"No one bothers about the confused people"
Care for people with psychosocial disabilities
in rural South Africa

Stine Hellum Braathen
Stellenbosch University, Dept. of Psychology
SINTEF Technology & Society, Dept. of Health
This presentation

- Problem statement
- Objective
- Research Questions
- Theoretical points of departure
- Methodology
- Results - Context and case study
- Single-case analysis and discussion
- Conclusions
Problem statement

• In LMICS, including South Africa, the gap between the need for mental health services and available services is critical
  – Lack of priority at policy level, lack of equipment, personnel, medication, low mental health literacy
• The majority of people with mental disorders are not diagnosed or treated
• Consequences are poor health outcomes and not realising the full potential and participation in society for people with disabilities
• Call for more community-based mental health services, for task-shifting and a move towards medical pluralism

• Lack of evidence on:
  – Family and community care
  – Traditional systems of healing
  – Medical pluralism
Objective

The overall objective of this project is to explore structures of care for people with psychosocial disabilities in a rural part of the Eastern Cape Province of South Africa.
Research questions

• How are people with psychosocial disabilities cared for at various levels/ by various people and institutions?
• What is the rationale for choosing and applying the different care strategies for and by the various people?
• How are these care strategies implemented?
Theoretical points of departure

- Psychosocial disability
  - Disability
  - Mental disorder

- Care
  - Ethics of care
  - Health care
  - Occupation as care
  - Ubuntu
If no one cared for others, society would cease to exist within a generation or two (Eva Kittay)
Care

• The overall aim of care is to maintain the world by meeting the needs of ourselves and of others
  – Essential for human survival
• Care in this PhD:
  – Ethics of care
  – Anthropological approaches to pluralistic health care
  – Occupational participation as care
Ethics of care

On the most general level, we suggest that caring be viewed as a species activity that includes everything that we do to maintain, continue and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web (Fisher and Tronto, 1990).

Care is helping individuals achieve at least a basic level of well being, meaning, at a minimum, survival and as much basic functioning as they are able to achieve (Engster, 2005).
Ethics of care

- Relational theory
- Care is a flexible concept
- Care is cultural, contextual, individual, economical and political
- Care vs dependency care
- Care can be hands-on, supervision or financial assistance
- Politics of sameness
Pluralistic health care

- Health care is a local cultural system
- Patients and healers are key components
- The different systems of care co-exist
Sectors of healing and care

(Kleinman, 1980)
Occupational participation as care

• Occupation: things people do in their everyday lives
  – Work
  – Play/social activities
  – Activities of daily living

• Through occupation people get the
  – opportunity to express choice
  – make decisions
  – experience achievements and enrichments

• The meaning of occupation is socio-culturally derived
Methodology

• Qualitative study design
  – Complex issues
  – Exploratory
  – Meaning

• Case study research
  – In-depth information about contemporary issues, events or phenomena in their natural real-life contexts
  – Cases possess similar characteristics

• Qualitative studies commonly uses multiple data collection techniques: desk study, in-depth interviews, observation, pictures
Data collection

• Contextual study
  – Identify and explore people, institutions and places that offer some kind of care for people with psychosocial disabilities in Madwaleni
  – Contextual and cultural understanding of the setting in which the case studies function

• Case studies
  – In multiple case studies the cases are similar or have some commonalities, and they are studied alone, as well as in relation to each other and in relation to the overall study phenomenon
  – Each case is an in-depth description and exploration of a person from the perspective of the individual, and/or from their family members.
Informants - contextual study

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<thead>
<tr>
<th>Health providers – Government Health Services – Professional Sector</th>
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<td>Nurses</td>
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<td>Physiotherapists</td>
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<td>Occupational therapists</td>
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<td>Community health workers</td>
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<td>Care givers</td>
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<td>Psychology Intern</td>
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<th>Health providers – Folk Sector</th>
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<td>Faith healers</td>
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<td>Traditional Healers</td>
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<th>Popular Sector</th>
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<td>Reverend – Church</td>
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<tr>
<td>Manager - Home for people with special needs (charity-based)</td>
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<td>Chiefs (local governance)</td>
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<th>Xhosa-speaking academics</th>
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<td>Stellenbosch University</td>
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# Case studies

## Case studies (all names are pseudonyms)

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<tr>
<td>1</td>
<td>Man with stress/ stroke/ mental illness (Khaya)</td>
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<td>2</td>
<td>Old woman with mental illness (Pumla) – Interview with her son (Andile)</td>
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<tr>
<td>3</td>
<td>Married couple with mental illness and family problems (Thamsile and Aseko)</td>
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<td>4</td>
<td>Old woman with mental illness (Nomabali) – Interview with great-granddaughter (Vuyelwa) and daughter-in-law (Sylvia)</td>
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<td>5</td>
<td>Girl with depression and family issues (Simkite)</td>
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<td>6</td>
<td>Woman with mental illness (Zoliswa) – interview with mother (Novusile)</td>
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## Psychiatrists

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<tr>
<td>1</td>
<td>Female psychiatrist from Tygerberg Hospital in Cape Town</td>
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<td>2</td>
<td>Male psychiatrist from Tygerberg Hospital in Cape Town</td>
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Results

• Context
• Case study
Eastern Cape Province
Eastern Cape

• Historically neglected province – former 'Transkei'
• Poverty is still rampant for a large part of the South African population
• Rural areas in South Africa, in particular areas in the Eastern Cape Province, remains the poorest, most underserved and historically neglected
Madwaleni
Madwaleni

- Hospital catchment area of approximately 150-200 000 people
- Severe shortage of piped water, sewage systems, electricity, roads and public transport.
- Unemployment estimates around 80-90%
- Most people live at or below subsistence level.
AmaXhosa

- Xhosa-speaking people comprise the majority of the population of the Eastern Cape
- The amaXhosa people are a group of clans within the Nguni, Bantu-speaking people in southern Africa
- The culture is patrilineal, with a strong hierarchical system of kin networks and chiefdoms
- Ancestors play an important role in guiding traditions and cultural practices.
- Mental disorders are bound up in complex belief systems, with culture bound syndromes and culture specific events closely linked to the understanding and treatment of mental disorders.
- There is widespread use of traditional healers in the management of mental disorders among Xhosa-speaking people
- Deeply rooted in Ubuntu philosophy
Health providers
Mental health care in the professional sector

- No psychologist
- No psychiatrist
- No mental health nurse
- No social worker
- No dedicated personnel working with mental health and mental illness
- Two community psychologists from 2012
• Lack of referral and collaboration

As it is now each part of the health care only know of and focusses on their bit of the treatment, and knows nothing of what has happened before, in other parts of the health system, and so the continuity of care is not good. Patient information is only in their health books, which patients keep themselves. If they don't have this, the health personnel know nothing of previous care and treatment (Nurse).
• No formal collaboration with other sectors of healing and care
• Lack of focus on mental health and mental disorders:
  — Limited services
  — Mental health is nobody's responsibility

*No one bothers about the confused people*
*Nurse*
Management of mental illness

• Clinic
• Referral to hospital
• Hospitalisation for up to 72 hours
• Antipsychotic medication
• Referral to psychiatric wing Mthatha
Mental health care in the folk sector

• Faith healers/ traditional healers/ prophets
  – Ancestor-based
  – Faith-based
  – Combination

• Mental disorders are caused by:
  – Witchcraft
  – Evil spirits/ zombies
  – Suffering/ stress
  – Jealousy
If a person is mad there is no question, you just see that the person is mad! They were running away, you have to tie them up. It's serious. Some was just intoxicated by the evil spirit, like zombies. (They are intoxicated) by those people, they are wizards. These people (wizards) are working during the night when people they can't see them....it's like magic, like magicians. Because they do things we cannot see, which you don't understand.

(Traditional healer)
• Treatments are based on:
  – Prayers
  – Communication with ancestors
  – Herbs
  – Sniffing
  – Water
  – Dreams
Popular sector

- People with mental illness
- Family members
- Community members
- Local governance
- NGOs
- Church representatives
Pumla's story
Pumla's illness

She was 'sick of the brain' about ten years ago, and she has never gotten well again. She just got 'crazy'; shivering heavily, bleeding blood from the nose and mouth, running around aimlessly, running away, being violent and not knowing what she was doing. She was a danger to herself and others. At night she thought that she was being attacked by her small grandchild and by some men in the community who were trying to kill her, but this was not real. The child was sleeping, so she was seeing things. When she was running away she was running from those people she thought were attacking her. We were all shocked when this happened. There must always be someone accompanying her now. She can communicate, but there is nothing she can do. The bleeding stopped after one day, but the rest of the symptoms lasted for about six months, on an everyday basis, before we took her to the hospital for treatment.

(Pumla's son Andile)
Pumla's treatment

At the hospital a nurse looked at my mother's head, and said that she did not know what was wrong with her, but she gave her some medicine. We were not told what it was, or what it was for, just how many and at what time to take the tablets. They also gave her painkillers for a bad headache she had, and told her to go to a traditional healer for help and medicine, and to combine these treatments. So we sought help from a spiritual healer just a few minutes' walk from our house. The healer gave my mother a bottle of something to drink; a mix of juices and herbs. After this she got a bit better; she stopped seeing things, and she shivered less.

(Pumla's son Andile)
Psychiatrists comments

• Not conclusive, but her symptoms could be:
  – Psychosis due to stroke/ other medical condition
  – Dementia due to stroke/ other medical condition
  – Depression
Single-case analysis and discussion

• Pumla has symptoms that are universal in nature
  – Family has little understanding of the symptoms or how to deal with them
• Pumla receives care from all three sectors of care
  – Popular sector: Immediate and extended household
    • Help in seeking care and making care decisions
    • Practical care: ADL
  – Professional sector: Hospital
    • Medication for immediate and acute symptoms
    • No diagnosis/ explanation
    • Referral to folk sector
  – Folk sector: Traditional healer
    • Medication for immediate and acute symptoms
    • No diagnosis/ explanation
Key challenges

• Mental health literacy
• Practical challenges
  – Terrain
  – Poverty
  – Lack of resources
• Occupational deprivation
• Lack of support for the family
Key challenges cont.

• Limitations of professional health care
  – Lack of skilled health workers
  – Lack of appropriate diagnosis
  – Lack of medication
  – Lack of psychological treatment

• Complex web of different sectors of healing
  – Referral from professional to folk sector, but no mechanism to bridge the two sectors of care

• Lack of follow-up: Her immediate and acute symptoms were cured, but she still suffers from the aftermath of her mental disorder
Conclusions

• Shifting the focus of mental health care from cure to promotion and prevention
• Contextually appropriate interventions making optimal use of local resources
• Task-shifting and task sharing: Using an interdisciplinary team of lay and trained health workers from the professional, folk and popular sectors

http://inthealth.oxfordjournals.org/content/5/1/38
Stine Hellum Braathen
PhD candidate—Stellenbosch University
Research Scientist – SINTEF Health, Norway

stine.h.braathen@sintef.no