hides so that nobody can see and know that he is using."

Theme 2: Reminder cues. The participants mentioned several cues that helped them to remember to take their medication. Some participants used the alarm of a mobile phone to inform them when the time to take the medication had reached. Others placed their medication bottle somewhere where it was clearly visible, to remind themselves. In addition, most participants carefully selected an appropriate time for medication intake. A 25-year-old man from an urban area described this:

I decided only in the morning, because in the evening there is a lot. I might work there in the evening, fighting with friends. So I might find myself coming home and just set to sleep, so I won't take my medication, or come back from work, tired, I forget to take my medication. That's why I said, it is only in the morning. Because I wake up, I brush my teeth, take my medication, and go to work.

Theme 3: Health care service factors. Several issues came up with regard to health care service factors that were perceived to affect treatment adherence. The participants agreed on the importance of being adequately informed. A 28-year-old woman explained how she knew she had to complete treatment:

From the seminar that I got from the doctor, he told me, "This disease is not finished, so if you don't finish the medication, it will come back." So that is enough for me to see that I have to continue.

According to the participants, apart from providing health education, health care staff could facilitate the patients' adherence to treatment by providing reminder

cues, by ensuring supervision of medication intake, and by providing patients with financial or material assistance. The attitude of health care staff toward patients was also discussed. None of the participants complained about their own experience with health care staff at the clinics they attended. Generally, they stated that health care providers should be polite and supportive.

Theme 4: Socioeconomic factors. The socioeconomic challenges most participants faced were perceived as a barrier to following the instructions they had received and that, they believed, had to be complied with strictly. For example, participants were told not to take the medication on an empty stomach, and most participants experienced that the medication increased their appetite (see Figure 1, arrow 7). Some had to struggle (financially) to get enough food, and this struggle was aggravated by the instruction not to do any heavy work during TB treatment. A 25-year-old porter said,

> With my job, I have a friend whom I used to carry his luggage. So when I got this, he said to me, "I give you the afternoon food, but for the evening, you just find yourself." So after this, because I was provided with the afternoon meal, I decided to take the light work. That way I can do two or three jobs a day. I get 2500 or 3000 shillings and then I just stop, because I will use the money. So I did that for almost two months. But in the meantime, my health was improving. So I decided, I can also increase the workload, but not that much, because of the [doctor's] instructions.

Other participants reported on the difficulty of paying for transportation to the clinic to collect their medication every 1 or 2 weeks. Although the socioeconomic difficulties were perceived as barriers to adherence, these difficulties did not actually lead to nonadherence in the participants. It seemed that the participants' strong intention to adhere helped them to cope with the perceived socioeconomic challenges. A 35-year-old woman who indicated that she could hardly find enough money to pay the bus fare to the clinic explained how she nevertheless managed to attend every week: "I have no choice. I have to come, because I am sick and I want to get better."

Theme 5: Substance-abuse factors. All participants suggested that alcohol abuse was the most important barrier to TB treatment adherence by others, either because these others knew that alcohol and TB treatment cannot be taken together (at least, that is what patients were told in the clinic), or because alcohol abuse made them careless about their health. Other substance-abuse factors mentioned as possible barriers to treatment adherence included smoking and drug abuse, for similar reasons as alcohol abuse.

Effects of TB Treatment

As described in the presentation of the two categories of themes, the effects of medication intake influenced the participants' intention to adhere and the perceived barriers to adherence. For example, the curative effect of treatment strengthened the participants' beliefs that TB is curable (see Figure 1, arrow 6), and adverse effects of treatment (such as feeling hungry) aggravated the perceived socioeconomic difficulties that participants had to cope with (see Figure 1, arrow 7).

Discussion

In this study, we explored patient perceptions of adherence to TB treatment and constructed a preliminary theoretical model of treatment adherence behavior based on content analysis of patient accounts. The study participants who were adherent to TB treatment revealed that the intention to adhere was the most important determinant of adherence behavior. This intention was preceded by the decision to seek biomedical health care (as opposed to traditional health care), and shaped by knowledge and beliefs about TB treatment and the motivation to be cured. The intention to adhere helped participants cope with the perceived barriers to adherence, and to create an adherence-enabling environment in which the presence of social support played an important role. Social support was perceived as a direct facilitator of adherence to TB treatment by being a means of emotional and financial help, and by reminding patients to take their medication. In addition, social support strengthened the patients' intention to adhere by contributing to perceived social pressure.

Our finding that the patient's intention to adhere is a major determinant of adherence behavior is in agreement with two commonly cited cognitive health behavior theories: the Theory of Reasoned Action (TRA; Ajzen, 1988) and the Theory of Planned Behavior (TPB; Ajzen, 1991). According to the TRA, the intention to behave in a certain way is determined by two independent variables that are also reflected in our study findings: attitudes toward the behavior and subjective norms (i.e., perceived social pressure; Ajzen, 1988). In agreement with the TRA, we found that knowledge and beliefs about TB treatment (attitudes toward the behavior) underlie the patient's intention to adhere, and that social support induces perceived social pressure toward treatment adherence (see Figure 1, arrows 1 and 5, respectively). In the TPB, perceived behavioral control (i.e., self-efficacy) is included as a third variable that determines behavioral intention (Ajzen, 1991). Contrary to this, we found that the intention to adhere can help overcome the perceived barriers to TB treatment adherence. However, not all barriers to adherence are under volitional control, and therefore it would be too simple to conclude

that all patients who do not manage to overcome the barriers to adherence lack the intention to adhere. Nevertheless, our findings suggest that when counseling nonadherent patients, an assessment of the patient's intention to adhere is a crucial first step.

One of the limitations of the TRA, the TPB, and other health-behavior theories is that little attention is paid to the role of sociocultural factors (Ashing-Giwa, 1999; Munro et al., 2007). We found that the knowledge and beliefs about TB treatment of Tanzanian patients were colored by biomedical and traditional health beliefs, and that confidence in biomedicine was an important first step toward the intention to adhere to treatment. According to the participants, many TB patients in rural settings use traditional medicines against TB and refuse to seek biomedical health care. This could be regarded as a form of primary nonadherence; i.e., failure (refusal) to take any medication at all (Farmer, 1999), and indicates that we must expand our evaluation of the processes that result in nonadherence to the period before patients start visiting the health care facility.

The distinct confidence of the participants in biomedicine, their belief that doctors' instructions need to be followed, and their strong motivation to be cured reflect elements of Parsons's Sick Role Model (Parsons, 1951). According to the Sick Role Model, patients are expected to want to be cured as soon as possible (i.e., return to the healthy, nondeviant state again), and to comply with their doctor's advice. In return, they are temporarily exempted from their normal activities and have the right to receive adequate health care (Parsons). The motivation of the participants to be cured could be interpreted as a desire to return to the healthy state, and to be able to perform normal social roles again. Patients who stop adhering when they start to feel better might perceive that they have already returned to the normal, healthy state again. At this point, the necessity to continue taking the medication could be perceived as more disrupting to one's identity than the illness itself, and cognitive factors such as knowledge about the necessity of completing the full treatment course become particularly essential at this stage.

It seemed that the participants had misperceived or taken too literally some of the instructions they received from health care workers. Some of the instructions—such as the prohibition to work hard or have sexual intercourse during TB treatment—were actually perceived as barriers to adherence by the participants. Although the study participants managed to cope with these perceived barriers, other TB patients might not. It is therefore important that health care workers evaluate carefully how patients interpret the instructions they receive with respect to TB treatment.

Another sociocultural aspect of adherence that was raised by the participants was the role of stigma, and in particular stigma related to the association of TB with HIV. In Tanzania, 37% of patients with TB are coinfected with HIV (WHO, 2010), whereas the estimated HIV prevalence in the general adult population is 5.7% (WHO, 2009). Negative attitudes toward people living with HIV/AIDS are widely present (Genberg et al., 2009; Mill, Edwards, Jackson, MacLean & Chaw-Kant, 2010), and can be projected on patients with TB, as well (Naidoo, Dick, & Cooper, 2009). Other studies have indicated that the fear of stigma can discourage patients with TB from seeking health care at all (Courtwright & Turner, 2010; Gebremariam, Bjune, & Frich, 2010; MacDonald, Rigillo, & Brassard, 2010). Because of feared or perceived stigma, most of the participants were reluctant to talk about their disease with community members or peer patients. Surprisingly, though, they all knew of stories of other patients with TB, and had gathered a large part of their knowledge about TB treatment from these stories. Considering that information sharing between patients and communities will improve community knowledge about TB treatment, reducing TB stigma could eventually have a substantial impact on treatment adherence.

Study Limitations

It is often argued that qualitative research that is preceded by a review of the literature could lead to bias in the process of data collection. We avoided this by being sensitive to new concepts that came up in the interviews and by paying attention to the validity and reliability of data analysis. We interviewed a selective group of 11 patients on community-based DOT only. We did not interview nonadherent patients (that is, patients with less than 80% intake of prescribed doses) because we did not encounter such levels of nonadherence in the pool of patients from which the participants were selected. Moreover, we interviewed patients in a relatively early phase of treatment. Thus, the model of treatment adherence behavior that we present in this article is based on the accounts of a selective patient population only. It should be viewed as a preliminary adherence behavior model that warrants further studies to validate the underlying theories; to confirm its applicability to other patient populations, including nonadherent patients; and to evaluate its relevance to the design of effective adherence-promoting interventions. Nevertheless, we think our findings provide some potential avenues for strategies that could help patients to adhere to TB treatment.

Conclusions and Avenues for Adherence-Promoting Strategies

The main finding in this study was that the patient's intention to adhere to TB treatment plays a major role in the establishment of adherence behavior. This intention could be strengthened by improving community knowledge

about TB treatment. Social support is perceived as a direct facilitator of adherence, and in addition, social support strengthens the patient's intention to adhere by inducing perceived social pressure. Thus, involving a close relative or spouse in the treatment of patients with TB, and making this person coresponsible for adherence to treatment—such as is done in community-based DOT programs—could have a positive impact on treatment adherence. Finally, the intention to adhere seems to help patients cope with the perceived barriers to TB treatment adherence. This finding implies that helping patients to overcome perceived barriers to adherence (e.g., by the provision of monetary or food incentives) could be effective in patients who intend to adhere, but not in patients who lack this intention.

By exploring patient perceptions of adherence to TB treatment, and by developing a preliminary theoretical model of adherence behavior, we have contributed to a general understanding of how adherence behavior is established. Further studies in larger, nonadherent patient populations should confirm the validity of the adherence behavior model presented in this article.

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Declaration of Conflicting Interests

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