Towards an integrated and accessible mental health care system in Timor Leste

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Introduction

This paper reports on preliminary research carried out by an inter-disciplinary Australian and East Timorese research team which aims to 1) assist the Timorese Ministry of Health (MoH), Timorese NGOs and local communities to develop, deliver and evaluate accessible, culturally sensitive and integrative mental health services; and 2) contribute to the development of more integrated and sustainable health sector policies globally. Three key findings from the preliminary study were 1) the importance of traditional healers and customary practices in the success of mainstream treatment for any health condition; 2) the need to fully understand customary practices, underlying principles and traditional healers' perspectives about health and mainstream health services, to build effective partnerships with the traditional healer community and to carry out an ethnographic study of their practices; and 3) given the sensitivities and complexities about culture, belief systems and mental health, collaboration with East Timorese researchers is a critical component of advancing knowledge in this field.

Mental Health in Timor Leste

Health is a 'state of complete physical, mental and social well-being, and not merely the absence of disease' (World Health Organization). Mental health is not just the absence of mental disorder. It is defined as 'a state of wellbeing in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community' (World Health Organization 2014). Mental, neurological, and substance use disorders are common worldwide and contribute 10.3% of the global burden of disease (Murray et al. 2013). In Timor Leste, an epidemiological study undertaken in 2004 suggests that the percentage of persons with severe and disabling mental disorders needing urgent treatment varies between 2.0% and 2.8% of the adult population (Silove et al. 2008). Data from the Ministry of Health indicates a steady rise in mental illness caseload from 2,109 cases identified between 2004 – 2007 to 2,855 cases in 2008 and 3,743 in 2009. Of the 2009 caseload, 33% had a primary diagnosis of psychosis followed by 22% of cases of epilepsy (Ministry of Health Timor Leste 2010).

Mental health services in Timor Leste

Timor Leste has continued to strengthen its mental health care system every year. Prior to independence, no state-sponsored mental health services were available in the country. Since then, considerable effort has been made towards the provision of a community-based services that are integrated into the mainstream health sector (Ministry of Health Timor Leste 2010). All basic health services, including mental health services are provided through the Ministry of Health (Hawkins 2010). There is one national hospital located in Dili at which the only psychiatrist in the country is based, one large regional hospital in Baucau and four smaller hospitals in Suai, Maubisse, Bobonaro and Oecussi. None of these hospitals are able to provide inpatient mental health care. The only inpatient mental health care facility in the country is the Centro São João de Deus run by the order of Brothers Hospitallers (A Ordem Hospitaleira de S. João de Deus).

At sub-national level, each of the 13 districts has a district health office that coordinates clinical services for the area. These services are provided to the population through a network of 65 community health centres (CHCs, one per sub-district) that provide primary health services, out-patient clinics, simple lab testing, health promotion and preventative healthcare (immunisations); only 8 CHCs have in-patient services. There are also 193 health posts located across the country that are generally staffed by midwives and nurses and can provide basic medications but not laboratory or in-patient services. In addition, a community-based service (Community Health Services, Saude na Familia) makes monthly

visits to each village to deliver health promotion, nutrition interventions, maternal and child healthcare, infectious disease control and environmental healthcare. It is within these community health services that basic mental health services are provided.

Each district has an allocated mental health worker with basic training in mental health and a background in nursing or public health. Primary health care doctors and nurses are authorised to prescribe and/or renew prescriptions for some psychotherapeutic medicines. Primary health care nurses with mental health training are also authorised to diagnose or treat mental disorders. Referrals for initial assessment can be made to counsellors working with one of two non-governmental organisations providing specific mental health services (PRADET based in Dili and the Centro São João de Deus in Laclubar). Priests and nuns in the Catholic Church also provide informal care through a range of pastoral services. In terms of training, the majority of primary health care doctors have not received official in-service training on mental health within the last five years, whereas the majority of primary health care nurses have. Official referral procedures for referring persons from primary care to secondary/tertiary care exist, as outlined in the National Mental Health Strategy 2011-2015, as do referral procedures from tertiary/secondary care to primary care. How well this has been implemented, however, is currently unknown.

The role of traditional healing in mental health

Transcultural psychiatric studies have long shown that culture provides the context in which an illness is experienced, and shapes an individual's illness explanatory model that affects his or her interpretation of symptoms (Kleinman 1980; Mitchelle 1982; Wong 2010). Studies in low- and middle-income countries have consistently shown that individuals with mental disorders typically seek traditional and religious healers before going to a doctor or mental health specialist (Mkize & Uys 2004; Bekele et al. 2009; Giasuddin et al. 2012; Adeosun et al. 2013). The consequent delays in seeking appropriate mental health care can have significant detrimental effects on the mentally ill individual.

In Timor Leste, customary health and healing practices are deeply embedded in the inter-relationships between people, the ancestors and the environment. While these ancestral traditions can also be characterised as nominally animist, since the time of Indonesian occupation the majority of Timorese have also converted to Catholicism (Durand 2004).[1] In more urban contexts in particular, approaches to health and healing have been shaped by the influence of Christianity and in particular charismatic (and universalising) faith-healing practices common to both the Catholic and Protestant traditions. It is therefore understandable that customary practices can influence the outcomes of formal health interventions. Family and community bear the greatest responsibility for care of the mentally ill (Silove et al. 2008; Government of the Democratic Republic of Timor Leste 2010; Ministry of Health Timor Leste 2010) and at this level, customary health and healing practices often operate as complementary care to formal health services (McWilliam 2008). A 2004 epidemiological study found that 73% of those with clinical diagnosis of psychotic and non-psychotic disorders attributed their condition to 'supernatural' causes. Of those diagnosed with psychotic disorders, 81% consulted a traditional healer (Silove et al. 2008). The role of customary practices and strong customary social bonds in supporting mental health disorders requires further investigation (Loch 2007; McWilliam 2008).

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[1] Prior to 1975, the Catholic population is estimated to have ranged from 15-30%, during the occupation (1975-1999) this rose to over 90% (Durand 2004). There are many reasons for this increase, not least the requirement in the Indonesian constitution (put in place under the anti-communist regime of President Suharto, 1966-1999) that citizens must ascribe to one of the world's five major religions: Islam, Hinduism, Christian Protestantism, Christian Catholicism and Buddhism. During the occupation, the choice of the vast majority of the population to become Catholic (rather than something else) was partly historical and partly due to the support the church gave to the Timorese resistance (pers. comm. Balthasar Kehi 2014). Nevertheless, there were also many personal reasons for conversion during this time and many people made the choice out of personal faith.

The Timorese Government aims to "provide holistic, safe, effective, high quality mental health care for all Timorese to meet their health needs, following international standards of care" (Ministry of Health Timor Leste 2010). To do so, the National Mental Health Strategy 2011-2015 set out several ambitious objectives including 1) the implementation of community-based service that is integrated into the mainstream health program, and is accessible, responsive and at no cost to the population; 2) the implementation of a crisis response plan for those with no immediate accommodation or family support; 3) maintenance and annual review of psychotropic medication on the National Essential Drugs List; 4) distribution and delegation of service delivery across agencies; 5) availability of adequately trained and permanently employed mental health staff; 6) provision of ongoing training, supervision and peer support; 7) inter-sectoral collaboration and coordination; and 8) the adoption of a comprehensive approach to therapeutic interventions (i.e. not restricted to drug therapy), with a strong focus on counselling and family involvement that is consistent with indigenous models of care. In aiming for an approach that is consistent with indigenous models of care, Timor Leste is one of the few countries actively searching for strategies to integrate traditional/faith-based care into mainstream health care.

Objectives

This preliminary research aimed to strengthen current knowledge of customary health and healing practices and their roles in relation to mental health care with a view to assisting the East Timorese Ministry of Health, and in particular the Department of Mental Health, in its objective to provide integrated mental health services.

Methods

Focus group discussions (FGDs) were conducted in Dili and Baucau in Timor Leste in 2014- 2015. Adults (18 years or older) representing one of eight stakeholder groups were invited to participate in the study. These groups were: 1) Policy makers and senior management staff within MoH; 2) Service providers/case workers managed by the Ministry of Health; 3) Service providers/case workers managed by NGOs; 4) Traditional healers; 5) Church healers; 6) Day clinic staff; 7) Women's support group members; and 8) Service users/families. Five to ten individuals were included in each focus group.

Data collection and analysis

The FGDs explored the following 6 key themes: 1) Understanding of mental health and mental illness; 2) Approaches/interventions to manage mental disorders; 3) Becoming a customary health practitioner; 4) Strengths and weaknesses of customary approaches to mental health; 5) Acceptability of integrating customary approaches to mental health care system; and 6) Engagement and linkages between traditional and modern health sector policies and practice.
All FGDs were conducted in the local language (mostly Tetum), with the assistance of an interpreter, and each FGD lasted approximately two hours. All FGDs were audio recorded and a framework approach was used to analyse the data.

Results

Types of informal healer and healing practices
The research identified a range of different types of informal healer and healing practices currently in use in Timor Leste. Customary approaches to healing are generally either associated with the *uma lulik* (sacred ancestral house) and/or nature spirits. Informal healers also operate within both the Catholic and Protestant traditions as well as within the Chinese-Timorese and Islamic communities. In Timor-Leste both male and female informal healers can be found.

Different types of healing practice draw on different world-views and consequently employ different diagnostic techniques and treatment approaches. Some healers for example choose to observe their client before making a diagnosis, others listen to life histories, and others still may use a combination of divination and augury techniques. Customary and other informal healers use a complex

vocabulary for describing mental illness, including symptoms and causes. Different therapies or treatments are recommended based on diagnosis including: prayer, the laying on of hands, animal sacrifice, the preparation of herbal medicines or a call to repair social relations and repay debts to ancestors, family, and between wife-givers and wife-takers.

The research also found that informal healers are the 'first-line' or first recourse in pathways to healing. Although no formal avenues for interaction between informal healers and the mainstream health service exist, they are nevertheless aware of each other and often communicate with each other in practice. In some cases, informal healers will refer patients to mainstream health care, while in other cases they receive those for whom mainstream care was not successful. Some, but not all, informal healers get paid for their services and all participants (including healers) acknowledged that there are charlatans who over-charge and in some cases abuse their clients.

Participants reported that patients and families tend to seek all possible pathways to healing. Informal healers and healing practices were reported as playing a key role in 'opening the path' for healing before seeking treatment through the formal health sector.

Positive and negative aspects of informal healers and healing practices

The research found both positive and negative aspects associated with informal healers and healing practices. On the positive side, patients and families are more likely to believe and trust informal healers. In approaching informal healers, they demonstrate a desire to take responsibility for themselves and seek diagnosis/treatment. In doing so they are also more likely to address any problematic relations within the family and others which may influence long-term health outcomes. On the other hand, stakeholders from the formal sector felt that informal healers and healing practices could provide short-term fixes but not provide long-term treatment or solutions. Informal care was reported to have a higher financial cost and its unregulated nature was perceived to be more vulnerable to harmful practices and abuse. It was also felt that dissatisfaction with the informal sector delayed engagement with the formal health service, resulting in their conditions being more severe when they arrive to the formal sector.

Impressions from the formal sector

Stakeholders from the formal sector in the public and NGO sector stressed the need to respect patient and family choices in relation to informal healers and healing practices. They suggested that they could not force or oblige people to operate within the formal sector but can only inform and educate. They expressed a need and desire for the formal sector to build trust with the informal sector and sharing knowledge about mental health and informal healing practices. Those operating the formal health system called for more training and resources for mental health in particular in relation to ways of combining therapy and medication. They also highlighted the need for a reliable supply of medication.

The way forward

Finally, stakeholders suggested that more detailed research to identify beneficial and harmful practices and build up knowledge and understanding of informal diagnostics, therapy and treatments is necessary and this cannot be achieved without dialogue and collaboration between the formal and informal 'mental health' sectors. In the meantime, there is an ongoing need to educate – raise awareness of mental illness and pathways to healing.

Discussion

The findings clearly indicate the need for both formal and informal health systems and this is reflected in Government's policies, such as the National Mental Health Strategy 2011-2015 that calls for an integrated and comprehensive health system that embraces both modern and indigenous models of care (Ministry of Health Timor Leste 2010). The findings are also consistent with international experience in that in many countries people seek out traditional and religious healers before consulting a doctor or mental health specialist.

Historically the formal and informal sectors have worked independently of each other. While each sector has its pros and cons, coordination and collaboration of care across these two sectors can be complimentary and could enable a more comprehensive, effective and efficient community-based set of services that better meet the needs of the population while respecting/protecting local customs.

For instance, the formal health care system may be able to improve and/or cure some health problems but they are poorly resourced and the service providers generally have inadequate training. The 'formal' system is also a relatively 'new' approach/paradigm to health for many people in Timor Leste and therefore not yet fully understood and trusted. Many services were introduced based on international best practices but have not been tailored adequately to the Timorese context and are often delivered in settings that are strange and uncomfortable to the patients. And hospitals, by definition, are places for people who are ill and should be avoided if possible. It is therefore understandable that they are scary for many people. Formal health care is not available or accessible for many people in the country and the services are primarily curative in focus rather than preventative or recovery-oriented. Alternative models of care, including customary practices have their own set of challenges in that most people providing alternative care in Timor Leste are not aware of or trained in mental health and often deliver ineffective 'treatments' which delay going to the clinic. With delays in treatment seeking and/or sometimes harmful customary practices, a person's condition is often worse by the time they seek care at a clinic or hospital.

However, if appropriately trained and supported, alternative care providers such as traditional healers and customary practices have many advantages that enables them to play a key role in mental health service delivery. For instance, customary practices tend to be holistic in its approach. They are also more accessible because 1) there are greater numbers of traditional healers compared to health providers in the country; 2) they are generally trusted by the community members; and 3) they are based in the community. Customary practices are also a more acceptable model of care by community members because of its close alignment with traditional beliefs and are in fact considered essential by most people to opening the pathway to healing. If the pathway to healing is blocked, then any kind of treatment will not be effective.

While opening the pathway to healing is a critical part of health and healing, there are potentially other roles that traditional healers can play in mental health service delivery. An effective mental health care system requires appropriate and timely mental health promotion, prevention, early detection, diagnosis, treatment, rehabilitation and social support (World Health Organization 2010, World Health Organization 2013). Treatment must include both pharmacological and non-pharmacological interventions such as psychoeducation and psychotherapy (e.g., behavioural activation, cognitive behaviour therapy, interpersonal therapy, etc.) and recovery must include rehabilitation and social support to facilitate reintegration back home, at school, at work, and in the community (Patel et al. 2007). While the ability to provide such non-pharmacological services are desirable for many current mental health officers in Timor Leste, most do not have such training and there is currently insufficient human resource capacity to provide such support.

The shortage of mental health specialists is not specific to Timor Leste. No nation has sufficient human resources to meet all of the mental health needs of its citizens and most low- and middle-income countries face significant shortages (Kakuma et al. 2011; Scheffler et al. 2011). Most countries will never have enough specialists and therefore strategies that effectively make the best use of specialists and mobilises other human resources, across sectors and systems (health and non-health, formal and informal, private sector, industry, community members) - known as task-shifting - are essential to develop adequate human resources to meet mental health care needs (Kakuma et al. 2011). While some tasks require specialists such as psychiatrists, neurologists and psychologists, other tasks can be delivered by non-specialists. For instance, general physicians, nurses and community volunteer workers can be trained to detect, diagnose and treat common and less complex disorders such as mood and behavioural disorders while the specialists focus on diagnosis and treatment of more severe and complex cases. Similarly, community members, traditional healers, faith-based healers, teachers etc can be trained to detect and refer someone with a potential mental disorder to a clinic or hospital, to use a screening tool, to provide basic counselling, to follow up to makes sure they are taking their medications properly and practicing other recovery-regimes such as self-monitoring, continuing their therapy etc.

Given the significant financial and human resource constraints in the public system in Timor Leste, traditional healers can play a key role in contributing to mental health care. However, collaboration between formal health system and traditional healers can be quite challenging. International evidence has consistently shown poor relationships between traditional healers and mental health professionals due to a variety of reasons including deeply embedded conceptualisations about

mental disorders and its causes which conflict with biomedical models, and mutual lack of trust, respect, consideration and understanding of their respective models of care. (Sorsdahl et al. 2009; K. Sorsdahl et al. 2010; K. R. Sorsdahl et al. 2010; Sorsdahl et al. 2012; Sorsdahl et al. 2013).
Despite such challenges, such collaboration is feasible. While there is currently no formal mechanism for collaboration for mental health care (Silove et al. 2008; Hawkins 2010), this has been done in maternal reproductive health, where traditional birth attendants were introduced to perform a range of tasks including outreach and case finding, health and patient education, referrals, home visits and care management (Ribeiro Sarmento 2014). Through this collaboration, traditional birth attendants significantly improved their knowledge, attitude, and behaviour and their capacity to provide appropriate advice for antenatal care. Furthermore, this new model of care has increased access to reproductive health services particular for women in rural communities and reduced maternal mortality rates.

The emphasis on the need for mental health services to be aligned with customary models of care and the experiences of establishing partnerships with traditional birth attendants provides a unique and timely opportunity to establish an effective collaborative mechanism between traditional healers and the formal mental health care system. In fact, initiatives to foster respectful and considerate dialogue to better understand both perspectives have begun. The Ministry of Health organised a Forum in July 2015, in collaboration with the University of Melbourne, which brought together over 60 government, international, academic and community stakeholders, including traditional healers. This Forum aimed to stimulate dialogue on mental health policy and practice in Timor Leste and consider how inter-sectoral partnerships might be realized to build an integrated system of care. An enactment by the traditional healers of current customary practices and role play based on their interactions with local and district mental health nurses was a highlight of the Forum and produced lively discussion regarding the capacity building and research needs and policy changes required to develop an integrated approach to mental health care in Timor Leste. The demonstrated openness and desire to dialogue and engage between the formal and informal sector suggests that Timor Leste is in an ideal position to take lead in this area for both research and development.

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