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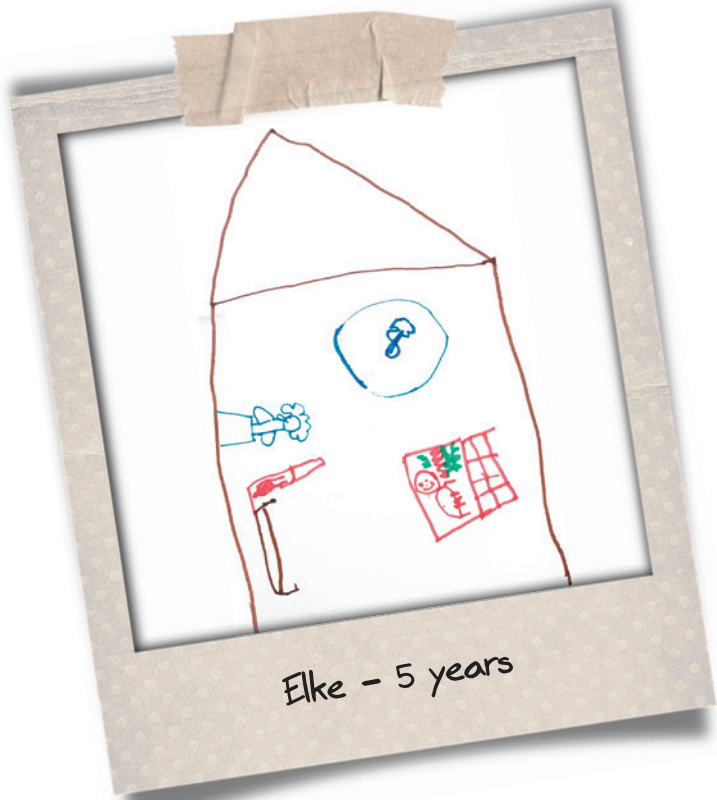
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Tuberculous Meningitis: Barriers to adherence in home treatment of children and caretaker perceptions

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SUMMARY

Introduction: In-hospital treatment of children with tuberculous meningitis (TBM) is not a feasible option in many resource-poor countries. Home-based treatment has shown to be a viable alternative. Adherence is an important factor determining success of treatment.

Objective: Identify possible barriers to adherence of home-based treatment and caretaker perception of the disease.

Method: A qualitative study consisting of 11 in-depth semi-structured interviews was performed based on principles of the health belief model.

Results: Barriers of adherence identified include poor understanding of the disease and transmission route, difficulty with medication administration and side effects, lack of access to the healthcare facility, long waiting times and hidden costs of transportation. Caretakers showed good appreciation of the adverse effects of noncompliance and benefits obtained from taking treatment in the home environment.

Conclusion: Improved doctor–patient communication, information brochures, structural changes to hospital settings, provision of financial and peer support all contribute to optimal TBM home-based treatment.

INTRODUCTION

Tuberculous meningitis (TBM) is the most severe complication of tuberculosis (TB) and mainly affects young children [1–3]. Although in-hospital treatment is regarded the norm [1], long-term hospitalization may negatively affect the child as well as the family [4]. In addition, the continuous rise in cases of multi-drug resistant TB has decreased the availability of beds at local TB hospitals [5]. Under certain conditions, home-based treatment is a viable alternative [6]. An important factor determining the success of any TB treatment program is adherence. The average adherence rate to TB treatment in children is 67% [7]. TBM is related to high mortality and morbidity. The severity of the disease is associated with poor outcome (sequelae such as cognitive-, vision-, hearing- and motor impairment) [2, 8]. Nonadherence will increase severity and further worsen the outcome of TBM disease. In addition, nonadherence is one of the major causes of drug resistance and death [9–11].

The aim of this qualitative exploratory study was to understand the social process of adherence by identifying possible barriers of adherence to home-based treatment. Improving the current TBM home-based treatment program (HTP) will provide a structured base for implementation of future programs. In order to do so, the use of theories on health behaviour is recommended [12]. Research supports the utility of the health belief model (HBM) in explaining adherence [12, 13]. This model (Figure 1) is clarified elsewhere [12].

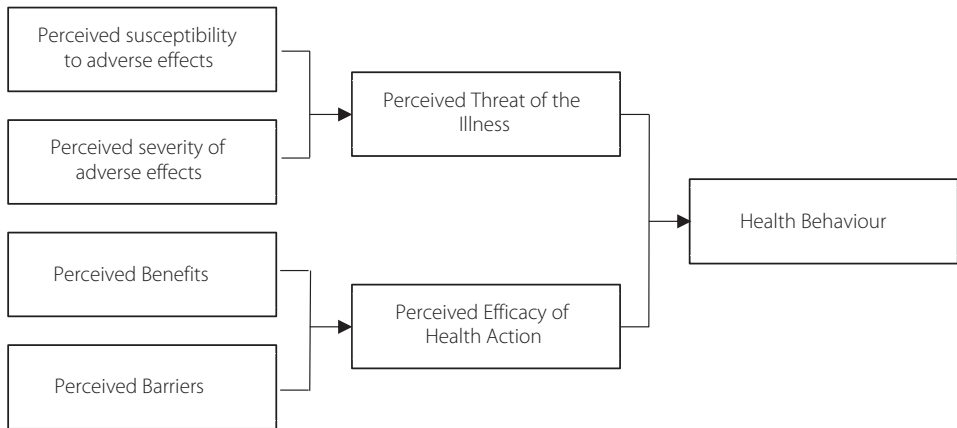


Figure 1. HBM predicting good adherence, adapted from Munro *et al.* [12].

Methodology

This study was conducted in at Tygerberg Children’s Hospital (TCH) in the Western Cape Province (WCP) of South Africa. The WCP has one of the highest TB rates in the country [14]. A recent study at this site reported 14.9% of all culture-confirmed TB cases in children

younger than 13 years of age were from TBM [15]. All children in the HTP received local standard care (6 months treatment; daily doses rifampicin, isoniazid, pyrazinamide, ethionamide and prednisone) [6]. Besides occasional prescribed vitamin supplements and cough medication, no additional medication was given by caretakers.

Factors determining the efficacy of TB programs are often difficult to quantify as they are influenced by differences in perception, which vary between groups and are expressed only in subtle variations of emphasis [16]. A qualitative approach is essential to describe the structure of barriers to adherence in the HTP, in order to operationalize innovative strategies to reduce these barriers. A key stakeholder group was given the opportunity to articulate their needs and priorities. This provided insight into the experiences, perceptions, practice and social process of adherence in children receiving their TBM treatment at home.

The sampling strategy used for this study was purposive sampling based on preselected criteria. These criteria included children aged 0–15 years in the HTP and those who had completed the HTP in the preceding 6 months. HIV-positive patients were excluded from the study as HIV co-infection complicates TB treatment [6]. The study population consisted of 11 families, 6 with a child in the HTP and 5 who had completed the HTP in the preceding 6 months.

Between March and June 2009, semi-structured interviews were conducted in the language of the caretakers' choice. An interview guide based on the HBM was used for each interview.

The crude data were transcribed verbatim and analysis of the transcripts was based on the framework approach. Analytical categories were used to describe and explain the phenomena of adherence. These categories were deduced at the beginning and partway through the analysis process. Quotes have been selected to illustrate the identified themes. Ethical approval was granted by the Human Research Ethics Committee of the Stellenbosch University.

RESULTS

Demographics

Caretaker age ranged between 24 and 57 years, while the children were aged between 6 months and 12 years. Three caretakers were employed, two others stopped working during the HTP. All children were from low-income households (consisting of 3 to 17 people) and reported an average income of 2.19 US dollar (R18.47 [17]) per person in the household a day. Three households reported an income below the international poverty line of 1.25 US dollar a day [18]. All caretakers had completed 6–12 years of schooling. Four children were attending school at the time of the study.

Perceived susceptibility

The general understanding of TBM was very limited and the transmission route of TB was unclear to most caretakers. Explanations offered by caregivers for possible causes of TBM included: 'a dirty environment' and 'the child falling on the head'. Two caretakers mentioned contact with a TB infected person. Caretakers reported that they never skipped medication as they worried about the effect on their child: 'I was afraid he would become sick again'. Even though the underlying mechanism was not well understood, the perceived susceptibility to the adverse effects of nonadherence was average to high.

Perceived severity

Caretakers seem to appreciate the severity of the disease. Emotive terms were used when asked to explain their understanding of TBM: 'difficult', 'very dangerous', 'very worrying' and 'a strong disease'. These experiences proved to be a key factor in understanding the importance of adherence to treatment. The period before diagnosis was experienced by most caretakers as emotionally distressing, 'It's a very painful experience and the disease itself is very hard for the parent as well as the child'. Many caretakers thought their child might die at some stage.

Caretakers felt it was their responsibility as parents to take care of the child and put the child's well-being first: 'He is my priority and because of that I make it everybody else's priority too'. The overall perceived severity of the adverse effects of nonadherence was considered very high.

Perceived benefits

The greatest benefit of the HTP for caretakers was having their child at home seeing them flourish. If the child had been hospitalized, caretakers would have had to travel daily for visits which would often be unaffordable: 'I did have problems when my child was in hospital, because I couldn't make an income'. Having the child at home gave caretakers the feeling of being able to contribute to the process of healing: 'I experienced that I'm good mother'. Caretakers felt the medication was beneficial and would cure their child. They observed improvement, and witnessed the child was starting to feel better after initiation of treatment. Caretakers did not report disagreement (or conflict) with the doctors during the HTP and trusted their professional advice. The contextual aspects of the medical setting (the child being at home) was highly appreciated and caretakers believed the treatment was effective. Therefore, the perceived efficacy was considered high.

Perceived barriers

Perceived barriers to the HTP mainly related to medication and monthly follow-up. Although the procedure to administer medication was easy, giving medication was quite difficult for most caretakers: 'We had to struggle . . . fight with him'. Vomiting often complicated administration of medication while bad taste and odour of medication were reported to cause nausea. Other side effects mentioned were weight gain, skin rashes and behavioural changes (motor restlessness and aggression). The calendar, serving as a reminder to administer medication, was appreciated and used by all caretakers. In situations where the health of the child deteriorated, or medication was insufficient, some caretakers experienced difficulties obtaining assistance at the local clinics as their medical care was provided by TCH. In some cases, patients were even turned away from TCH by administrative staff or nurses when they attended prior to their monthly follow-up appointment.

The average travel time to reach the TCH using different forms of public transport was 2 h and cost about 7.11 US dollar (R60.00 [17]). Remuneration of travel costs by the TCH was highly appreciated and diminished this barrier.

At TCH, waiting times were considered burdensome. Some hospital visits lasted up to 9 h with most time spent waiting at the pharmacy (up to 6 h). Nurses and doctors showed a genuine interest in the child and caretaker, who felt supported by TCH staff. The doctor would persevere to ensure optimal communication: 'The doctor always explained twice again over . . . she would make sure'. However, information provided at discharge appeared to be difficult for caretakers to recall.

Caretakers felt supported by their family, friends and their church. Caretakers did feel the need to share experiences and expressed willingness to help others. One of the few caretakers who met another caretaker in the HTP explained: 'It was very nice to meet them because . . . we could talk about it, explain to each other how it is and how it feels'.

None of the children were seen by a traditional healer before diagnosis or during the period of the HTP. Three children received ointment at a local clinic and a church before the diagnosis of TBM was made. There were several perceived barriers of the HTP, the main being contextual aspects of the healthcare setting and side effects of medication, which resulted in a struggle with the child while administering medication.

DISCUSSION

The perceived threat of the illness was found to be high. Even though perceived susceptibility was average due to lack of understanding of the disease, the perceived severity of nonadherence was considered very high. The perceived efficacy of adhering to treatment appeared to be average. Although the perceived benefits were high (seeing the child flourish at home), there were several perceived barriers (waiting times and side

effects of treatment). Based on the theory of the HBM, good adherence is expected in this population. San Sebastian et al. [19] showed that general knowledge of TB improves adherence. The families understanding of disease and knowledge of disease management might significantly improve adherence [13].

Absence of symptoms is a common reason for nonadherence [20]. This was not reported within the study population, which could be explained by the high perceived severity of nonadherence. It was not as much the number of medicines, a common barrier for adherence [21], but side effects such as nausea and vomiting that complicated administration of treatment. Literature supports the fact that patients stop medication because of adverse effects [19, 22].

Inconvenience of hospital visits was another barrier that was identified. Several studies showed that long waiting times at health facilities negatively influence adherence [23–25]. Accessibility plays an important role in adherence to treatment [16]. Although caretakers only had to attend to TCH once a month, lack of accessibility could potentially have reduced adherence. Hidden costs of treatment could explain nonadherence [24], in this study, time taken off work and transportation costs were mentioned specifically. However, remuneration of transport money diminished this barrier.

Increasing support can improve adherence to treatment [24]. Although caretakers experienced great support from their social network, there is an interest in sharing experiences with peers which is not possible in the current setting. Caretakers felt supported and understood by doctors and nurses, which is a key factor in successful adherence to treatment [23, 25–27].

Munro et al. [12] identifies two main criticisms on the HBM: (i) no definitions have been constructed for the individual components and (ii) the positive effects of negative behaviours and social influences are not included. These criticisms were considered in the study design. Interpretation of the constructs of the HBM was adapted from Redding et al. [28] and conceptualized using the variables affecting paediatric adherence as described by La Greca et al. [13]. In addition, mediating factors such as educational level [28] and cultural beliefs [29, 12] were taken into account.

There were no non-responders, all eligible families agreed to participate. The limitation of this study was the fact that conclusions were based on eleven interviews, although a saturation level of 97.9% was reached after three interviews. In addition, social-desirable answers could have biased the outcome of this study. Results are to be interpreted with care.

To optimize the current HTP, improvement of the caretakers' understanding of TBM is vital. Easy readable brochures have shown to improve knowledge of the disease in a low literacy population [30] and could possibly increase understanding and doctor–patient communication. In addition, structural changes in the hospital setting could

decrease barriers concerning waiting time and peer support. Other institutions considering implementing this structured, home-based treatment of TBM, should take note of the key role that the doctors and nurses' full commitment to the program plays in the success of the program.

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Author contributions

S.L.vE. contributed to the conceptualization of the project, developed the initial questionnaire, carried out the interviews and analysis, and drafted the initial article. P.S. contributed to the conceptualization of the project, helped revising the questionnaire, contributed in the understanding of the results, and assisted in the write up and revision of the article. I.H.M.S contributed to the conceptualization of the project, contributed to the understanding of the theoretical framework, helped revising the questionnaire, contributed in the understanding of the results and assisted in the revision of the article. R.vT. contributed to the conceptualization of the project, helped revising the questionnaire, contributed in understanding of the results and assisted in the revision of the article. J.F.S. was the South African supervisor of the project, contributed to the conceptualization of the project, and assisted in the revision of the article. A.M.vF. was the Dutch supervisor of the project, contributed to the conceptualization of the project, and assisted in the write up and revision of the article.

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