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Perception Of Tuberculosis Patients' Quality Of Healthcare In Australia And Malawi

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Abstract: Purpose: While Tuberculosis (TB) is predominantly a disease of the developing world, it does still affect individuals living in the developed world. Although research on TB is extensive, patients' perceptions of care remain unknown. This article reports on research that investigated Pulmonary TB patients' perspectives of healthcare care. Design/Method: For this qualitative component of a mixed method descriptive study, 194 participants responded to open-ended questions in a survey and demographic questionnaire. The participants were drawn from a developed and a developing country. There were 44 participants from Australia and 150 from Malawi. Findings: There was widespread dissatisfaction with care. Four themes emerged: insensitivity and judgmental attitudes, inadequate resources, nurses' lack of specialty knowledge and experience, and limited advocacy. Discussion/Conclusion: Patients are dissatisfied with their healthcare care. Nurses' judgmental attitudes and stigmatization are impacting on patients' wellbeing and health disparities. Implications: Improving attitudes and overcoming discrimination remains a key challenge.

Keywords: Discrimination, patient dissatisfaction, quality of healthcare care, stigma, Tuberculosis

I. INTRODUCTION

Tuberculosis (TB) is a highly infectious disease that has afflicted people for generations even though it remains preventable. The disease is currently second only to HIV/AIDS as the greater cause of death worldwide from a single causative agent, with 95% of TB cases and deaths occurring in developing countries (World Health Organization, 2014).

Success with health care is substantially related to the social, economic and epidemiological contexts of each country (Dean & Fenton, 2010; Dye & Williams, 2010). People in developing countries continually experience economic hardship, poverty and malnutrition (Hanson, 2002; Belo, et al., 2006), and the prevalence of TB particularly among the disadvantaged minority groups is disproportionally higher than those in developed countries. TB has considerable psycho-social and physiological consequences (Gerrish, Naisby & Ismail, 2013) and stigmatization and isolation are major psychological problems (Author one).

In the developing country of Malawi, malnutrition is a key problem because people on low incomes cannot afford the required minimum calories to improve their health (Gurung, Chhetri & Jha, 2012; van Lettow West, van der Meer, Wieringa, & Semba, 2005). TB and malnutrition are confounding health problems as "malnutrition predisposes the development of clinical disease and Tuberculosis often exacerbates malnutrition" (van Lettow West, et al., 2005, p.211). Furthermore, poverty, malnutrition and overcrowding create a high risk of exposure for the illness and for those who have contracted TB, these socioeconomic factors limit return to optimal health.

In relation to the incidence of TB in the countries researched in our study, Malawi was substantially higher than Australia. In 2010 the incidence was recorded as 219.0 per 100,000 people (World Health Organization, 2011) compared to 6.5 per 100,000 people in Australia (World Bank, 2012).While there has been are ported decline in the prevalence of TB in Malawi over the last decade there are limited accurate registration systems for TB as well as HIV/AIDS (Glaziou et al., 2011). In regard to Australia, although the incidence of the disease is slightly higher in Aboriginal and Torres Strait Islander populations (World

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Bank, 2012), the majority of people diagnosed with TB have originated from countries within the Western Pacific and South East Asian regions (Lumb et al., 2008; Lumb, 2011).

Increasingly, there is more research being conducted on TB worldwide and the disease remains firmly on the global health agenda primarily due to the relationship with the HIV/AIDS epidemic (Chimzizi & Harries, 2007; Dye & Williams, 2010; Jamison et al., 2006). Literature searches identified research has focused on three perspectives: public health (Asamenew, 2011; Finnie et al., 2011; Zahir, 2011), anthropology (Scott, 2009)and healthcare (Saadeh, 2010; Zvavamwe, 2006). The majority of studies investigating TB care are on health service systems, direct observed therapies, implementation and treatment and compliance (Garner, 2003;Heller, 2006; Hu et al., 2008; Moonan, 2011; Okuonghae, 2007; Xu, Diwan, & Bogg, 2009).

While there is extensive literature on the physiological aspects of the disease, psychosocial, emotional and spiritual domains of care remain unexplored. The healthcare literature has not comprehensively investigated care of people with TB, nor patients' experiences of their care. There are no studies on patient satisfaction and the impact of care. Some studies have acknowledged the importance of nurses' role (Gerrish, et al., 2013; Toth, Fackelmann, Pigott & Tolomeo, 2009) and one historical study researched institutionalized isolation in Australia (Kirby & Madsen, 2009). As patient satisfaction is a key outcome of healthcare (Solberg et al., 2008) and dissatisfaction may result in poor treatment compliance and suboptimal clinical outcomes, we sought to research this gap in the literature by investigating and comparing TB care in a developed and a developing country.

II. BODY TEXT

A. Conceptual Framework

Following the literature review, a conceptual framework based on the principles of humanism, human rights and social justice was selected. With this framing, participants' perspectives are heard and listened to and each individual experience is acknowledged. These types of frameworks are often referred to as transformative, because there is a focus on valuing individuals with important experiences to share (Mertens, 2009, Mertens, Bledsoe, Sullivan & Wilson, 2010, Mertens, 2012). Furthermore, the transformative action of speaking out can empower people who have previously felt marginalized for not being heard (Glass, 2010; Rose & Glass, 2008). The framing, schematically illustrated in figure 1, focuses on the participants' emotional safety throughout the complete study.

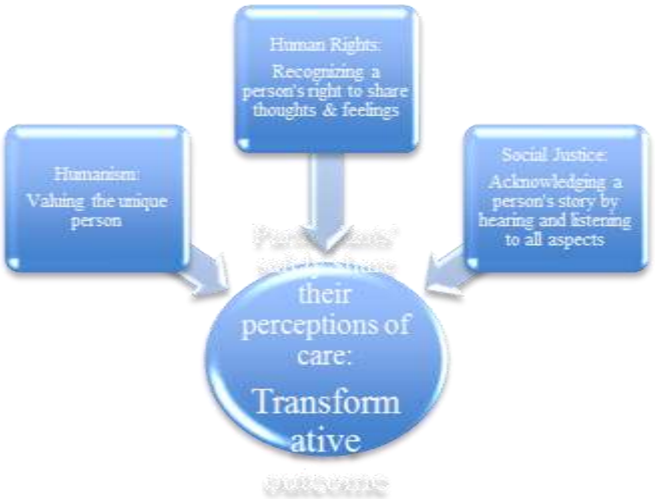

Figure 1. Conceptual framework.

B. Research Design and Methods

A mixed method descriptive study was selected to explore the perspectives of healthcare care for patients with pulmonary tuberculosis in Australia and Malawi. The choice of mixed methods was intentional in order to give strength to the design and offset any potential methodological weaknesses that can occur with just one method (Creswell, 2009). The quantitative component included a Likert scale questionnaire (see Authors). This article focuses on the largest component of data, that being the qualitative open-ended survey questionnaire comments.

C. Ethical Considerations

Formal ethics approval was obtained from [insert name of university] Human Research Ethics Committee and each health care facility in Australia and Malawi before data collection commenced. Participants were screened for eligibility and if willing to participate, further explanation of the study was provided. Each person was informed that participation was voluntary and information provided would remain anonymous. The researcher collected all of the questionnaires.

D. Participant Recruitment, Selection and Site Inclusion

The number of participants recruited for the overall study was determined statistically and is detailed elsewhere (Authors).Participants were drawn from two metropolitan hospitals in Melbourne, Australia and three Southern and Central hospitals in Malawi. The data from Australia was collected over a twelve-month period and from Malawi over a four-month period.

A non-probability purposive convenience sampling approach, frequently used in clinical healthcare research was selected to ensure the data was collected expeditiously(Roberts, 2002). The research team considered other sampling methods could have resulted in the data collection being protracted particularly as this was across-country study with only one member of the team travelling between two countries. The selected inclusion criteria were: People with TB who were experiencing a first or recurrent episode of acute pulmonary TB; inpatients or outpatients and those 18 years or older. Over a ten-month period, there were 194 patients recruited, 44 in Australia and 150 in

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Malawi.

E. Data Analysis

Following guidelines by Roberts and Taylor (2006) data were manually coded, emerging patterns of data were identified and the data were grouped into themes. To identify themes, firstly, the researcher read and re-read the open-ended survey responses. Secondly, remaining team members reviewed the data for accuracy, and thirdly, the team confirmed the emerging patterns of data. Confidentiality was maintained by assigning individual codes for each participant.

III. RESULTS AND DISCUSSION

A. Participant Characteristics

There were no differences between both groups in terms of age, gender, marital status and employment. The Malawian participants were significantly sicker and more were inpatients. While Malawians reported that acute TB interfered more with their physical and mental wellbeing than those in Australia, less Malawians reported general poor health. The demographics are outlined in table1.

Table 1. Patient Demographics.

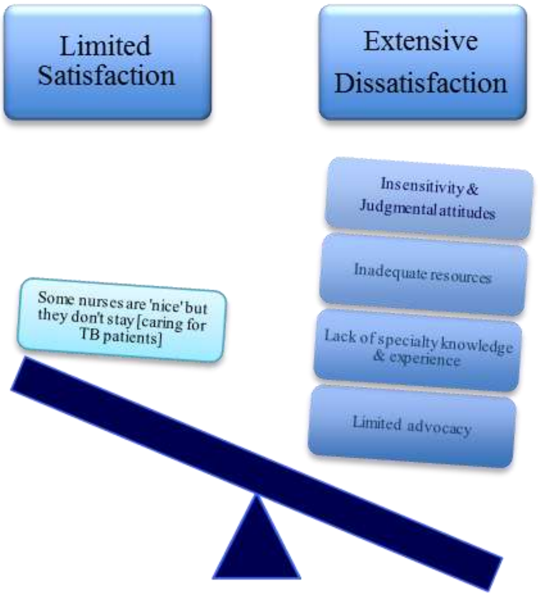
	Australian group n=44 *N (%)*	Malawian group n=150 *N (%)*
Age categories		
18-24	12 (27.3)	41 (27.3)
25-34	13 (29.6)	55 (36.7)
35-44	7 (15.9)	30 (20.0)
45 +	12 (27.3)	24 (16.0)
Male gender	23 (52.3)	90 (60.1)
Marital status: Married	19 (43.2)	73 (48.7)
Employed	31 (70.5)	114 (76.0)
Inpatient	19 (43.2)	118 (78.7)
First episode	36 (81.8)	76 (50.7)
Severity of TB symptoms		
Mild	26 (59.1)	62 (41.3)
Moderate	14 (31.8)	23 (15.3)
Severe	4 (9.1)	65 (43.3)
Acute TB		
Affected physical wellbeing	19 (43.2)	114 (76.0)
Affected mental wellbeing	11 (25.0)	106 (70.7)
Patient-reported poor general health	9 (20.5)	13 (8.7)

1. Perceptions of Healthcare Care:

There were overwhelmingly negative perceptions of healthcare care from both groups. Although it was occasionally noted that some participants shared an isolated satisfying moment regarding a perception of a nurse, the perceptions regarding care was dissatisfaction. Dissatisfaction was evident in comments on the survey questionnaires and also in un-prompted participant conversations with the researcher. Data revealed that nurses were rude, discourteous, lacked empathy and were disrespectful and negligent in patient care. Participants identified nurses' lack of availability, poor knowledge and education about TB and delays in responsiveness to their patient care requests.

Dissatisfaction had four embedded themes: *insensitivity and judgmental attitudes*, *inadequacy of human and material resources*, *nurses' lack of knowledge and experience* and *limited advocacy*. The first two themes predominated in the data. While there were no positive themes, as indicated above, occasionally a participant referred to a positive interaction with a nurse. Figure 2 visually illustrates these findings.

Figure 2. Patients perceptions of TB care.



2. Insensitivity and Judgmental Attitudes:

Participants perceived nurses to be task-oriented in care provision and lacking sensitivity to their needs. One of the people from Malawi said,

Some nurses are extremely rude to the patients and they just don't care. Some do not even touch the patients. Patients are not free to express their concerns about how they are actually feeling.

Participants often reflected on ineffective communication and it was evident they were considerably marginalized. They did not feel able to speak with nurses because nurses appeared to ignore their concerns. For instance, an Australian participant said,

If you tell nurses what you need, it takes a long time before you have any help from them. I think they need to be educated that when patients express concerns, they need to act quickly.

Yet it was clear that patients lamented the lack of respect shown to them by the nurses. This statement from one of the Malawian participants typified this issue.

I wish to see change in the way nurses speak to patients. They really do not care about the patients …we, as TB patients, we lack care.

In relation to specific care, participants felt stigmatized and isolated following their initial diagnosis. An Australian patient highlighted,

The main issue I have about my diagnosis of TB is the social stigma attached to it and the reaction of other people to my disease... I feel more can be done to educate people: [that it's] spread the same way as a cold, especially to contain cultural groups who may tend to ostracize TB patients to a greater extent… [Nurses need to realise] how isolating and demeaning such behavior is.

Participants experienced physical and mental isolation in care. One of the Australian participants explained, Look, let me be honest with you, probably you are the only person who has chatted with me for this long… Don't get me wrong, [nurses] are nice, but they don't stay… perhaps they are scared they will catch TB too. Ooh, it's hard. [I am] in this room day and night. Sometimes [I] cry.

While participants were not satisfied with TB care, some strongly verbalized their perceptions of care and were committed to ensuring future patients did not have the similar experiences. The following statements from a Malawian and Australian participant respectively implied they were determined to address the experienced discrimination against TB:

I speak because I would like people to know. They may think all is okay in our hospitals but it's not. I am not dreaming about all this, it's a reality.

How can I be of any help [so] that no one else experiences this pain? I have really suffered so much.

It was evident that injustice fuelled a strong drive to identify their perceptions of care. They wanted to make a change and freely speak up against injustices experienced through their illness. In the interactions with the researcher, they wrote their thoughts and freely spoke about their care.

3. *Inadequate Human and Material Resources:*

Poor resources were a major issue for participants from both countries although it was more problematic for the Malawian group. Inadequate human and material resources occurred concurrently. Frustration was expressed due to shortage of services and healthcare staff and in Malawi there was limited personal protective equipment for staff and guardians. There were very high nurse-patient ratios and at times, no nurses were on duty. One participant stated,
We don't have enough services, especially at night. Sometimes we have no nurse on duty and it is very difficult to have that help if there is no one to give it...the government should employ more people. There [are] not enough healthcare staff.

There was a lack of privacy in many aspects of care. Poor infrastructure resulted in overcrowding in the Malawian wards. Due to the limited amount of beds, some patients had their mattress on the floor and had to be cared for under other patients' beds. One participant claimed,

I guess this is something I must get used to, I don't know how. I see people everywhere on the ward, patients placed under each other's bed, some dragging their mattresses from the floor…. All these patients obviously need treatment and rest. This is not the way, but how else can these patients be accommodated?

Despite the wards being overcrowded in Malawi, more people with TB continued to be admitted for care. People with TB who were hospitalized in Malawi identified the difficulty with engaging in private conversations because only curtains separated their beds. While privacy was a concern in terms of inadequate resources, disclosure of TB to participants' previous personal and professional contacts conflated the problem in both countries. Once a person is confirmed as a TB suspect, the person's contacts need to be traced. Participants believed their privacy was violated and they again experienced further stigmatization:
I feel that my privacy has not been fully protected...Given the need to test contacts, there is very little in the 'say of privacy', hence the reaction of others needs to be addressed.

Inadequate resources were also problematic in terms of treatment delays. Dissatisfaction was expressed regarding the delay from the time of diagnosis to commencement of treatment. For instance, one Malawian participant stated,

I was admitted about a month ago. It took three weeks to have a diagnosis of TB. Yes, three weeks just waiting. I hadn't had my sputum sample taken, hadn't had any X-ray, for three weeks… Such things [are] not good for the people. We people suffering from TB are dying in masses; we are finished really.

4. *Nurses' Lack of Specialty Knowledge and Experience:*

Lack of specialty knowledge and experience was evident throughout patient care although it was more marked in the Malawian group. Participants confirmed:
More self-discipline is required. More knowledge in the healthcare profession of TB is necessary.

Young nurses need more training [and] lots of experience.

Limited knowledge by medical staff compounded this problem particularly in Malawi were most doctors were of a junior rank. One Malawian participant said, Three-quarters of all doctors that come here are trainees…Those trainee doctors… have set us back because they, of course, haven't been working for long and therefore, lack experience. For example, if one happens to be [diagnosed] with TB, it takes them time to initiate therapy.

Nurses' poor knowledge was evident in both countries and this was voiced in terms of neglecting medication administration guidelines. One person from Malawi recounted that he tried to explain to a nurse this was not his first episode of TB and he knew nurses were not following the guidelines:

I told them …"you really are doing so much harm to the patients." They asked me, "What do you mean?" I told them, "No, you can't keep going like this. You are hurting many people." I told them that they should adhere to the guidelines for administering the TB medication … I told them they were giving wrong advice to people.

Although this was more problematic in Malawi, lack of knowledge and education also occurred in Australia. One person shared:

Sometimes medication is left outside with the food tray and there is no communication with the patient.

5. *Limited Advocacy:*

While participants in both countries had a strong desire for an increase in quality healthcare care, they thought clinical nurses did not support them in this quest. Participants considered nurses should advocate improving conditions for patients as well as nurses. Some believed nurses were‘ victims’ in their health care system because they complained of the conditions to patients rather than health care administrators. One person from Malawi said:

Here in Africa the nurse-patient care is very low in standards… [The nurses] complain they are not paid enough [and] their working conditions are not good. I think the whole system needs a total change.

Another participant in Malawi related the ongoing problem of patient hunger. This was an example of a situation where he believed the nurses should have taken a stronger role in patient advocacy.

Let me not beat about ‘the bush’, we need food. It would be helpful if the nurses would campaign for that. I suffer so much during the early hours of the morning. I even dread going to sleep. I do suffer greatly. You’ll notice that in the early hours of the morning, so many patients are awake, turning, tossing, moaning because they are too hungry to sleep. Sometimes we receive some milk, a small cup of milk and that’s after so long… A really small cup which doesn’t go far. …I think the nurses can help us that way.

One Australian participant viewed this as nurses not advocating for necessary positions.

There is no liaison nurse at the hospital. TB Liaison nurses in public hospitals are a great help ‘re’ patient attendance. In fact, this position is essential and assists with informed patient care.

Australian participants also spoke of the shortage of TB community nurses and translators. Like TB officers in Malawi, community nurses in Australia follow-up outpatients to ensure they attend their appointments and are compliant with treatment. Most of the people with TB who were being treated in Australia are migrants, are not conversant in English and require translators for their care.

B. *Study Limitations*

The data reported in this paper are related to the qualitative findings and are not generalizable. This may be perceived as a limitation even though many of the findings have confirmed earlier studies. The findings, however, may inform future research on possible relationships between dissatisfaction, stigmatization and treatment compliance from the perspectives of patients as well as nurses.

A limitation of the study was that it was conducted in only a selection of sites in Australia and Malawi. A larger study across many metropolitan, regional and rural sites may have given greater strength to the findings and/or provided differing participant experiences.

C. *Discussion*

Discrimination against marginalized patients has increased to the point that it is recognized as a public health issue particularly in relation to TB and HIV/AIDS and has become a global concern (Dean & Fenton, 2010; Mazorodze, 2012).We found as did other researchers that judgmental attitudes and stigmatization were impacting on patient wellbeing and health disparities(Gerrishet al., 2013; Pulerwitz, Michaelis, Weiss, Brown and Mahendra, 2010; van Rie, et al., 2008).

In our study participants did not have a positive relationship with the nurses. Overall poor quality care, ineffective communication and stigmatized behaviors affected participants’ health status and they did not believe they could freely converse their health concerns. These findings confirmed earlier research by Merkouris, Papathanassoglou & Lemonidou, (2004) where patients did not believe nurses advocated for their positions and conditions. Similarly, research by Gerrish and colleagues (2013) revealed people with TB who were being treated felt stigmatized, yet these individuals did not believe the stigma affected treatment (Gerrish et al., 2013). In our study, while participants did not make a direct link between stigma and treatment compliance it could be postulated that their dissatisfaction may contribute to poor compliance. Further study is recommended to establish whether there is a relationship between these issues.

Results identified a widespread dissatisfaction with TB care in both countries. Nurses’ judgmental attitudes, insensitive and non-empathetic interactions were compounded by limited health care resources. Poor communication with marginalized patients confirmed earlier research and it is evident that social structures were negatively impacting on prevention (Dean &Fenton, 2010). We found as did Özbe, (2001) that delayed responsiveness in care and lack of empathy in care provision was common. Similarly to the African study by Wandwalo, Kapalata, Tarimo, Corrigan and Morkve, (2004)lack of knowledge and poor communication inhibited quality care.

Furthermore, while more pronounced in Malawi, nurses’ poor working conditions typified by heavy workloads and limited advocacy for people with TB resulted in an interruption to mental and physical wellbeing. These, combined with TB stigmatization did result in widespread dissatisfaction for both cohorts of participants.

While Australian hospitals had higher level of facilities than those in Malawi, Australian participants also experienced some specific resource inefficiencies. One of the issues was related to those participants who had limited English proficiency and the scarcity of available interpreters. Due to this issue, ineffective communication resulted and care

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provision was perceived as culturally insensitive. Linguistic compromise as was found by Anderson et al., (2003) will considerably affect developing trust and treatment compliance.

In relation to patient satisfaction specifically, if nurses are dissatisfied with working conditions or are burnt out, patient satisfaction is lower (McHugh, Kutney-Lee, Cirriotti, Douglas & Aiken, 2011). This is an issue for further research because as our results indicated, nurses were stressed and did not enjoy healthcare practice. This could have contributed to their sense of overall dissatisfaction.

Our research has also confirmed earlier findings related to the effect of discrimination. What this research adds is the exploration of participant experiences from a developed country where there are considerably more resources.

However, Australian participants were also consistently dissatisfied with their care. Therefore, the challenge for health care providers is to improve the health status of people with TB, and provide care based on principles of social justice and human rights. It is strongly evident that people with TB were endeavoring to improve their own physical health as much as they could while also straddling the enormity of social stigmatization. This is a considerable obstacle to health status, which requires public health providers to widen the current lens of care.

It is critical that all health care providers develop knowledge and skills to adequately care for their patients. Understanding how patients from many diverse backgrounds comprehend a disease is essential to the implementation of effective healthcare strategies (Gerrish, et al., 2013).

D. Conclusion and Implications

People with TB experience many physical and psychological losses. Feelings of isolation and powerlessness resulting from societal attitudes and stigma associated are compounding factors. Nurses have contributed to these negative experiences and it is strongly evident participants were dissatisfied with their care. Lack of involvement in care resulted in participants experiencing greater isolation.

While stigma is not a new phenomenon, more research is needed to explore the reasons for continued marginalization of TB patients in both developing and developed countries. Discrimination remains a key challenge to care.

The social barriers participants identified as impinging on effective TB care have emerged throughout the themes of dissatisfaction. The findings suggest a strong need to improve TB care in both countries with a key focus on the patient as a human. Collaborative healthcare strategies are necessary to: address effective interpersonal communication; improve knowledge and education of nurses; rectify inadequate resources particularly in Malawi and improve patient advocacy.

This study provided participants with opportunities to have their care perspectives heard in an emotionally safe environment. An integral research objective included participants freely sharing their experience. The researcher was trusted and participants spoke without judgment. This was a critical process as the data revealed high levels of discriminatory practices.

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