Health, masks and music: Narratives of empowerment in a South African community music therapy project based in a tuberculosis hospital

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Abstract

This article introduces the Music Therapy Community Clinic’s (MTCC) Music for Health Project based in a tuberculosis (TB) hospital in South Africa. The value of this community music therapy project is explored from various narrative frameworks pertaining to health and the TB disease. Initially viewed from a reductionist medical narrative with a primary focus on treatment of physical symptoms, music therapy offers patients a diversion from their illness, but is perhaps a luxury rather than an essential form of therapy. The project is then considered from a narrative framework of empowerment, placing TB as a disease that predominantly affects those who are disempowered through poverty, stigmatization and isolation. Three case studies explore how community music therapy serves to empower patients on individual and collective levels, and consider possibilities this may hold for influencing the health behaviour of patients. As TB is becoming a pertinent issue worldwide, the article may offer possibilities for the role of creative approaches in the care of TB patients.

Keywords

Community Music Therapy ; empowerment ; Tuberculosis ; social health ; music and health ; music therapy in a medical context
Introduction

Narratives are constructed and interpreted. They lend meaning to what happens in daily life. We all have our biographies. What happens to our bodies is related to our identities as persons. These narratives are not simply personal stories, but sagas negotiated in the contexts of our intimate relationships. These understandings are also constructed within a cultural context that lends legitimacy to those narratives. (Aldridge 2000: 14)

The MTCC is a non-profit organization that renders professional music therapy services to underprivileged and previously disadvantaged communities in South Africa. The broader vision of the organization is to use active music-making to have an impact on the psychosocial fabric of the communities in which it works.

In March 2007, the MTCC was invited to initiate the Music for Health Project at a hospital for patients with TB – an infectious and highly contagious, bacterial disease that most commonly affects the lungs (World Health Organisation 2012), in partnership with Community Health and Arts Trust (CHAT). CHAT is a non-government organization that aims to provide artists with relevant business skills, as well as offering them skills for using their art forms to uplift communities such as this hospital.

The hospital grounds offer a scant appearance. Wards are separated by slightly untidy grass lawns to ensure good ventilation that prevents the various strains of TB from spreading between wards. Patients, with taut, thin faces and bodies, sit basking in the sun,
or remain cooped up inside wards that seem to accommodate large numbers of patients. In some of the hospital wards, staff members are required to wear surgical masks to avoid being infected with TB. This presents a clear differentiation between patients and professionals, those who are ill and those who are healthy and do not wish to become ill. These surgical masks can restrict communication and relationships between staff and patients. At the same time, the masks allow professionals to make some form of contact with patients, whilst remaining protected.

Our introduction to the hospital grounds and wards brought with it the usual excitement about the possibilities for music therapy within this new context. Could we march through the hospital grounds together with patients, staff and family members, playing assorted percussion instruments and singing as Trygve Aasgaard did to draw children to join his ‘music hour’ each week at the paediatric oncology ward where he worked in Norway (Aasgaard 2004)? Aasgaard described how the ‘music hour’ sought to ‘give these patients a voice and bring people together to perform and enjoy music, not as an alternative to the medical treatment, but as a natural agent of health promotion’ (2004: 149). Music connected patients to ordinary life through moments of laughter and joy, connected patients to one another by providing opportunities for the development of relationships and connected patients to life beyond the hospital walls by enabling them to send recordings of their music to friends and family. Alternatively, would we need to be available to share a variety of distinct musical encounters with patients beside their beds or in the hospital corridors as Chris Wildman has done in his work with children in a hospital burns unit (Wildman 2010)? Through music, Wildman enabled children who had
been disfigured by their burns to rediscover a sense of self as they heard and valued the sounds they could create. Through music, Wildman drew children from different cultures together to support and share life with one another. Would there be possibilities of facilitating collaborations between musicians and patients as took place in Australia in a project In Your Own Time that drew together members of a symphony orchestra with adolescents from a large paediatric hospital ward (Kildea 2007)? Through this collaboration, musicians were able to empower young people by offering shape and form to their musical ideas, so that they could create aesthetically pleasing musical products as expressions of their lives both in and beyond the hospital. These were merely a few of the ideas and possibilities that inspired us as we began the journey of assessing what we might offer in this particular hospital context.

Our excitement was mingled with questions and some anxiety. Would we be putting ourselves at risk by working in this hospital? Could we become ill with TB?

As the project began, two music therapists from the MTCC facilitated five music therapy groups at the hospital. Three of these groups offered therapy for babies, toddlers and pre-school-aged children, respectively. One group was an open group inviting adult female patients or staff members interested to attend. This was held in a ward for women who are very ill with (drug-sensitive) TB. The last group was a short-term, semi-open group for adolescent or adult patients with multi-drug-resistant TB. Whilst patients were initially referred to this group by occupational therapists, group members could invite other hospital patients or staff members to attend. The particular activities the MTCC
continues to offer, or encourages patients to offer, differ with each group we run at the hospital and are defined by each context. Activities can include drumming circles, instrumental or vocal improvisations, singing known songs, musical games, dancing or songwriting.

As music therapists at this hospital, our personal understandings or fears of TB influence how we manage those who suffer from this illness, just as these influence the way patients may view themselves, and the coping mechanisms they employ as a result. Similarly, the way we utilize our music therapy skills within this hospital community will be influenced by the narratives we associate with TB, the hospital, the patients and the value our music therapy might hold in this context. Whilst we have not yet had to wear surgical masks in our work, the narratives we construct (and those that construct us) become ‘masks’ that restrict or aid communication, understanding and relationships with others.

In this article, I consider the work of the MTCC at this hospital from various narrative perspectives as they play out in the South African context. With the risk of isolating and thus perhaps simplifying complex discursive positions, the first case study is viewed initially from a reductionist medical narrative. An alternative narrative view then offers a notion of empowerment, placing TB predominantly as a disease that affects those who are often marginalized, disadvantaged, stigmatized and thus disempowered. It is from a discourse of empowerment that I offer further work of the MTCC at the hospital. I consider the value this community music therapy project can have for empowering
patients on individual, collective and cultural levels. As TB is becoming a critical issue for many countries besides South Africa, this article may offer a helpful starting point for discussions around the role music can play with those who suffer from TB.

A medical mask

Vignette 1

Emihle,³ a little girl of two years, suffered from AIDS and extreme drug-resistant TB with additional complications. She spent most of her day in the children’s ward of the TB hospital, propped upright in a baby chair, a blanket wrapped around her thin frame. A tube protruded from her nose and Emihle strained her body with each breath. Her face seemed set in a constant frown.

I doubted whether Emihle would be able to respond to our music at all, even if she wanted to. As I started to strum the guitar to begin our babies’ music therapy group, I noticed a slight change in Emihle’s face – perhaps showing interest, or even excitement. Later, I held a beater out to Emihle for her to play a tambourine. To my surprise, she slowly lifted a tiny hand and clasped the beater tightly. With much determination, Emihle beat the tambourine. She barely achieved an audible sound, but continued regardless. As she noticed me singing, timing my phrases to match her beats, she looked up at me, showing her awareness that she was actively influencing our music, even if she could not make a sound herself. Soon, both her hands extended outwards and she began to playfully explore different ways of tapping the tambourine.
In later individual sessions with Emihle, she pointed to our guitar when we walked into her room, clearly indicating that she wanted to make music with us. Emihle smiled whenever we sang playful songs and occasionally let out a tiny laugh. She enjoyed clasping a set of bells and, even though she had no strength to make a sound with these, she refused to allow us to help her play. She was completely involved in every musical moment, guiding our music with her clear movements. A nurse who witnessed one of our sessions was touched to see how responsive and joyful Emihle became whilst making music, despite the severity of her illness.

The frown on Emihle’s face communicated just a little of her physical pain. TB is spread through airborne sputum droplets. Whilst the disease most commonly affects the lungs (pulmonary TB), it can also affect the spine or brain (World Health Organisation 2012). Symptoms include coughing, chest pain, weakness, weight loss, fever and night sweats. Whilst the side effects of the six-month course of TB medication may include rashes, nausea or joint pains, if patients complete this medical treatment, drug-resistant TB is completely curable. However, co-infection of TB and HIV or resistant strains of the disease such as multi-drug-resistant TB (MDR-TB) and extreme drug-resistant TB (XDR-TB) makes this illness a growing concern in South Africa and worldwide. HIV and TB form a lethal combination, as HIV lowers the immune system and the majority of TB deaths have involved patients with an HIV co-infection (Du et al. 2007). Emihle’s medical prognosis was poor, and at her stage of illness there may have been little doctors could do but to ease her suffering as much as possible.
This medical narrative offers an explanation for TB that isolates the disease to physical entities and symptoms within individual patients (Pavlicevic 2006). This creates a comfortable divide between the so-called healthy society and those suffering with an illness such as TB; between those whose health may be compromised by immune deficiencies such as HIV and are thus vulnerable to TB infections, and those who have access to healthy lifestyles. Those of us who work as professionals with TB patients can decide how we can best manage these ill individuals; we can show empathy, whilst minimizing the risk to ourselves. If we do become ill, we have the resources of wealth that afford us medical aids and private, often more efficient, health-care services. By reducing TB to a collection of symptoms, we put on ‘medical masks’ that might appear to protect and distance us from the possibly unbearable lives and suffering of those we witness each day.

Music therapy, if viewed primarily from this medical mask, offers patients an enjoyable form of entertainment, a diversion from their illness and from painful hospital procedures. Music is an activity that can occupy patients to prevent boredom. This can have immense value, especially when extremely ill children such as Emihle can participate. But this music must not interfere with important hospital treatments and procedures. As music therapists working in a hospital alongside doctors and nurses who are hard pressed to keep to tight schedules, there are times when we may feel sidelined, perhaps considered as volunteers coming to be ‘nice’ and friendly to patients – offering a luxury rather than essential service. Whilst some of our sessions run with few interruptions, we often work in the midst of children screaming as they are given their
medication or taken away for a bath, we have had patients removed from sessions to see a doctor and occasionally had nurses pushing patients in wheelchairs through our group space. Whilst we do need to make way for important medical routines and offering patients a diversion from their illness is a valuable part of our role at the TB hospital, do we not offer something more than this? Is this particular medical narrative with a focus predominantly on pathology and cure all that needs to be considered in the care of TB patients?

The emergence of resistant strains of TB marks the failure of the medical model for the control of this apparently curable disease (Singh et al. 2007). There are a number of factors that have contributed to the emergence of MDR and XDR-TB, ‘including high treatment interruption rates of drug-sensitive TB and consequent low cure rates, together with the HIV epidemic’ (Singh et al. 2007). Despite the implementation of strategies to ensure that all patients have access to treatment, are educated about their illness and encouraged to complete their medication (World Health Organisation 2012), cases of XDR-TB have continued to increase due to non-compliance to medication. It almost appears that some patients are choosing to remain ill, to put themselves and others within their families and communities at risk. Or could there be another explanation, an alternative narrative that holds more power in the lives of these patients? Aldridge notes that ‘what we singularly fail to see is that our current thinking about health is dominated by a medical thinking that ignores much of the reality of the persons we intend to treat and support’ (2004: 42).
Health and empowerment – complementary masks

Health, empowerment and community music therapy

An alternative to this particular medical narrative conceptualizes health as a dialogic, relational construct, with biological, psychological, social and cultural aspects, rather than merely the absence of physical symptoms (Stige 2002). Health is associated with an overall quality of life. On a social or cultural level, health includes the ability to participate in social life, and to experience mutual care within a community. This will be affected by the social, cultural and economic resources that afford collective and individual health (Pavlicevic 2006). In this view, TB cannot be isolated to a specific patient, but belongs to a community, a context and society that displays its own set of struggles that influence the illness of individual patients. This does not discount the importance of treatment of physical symptoms, but insists that the TB disease is viewed through a variety of complementary masks or narratives – each with its own particular focus. In addition to considering which drug might work best, it becomes important to consider what support systems a patient has, what community beliefs have influenced this illness, and even, what our own roles are in promoting the health behaviour of those with whom we work.

Emihle’s diagnosis of AIDS and XDR-TB is inextricably related to her disempowering social circumstances. There are higher rates of TB amongst impoverished and marginalized groups of people, showing that TB is a disease that is born through poverty, as much as it is caused by biological factors (Singh et al. 2007). Those who are poor or socially excluded face greater exposure to many health threats and are thus more
vulnerable to contagious diseases such as TB. Further, when they fall ill their lack of access to resources such as health care or employment leaves them less likely to receive adequate care (World Health Organisation 2005). It is likely that Emihle acquired HIV at birth from her mother, possibly indicating that she did not have access to health care that can reduce the risk of mother to child transmission (Coovadia 2005). It is possible that a lack of access to a healthy diet soon left Emihle’s immune system unable to cope with her exposure to the TB disease. She may have been infected directly with XDR-TB by a caregiver or close community member who acquired this resistant strain of the disease due to his or her own failure to comply with early TB treatment. Alternatively, Emihle had possibly not received adequate treatment for initial and repeated diagnoses of drug-sensitive TB.

At two years of age, Emihle may not have understood the extent to which her own deprived living conditions had affected her illness. However, her frown was an attempt at conveying perhaps not only her physical pain, but also her feelings of being out of control and alone. She was isolated from her family (her mother could not visit often due to transport costs), her home community and even from interacting with other children in the ward. She had become a passive receiver of countless medical treatments. She could not speak and her movement ability was limited. Once a possibly lively and energetic child, she seemed reduced to a very ill patient. Like Emihle, many young children suffering from TB might be hospitalized for as long as eighteen months and this can negatively affect their development due to a lack of stimulation and lack of contact with their primary caregivers (Caelers 2007).
The World Health Organisation’s ‘stop TB strategy’, with the goal of dramatically reducing the global burden of TB, has accounted for various narratives that contribute to the TB crisis (2012). Whilst calling for the enhancement of health services and high-quality treatment to be made available to all patients, the strategy also suggests that patients and communities suffering from TB need to be empowered.

The philosophy of empowerment supports the idea that ‘all people are competent and have equal value’ (Rolvsjord 2004: 102). Like social health, empowerment is connected with collaboration, mutuality and respect between community members. Empowerment is a multi-level construct including individual, organizational and communal levels, which are interdependent. The responsibility for the empowerment of individuals within a community therefore lies jointly with these individuals but also with the community and the public. Thus, just as being healthy is empowering (as good health enables easier access to social and communal life), it is an empowered individual living in an empowered community who will have the resources that afford the possibility of living an optimally healthy lifestyle. The medical mask is thus complemented by a mask that focuses on empowerment.

The discourse of community music therapy emerged as many music therapists felt a need to consider individual clients as situated within cultural and social contexts that needed to be accounted for (Stige 2004). Community music therapy is negotiated in context, and may involve working with entire communities rather than only individuals or small
groups of clients. Based within this narrative framework, the MTCC recognizes that ‘the
music of music therapy is health musicking’; it is the shared and performed establishment
of relationships that may promote health (Stige 2002: 190). Thus, our focus in the
hospital music therapy groups is on the relationships and identities, expressions and
explorations that are performed through music, rather than the aesthetic (or
entertainment) value of this music. By offering patients access to music, and experiences
of making music together within the hospital, we aim to offer patients access to social
relationships, community (Pavlicevic 2006), and to encourage them to participate actively
and contribute to this social community. In this way, through music, we aim to empower
patients.

If the Music for Health Project serves to empower patients, this suggests that the MTCC
could play a valuable part in offering comprehensive health care to patients at the TB
hospital. I turn to consider how music therapy in this hospital has empowered patients on
individual, collective and cultural levels.

**Performing ourselves**

Our lives have the potential to become a work of art in which our identities are
constructed and maintained each day, thus a performed identity and a functional aesthetic
(Aldridge 2004: 41).

In music therapy, Emihle’s frown gave way to intrigue and an occasional smile. The way
in which we express ourselves to others is inherently musical. When we communicate,
we use our bodies, and often communicate more through gestures and facial expressions than through our verbal language. These gestures have the musical qualities of timing, contour, volume and dynamics – and can therefore be shared in music (Ansdell 1995). Just as we are all born with an innate drive and capacity to socialize with others through these communicative acts, so the ability to participate in making music with others is innate (Stige 2002; Trevarthen 2002). As music therapists, our training enabled us to notice tiny gestures that Emihle made and translate these into music, thus responding to her communicative acts and relating to her as a person.

Through music, Emihle was empowered, as she was offered a sense of competence and control and able to participate within the social world (Rolvsjord 2004). Emihle chose to participate in music by pointing to the guitar as we entered her room, and she chose how to participate. Though she did not have the strength to make an audible sound with a musical instrument, the music we improvised together with Emihle indicated that she was communicating herself to us – we were helping her to co-create our shared music. Her movements conducted and guided the music, allowing her to become an active participant, performing herself to others as a competent musician (Rolvsjord 2004). She even chose to resist our offers to help her make music, showing her strength and willingness to retain some sense of control, and her enjoyment of the power that she was offered through music. Whilst the identity Emihle mostly performed in the hospital seemed to engender her illness and pain, in music she was empowered to become, for a few moments, her healthy self, celebrating her potential and ability (Aldridge 2004).
Emihle passed away after we had shared only three music therapy sessions with her. In these last few weeks of her life, music offered Emihle the opportunity of performing herself, transforming her short life into a ‘work of art’ – an aesthetic record of her character that remained despite the constraints placed on her by her physical illness. For Emihle, it was possibly enough to have had two therapists and a nurse to witness her performed healthy identity. However, if health is situated and constructed within social life, and if music can allow people access to relationship and community, does this not suggest that we need to work not only with individuals, but also with a social context (Pavlicevic 2006)? The following case study considers a music therapy group where, through musicking, women are encouraged to regain access to social relationships and community.

Performing together

Vignette 2

Every Tuesday morning, we run an open music therapy group in a ward catering for women who are particularly ill with TB. We arrive as breakfast is cleared and medication is handed out to the women who may remain in their beds, sit outside or in the rather dreary lounge (consisting of an odd array of chairs set on either side of a passage way, with a television screen attached to the wall at the end of the passage). The depression in this ward is tangible. The ward is reasonably quiet, the silence broken occasionally by coughing, moaning, the clatter of medical equipment or brief words of conversation shared between patients or nurses.
Music therapy sessions begin as we walk around the ward singing, inviting those interested to join us. Women are then encouraged to offer their name and share how they are feeling. The remainder of sessions is often filled with singing songs that group members contribute, or improvising with voice and percussion instruments. In many sessions, women have sat, grasping instruments without playing, giving no suggestions of songs they enjoy, simply allowing us to make music as we like, as if it makes no impact in their lives whether we are there or not. Often the first thing we are told by most women in the group is, ‘I can’t sing, I’ve lost my voice’. As a result, we may choose an assortment of songs to sing that different women might identify with. This selection would need to include Xhosa, Afrikaans and English songs to meet the linguistic diversity of the group.

With encouragement, some women may offer songs that have meaning for them. These are songs that remind them of their families and home communities. Sometimes, others will recognize a song that is offered and begin to join the singing, contributing to what can become a powerful, energizing performance, beautifully rendered by women who had earlier remarked that they could not sing. As favourite songs are repeatedly shared in our group, all group members begin to learn these songs, enabling them to join in. In this way, songs transport women home, as well as connecting us with others in the group and hospital community. Songs have often led to quiet tears or cheerful laughter amongst group members.

In many cultures, music serves as a resource that allows access to social recognition or relationships (Pavlicevic 2006). In South Africa, singing is naturally understood as linked
to social engagement and participation. A TB cough can physically affect the vocal cords, and thus affects a patient’s ability to sing and participate in community through song, or to communicate adequately at all. This physical loss of voice is accompanied with the loss of voice patients experience in their home communities. The TB illness depletes a patient’s energy levels, leaving them less able to cope with everyday duties. Admission to hospital may imply that patients will lose their employment, as well as losing the ability to care for their families. Thus, patients lose their status, sense of agency and purpose. Patients may also feel that they have no voice within this circumstantial hospital community, where daily medical routines and the constraints of their illness dictate much of their behaviour.

Further, a diagnosis of TB is accompanied with a negative stigma. Many fear the disease due to the number of people who have died from TB. There is a belief in some communities that a TB hospital is a ‘one way institution, a place where you don’t come out alive’ (Thom 2007). Some also perceive that anyone with TB will most likely have HIV as well, and thus the stigma of having TB is compounded by the already powerful stigma faced by those with HIV.

In empowerment philosophy,

the importance for the individual, as for groups in society, of having a voice and of participating in the community is strongly emphasized. This is understood as an
important health issue and is seen as a valuable goal or outcome, as well as part of the process of empowerment. (Rolvsjord 2004)

If women are to find their voice (whether they can physically speak or not), it is important that the relationships we develop with women in our music therapy group are collaborative, mutual relationships. Those with whom we work need to be recognized as having resources, potential and ability of their own, which enables them to contribute to their own development and healing, and to that of others (Rolvsjord 2004).

In our music therapy groups, each woman is acknowledged as an important contributor to this group and ward, whether they contribute by singing, offering a song or just their name, or by choosing not to join our group. As in any community music therapy work, our roles as therapists need to be flexible (Stige 2004). Women who choose to join our group take as much responsibility for guiding the process as we do, so that we work together to enhance the health of all within the ward. At times we, as therapists, do not know a song and simply listen or hum along as women lead the musical process. At other times, we may offer support by playing guitar or singing softly.

Our experience of work with the women in this ward is that they often find their voice in our music, literally and metaphorically, if we allow enough time. As we sing, women who are isolated from their home communities and music can re-create and remember these relationships. For some, singing songs they request has led them to verbally share memories that these songs elicit. At the same time, the songs that we learn together as a
hospital ward community can build relationships between patients. Rolvsjord (2004) notes that an empowering relationship often leads people to seek out new relationships. This has been shown in our music groups as women, who initially only communicated with those who spoke their language or shared some of their cultural understandings, have begun to sing songs from other cultures or language groups. One Xhosa lady in the ward consistently asked to sing the Afrikaans song, ‘Suikerbossie’, a song about a man’s love for his girlfriend. She had learnt the song in our group, and had come to enjoy sharing this song and sense of community with some of the Afrikaans speaking women in the ward. As relationships have developed, our music therapy group has become a space where women have begun to verbally share their experiences of hospital life. As we are ‘outsiders’ who only visit the hospital once a week, patients seem to feel comfortable sharing with us and one another their grievances such as dislike of a particular nursing sister, days when the food is unsatisfactory or their sense of loss when a friend leaves the hospital or becomes exceptionally ill. In this way, patients are able to find solace and support in their daily struggles. Through music, a diverse ward can be transformed into a supportive community, as women learn from and help each other.

Musicking can empower patients individually by encouraging their participation and contributions. Further, musicking can create opportunities for community and social interaction that can empower all participants within this community. However, at a meeting with hospital staff and management prior to beginning this project, when we enquired where our music therapy skills could be most helpful within this hospital community, all responded with one question: Could our music invite patients towards a
culture of compliance to medical treatment? The Music Therapy Community Clinic began to work with MDR-TB patients (those presenting the highest risk for non-compliance to medication) in collaboration with the occupational therapists at the hospital with the aim of motivating patients to take responsibility for their medical health care.

Performing a changed identity

Vignette 3

Xolile (see endnote 2), a large Xhosa man, was a patient who joined one of the short-term music therapy groups we run for patients with MDR-TB. As we started each session with a drumming circle, Xolile expressed much anger or frustration, as well as power and possibly a desire for control through his loud, incessant drumming that did not allow others to participate with him. In contrast to this dominant playing, when asked for ideas of songs to sing or musical beats, Xolile had little to offer. When asked about himself, he offered only details about his illness and hospital life.

After a few sessions, we asked once more for songs. Xolile retorted that we knew nothing of his culture and so would not be able to sing the song he had in mind. We encouraged him to teach us the song. A few moments later, his persona had transformed. Together with a friend, he had written the words of the song out on a board for all to read. Xolile and his friend then sang each part of the song (including both male and female parts), whilst clearly pronouncing and indicating each syllable of each word, correcting or encouraging us as we sang along.
After asking permission from the other group members, Xolile brought some female patients to the following session to help us learn the song. He became invested in his role as a teacher, guiding the group, and we learnt some new songs as well. Xolile became excited. He wanted to perform to other patients at the hospital. This enthusiasm encouraged others in the group to offer songs of their own, so that patients of different languages and cultures could join in with our music. When we asked why we should perform, and what message we could offer patients through our music, Xolile (who was now much better and preparing to leave the hospital) clearly stated that he wanted to give other patients hope. He wanted them to know that TB can be cured, that they can get better.

Unfortunately, the music performance Xolile wanted to arrange never took place. Groups we run at the hospital often undergo unexpected changes due to patients who leave or new patients who arrive at the hospital or occasional days when patients simply seem unmotivated to attend. On the date we had planned to perform only Xolile arrived at our session, explaining that many others in the group had left the hospital. He thus opted to cancel the performance, rather than performing without their support. But, perhaps, I could hope that Xolile performed for others anyway – not a musical performance, but a performance of the possibilities and new identity he had discovered within the hospital that he could offer to others.

Xolile offered a pertinent commentary on our roles as white music therapists within the hospital. We knew nothing of his culture. Whilst the music therapists at the MTCC have
gone to efforts to learn to speak Xhosa, our country’s segregated past has left us with little knowledge of the cultures, lifestyles and language of many with whom we work. Some patients have also travelled to this hospital from rural communities with fixed norms and customs of which we have little or no knowledge. On what basis can we discern the value music therapy holds for the patients? In fact, are we as female therapists entitled to work with these Xhosa men at all, based on their views of gender roles? Coupled with this lack of cultural knowledge, our own histories as privileged white South Africans have left us with little personal experience of poverty or struggle. How can we then presume to enter this hospital (where patients are predominantly black or ‘coloured’ and from relatively disadvantaged communities) and suggest that we want to collaborate with patients as equals, to work together, to enhance their health? These masks, of our identities as white, female South Africans and as professionals distance us from patients, and seem impossible to remove.

Perhaps, however, there is no need to attempt to remove all these masks – but merely to acknowledge their presence and the effect these masks may have on this group, as well as we acknowledge and attempt to work with the many masks that group members bring along with them. In this way, the diversity of members within this group can serve to offer all who participate a rich and varied experience.

Xolile’s comment that he could not sing a song because we did not know it, not only highlighted our separateness, but also his ‘patient’ role at the hospital. Whilst Xolile chose to attend our group every week, he restricted his participation to either doing what
we offered or not participating at all. This may have reflected his experience of being in this hospital – his choices were limited to complying with demands of medical staff or exercising power through non-compliance – due to the stigma of having TB, the lack of work, the stripping of important roles of care-giver or breadwinner, many patients with TB either neglect their symptoms until a very late stage in their illness, or may abscond from the hospital, or stop treatment in order to return to work or families (Nullis 2007). These patients will then utilize public transport systems and seek employment, thus becoming a health risk to their families, communities and the wider public (Singh et al. 2007). The disempowered role of being a patient thus serves to disempower others by placing them at risk for being infected with TB.

Xolile was right – we could not sing his song for him. Our music group also offered one area of the hospital where Xolile could exercise power by choosing not to participate or to cooperate. This experience in itself may have been empowering for Xolile to some extent. However, we felt that Xolile held some interest in making music due to his regular attendance at the group. Thus, we chose to challenge him to move beyond his patient role, to exchange this for a different mask. We invited him to take responsibility, own his identity as a Xhosa man with cultural musical knowledge, and teach us his song. Xolile then became a valuable contributor to our group – a teacher, someone able to motivate others (Rolvsjord 2004). Xolile was empowered on a cultural level, to own an identity and explore possibilities that moved beyond his illness. Rather than simply receiving music therapy as yet another treatment or choosing not to, he could contribute to the hospital community.
When discussing our group performance, patients shared their hopes of drawing other patients out of their wards to join in with our music. If, through “musicking”, we can explore, affirm and celebrate the possibilities for relationships within a community, this suggests that “musicking” is in fact a way of knowing our world … and in knowing it, we learn how to live well in it’ (Small 1998: 77). A valid goal for community music therapy work could then be social change (Stige 2004). Xolile and our music group would have taken on important roles of motivating other patients, leading their communities towards possibilities and change. The fact that Xolile had encouraged new patients to join our group suggested that his sense of leadership and responsibility extended beyond our music session time and group. Could these new leading, competent roles and sense of responsibility encourage patients to comply with their medication and thus set an example for others? Whilst music therapy can not encourage compliance in isolation to adequate medical care, education about TB and medication, perhaps we can aim to create an empowering community within the hospital, a community where patients encourage and support other patients, where patients can enjoy their participation in music and community and thus experience social health despite their illness. This might in turn empower patients towards making optimal health-care decisions, for themselves and their communities.

**Conclusion**

Our work at this TB hospital has not yet required us to wear surgical masks as we have worked with non-infectious patients or worked in rooms that offer some protection against TB infection. As we initiate new groups at the hospital, however, we have to
continually ask medical staff what precautions we need to take to minimize the risks of becoming infected with TB. This leads to some debate around whether we can actually do music therapy whilst wearing surgical masks, as well as what risks are necessary for this work and what risks are not worth taking.

As we continue to develop the Music for Health Project, we also need to constantly re-consider the narrative masks that we bring to this context, and how this could hinder or aid our work within the hospital. As music therapists, we are both created by and create the social contexts in which we work (Pavlicevic 2006). The narratives we construct, the way we think about, talk about and offer music therapy within this context are our masks. Masks that separate our wealth and their poverty, our health and their illness, our professional status and their patient status or even our community music therapy and their traditional/cultural music can be disempowering to both patients and us as music therapists, even as these masks may supposedly distance and thus protect us from the illness and suffering we experience at the hospital.

Empowerment, in many ways, involves coming to terms with or even removing some of these narrative masks so that we can meet patients as authentic equals and develop a community music therapy project in collaboration, a project in context that works for patients and for us. Yet just as surgical masks may enable us to meet with patients who we would otherwise be isolated from, there are masks we might use to make closer contact with patients. These might be masks that highlight our shared humanity and support the development of mutual relationships, masks that enable all to contribute
something meaningful to our music and this community, masks that empower both us and those with whom we work.

If empowerment is as important for preventing an increase in the TB crisis as medical treatment, then projects such as the Music for Health Project could have much to offer in this context.

Acknowledgement

I would like to thank Mercedes Pavlicevic for her comments and insights on an earlier draft of this article.

References


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Notes

1 For more information about the MTCC, refer to www.music-therapy.co.za

2 As two music therapists from the MTCC (including myself) worked at this hospital together, I use the plural to refer to our collaborative clinical work. However, my own thoughts regarding this work as presented in this article are offered in the singular.
All names in this article have been changed to protect client confidentiality.

‘Musicking’ refers to a term introduced by Small (1998), who suggested that music is not an object but an activity that humans engage in. ‘Musicking’ is a social activity and offers a means of performing our identities in a context of others.

Xhosa and Afrikaans are two of the eleven official languages spoken in South Africa.

A Xhosa speaking person will often refer to themselves as a ‘Xhosa’, to indicate that they belong to the Xhosa nation.

Although I do not enjoy distinguishing groups of people based on race, in South Africa it remains important to do this at times to clarify the different privileges, histories and stereotypes still associated with various race groups.