ARE PEOPLE-CENTRED MENTAL HEALTH SERVICES ACCEPTABLE AND FEASIBLE IN TIMOR-LESTE?

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BACKGROUND
WHY IS MENTAL HEALTH IMPORTANT IN LOW- AND MIDDLE-INCOME COUNTRIES?

PUTTING PEOPLE AT THE CENTRE OF GLOBAL MENTAL HEALTH

• People-centred mental health care is a recent influential paradigm

• WHO define people-centred health care is:

  “an approach to care that consciously adopts the perspectives of individuals, families and communities, and sees them as participants as well as beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways”
EVOLUTION TOWARDS PEOPLE-CENTRED MENTAL HEALTH

Biomedical model

Person-centred care

- Personhood
- Individualised care
- Recovery

People-centred care


Framework on integrated, people-centred health services
**WHO FRAMEWORK ON INTEGRATED PEOPLE-CENTRED HEALTH SERVICES**

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<td>1</td>
<td>Empower and engage people and communities</td>
<td>Involved in own health decisions</td>
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<td>Strengthen governance and accountability</td>
<td>Involved in health policy making</td>
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<td>Reorient the model of care</td>
<td>Community-based services</td>
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<td>Coordinate services within and across sectors</td>
<td>Collaboration between Ministries of Health and Education</td>
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<td>Create an enabling environment</td>
<td>Political will</td>
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PEOPLE-CENTRED MENTAL HEALTH CARE IN LMICs?

Three key considerations

• Who are the people at the centre?

• How is mental health understood and explained?

• And what type of care is acceptable and feasible?
INTRODUCING TIMOR-LESTE
TIMOR LESTE

Lower-middle income country in South-East Asia
Population 1.3 million people
Cultural and bio-diversity
Post-conflict
11.6% prevalence of mental and substance use disorders
MENTAL HEALTH IN TIMOR-LESTE

Sociocultural explanatory models and care

Holistic notions of health and well-being

Traditional or faith-based healers provide much support for mental distress

Formal mental health system

Predominantly community-based mental health care

3 mental health professionals per 100,000 people

National Mental Health Strategy 2018-2022


CONCEPTUAL FRAMEWORK
PHD RESEARCH AIMS AND OBJECTIVES

Timor-Leste sociocultural and development context

Mental health system
- intersectoral collaboration
- participatory governance

Mental health and social services
- acceptability and feasibility

Acceptability
- the sensitivity of a health intervention to the local sociocultural dimensions of both its beneficiaries and implementers (Sekhon, 2017)

Feasibility
- resources, practicality and sustainability of a health intervention (Bowen, 2009)

Community settings
- social inclusion and exclusion of people with mental illness and their families
DESIGN AND METHODOLOGY
National DILI
Municipality BAUCAU
Administrative post
VENILALE
Administrative post
LACLUBAR
Administrative post

DATA COLLECTION

September 2017 to August 2018 (12 months)

Ethics approval received from UniMelb HESC and INS Timor-Leste
IN-DEPTH INTERVIEWS: \( N = 85 \)

- People with mental illness: \( n = 20 \)
- Families: \( n = 10 \)
- Mental health and social service providers: \( n = 23 \)
- Government decision makers: \( n = 10 \)
- Civil society members: \( n = 9 \)
- Other community members and organisations: \( n = 13 \)
DATA COLLECTION AND ANALYSIS

Interviews direct or interpreted in:
- English
- Portuguese
- Cairui
- Tetum
- Makasai

(~56 hours)

Informal observation in health and social services in Venilale and Dili

(~500 hours)

Data analysis: Framework analysis with N-Vivo software

Community presentations to validate findings

REALITIES OF DATA COLLECTION IN TIMOR-LESTE

- privacy and confidentiality
- permissions and snack packs
- transport

Researcher position
- public health, psychology
- language
- being Australian in Timor
THANKS JULIE

You put an end to a shadow past in our Relations. Now, Timor-Leste and Australia can look forward...
RESULTS

Acceptability and feasibility of mental health services
“Because when you go to a family affected by mental illness, you’re not only approaching that person; you have to get approval from their family.”
(Male civil society member, 29 years, Dili)

- Family roles
- Family preferences and needs
DIMINISHED PERSONHOOD

Altered capabilities and societal roles

- Not capable of making rational decisions
- Not trusted with socially significant tasks
- Bullying, physical and sexual violence
- Confined to house
POWER HIERARCHIES IN HEALTH

Power structures

Traditional and cultural perspective
- Big people (ema boot) versus small people (ema kiik)

Health perspective
- Medical hierarchy

Human rights framework
- General attitudes towards people with disability
WHEN INDIVIDUAL AND FAMILIES NEEDS AND RIGHTS CLASH

“So they family decided to have a meeting [...] They came to me and a spokesperson said that the family does not agree to unchain the person. The person who came to me was not the father, I said to him "you aren't the father, how can you say this?". After that, I learned that it was the powerful uncle.”

(Male service provider, 45 years)
PLURAL SOURCES OF CARE

Explanatory models of mental distress

• ancestral, spiritual, natural, trauma, poverty, bio-psycho-social

Customary healing

Government mental health care

• Home visits
• SISCa
• Visit hospital, clinic or service
• Saude na familia

NGO mental health care

• Pradet psychosocial rehabilitation (Dili)
• Klibur Domin long term stay option (Dili)
• São João de Deus inpatient psych hospital (Laclubar)
“We need a place.”

Male family member
46 years Venilale
FEASIBILITY CHALLENGES

Barriers at individual, service provider & health system levels

- Information/knowledge
- Transport
- Health system financing
- Staff capacity, training and support
- Medication supply
- Health information systems/data
SUMMARY

- Family-centred ecology of mental health (care)
- Plural and preferred types of mental health care
- Decision making in health setting
- Challenges to feasibility

Are people-centred mental health services acceptable and feasible in Timor-Leste? A qualitative study

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Abstract

People-centred mental healthcare is an influential concept for health system strengthening and sustainable development that has been developed and promoted primarily in Western contexts. It characterizes service users, families and communities as active participants in health system development. However, we have limited understanding of how well people-centred mental healthcare aligns with the multiplicity of peoples, cultures, languages and contexts in low- and middle-income countries (LMICs). Timor-Leste, a lower-middle income country in South East Asia, is in the process of strengthening its National Mental Health Strategy 2018-22 to align with people-centred mental healthcare. To support the implementation of this Strategy, this study investigated the acceptability and feasibility of people-centred mental health services in Timor-Leste. In-depth semi-structured individual (n = 57) and group interviews (n = 15 groups) were conducted with 85 adults (>18 years). Participants were service users, families, decision-makers, service providers and members of civil society and bilateral organizations across national and sub-national sites. Government and non-government mental health and social care was also observed. Framework analysis was used to analyse interview transcripts and observation notes. The study found that the ecology of mental healthcare in Timor-Leste is family-centred and that government mental health services are largely biomedically oriented. It identified the following major challenges for people-centred mental health services in Timor-Leste: different sociocultural perceptions of individual personhood, including a diminished status of people with mental illness; challenges in negotiating individual and family needs; a reliance on and demand for biomedical interventions; and barriers to health service access and availability. Opportunities for people-centred mental healthcare are
IMPLICATIONS

Photo: Tanushree Rao
IMPLICATIONS FOR PRACTICE

Health sector

- Increase population mental health awareness — incorporate sociocultural understandings of mental distress and address practical barriers for families (i.e. time and resource demands).

- Adopt a family-centred approach to mental health care, stigma reduction and social inclusion

- Facilitate participation of Timorese people with people with mental health problems and their families in health system strengthening

- Strengthen mental health services, with a focus on promoting recovery, reintegration and social inclusion

Social and other sectors

- Support emerging networks of people with mental health problems within civil society

- Ratify the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
IMPLICATIONS FOR CONCEPTUAL DEVELOPMENT

Three key considerations for people-centred mental health care in Timor-Leste

• Who are the people at the centre?
  • Central role of family

• How is mental health understood and explained?
  • Role of spiritual, ancestral and natural explanatory models of mental well-being and distress

• And what type of care is acceptable and feasible?
  • Sociocultural power hierarchies
  • Health access barriers
  • Social sector and human rights
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FOOD FOR THOUGHT? QUESTIONS?