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BARRIERS TO ACCESSING AND RECEIVING MENTAL HEALTH CARE IN EASTERN CAPE, SOUTH AFRICA

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ABSTRACT

The right to the enjoyment of the highest attainable standard of physical and mental health is enshrined in many international human rights treaties. However, studies have shown that people with mental disabilities are often marginalized and discriminated against in the fulfillment of their right to health. The aim of this study is to identify and reach a broader understanding of barriers to the right to mental health in the Eastern Cape Province in South Africa. Eleven semi-structured interviews were carried out with health professionals and administrators. The researchers used the Availability, Accessibility, Acceptability, and Quality (AAAQ) framework from the UN Committee on Economic, Social and Cultural Rights to structure and analyze the material. The framework recognizes these four interrelated and partly overlapping elements as necessary for implementation of the right to health. The study identifies eleven barriers to the enjoyment of the right to health for people with mental disabilities. Three categories of barriers relate to availability: lack of staff, lack of facilities, and lack of community services and preventive care. Four barriers relate to accessibility: lack of transport, lack of information, stigmatization, and traditional cultural beliefs of the community. Two barriers relate to acceptability: lack of cross-cultural understanding among staff and traditional cultural beliefs of staff. Finally, two barriers relate to quality: lack of properly trained staff and lack of organizational capacity. The results, in line with earlier research, indicate that the implementation of the right to health for people with mental disabilities is far from achieved in South Africa. The findings contribute to monitoring the right to mental health in South Africa through the identification of barriers to the right to health and by indicating the importance of building monitoring procedures based on the experiences and knowledge of staff involved in mental health care provision.

INTRODUCTION

The right to the enjoyment of the highest attainable standard of physical and mental health (from here on, the right to health) is enshrined in many international and regional human rights treaties, such as the International Covenant on Economic, Social and Cultural Rights (ICESCR); the Convention on the Rights of the Child (CRC); and the Convention on the Rights of Persons with Disabilities (CRPD); the African Charter on Human and Peoples' Rights (ACHPR); and the African Charter on the Rights and Welfare of the Child (ACRWC).[1]

The right to health includes both physical *and* mental health, thus:

> … efforts to recognize and uphold a human right to health must incorporate strategies to protect, respect, and fulfil mental health as well as physical health. Establishing and upholding affirmative mental health rights can fundamentally advance the dignity and welfare of persons with

mental disabilities, and, simultaneously, advance the recognition and development of the right to health generally.[2]

However, studies have shown that people with mental disabilities are often marginalized and discriminated against in their enjoyment of the right to health. [3,4] A number of barriers on both societal and organizational levels contribute to this, such as comorbidity, stigmatization, lack of affordable mental health services, and a general shortage of human resources for mental health care in many countries.[5]

Following the ground-breaking *World health report 2001* on mental health, issued by the World Health Organization (WHO), global initiatives have been taken to raise awareness of mental health and improve the status and health care of people with mental disabilities both in law and in fact, such as the CRPD and the WHO mental health Gap Action Programme (mhGAP).[6] In addition, many countries, including South Africa, have revised national laws concerning mental health care in the last decade.

The South African Mental Health Care Act was promulgated in 2004.[7] One of the main objectives of the Act is to regulate mental health care "in a manner that makes the best possible mental health care, treatment and rehabilitation services available to the population equitably, efficiently and in the best interest of mental health care users within the limits of the available resources."[8] As a means to reach this objective, the Act calls for the provision of mental health care services to be integrated into the general health services environment.[9] According to Draper, Lund, Kleintjes, et al., the Act was drafted through "an extensive consultation process, and has been praised for its human rights orientation and promotion of community-based care."[10] The Act explicitly aimed to adhere to human right standards. Unfortunately, it seems that the good track record in developing the Mental Health Care Act was not followed by an equally successful de facto implementation of the right to health.[11]

Extensive research has been conducted on the right to health, while less so on the barriers to care.[12] In a South African setting, studies have shown that various barriers exist in the implementation on the right to health for people with mental disabilities.[13] For instance, in a systematic review of mental health services research in South Africa, Petersen and Lund indicate that there has been significant progress in the decentralization of mental health service provision. However, they still find substantial gaps in service delivery, mostly due to insufficient resources to adequately support community-based services.[14] Their review points to barriers to mental health care delivery such as the decreasing number of mental hospital beds; early discharge due to shortage of beds; dehumanizing treatment and human rights abuses in psychiatric institutions and general hospitals; insufficient training of medical staff; lack of cooperation between traditional healers and modern medicine; stigmatization; and comorbidity. However, few studies have been based on in-depth interviews with staff in mental health care services (health professionals and administrators) and their perceptions of barriers to the right to mental health. The aim of this study is to identify and reach a broader understanding of barriers in implementing the right to mental health as experienced by health professionals and administrators in the Eastern Cape Province in the Republic of South Africa.

METHODOLOGY

Data collection

Following WHO guidelines, the mental health care system in South Africa provides mental health services in a decentralized model, integrating them into the primary care system. Primary health care clinics serve local communities. Some of these clinics have a small psychiatric unit; some also have outreach mobile teams serving remote areas. In the general hospitals, there are 72-hour emergency observation units to decrease unnecessary admissions to tertiary-level (specialized) hospitals. This study was carried out in semi-urban (Nelson Mandela Bay) and rural (Kirkwood) areas of the Eastern Cape Province in South Africa. The Eastern Cape Province is the poorest of the nine provinces in South Africa: HIV prevalence is high (26%), community-based care is scarce, and few nongovernmental support groups exist.[15] Mental health review boards are in place with the aim of upholding human rights for mentally ill patients.

Eleven semi-structured interviews with 12 mental health care stakeholders from the health care sector were conducted. One interview was conducted with the participation of two respondents at the same time. **Seven respondents were health professionals** at tertiary and district hospitals and primary healthcare services (three chief psychiatrist and four head nurses), while five respondents worked in public administration and were responsible for mental health coordination at the regional and district level. The respondents were selected as they are stakeholders actively taking part in, and perceived to have an influence on, the upper-level implementation of mental health services in the Eastern Cape Province. Eight of the respondents (chief psychiatrists and public administration staff) considered themselves as involved in decision making about and implementation of mental health policies on a "higher level"— actively taking part in both constructing and implementing policies. The remaining four respondents (head nurses) were only responsible for managing health care services in practice. The health care services and public administration units were selected by the research team at Nelson Mandela Metropolitan University as part of a larger research program.[16] Of the 11 respondents, eight had worked 10 to 15 years in the South African health sector, two respondents for a shorter period (three to five years), and two of the respondents had been working in the health sector abroad for a longer period and recently returned to South Africa. More than half of the respondents were of Xhosa and colored background. Two of the respondents were male and 10 female.

The interviews were conducted in November 2011 at the workplace of the respondents (with two exceptions). Each interview took approximately 45 to 60 minutes and was recorded and later transcribed. The respondents at the different primary, secondary, and tertiary health care facilities were contacted and agreed to participate before the interview process started. Informed consent of all respondents was obtained. No names or identifying details of health professionals or mental health coordinators have been used when reporting the results. The study was approved by the Nelson Mandela Metropolitan University Research Ethics Committee (Human), Port Elizabeth, H10-HEA-NUR-002 and received permission from the District Manager of the Cacadu Health District, Province of Eastern Cape Health and the Nelson Mandela Bay Health District. The interview guide addressed the categories of availability, accessibility, acceptability, and quality (see analytical framework below) in relation to the right to health for people with mental disabilities and focused on perceived barriers to the achievement of the right to health. The semi-structured interviews allowed for both consistency in the data collection and freedom for the respondents to elaborate on the topics. After conducting approximately nine interviews, main themes started to reappear in the empirical material indicating that data saturation had occurred and the main categories and themes had been collected.[17]

Data analysis

The material from the interviews was systematically coded using the tree model to identify phenomena that act as barriers to the implementation of the right to health and group these into overarching categories.[18] These categories were then structured in accordance with the analytical framework (see below). Approximately 20% of the material was re-coded in a later phase of the research process to ensure reliability. Since the aim of the study is to identify and reach a broader understanding of barriers in implementing mental health services, it is not the number of respondents addressing the same category or theme that is of interest, but the different categories or themes in themselves evolving from the interviews.[19] The presentation of identified barriers in the result section contains typical or illustrative quotations. Each of these is representative of the category it is meant to illustrate. From the perspective of empirical analysis, it is not the quote per se that is of interest, but the phenomenon it illustrates.

Limitations

This study focuses on two areas in the Eastern Cape Province, one of the poorest provinces in South Africa. Hence, the result may not be generalizable to other provinces or contexts. Furthermore, "top-level" stakeholders (chief psychiatrists, head nurses, and mental health coordinators in the public administration) were interviewed in the study. While these are important actors in the implementation of the *Mental Health Care Act*, other professionals such as

"ordinary" and assistant nurses and other health personnel interpreting and carrying out the Act in the daily work with patients are not included in the study. Also, the patients themselves would be important actors to include to fully understand barriers to mental health.[20]

ANALYTICAL FRAMEWORK

In order to structure the analysis, we use the AAAQ framework as it is presented in the UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 14, The Right to the Highest Attainable Standard of Health.[21] The framework consists of four interrelated and overlapping elements. *Availability* focuses primarily on the physical aspects of health services (such as hospitals, clinics, trained medical staff, medicines, clean water, sanitation facilities) and if these are available in sufficient quantity. This element of the framework also includes whether there are health strategies and programs such as national public health plans, preventive public health strategies, and health promotion activities. *Accessibility* requires that health services are accessible to everyone and has four overlapping dimensions: non-discrimination, physical accessibility, economic accessibility (affordability), and information accessibility (the right to seek, receive, and impart information on health). *Acceptability* requires that health facilities, goods, and services respect medical ethics and the culture of individuals, minorities, peoples, and communities. Health services must also be gender sensitive and mindful of needs at different stages of life. *Quality* requires that health care services be scientifically and medically appropriate, that health professionals be trained and skilled, and that drugs, medicines, and hospital equipment be scientifically approved.[22]

Arguments could be made against using the AAAQ framework for this study, since it was developed in General Comment No. 14 to the ICESCR, a human rights convention that South Africa has not ratified and is therefore not legally bound to implement. However, South Africa is a signatory state of the ICESCR implying that the state has an intention to ratify the instrument. South Africa is therefore obliged to "refrain from acts which would defeat the object and purpose" of the treaty.[23] Even if this argument were to be challenged, South Africa is legally bound by a number of other treaties that also enshrine the right to best attainable physical and mental health (for instance, CRC, CRPD, ACHPR, and ACRWC).

In addition to the AAAQ framework, the CRPD will be used to discuss the result of the study. The CRPD tasks state parties to identify and remove barriers for implementation of the convention to protect the rights of people with disabilities, including individuals suffering from mental disabilities. In other words, the convention supplements the AAAQ framework by further developing state obligations to fulfill the right to health.

RESULTS

Availability

Three categories of barriers relating to availability were identified in the study: 1) lack of staff, 2) lack of facilities, and 3) lack of community services and preventive care.

Lack of staff, especially lack of physicians and psychiatrists, is raised as a main concern by the respondents. Nurses often end up running the daily work at the health clinics without the expertise of physicians. The scarcity of physicians raises the issue of the hierarchical order within medicine and health care institutions, where physicians are the only professionals with the status and right to decide on a number of issues regarding the medical treatment of patients. Thus, lack of staff—more precisely lack of physicians—in combination with the hierarchical order in health care institutions is a barrier to health care.

A different set of barriers identified by the respondents relate to the *lack of facilities*. Respondents highlighted that integrating mental health care with primary health care has resulted in facility problems—for instance, a shortage of rooms. According to the respondents, patients suffering from mental disability are more seriously affected by this shortage:

> We sit with limited space and then, say when a patient comes here immediately for help and it's during clinic hours, we cannot see that patient as a new case because a new case will take you about an hour. (Respondent C)

The respondent above stated that mental health patients might need longer sessions in the initial care-seeking meeting, lowering the efficiency of staff and of room usage. Other respondents referred to cases where patients are asked to wait until closing time for initial care since rooms are available then for a longer period of time. Also, respondents raised the issue of mental health patients not wanting to talk about their health problems in front of other patients, for instance in the waiting room or in an open space. Thus, the shortage of secluded rooms concerns the respondents: they consider the availability of such rooms as important to respect the rights of the patients.

Another related problem is the virtual nonexistence of specialized facilities for mental health care, one of the more critical being the lack of facilities for children under the age of 15 requiring inpatient treatment. Those who are suffering from multiple diagnoses, in particular those who suffer from both substance abuse and mental disability, are also highly vulnerable:

> The service for substance abuse is dismal. So people who are on drugs and things like that get dismissed. They go to the clinic and the clinic sister says, "No—sorry, your problem is drugs, we don't treat drugs here." Even if you might have schizophrenia, or depression, or whatever. (Respondent K)

In the case above, there is a lack of facilities which can handle multiple conditions. This could either lead to lower quality in treatment by only treating one diagnosis at the time or situations where the patients do not receive treatment at all.

Related to lack of facilities is a *lack of community services and preventive care* and the impracticability of following up and treating patients in the community. This service is especially important for patients returning home after periods in treatment, for instance at a mental institution, or for patients who have been prescribed medication and need help to establish routines for taking it. The respondents discussed the risk of relapse into illness as a consequence of the lack of community services. They also raised the issue of the lack of prevention programs and identi-

fied various needs for preventive work. Respondents commented on what they perceive as a tendency by policy makers and politicians to focus on emergency care and primary health care while neglecting long-term community care.

Accessibility

Four barriers identified in the study relate to accessibility: 1) lack of transport, 2) lack of information, 3) stigmatization, and 4) traditional cultural beliefs of the community.

Many patients (and their relatives) lack access to vehicles of their own or affordable public transportation, forcing them to walk or hike to health service facilities if they want care. Thus, *lack of transport* might be a reason for patients not to access health care at all. However, the respondents also elaborated on the role of the South African Police Service (SAPS) when it comes to transportation of mentally disabled patients:

> … and the only transport, if the family cannot get this person to the casualty department or the hospital in their own private transport, is the SAPS, but that is also a problem because in the mental health act there is a section that states that, if the person is a danger to himself or to the community, it is the duty of the SAPS to retain this person or take him to the nearest safe. They are going to put him in the back of a van up to casualty where he's taken out of the police van. So what happens to the rights of the clients? (Respondent A)

Patients and relatives are referred to the SAPS for transportation to the emergency or casualty department. This is considered problematic by the respondents, especially in the case of aggressive psychotic patients, who might end up retained, in arrest, and/or handcuffed. The quote above implies conflicting police duties: on the one hand, the duty to fulfill the right of the patient to access care (transportation), and on the other, the duty of the SAPS to retain persons in danger to themselves or the community. The respondents also argued that the SAPS suffer from a lack of training in managing patients with mental disability.

Lack of information is identified as a major barrier in the interviews. For instance, respondents argued that there is a lack of information and knowledge concerning the treatability of mental disability in society. The general public is often not aware of lesser known mental health conditions and therefore they do not seek mental health care services. The respondents see this partly as a result of policy makers, politicians, and health reforms being focused on certain mental-health-related problems but not others. According to the respondents, there is awareness in society of psychosis as a mental disability affecting men in combination with substance abuse, showing itself through aggression and violence. However, depression and anxiety disorders, more often associated with women than men (compared to psychosis), is less visible in the public sphere.

> Anxiety disorders, I think, are grossly underestimated and not diagnosed at all. Again, they come to our attention if they have a panic attack or something like that, there must be, literally, hundreds and thousands of people out there with post-traumatic stress disorder, the amount of assaults and family violence, sexual trauma out there, I can just assume is staggering. (Respondent D)

Another information-related barrier concerns medical treatment and the use of prescribed drugs. The respondents described situations in which patients are reluctant to take their medicine due to side effects (such as impotence) or due to the fact that the patients do not trust or believe that the medication will actually help. In both cases, time to educate the patient about the medicine and possible side effects is considered important by the respondents, but lacking due to shortage of staff.

Another barrier of concern for the respondents is the *stigmatization* of people with mental disabilities by their family, friends, and society. Here the respondents distinguished between different ethnic communities in South African society. They considered prejudices toward people with mental disabilities especially present in the Xhosa and the colored communities. However, people within the white community also suffer from stigmatization due to mental disability. Such stigma discourages people from seeking care for mental-health-related problems. As the respondent below explains:

> When people come to the psychiatric clinic, people that are ignorant about mental health will tell them, "Ah, you are mad, you are crazy, you are a nut and you are this and you are that," so at the end of the day patients don't feel like coming here. (Respondent C)

This kind of stigmatization described by the respondents affects patients seeking access to care. However, stigmatization also affects the willingness of family members to bring mentally disabled persons to health care institutions. The new *Mental Health Care Act* is seen as one factor contributing to this situation. As discussed previously, patients suffering from mental disability are accessing care alongside physically ill patients. As a consequence, family members taking mentally disabled persons to health care facilities might run in to other members of their community and thereby risk stigmatization by association, making them reluctant to put themselves in this situation. The lack of secluded rooms adds to this problem as the mentally disabled and their relatives are mixed with other patients in the waiting rooms.

Another barrier identified in the interview material is *traditional cultural beliefs of the community*. According to the respondents many patients of Xhosa background consult with, or are taken by their family to, a traditional healer when they show signs of mental disability. This is particularly common if a person is suffering from psychosis. The reason for this is the culturally specific belief that such a person is either called to become a traditional healer (*ukuthwasa)* or possessed by evil spirits or demons (*amafufunyana*).[24] However, ifthe treatment does not improve the patient's condition, he or she might eventually seek out a public health clinic, sometimes accompanied by family members or even by the traditional healer. From the perspective of the respondents, this delay in treatment is considered to be a barrier to care. In some cases people are obstructed from accessing treatment:

> They tend to go to traditional healers first and what was amazing to me, was that a person could be really quite severely ill but he would get a lag time

of two to three years before the patient comes to see you and that's relatively common. (Respondent E)

The respondents also state that patients suffering from psychosis often consult traditional healers, whereas patients with mood or anxiety disorders are more likely to seek out public health care services. In other words, people suffering from mental disabilities seem to access health care to different extents due to cultural conceptions of particular mental illnesses.

Acceptability

There are two barriers related to acceptability identified in this study: 1) lack of cross-cultural understanding among staff and 2) traditional cultural beliefs of staff.

Despite the concerns expressed above when discussing cultural belief systems and their effect on access to health care for mentally disabled people, the respondents also expressed concerns about the *lack of cross-cultural understanding among staff*. This constitutes a barrier since staff not able to understand the culture of individuals or communities might not be able to give adequate care or equal care to all patients.

> As a white nurse working with a black person I don't understand some of the cultural background, then how am I going to understand their need to consult the traditional healer or how do I understand when they talk about these voices or these visions. (Respondent I)

The respondents discussed the possibility of closer communication or contact between psychiatrists or nurses and traditional healers as a way to enhance the cross-cultural knowledge and understanding among staff. Also, the "double competence" of some nurses and psychiatrists is recognized as helpful in removing such barriers, since they serve as "translators" between traditional cultural medicine and biomedicine. However, the respondents also consider the presence of *traditional cultural beliefs among the nursing staff and physicians* as a barrier to care.

> We had a junior doctor … you could see that he had a huge problem trying to balance what he believed, in spite

of being a doctor, he held a lot of traditional beliefs and it was very difficult for him to balance that with what psychiatry is saying in terms of what is treatable, what should be done about a psychotic patient. (Respondent E)

While the respondents consider closer cooperation between traditional medicine and biomedicine as a possible means to enhance cross-cultural understanding and knowledge among staff, they are also hesitant about health professionals holding traditional beliefs and consider that these might be a barrier to patients receiving the right treatment.

Quality

The study identified 1) lack of properly trained staff and 2) lack of organizational capacity as further barriers to mental health care.

The decision to incorporate mental health care into primary care in accordance with the *Mental Health Care Act* has resulted in some patients being incorrectly referred in the health care system. The respondents point to the *lack of properly trained staff* admitting the patients at primary level care as the main reason for this shortcoming:

> It can work if the total system, the total primary care is well oiled, well managed, well run, it must be [a] lean and mean operation, which mean[s] people must know what they are doing. There needs to be in place the correct skills at all levels. … So, now very often you find that in primary care the people are all up-skilled to manage diabetes and hypertension and know how to do a blood pressure, but do they really know how to cope or manage a psychotic patient? Do they really know how to manage the patient in a multidisciplinary holistic context? And my answer to that is no. (Respondent A)

Incorporating mental health care into primary health care without having sufficiently educated staff is seen as creating barriers to mental health care since patients suffering from mental disability might not get diagnosed or admitted in the right way.

Furthermore, the respondents point to imbalance in psychiatric training among staff as a barrier. While the nurses may have psychiatric training, physicians dealing with mentally disabled people usually do not:

> We don't have community mental health teams. You just have a nurse with psychiatric training. … What then happens is that, that nurse has medical cover from a doctor who doesn't know much about psychiatry and what will then happen is, the nurse with more psychiatric experience ends up having to refer to a doctor who doesn't have much psychiatric experience. (Respondent E)

Again the hierarchical order of the medical system (see discussion in availability) is identified as a problem, potentially worsening the effects of the shortage of psychiatrists or adequately trained physicians to deal with the needs of patients with mental disabilities. Respondents did note that outreach service can reduce the problem with lack of staff and undereducated physicians. In outreach services, psychiatrists go to different clinics in the community on a regular basis (twice a month) to provide extra assistance which allows nurses to manage patients in the interim.

The respondents recognize and support the aim of the *Mental Health Care Act* as a means to enhance the rights of mental health patients and to raise the quality of care. However, as seen above, the respondents also highlight the gap between the *Mental Health Care Act* and the practicalities and realities in implementing the Act. They are concerned with the structural failure in delivering mental health care:

> It's a matter of lack of organization. … Nobody is sure who is responsible to actually control the whole thing. It's just that total disjointed disaster. (Respondent K)

Since the aim of this study is to identify barriers to receiving mental health care in the Eastern Cape, much of the discussion with the respondents related to this topic of organizational capacity. The lack of resources, such as staff, facilities, and transport, were mentioned and referred to as a problem of organizational capability. The respondents thought that a more effective and professional administration would deal with these barriers more efficiently. However,

the respondents also commented on global inequalities when discussing the barriers South Africa faces when delivering mental health care:

> South Africa is not a first-world country; we have limitations of staff and resources. Therefore, you have to look at what is practically necessary to do and still protect the rights of the mental health care user. (Respondent A)

Statements such as the quote above acknowledge that South Africa might lack the resources needed to deal with some of the barriers identified in the interviews. This type of quote brings to the fore the issue of progressive realization of social and economic rights, which will be discussed at the end of the next section.

DISCUSSION

The *South African Mental Health Care Act* integrated mental health care services into the general health services environment. This has, at least on paper, evened out the differences in physical availability of clinics between patients seeking physical health care and those seeking mental health care. Hence, the reform can be seen as a step forward in the recognition that physical and mental health are two sides of the same coin, strengthening, at least in theory, the right to health for people with mental disabilities. However, physical availability of health care institutions is not enough to fully respect, protect, and fulfill the right to health. The AAAQ framework extends beyond mere availability issues. It also emphasizes accessibility, acceptability, and quality. With the AAAQ in mind, this study has identified 11 types of barriers to the enjoyment of the right to health for people with mental disabilities. This section discusses some of the complex ways in which these barriers interact and reinforce one another, as well as some of the implications for compliance with the CRPD.

Lack of staff—in particular, lack of physicians—is identified as a general issue for the enjoyment of the right to health in South Africa.[25] However, this problem is particularly acute for people with mental disabilities as shown by the related barrier *lack of properly trained staff*, including the huge shortage of psychiatrists who can properly identify and treat people with mental disabilities. If this imbalance is not rectified, the situation could be considered a violation of the CRPD, which obligates states to provide

persons with disabilities the same range, quality, and standard of health care provided to the non-disabled, and to provide health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention.[26]

Lack of facilities is another general problem interfering with the enjoyment of the right to health. According to the respondents, this problem has become more acute because recent reforms integrated mental health care with primary health care without adding the resources needed to expand those facilities to accommodate more patients. Again, the general problem of shortage of rooms (including secluded rooms) is particularly problematic for people suffering from mental disabilities due to both the time needed for initial consultations and the sensitive nature of their medical problems.

Another issue raised by the respondents is the lack of specialized inpatient treatment facilities for children. Although not further developed by the respondents in this study, this situation is particularly worrying, since children with mental disabilities belong to two particularly vulnerable groups at the same time whose situation must be considered from an intersectional perspective. From a human rights perspective, the lack of treatment facilities for children and the lack of properly trained staff to deal with children's mental disabilities become violations of the right to health enshrined in both the CRC and the CRPD.

A further challenge discussed by the respondents is a lack of facilities to cater for the needs of people suffering from multiple conditions, such as mental disability and drug abuse or HIV and mental disability. Earlier research has shown that patients with multiple conditions where mental disability is one of the medical conditions are particularly vulnerable.[27] It is interesting to note that respondents do not refer to HIV as a barrier outside this context considering the high rate of HIV in South Africa and the Eastern Cape province. Related to the barrier *lack of facilities* for people with comorbidity is, again, the *lack of properly trained staff* that can identify comorbidity.

Lack of transport is identified as a reason for patients not accessing health care in general, but again the problem is particularly acute for patients suffering from mental disabilities, the most obvious being in cases of psychosis. As mentioned previously,

the SAPS is responsible for transporting patients suspected to suffer from a mental disability to the nearest emergency or casualty department. However, aggressive psychotic patients might instead end up in police custody or arrive at medical clinics in handcuffs, partly due to a lack of knowledge and proper training of the police. The results of the study point to the *lack of properly trained staff* within the police force as a barrier to the enjoyment of the right to health for patients suffering from mental disability, which highlights that health care services cannot be seen as the sole responsible sector for the implementation of the right to health. There is also a need to focus on other sectors in society, such as the police, and collaboration or partnership between different sectors when evaluating and implementing the right to health.[28]

No less than five barriers have been identified relating to information and knowledge concerning mental disability. The first of these is *lack of information* and knowledge among the general public concerning both the existence and treatability of certain mental disabilities that acts as a barrier preventing people from seeking medical help. The respondents note that people (most often women) suffering from mood and anxiety disorders are at a higher risk of not receiving adequate treatment as their symptoms are less obvious than for other mental conditions such as psychosis (most often men). Earlier studies partly support this position. Seedat, Williams, Herman, et al. show a high level of unmet need for South Africans with common mental disorders, such as mood, anxiety and substance abuse. However, partly in contrast with the views of the respondents, Seedat, Williams, Herman, et al. demonstrate that more women than men receive treatment, mostly due to a higher number of women with mood and anxiety disorders, and fewer women with substance abuse disorders. This might be a result of men with psychosis initially turning to traditional leaders, while women with mood and anxiety disorders, if recognized, turn to public health care facilities.[29]

People with mental disabilities also lack knowledge about the side effects and usage of prescribed medicines, which hinders their trust in these drugs and the effective treatment of their diagnosis. The time needed for medical staff to educate patients concerning these issues is scarce and relates to both *lack of staff* and *lack of properly trained staff*. *Lack of community*

services also touches upon the issues of information and knowledge. Community services are important for preventive care and information about mental disabilities as well as provision of care (such as medical prescription and rehabilitation) for formerly institutionalized patients. Earlier research by Moosa, Jennah, and Vorster, for instance, raises similar concerns and concludes that community psychiatric services fall short of what is required by South African legislation and policies.[30]

Another barrier relating to information and knowledge is *stigmatization* due to cultural perceptions of mental disability in society. People suffering from mental disabilities run the risk of being ridiculed, abused, and excluded by society. The extent and form in which stigmatization shows itself varies between cultural groups, but is nevertheless present in all sectors of society, meaning that people with mental disabilities, and friends and relatives of such persons, might be reluctant to seek help from health care institutions.

Another barrier identified in the interviews is the consequences of certain *traditional cultural beliefs of the community*. The respondents argue that some cultural perceptions and understandings of mental disabilities within the Xhosa community—particularly psychosis—make patients inclined first to seek the help of traditional healers rather than visiting a medical clinic. Practices associated with cultural perceptions pose a particularly interesting problem from a human rights perspective. On the one hand, according to the UN CESCR's General Comment No. 14, "health services should be culturally appropriate, taking into account traditional preventive care, healing practices and medicines."[31] On the other hand, states are also obliged to "discourage the continued observance of harmful traditional medical or cultural practices."[32] The CRPD goes even further and obligates states to "take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities."[33]

Earlier research shows that traditional healers may play an important role in addressing mental health care needs in South Africa by offering cultur-ally appropriate treatment.[34] Furthermore, a recent study made in Uganda by Abbo, Okello, Musisi et al. "suggests that there may be some positive effects for patients with psychosis who combine both biomedical services and traditional healing."[35] In addition, in certain settings traditional healers are more accessible than biomedical forms of mental health care.[36] However, since traditional healing practices vary immensely, more research on the subject in local contexts is needed in order to establish whether particular traditional medicine and practices contribute positively or negatively to the treatment of people with mental disabilities.

The respondents in our study expressed concern that some patients might not receive adequate care for years due to seeking and receiving treatment from traditional healers, rather than from public mental health services. Meanwhile, the respondents acknowledge the impact of traditional beliefs on society and would like to see a closer cooperation between traditional medicine and biomedicine, for instance, between health professionals and traditional healers. However, the respondents are ambivalent in this regard. When addressing *traditional cultural beliefs among staff* they again expressed concern that some patients might not receive adequate care due to lack of properly trained staff. Thus, the respondents make a distinction between traditional beliefs in the community (among patients, family members, and traditional healers) and traditional beliefs among staff. They recognize the importance of communication between the two "belief-systems." However, they are skeptical toward staff holding traditional beliefs within the health care sector.

Lack of organizational capacity is identified as a barrier to the enjoyment of the right to health. According to the respondents, the insufficient and ineffective organization of the health sector is an overarching problem in the implementation of the *Mental Health Care Act*. The respondents also point to the inefficient use of available resources as a result of ineffectual administration. Community services are critically neglected: the respondents hold mental health coordinators and policy makers responsible for prioritizing emergency care and primary health care at the expense of community services.

All in all, the respondents point to a constant lack of resources as shown in the discussion above. They also recognize the global inequalities that affect South Africa's capacity to deal with barriers to the right to health. This raises the question of what progressive realization of human rights means. The term "progressive realization" is mainly used in the context of economic, social and cultural rights, such as the right to health. However, progressive realization does not mean that a state can neglect the obligation to fulfill those rights of "meaningful content."[37] A "minimum essential level" of each right must be fulfilled; retrogressive measures taken against their fulfillment are not permissible; and states have an obligation "to move as expeditiously and effectively as possible" toward their full realization.[38] Furthermore, despite the word "progressive," there are obligations of immediate effect for socioeconomic rights, such as the "obligation *not to discriminate* between different groups of people in the realization of the rights in question."[39] The UN CESCR's General Comment No. 20 explicitly mentions health status (in which it includes mental health) as a prohibited ground for discrimination.[40] In other words, equal attention must be put on mental and physical health care when implementing the right to health.

CONCLUDING REMARKS

This study, as well as earlier research, shows that the implementation of the right to health for people with mental disabilities is far from fulfilled, even at a minimum level, in Eastern Cape Province, South Africa. The *Mental Health Care Act* can be considered a positive move forward by South Africa to fulfill its obligation toward the full realization of the right to health. However, developing laws and regulations for the fulfillment of human rights is only one of many steps on the road to actually fulfilling state obligations. This study makes evident the usefulness of the AAAQ framework in monitoring the implementation of the right to health. In addition, this paper demonstrates the usefulness of the framework for study design and for structuring and presenting study results. Finally, this research shows the importance of building monitoring procedures that include the experiences and knowledge of staff involved in actual health care provision.

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