# The role of *Ubuntu* in families living with mental illness in the community

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# **Abstract**

Background: Families living with mental illness are a vulnerable group in the community. In the African culture, it is accepted that families are embedded safely in a community. In accordance with the principles of Ubuntu, people with mental illness should be well supported and cared for by their families and the wider community. Traditionally, people with mental illness are institutionalised, out of sight of the family and the general population. However, the deinstitutionalisation of mental health services has changed the structure and mode of caring for people with mental illness. The family and community are now regarded as the dominant care givers and providers.

Method: A qualitative grounded theory method was used.

Results: This article discusses research in progress that demonstrates how families in the community experienced stigma and isolation in the community, as well as crime. There was little support from the community in assisting families to shoulder their burden of care. In this article, we reflect on the possibility that the spirit of Ubuntu may well assist families living with mental illness, despite the burden that communities have to shoulder when fulfilling their own family obligations.

Conclusion: In a community in which Ubuntu is the underpinning life philosophy and way of life, these values could be reinstated and revived to promote the survival and recovery of families living with mental illness in the community, and to reintroduce humanness in the community.

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# Introduction

Deinstitutionalisation in South Africa commenced in the 1970s, as care for people with mental illness was integrated with that for other chronic illnesses in the primary healthcare service system. According to Lazarus,1 there is "no standard definition of deinstitutionalisation". Deinstitutionalisation is not just the discharge of patients and the downsizing of hospitals. It includes the development of community-based services, and better access to beds in general hospitals in case of acute relapse.

Deinstitutionalisation resulted in people with mental illness living with their families in the community instead. Caring for people with mental illness became the responsibility of their families and the community. The deinstitutionalisation process aimed to decrease admission to long-term institutions, which historically had become living quarters for many people living with mental illness, resulting in them becoming disconnected from their families, and hidden from the community and society.2

Concerns emanating from deinstitutionalisation include indiscriminate discharges, inadequate family and community preparation and support and community resources, continuity of mental health care, and revolving door admissions1 and homelessness.3

Sewpaul<sup>4</sup> and Hochfeld<sup>5</sup> critically discussed the political and social power discourses, as reflected in the draft South African Family Policy.6 The discourse on self-reliance for both individuals and families illustrates a paradigm shift towards neo-liberalism, after the transition to democracy in South Africa. This neo-liberalism is a global shift, in which the family is seen as an autonomous unit that is "responsible for its own maintenance".7 This is opposite to the way of living and thinking in African communities, in which "we are, because you are" and "your child is my child" are enshrined in the philosophy of Ubuntu.8 According to this philosophy, community is important, and family and community needs are prioritised above those of individuals.

Ubuntu is defined as "an ancient African worldview, based on the primary values of intense humanness, caring, sharing, respect, compassion, and associate values, ensuring happy and qualitative human community life in the spirit of family".9



This definition embraces both community and family, using core values that may need to be reintroduced in order for individuals and families living with mental illness to live a full and healthy life within the community. The extent to which Ubuntu practices were embraced is the subject of this article.

# Method

The article is based on a specific phase of a broader research study on understanding mental illness in the community. It reports on an in-depth appreciation and understanding of the experiences of caring for people with mental illness in the community and, similar to the larger study of which it is a part, it is qualitative in nature.10

In this reported phase of the study, theoretical sampling was used. It was found that four families and three community development agents working in nongovernmental organisations (NGOs) adequately and comprehensively offered information on the subject of caring. The targeted communities, from which the sample was derived, were the Zulu-speaking communities of Umlazi and KwaDabeka in KwaZulu-Natal.

Individual interviews were conducted with respondents using one primary question, from which other related questions evolved. This line of questioning was in accordance with the use of grounded theory,11 in which interviewees are regarded as experts of their own lives and their views inform knowledge, rather than the other way round. The interviewees offered rich data, which form the main theme and subthemes that are discussed in this article.

Ethical issues addressed in this phase of the study were numerous, considering the sensitive nature of the study, but were adequately dealt with as the primary researcherauthor is a professional nurse and counsellor. Painful and emotional issues raised by respondents were handled through referral and on-site counselling. Ethics clearance to conduct the study was also secured from the University of KwaZulu-Natal, under whose auspices the study was conducted. The Ethics Committee of the University of KwaZulu-Natal gave clearance for the research, from which all the data were derived.

### **Trustworthiness**

Since this is a qualitative study, addressing trustworthiness was more relevant than addressing validity and reliability, and was considered to be more applicable to quantitative research.

Guba's<sup>12</sup> strategies of trustworthiness guided this phase of the study as follows. Credibility was achieved by prolonged engagement in the field. This involved building relationships before, during and after the interview. Reflective journals were kept throughout the fieldwork, and the analysis process helped to keep track of research content and process. Triangulation of two different samples was used to view the picture of caring from different vantage points. Transferability was achieved by ensuring a dense description of data that respected interviewees as experts of their lives. Dependability was achieved by rigidly describing the methods of data gathering, data analysis and interpretation. Finally, confirmability was ensured by submitting the entire research process to an audit, through use of peer consultation, supervision and examination.

# Research aim and question

The study aimed to understand the caring for families living with severe mental illness, as well as their challenges, coping strategies and desires.

One key research question served to generate further exploration, and guided the interviews with both sets of respondents: "How can families living with mental illness in the community be cared for?"

This question did not specifically raise Ubuntu as the principle that should or shouldn't be applied when in caring for persons with mental illness, in order not to prejudicial responses. However, the respondents linked Ubuntu to treatment and care, so this key notion became the organising theme of the article.

### **Theoretical framework**

The study used grounded theory, both methodologically, and as a frame of reference for understanding and organising data. Grounded theory was best suited to this phase of the study, since inside perspectives devoid of preconceived ideas were necessary to comprehensively understand respondents' experiences of mental illness, caretaking and care giving. Grounded theory is further justified because families, communities and their caregivers have a wealth of information and data to share in building block-by-block<sup>10</sup> knowledge and theory pertaining to this study. Daly13 recommended the use of grounded theory as a valuable method in family studies, with which this phase of research is involved. Grounded theory is compatible with the diversity and richness of data that reside in a multiplicity of complex processes and layers of meanings that are typically found in family work. Hence grounded theory was used to discover this rich data, and multiple meanings and processes involved in caring for persons with mental illness.11

# Results

The following descriptions by family members of people with mental illness reflect how care giving is viewed in relation to mental illness.

These descriptions aptly introduce the concerns and themes addressed in the study, and in this article:

"Ubuntu ... No. I don't see it."

"... when I have a problem, the neighbours, they close the doors and peep through the windows. Our people are bad people. They hate each other."

"When you are in trouble, it becomes your problem, our nation has got negative attitude, when you are happy, they are not happy, when you are sad and upset they get happy."

"We noticed ... neighbours have started stealing from her, but she has no ability to defend herself."

From these responses, it is abundantly clear that Ubuntu was not serving families, least of all families in which mental illness existed. There appeared to be elements of hate, distrust, and even exploitation of defenceless families, all of which are far removed from the Ubuntu way of living.

The conversations with the participants will now be analysed and discussed, using grounded theory. Subthemes or tributary nodes also emerged as the discussion unfolded, and are presented with corresponding respondent quotes to support their inclusion.

# The problem and its context

Families caring for family members with mental illness form a vulnerable group in the community. They are isolated and stigmatised, and are often targets of crime.

Although democracy in South Africa is now 18 years old, the effect of dismantled families, due to separate development, is still acute. This separate development means that families have been left to fend for themselves, and survive with minimal infrastructure and support as a separate group from the rest of the community. Value systems have shifted to valuing self, which in turn, is dependent on each person's "access to materials and wealth". 14 Many families living with mental illness have become vulnerable, since their primary role is that of surviving everyday life, while access to wealth is beyond their reach. In addition, because of a scarcity of resources, they cannot compete for resources or build wealth, enhancing their position as a vulnerable subgroup of society. Within the community, they have become the focus of maltreatment, inhumanness and stigmatisation, as evidenced by the above cited quotes.

Engelbrecht<sup>15</sup> and Lamb and Bachrach<sup>16</sup> found that people living with mental illness in the community experienced various challenges, such as high levels of burden of care and stigmatisation and little social support. Lamb and Bachrach<sup>16</sup> explained that there was a new generation of uninstitutionalised persons who were living with severe mental illness. These people were homeless and have been criminalised by society, as evidenced in the present study. Despite mental illness being common, communities continue to harbour "negative beliefs about mental illness". 17 Examples include believing that a person with mental illness is possessed by demons, is the victim of witchcraft, or is suffering because certain rituals have not been performed.<sup>18</sup>

# **Burden of care**

High levels of burden of care were apparent in the interviews:

"I was working as a full-time nurse and paid someone to stay with him ... Even now the grant is R800. I do take care of him ... I joined insurance for him ... We used to struggle, and made money by playing stokvel..."

Financial dependence was a significant burden. The above quoted participant had multiple financial responsibilities, since she also took care of her grandchildren, paid school fees and fulfilled basic needs because "their mothers don't pay. They are not working". On diagnosis of a mental illness, it is a challenge for the affected person to retain a job, or gain re-employment after recovery from an episode. 19 In a country where unemployment is high, the individual with mental illness competes for limited employment opportunities in the community, notwithstanding a previously favourable employment record. Markowitz20 asserted that people with mental illness are more likely to be unemployed and experience diminished self-esteem, with minimal social support.

The burden of care deepens when the person manifests bizarre behaviour, as in the case of schizophrenia, or is viewed as lazy, as in the case of depression. Negative symptoms of schizophrenia include poor self-care, restlessness, low drive (or life energy) and need for supervision and assistance from family members.

An example of low drive is shown in the following quotation:

"... He is stable now and he likes to work, even though he would not do a strong job. He would say he is tired because of the medication. He likes to sleep".

If the person with mental illness is the primary care giver in the family, financial strain and hardship is inevitable. In addition, it was clear from the literature<sup>21-23</sup> that special care needs, such as medication, hospitalisation, therapeutic interventions, and even travelling to and from service centres against a background of poverty and crime, become difficult to shoulder.<sup>15</sup>

# Stigma in the community

The following quotation indicates that people living with mental illness were vulnerable to abuse and stigmatisation in the community:

"After she married him, she took him, a person living with mental illness, away from my house, and took him to be a tenant somewhere and then he was abused there where he was staying and paying rent with his disability grant... They found him totally confused. Now he is picking papers all over the location".

In the Zulu community, the expression "picking papers" is often used to refer to a person with mental illness in a derogative way. The mother further explained that he would dress in his suit, and pick up papers.



This behaviour upset her:

"My daughters ... run from my house, they are not willing to come and stay here because they get upset seeing their brothers, both living with mental illness, behave like that".

Furthermore, the neighbours seemed to blame the mother for the fact that members of her family were living with mental illness. They suggested:

"Why don't you slaughter a goat and stop this? ... But I am a Christian ... I do not do those traditional things".

This theme, noted in literature on mental illness, 16,20 was strengthened by interviews conducted with healthcare givers and community developers. One participant indicated the following:

"This one guy ... he sounds very psychotic, has been kept in one room in the house ... never leaves the house.... This kind of illness is ... very much kept under the carpet, and linked with huge embarrassment".

Families living with mental illness experienced much ridicule.15 To protect themselves from embarrassment, they often isolated themselves and the person with mental illness, or even hid the person from others, in order to maintain a certain image and social status in the community. As isolation increased, so did the struggle to live with, and overcome, the effects of the mental illness. Ubuntu means: "I am because you are, and you are because we are", umuntu ngumuntu ngabantu,24 so hiding a person with mental illness and isolating him or her defies the root principles of Ubuntu, of community and shared caring.

# Is Ubuntu fading?

Different reasons for Ubuntu fading in communities might relate to the challenges experienced in modern times. Communities in the urban and township areas are experiencing a change in cultural practices, due to changing perceptions of what is now considered to be a good or successful life.20 Communities are often held captive to notions of neo-liberalism that favour the individualism of the Western world, over the communalism that underpins Ubuntu lifestyles. Hence, youth, in particular, measure themselves according to what they own, and not how they contribute to the family and community. This influences how people value each other, and makes it difficult to trust people living in one's community.25

Other important contributors are high levels of unemployment and poverty. People are struggling to survive, and believe that they need to be looked after, and not look after others. Human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) further exacerbates the burden of care, contributing largely to "self first" thinking. In the face of extreme poverty, community members who are often paralysed by their problems, become disempowered and helpless. Crime in these communities, and gangs, also feed off the little that might be available in the houses of the poor, stretching limits of care.26

Although the sensitive and friendly spirit of Ubuntu was all but abandoned in some of these homes,27 Ubuntu sometimes shone through, even in difficult times.

An NGO participant and family members involved in the research study mentioned:

"I saw some neighbours bringing him back from the bus station, telling me that he told them that he was going to work... They know that he is sick".

"Yeah, we know each other, if you stop in one house and ask 'Do you know Sarah?', they will know where, even the young kids".

"I feel so happy, I do visit some people at the squatters, and some family I gave them three beds because they were sleeping on the floor".

The above responses illustrate the spirit of Ubuntu, of caring, helping, and being involved in one another's lives, in spite of the many hardships experienced by the community. It was evident that some people knew each other, and lived in friendship and harmony together. One of the participants reached out to those who she perceived as being more in need than herself, in spite of her high burden of care through looking after all her own children, as well as her brother with mental illness. Although the deinstitutionalisation of people with mental illness in South Africa was initiated in the 1970s,2 the development of adequate community programmes and alternative community services lagged behind, despite being recommended. In this regard, Lamb and Bachrach<sup>16</sup> highlight that deinstitutionalisation relates to changing the locus of caring for the family, as well as the service planning that is individually and culturally relevant, hospital care that is available when necessary, and involvement of persons with severe mental illness in their service planning, without preconceived plans being imposed on them, in order for continuity of care to be achieved. The responses do reflect the ideals espoused in these recommendations, but only reach the level of a small shift in locus of care.

An element of service planning, that is also culturally relevant, might include setting up client-friendly communitybased services to fulfil the needs of people living with mental illness and their families. This could serve as a bottomup approach, and help those with problems to become involved in their own plans for care.

Since Ubuntu was mentioned by participants when answering the core question concerning care in this study, it became the centralising theme of this article. The section that follows, is a discussion of how Ubuntu may guide the care of people with mental illness in the community. This will be achieved by defining community in relation to Ubuntu. The values of *Ubuntu* will be outlined, and how these may contribute to better managing people living with mental illness in the family and community.

# Possibilities embedded in Ubuntu

What is Ubuntu? Modi<sup>14</sup> argues that "Ubuntu is not just an African concept. It is a reality of humanity which modern people deny". Its values include respect, true love, honesty, compassion, humility and unity. Modi<sup>14</sup> also believes that in South Africa, communities must be transformed so that crime and cruelty can be replaced by peace and prosperity. Averweg<sup>28</sup> argues that *Ubuntu* is a philosophy and social approach on how to relate to others. He explains that within this world view, people can find fulfilment in their interaction with other people. The essence of *Ubuntu* is that a person will not only provide for himself or herself, but will also enable the community by sharing his or her own good fortune and wealth with others within it.

What is a community? Averweg<sup>28</sup> suggests that there are at least three understandings of the term "community". Firstly, community is geographically located; secondly, it involves a place of interest; and finally, it is a political entity. "Community" as a concept might also include specific social processes that produce different relationships that range in meaning and significance.<sup>28</sup> It is this latter concept of community that has relevance to the topic of caring for people with mental illness in the community. The authors believe that building a sense of community and reinstating the spirit of *Ubuntu* will improve the care of a person living with mental illness in the family and community. A caring community, that is part of the larger geographical community and society, may then infiltrate other sectors, thereby promoting national Ubuntu, caretaking and care giving.

# **Ubuntu values**

Poovan et al<sup>24</sup> explain that the central values of *Ubuntu* are survival, solidarity, compassion, respect and dignity. These need to be examined in order to promote their application;

### Survival

Survival refers to the ability of people to survive in the face of difficulty and hardship, not through self-reliance, but through "brotherhood and care".9 In the context of this research, families living with mental illness should not have to struggle alone with mental illness, extreme poverty, crime, and the effect of HIV/AIDS in the community.

An old mother should not lament:

"I don't know what will become of my boys (who are mentally ill)".

In a community that lives according to Ubuntu values, community members "develop a shared will to survive through ... personal responsibility, accountability, sacrifice, suffering, and the spirit of service".29 These characteristics can drive the caretaking of families living with mental illness. When the community is made aware of the daily struggles that families experience when coping with mental illness, it might be possible for family members to ask for assistance, instead of hiding, and suffering from lack of support. The human spirit in the community will allow families to be freed from stigmatisation. Survival is possible because the person with mental illness is regarded as a human being,30 with the same needs for respect and care, as anyone else in the community.

### Solidarity

The spirit of solidarity in African communities pertains to the combined efforts of individuals in serving their community. When the personhood of the African community member is entrenched in the identity of the community, a person is defined in terms of the community in which he or she is living.<sup>29</sup> Huxley and Thornicroft<sup>31</sup> note that people living with mental illness are among the most excluded in society. This exclusion occurs at different levels, from exclusion from participation in the workforce, to exclusion from the community's leisure activities. As solidarity includes bonds on an interpersonal, biological, and non-biological level, it is important for the person living with mental illness to participate in expressing these bonds of togetherness in the community. The togetherness can be expressed as singing, working, traditional dancing, storytelling, celebrating, performing rituals, and community living.29 Furthermore, assisting people with mental illness, by allowing them to do some work in the community, ensures that there is both support and protection from the community. According to participants in the study,15 people with mental illness have many skills, offering the community a rich variety of talent that can be used in community projects.

### Compassion

Compassion, as a value of Ubuntu, can assist people living with mental illness to be integrated and assisted in communal life, as this value describes the ability of African people to reach out in friendship to others, practising "humanism in a delicate and artful way".29 Weingarten32 refers to this spirit when describing how people, living together, may witness each other's lives, and how compassion allows one to be moved by another's story of pain and survival. By the act of compassionate listening and sharing in each other's life stories, respect is built, and the humanness and value of the person with mental illness is authenticated in the community. The friendship and care net can then also be cast wider to spread care giving as a joint undertaking and responsibility.

# Respect and dignity

This value is about respecting people living with mental illness as human beings or people living with problems like everyone else, allowing the person to be treated with dignity in the community. When affording the person his or her social place in the family and community, and when following the ukuhlunipa rules of respect, individual and community humanness is restored.



Although some people may struggle with daily living challenges, a need prevails to be respected as a "human", as spelt out in the following responses by persons and family members with mental illness:

"I am still who I am, even when you forgot who I am".

"I am not my illness".

"I want to be treated like everybody else".

These comments highlight the inherent need for dignity and respect, regardless of perceived worthiness or contribution in the family or community.

### **Recommendations**

This study did not specifically focus on Ubuntu, but its importance was strongly expressed. Future research could be dedicated to how families perceive and practise Ubuntu principles.

### **Conclusion**

Families living with mental illness experience many challenges in their struggle to recover from, and overcome the effects of mental illness. In a community in which Ubuntu is the underpinning philosophy and way of life, community members can become aware of these struggles. and assist in such a way that they become the support for, and protector of, persons living with mental illness. Ubuntu values, as discussed in this article, could be reinstated and revived in promoting the survival and recovery of families living with mental illness, and to reintroduce humanness in the community.

# **Declaration**

Some of this research has already been presented at local and international conferences by one or both authors.

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