

# “They Had to Catch Me Like an Animal”: Exploring Experiences of Involuntary Care for People with Psychosocial Conditions in South Africa

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## Abstract

Protecting the rights of people with psychosocial conditions is an important and controversial global aim, particularly in light of multiple calls for reduced coercion catalyzed by General Comment 1 of the United Nations Committee on the Rights of Persons with Disabilities, which stipulates the replacement of substituted care with supported care. Responding to this and other global calls for reduced coercion is complex globally but can entail particular challenges in developing countries, where resource shortages and environmental barriers are sometimes a significant factor in how people with mental conditions experience involuntary care and encounter limitations to their autonomy. To better understand these complexities, our study explored experiences of involuntary care among people with psychosocial conditions in South Africa. Participants described varying degrees of coercion within involuntary care and found that different approaches from professionals when they were in crisis significantly impacted their illness experience, including their ability to make decisions and feel dignified. Participants' reports include variable feelings and embodied experiences of coercion in different forms and degrees, ambivalence about compliance and resistance while being treated against their will, and gray areas between conventional separations of autonomy and paternalism. On the whole, our analysis troubles binaries about the use or disuse of involuntary care and illustrates the complexity of participants' experiences and views of coercive intervention, which could hold multiple possibilities for both care and autonomy.

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## Introduction

People with psychosocial conditions continue to face many barriers that can constrain their well-being and make access to health care and service provision difficult, particularly in developing countries.<sup>1</sup> The 2017 report on mental health and human rights issued by the Special Rapporteur on the right to health calls for a paradigm shift from biomedical approaches that are deficit-based and locate illness within the individual, toward a human rights-based approach that considers the social determinants of mental health.<sup>2</sup> The report also stresses the importance of prioritizing the voice of people with lived experience of psychosocial conditions, reducing negligence, and challenging assumptions that “mental health interventions always require pharmacological and psychological treatments.”<sup>3</sup> The emphasis on zero coercion forms part of a wider challenge to coercive care, exemplified in the adoption of General Comment 1 by the United Nations Committee on the Rights of Persons with Disabilities in 2014, which stipulates that all forms of substituted care (including involuntary and assisted care) for people with psychosocial conditions should be replaced by supported care that is “in the objective ‘best interests’ of the person concerned.”<sup>4</sup> The sentiments of General Comment 1 are further reiterated in the World Health Organization’s *Guidance on Community Mental Health Services: Promoting Person-Centred and Rights-Based Approaches*.<sup>5</sup> Some mental health care theorists and practitioners have expressed concern regarding this approach, worrying that emphasis on lack of coercion and on will and preferences may lead to consequences that are not in the long-term interests of people with psychosocial conditions. Debate surrounding the use or prohibition of involuntary care creates the potential impression of a binary of opinions regarding this issue.<sup>6</sup> As Michael Stein et al. note, the complexities surrounding provision for people with psychosocial conditions may be conceived of as moving between two paradigms, from a more paternalistic approach to one more universally focused on individual autonomy.<sup>7</sup>

To consider these global calls for reduced

coercion, *Health and Human Rights Journal* held a roundtable discussion in 2022 considering the impact of the Special Rapporteur’s report on mental health.<sup>8</sup> Many participants in the discussion praised the report for being a progressive and necessary measure in safeguarding the rights of individuals with psychosocial conditions, while emphasizing the importance of ensuring that responses also foster a community-oriented approach to human rights.<sup>9</sup> Faraaz Mahomed, South African speaker and technical advisor at UNICEF, used the platform to emphasize the 2015 Esidimeni scandal in South Africa, where 144 people housed at psychiatric facilities lost their lives due to neglect and starvation.<sup>10</sup> In the context of such crises, it is particularly important to understand and explore the voices and experiences of people with psychosocial conditions as they navigate the health care system in the country.

One key aspect of community- or rights-based approaches is understanding the views and challenges faced by people with psychosocial conditions themselves, including how people with psychosocial conditions experience coercive care in context. There are few qualitative studies exploring how people with psychosocial conditions in South Africa understand and experience involuntary care, particularly in the context of the General Comment 1 paradigm shift.

To contribute to this research, we conducted a phenomenological analysis of people with psychosocial conditions’ experiences of involuntary care. We interviewed participants at various psychosocial rehabilitation centers in South Africa. Considering our theoretical frameworks focusing on phenomenology of illness and relational capacity, we were particularly interested in two things: first, the extent that participants felt that involuntary care can cause harm or good, and second, how participants’ experiences of coercion and different forms of support could impact the mental capacity of people with psychosocial conditions. We also considered how and in what ways participants’ experiences and opinions about care were relational.

## Coercive care and General Comment 1

The Convention on the Rights of Persons with Disabilities is a binding legal document with over 160 signatories and the support of numerous disability groups.<sup>11</sup> General Comment 1's interpretation of the convention, in favor of supported care and rejecting substituted care, is globally influential and marks a radical departure in thinking from conventional "functional models."<sup>12</sup> Functional models are based on the notion that people with psychosocial conditions are at risk of losing their mental capacity to cognitively comprehend information about their condition and make decisions about treatment. On such occasions, a "substitute" may be appointed, who makes decisions in the best interest of the person with a psychosocial condition and promotes the restoration of their autonomy.<sup>13</sup> Safeguards often exist in cases of substituted interventions to ensure the use of least force for the shortest time possible to promote the return to health and decision-making autonomy of people with psychosocial conditions.<sup>14</sup> Nevertheless, functional models require that the right to autonomy of a person lacking mental capacity be suspended in the interests of that person's recovery.

General Comment 1 states that suspending a person's universal legal rights in this way violates article 12 (equal recognition before the law) of the Convention on the Rights of Persons with Disabilities and therefore unfairly discriminates against people with psychosocial conditions.<sup>15</sup> The general comment also challenges functional care by refuting the idea that loss of mental capacity is an adequate precondition for treating a person against their will. It states that "perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity."<sup>16</sup> The general comment recommends supported care as a replacement, in which a person is offered environmental and systemic support but has their decisions, or "will and preferences," fully respected regardless of their psychosocial condition or measurements of their mental capacity.<sup>17</sup> Further, the general comment emphasizes that stereotypes about people with psychosocial conditions that they lack mental capacity and therefore cannot exercise their legal

capacity are discriminatory. Extending from this, the presence of involuntary care could be said to discursively perpetuate this belief.<sup>18</sup> Accordingly, the only way to reduce involuntary care is to abolish it. The debate is a complex one, and people with psychosocial conditions straddle both the risks of unnecessary coercion and the impacts of illness if left untreated.

Coercion itself has various definitions—ranging from interpersonal influence to physical restraint—which serve as "treatment pressures" facilitating psychosocial or medical intervention for a reluctant patient. Involuntary care is one form of coercion, though the extent to which a person with a psychosocial condition feels coerced within involuntary care can also lie on a continuum, as becomes evident in our findings and discussion.<sup>19</sup>

A 2018 report of the Special Rapporteur on the right to health emphasizes that questions of human rights and the value of coercion are embedded in sociopolitical and historical contexts.<sup>20</sup> Read, Sakyi, and Abbey reiterate this sentiment by highlighting that there are great challenges to implementing General Comment 1's recommendations in developing countries, where stigma and insufficient resource provision remain an obstacle.<sup>21</sup> They also argue that tensions can arise between universalist human rights and local beliefs about mental disorder, which can make the prohibition of involuntary care precarious.

In this context, it is especially interesting to consider how an overarching set of international guidelines, such as the Convention on the Rights of Persons with Disabilities and General Comment 1, are experienced in different parts of the world by the people whose lives they are designed to improve. In this paper, we focus on people with psychosocial conditions in South Africa, a country with complex legislation but rather limited access to mental health care services and supports.<sup>22</sup> As is clear, questions surrounding coercive care exist in the contextually diverse interface of social relationships, manifesting both locally and in more universal and institutional rhetoric. The voices of people with psychosocial conditions require more representation and consideration, particularly

where putative policy and ideological decisions surrounding the use of involuntary care can eclipse contextual complexity.

## Theoretical framework

This research is located within a phenomenological paradigm and draws theoretical guidance from Havi Carel's *Phenomenology of Illness* and Camilia Kong's phenomenological work on "capacity in relationship."<sup>23</sup>

Carel's *Phenomenology of Illness* describes the life-altering experiences of illness holistically through the experiences of the person. Illness is associated with a breakdown in the habitual body, which can result in a variety of experiences, including losses in continuity, feelings of objectification and re-subjectification in the eyes of the self and other, loss of recognition, and loss of tangible relationships with the world.<sup>24</sup> When we use the term disability in this paper, we are most closely referring to the social model, where environmental circumstances can present barriers to the functioning of people with underlying "impairments." A person's recounted experience of their illness can include experiences of disability, but an analysis using phenomenology of illness aims to observe a person's overall reported experience, which can include but transcends the impacts of impairment, disability, interactions with doctors and others, and existential questions linked to illness and embodied change. Whereas disease conventionally refers to a combination of biological symptoms, illness is broader than this, referring to a subjective view of the person rather than aiming to determine an independent "concrete reality."

Some of the key experiences of illness that Carel describes, and that we consider in our analysis, include the following:

- loss of wholeness, where the body feels unrecognizable and disconnected from the self;

- loss of certainty, where participants could find themselves unsure if they are able to describe their experiences accurately, or struggle to find direction in their lives and experience;

- loss of control and continuity, where the predictability of a person's life is upended, often leaving them feeling stranded and having an experience of their body as no longer transparent, but limiting and awkward; and

- loss of the everyday world, which could include an experience of there not being a shared world with others that makes sense and is safe.<sup>25</sup>

Each of these experiences could also result in bodily doubt, where a person loses confidence in their embodied participation in the world, accompanied by an experience of being disconnected.<sup>26</sup> In the words of Giovanni Stanghellini, "if my body-based involvement in the world is switched off, my *grasp* onto the world will fade away too."<sup>27</sup>

Following General Comment 1's stipulations on the use of supported rather than substituted care, we also draw on Kong's work on phenomenology and capacity, particularly her relational and interpersonal conceptualizations of the latter concept.<sup>28</sup> Kong understands capacity as being contingent on the environmental and interpersonal relationships that are present in a person's life and in the decision-making process.<sup>29</sup> She argues that certain normalized environments and relationship limits can constrain or enable the flexibility with which people with psychosocial conditions can exercise embodied mental capacities.<sup>30</sup> The texture of relationships between people with psychosocial conditions and professionals, she argues, can also impact whether people with psychosocial conditions' normative decisions about their lives are respected as valid, which can in turn affect the possibilities of these individuals to express themselves adequately. She writes that capacity "competencies" can be increased in terms of "socially acquired perceptual, psychological, emotional, and cognitive skills necessary to engage with the world and make choices in accordance with one's values."<sup>31</sup>

She further recommends that more work be done to understand what the experiences of people with psychosocial conditions are in this interface, and what will be useful in supporting capacities. Conducting a phenomenological analysis can in itself represent a form of radical empathy toward

suspending our views of the experiences of people with psychosocial conditions, representing them in their complexity and contradiction.<sup>32</sup>

## Methodology

This research was performed in accordance with the Declaration of Helsinki. We attained ethical approval for the study from the Research Ethics Committee: Social, Behavioural and Education Research at Stellenbosch University. We recruited participants through nonprobability, purposive, and snowball sampling. Selection criteria were that participants had previous experience of being involuntarily admitted in South Africa and were in psychosocial rehabilitation. We located most of our sample at two of the main psychosocial rehabilitation facilities in Johannesburg, which we visited in person to conduct interviews and to snowball participants. Rehabilitation facility staff approached certain residents to request interviews on our behalf, which may have resulted in selection bias. Some participants were also snowballed from other residents whom we interviewed. We conducted all the interviews in Johannesburg.

We conducted nine individual interviews and two focus group discussions. Individual interviews ranged between 60 and 90 minutes. Our focus groups included six and five participants, respectively. The first was 120 minutes long, and the second was 90 minutes. In the interviews and focus groups alike, our questions centered around participants' experiences and views of involuntary detention, hospital admission and treatment, and possible alternatives or improvements to current systems. In the focus groups, we used semi-structured questions to introduce a topic, after which the participants discussed these issues. As far as possible, we encouraged participant interaction and limited researcher questions. There was no specific age range, race, or gender requirement, but we made efforts to ensure that participants varied in these aspects. While we note that demographic characteristics may impact the participants' frames of reference and experience, a close analysis of race, gender, class, and other demographic factors and

their influence on results is beyond the scope of this study.

## *Analytic method*

We first thematized our transcribed interviews in a table. We then grouped these phenomenologically, with an emphasis on how embodied and inter-relational interactions impacted participants' experiences of involuntary care. We used a combination of Carel's *Phenomenology of Illness* and Kong's conceptualization of capacity as guiding frameworks for our analysis.<sup>33</sup>

## Findings

Our findings begin with participants' views about whether involuntary care should be practiced. We then focus on how participants' embodied experiences of illness impacted their experience, before addressing some of the complexities in participants' accounts of experiences of loss, fear, and embodied restraint. This then leads us to analyze the different ways that participants experienced and responded to coercion, including a consideration of participants' descriptions of cooperation and compliance. We conclude our findings with participants' views about how the health care system could be improved, as well as an exploration of some of the gray areas that certain participants introduced that fall between the binary nodes of "autonomy" and "subjugation."

## *Participant views about whether involuntary care should be practiced*

Participants' accounts of their experience of involuntary care were extremely complex and often held contradiction. Nevertheless, participants sometimes shared their overall feelings about whether involuntary care should be practiced. This seemed important to capture since some participants held overarching beliefs about involuntary care even though the content of their accounts about involuntary care could be subtle and hold mixed feelings. The participants we interviewed had various opinions. Some felt that involuntary care was an unnecessary injustice they had to bear, and



some felt that it was a beneficial practice important to their well-being and safety, even though it could be traumatic.

The extract below is from a participant who, on the whole, opposed the practice and felt they had to “survive” it:

No, I didn't think I needed it, not at all, but it happened. You see, I can survive. I'm a survivor. So when I realized, okay, I'm locked up in this ward, then I will behave myself and I will be a model patient. I mean, that's how it is, we survive. (participant 1)

Some participants viewed involuntary care as a necessary function that prevented them from harming themselves or others or from humiliating themselves in public:

The police had to come and fetch me and, um, out of that perspective, I think it was excellent. If it hadn't been for those two incidents, I wouldn't be here today, where would I have ended up who knows. (participant 2)

Some justified their support for involuntary care by arguing that the system had few motives to intervene if not in the interests of people with psychosocial conditions. The word *minag* in the following excerpt is an Afrikaans word that means “to condemn” or “to slight,” and the participant seems to suggest that involuntary care is intended not to demean people but to help them:

We use the word “minag” is to denounce a person's right to decide about his own health and whether it should go into an institution or not, whether he should be hospitalized or not, it's [involuntary care] not to undermine that, it is to um, uh protect the various parties, both the patient and bystanders. (focus group 1)

Some participants emphasized that despite involuntary care potentially being undermining and distressing, it protected them and was ultimately the best way to preserve their safety and well-being:

So sort of it felt, it felt like quite invasive at the time, and quite traumatic. But in retrospect, you

feel like it was the necessary action and it's and it's benefited your life. As it stands now, having had that experience, having been institutionalized you feel like it was the best thing for you. (participant 10)

The participant below advocated for involuntary care, noting that objections or “complaints” that people with psychosocial conditions have about the practice are unwarranted in that they believe that it protects people with psychosocial conditions and others:

I think, I think, people with mental illness shouldn't complain too much, the system is trying what they can to do for us, and I am really here today to try to improve things ... They have to do it [treat a person who is “wild”] against your will for their safety and your own safety, so that you don't hurt yourself and other people around you. (participant 5)

While participants expressed some of their opinions about the practice of involuntary care as either in favor or against the practice, most participants had very nuanced and sometimes ambivalent views and experiences of involuntary care that were often relational and contextual, as explored below.

### *Embodied and inter-relational experiences of involuntary care*

In this section, we represent participants' experiences in more localized interactions with police and psychiatric professionals. We begin by outlining some participants' experiences of fear and dislocation and how this experience and its causes could impact the decision-making capacity of people with psychosocial conditions. We then consider participants' inter-relational experiences as they negotiated their care with professionals.

**Disconnection and loss.** Many participants described forms of loss and disconnection in their experience of being involuntarily committed:

It felt like, I don't even know do I have the words, but let me try. It was um ... very alarming, because you realize that, your worth, you lose all your total worth. It undermines your total worth, you don't even exist as a, as a lesser voter in this country,

nothing. No rights. You have no say. Ja, that was quite, quite difficult to say, harsh realization. When they said you've been certified. And to know your rights and to be subjected to that was, it was just a nightmare. (participant 1)

The participant's description portrays how traumatic the loss of autonomy and rights was. A level of bodily doubt accompanies this trauma, expressed in her sense of a loss of self-worth and feeling outside of recognizable embodied and linguistic frames with which to understand and express her experiences ("I don't even know do I have the words").

Several other examples of participants' experience akin to what phenomenologist Stanghellini describes as a "losing a grasp on the world" are presented below.

Loss of memory was a particularly significant experience for many participants:

Very little, I can remember that I was in a straitjacket in the back of the ambulance, But very little. (participant 2)

Another experience was a loss of a sense of time and space:

I was trying to see out the window, what, where the van is headed and it seems to journey forever. (focus group 2)

Finally, participants expressed a loss of a sense of embodied self-determination and autonomy:

I didn't know what I was doing. (participant 9)

These examples illustrate how participants could feel a strong sense of detachment and what might be described in *Phenomenology of Illness* as a loss of continuity, certainty, and control and a loss of wholeness in the experience, which felt undignified to some. A theme that we noticed was that involuntary care could sometimes make thinking and being present in the moment difficult for participants; where participants' autonomy was constrained, it seemed harder for some to reflect on their circumstances and make decisions. The

section below builds on this theme.

**Fear, criminalization, and decision-making capacity.** Fear and criminalization are potentially significant factors impacting the capacity of people with psychosocial conditions to think, express, and communicate their experience and decisions.

In the following extract, the participant expresses how their illness caused debilitating fear that required an involuntary intervention. We asked the participant if they felt they would have been able to go with the police voluntarily if someone had spent more time explaining the nature of their illness:

That's a difficult question to answer because I was also afraid and I always do feel fear when I become ill. I was afraid, so, it maybe because of the fear that the sort of quiet approach with me ... "Jane, you're not well, we need you to go to hospital" ... take it slow ... whereas sister Flora [pseudonym] was fast and furious, she didn't waste time. So as I say ... a fear that is there ... I begin to feel afraid, that slow very gentle approach might have been wasted. (focus group 1)

This participant experienced the nurse's use of force as necessary on the basis that a less firm response may not have been helpful. Nevertheless, the question remains as to whether this kind of response by the nurse also caused the fear that necessitated its use. In other words, it raises the question whether the participant would respond in the same way to someone using a more or less forceful response.

Interestingly, experiences such as this coexisted alongside scenarios where the experience of being picked up by the state was frightening and dislocating in itself:

I was shocked, it shocked my body. It was a big shock to me because your mind, suddenly your mind goes clumsily, what have you done, because when you see a police van, it was like, they only there for something terrible that you've done. (participant 4)

On the whole, experiences of fear, criminalization, and pressure were part of the illness experience for participants. These experiences could become

disabling for some and make it difficult to make congruent decisions. For some, it seemed like stronger forms of coercion that were against their will were a valuable response to their fear and confusion, while at the same time the experience of involuntary coercion was felt as criminalizing and even accentuated or caused some fear. Some participants seemed to describe how coercion could become “disabling” and iatrogenic, which could increase the likelihood that involuntary measures would be required. Based on these varying and complex experiences, some participants seemed to describe involuntary care as contributing to their struggles and the unpleasantness of their illness experience, while still being valuable in certain circumstances.

**Experiences of restraint and restriction.** Participants had various views and experiences regarding being restrained and constrained. Some described being difficult to control:

They had to catch me like an animal, like a wild animal at the police station and Gordon's Bay. The police had to surround me and make the circle smaller until they could grab me. Yes and that was really unpleasant. But I was running around in my speedo and um, I was completely naked. So that's what they had to do. (participant 10)

In the second example, the participant feels that the police response was a necessary response to their actions (“had to”). However, in some cases, participants felt that professionals could overextend their paternal authority:

I have to walk at night, the Sister didn't want me to walk beyond a certain point and uh, I felt I needed that space and I took it. I went beyond that certain point and, wow! She was very bitter, whoever else was there on duty, and I was strapped to the bed. (focus group 2)

This participant felt that the professionals responded over-restrictively or vindictively, and seemed to have some resentment about this.

On the whole, restraint and restriction resulted in complex and sometimes tense negotiations between people with psychosocial conditions and

professionals, in which some experienced shame, indignation, and disempowerment, despite many feeling that it was a necessary response to their behavior and mental state.

### *Experiences of compliance*

Compliance with detention exemplified people with psychosocial conditions conforming or adapting to requirements set by police or hospital staff. Some participants found that compliance prevented violent confrontations and was helpful in grounding them. Nevertheless, participants also associated compliance with discomfort, loss of control, and loss of wholeness:

I was also manic um, I went into a park and they followed me into park and they spoke to me. Eventually they grabbed me and they put me in the back of the bakkie. I didn't resist. So it wasn't violent. But it was all the same traumatic for me. (participant 1)

The participant's use of language such as being “grabbed” and “put” exemplifies the experience of being objectified, which could result in loss of a sense of control and wholeness, as previously described.

One interesting tension occurred where a participant was asked to take personal responsibility by a professional in the detention process:

Professional [as recalled by participant]: I know you don't like this now and we, we pinning you down and whatever, but if you promise me that you will not be aggressive, I will ask them to let you go. What's your answer?

Participant: Doctor, I will be calm now. [So they left me and they treated me.] (participant 5)

Participants in this type of scenario seem to agree to fulfill their role in the involuntary encounter without necessarily embracing its use. This raises interesting questions about whether being given choices to conform to the requirements of involuntary care is useful or whether it is undermining and an exploitation of power on the part of profession-



als. The data support both scenarios. Being given a choice did seem to afford some participants a measure of agency, although they felt uneasy:

Professional [as recalled by participant]: Do you want the police to take you to hospital, or do you want the ambulance?

Participant [to interviewer]: I didn't want to go to hospital but I didn't want to travel in a police vehicle. So I got the ambulance. (focus group 2)

Thus, participants did exercise these choices despite sometimes feeling compelled or objectified in doing so. Some level of ambivalence seems evident from the experiences of participants in these interviews.

### *Experiences of cooperation and collaboration*

Participants often appreciated when police were especially kind and helpful, and at times there was a sense of camaraderie and collaboration between the two parties. In some cases, there was a mutual sense of responsibility for ensuring that detention did not become violent:

I want to say that the police are well-behaved—hey, even the guy who took me to Sea Point was polite and friendly, and the guys who took me to Tara from Helen Joseph uh, it was funny actually because it was like the judge, because I was polite and I was friendly and I wasn't misbehaving at all and the policeman came and dropped me off and said, "Well, we hope this doesn't happen again." [giggling] (focus group 1)

In this example, there is a humorous tone in which participants and police officers together seem to mock the procedural nature of the participant's involuntary detention. The tone could have various functions. On the one hand, it could be a way for the two parties to diffuse tension around the fact that the police personnel are in the process of suspending the autonomy of people with psychosocial conditions. This could be a way of deflecting from the violence of the situation and therefore minimizing and perpetuating that this is a necessary though undesirable act and circumstance.

However, the humor could also represent a subversion, where both participants are aware of

the process and procedures of which they are a part, and mischievously satirizing the legal process and its procedural nature. For example, an involuntary certification could determine that people with psychosocial conditions have no mental capacity, but the people with psychosocial conditions and policeman are able to recognize that they are nevertheless communicating clearly and cooperating with each other. In the above exchange, the participant does not seem to find the encounter to be shameful or traumatic as in other scenarios outlined above, and the greater level of trust seems to mitigate the violence and trauma associated with the confrontation.

Related to this, some felt that taking personal responsibility for recovery was the best way to make use of a system designed to promote their health and reintegration into society. They somewhat paradoxically saw engaging with and accepting involuntary care as a form of participation and cooperation with health care workers that was intrinsic to their recovery—and that of people with psychosocial conditions in general—even if care and detention could be difficult, involuntary, and sometimes traumatic:

No matter what happened to you, yes, it must, might feel embarrassing to you, but by sharing with other people they, they are able to help you and understand you. If you don't, you, you, just, you just, if you don't cooperate then it means it's to your own downfall, it's not going to benefit you in the end. (participant 9)

In the extract below, the participant suggests that professionals do not intrinsically wish to treat a person against their will, and in fact might struggle while trying to do so, but follow through with their practice in order to help people with psychosocial conditions. Cooperation could therefore make life easier for both parties and facilitate opportunities for the recovery of people with psychosocial conditions. For some participants, being "difficult" and losing the commitment of professionals to their care and recovery could be a lost opportunity:

They won't understand you so they might just feel, "Oh this guy is just stubborn, we're just going

to treat him and you know, we're not going to bother much about him because he doesn't want the help. He's not responding to, to our action of trying to treat him, to treat him to get him better." (participant 1)

On the whole, experiences of cooperation and collaboration seemed less traumatic for participants, though many inevitably felt the discomfort of being involuntarily confined.

### *Suggestions for improvement: Support and understanding*

Many participants felt that the system could be improved by police and health care workers offering empathy to people with psychosocial conditions that is comparable to the empathy offered to people without such conditions:

I just feel, I just feel the, the, the police and all these people working with people with mental illness could just have a softer approach with these people. Try and really think what's going to be the best for this person, not to, to hurt him or anything physically, hurt him or whatever ... if someone is a normal person, you, you going to approach him in a different way ok. (participant 6)

Similarly, another participant felt the system did work, and served a valuable function, but could be improved by a degree of greater empathy:

Alex, you know, um, you know, all I think the system must bring in more is a little bit more understanding and empathy. But you know what, sometimes, you have to take control when a mental patient is out of control. So they can't stop this completely. (participant 10)

They also put particular emphasis on the importance of understanding a person's past experiences and vulnerabilities and choosing or finding people who the person with a psychosocial condition is more likely to respond well to:

What I feel, if health care workers get, if they talk to a person, if they say this guy is not responding to men, because like I said he might have been molested or raped or something, try a woman, try

a woman, but let someone sit in for safety or be close by. (participant 10)

Some participants felt that they could understand the struggles of professionals and why empathy was sometimes difficult:

Ja, ja, I can do. I can carry on doing. I do get into a condition where I'm quick to anger and I get annoyed fast ... So I do do that, ja, I can make it hard. (participant 3)

Overall, there is a sense that greater empathy and understanding can be enabling for many and can reduce the discomfort and suffering associated with involuntary care.

### *Gray area: Peer support, self-reflection, and "voluntary proxies"*

Some participants raised the possibility of peer support, where a person with previous experience of the illness and treatment explains the process to the person who is in the process of being admitted:

Like, maybe like, arrange a meeting with a person that like, had a previous experience of what a person is going through that time. And, like, let them talk like about what, what this condition is, like, what it does to one's health. Because like, just some, some facts, like they can make a person change a decision ... it's a mental, it's a chemical imbalance in your brain, which causes you to hear voices. (participant 7)

Others described a gray area in which they consented to having a person assist them in making decisions, even if this was in a broader context of refusing treatment:

Like for instance, when I was sick at some point and my dad had to come here and I had to see a psychiatrist, and my psychiatrist told my dad we might need to change medication and whatever, and my dad would look at me and say, are you comfortable with that, what difference will this medication make? That kind of thing, so in a way I felt empowered and cared for and when I was confused I'd say, dad please choose for me, you know. (participant 1)

The participant shares the decision with her father in a consensual and supported manner. This highlights a theme throughout, whereby participants often have varying degrees of autonomy in a given moment and can often actively participate in how they would like to be treated, even if they are considered unable to make overarching decisions about whether they will be treated.

## Discussion

In the above, we used a phenomenological analysis to explore participants' experiences of involuntary care. There are many bifurcations in policy and rhetoric concerning whether involuntary care is discriminatory and disempowering or beneficial and protective. Our phenomenological analysis troubles the binary by illustrating intersections, complexities, ambivalences, and subtleties in participants' experiences and views about involuntary care.

Many participants held many mixed feelings toward involuntary care. Some positive and negative experiences are encapsulated in Christina Katsakou and Stefan Priebe's systematic review, with particular emphasis on how difficult participants found the loss of autonomy and dignity, and the benefits they experienced in being treated like a person.<sup>34</sup> Adding to this, we found that participants' experiences were often "ambivalent" in that participants encountered contradictory views surrounding involuntary care. Participants described involuntary care as traumatic and a source of confusion, disorientation, and fear, while simultaneously having beneficial impacts on their overall well-being. Participants also often spoke about involuntary care as traumatic, disorienting, constraining, and undignified and yet also as a relief, containing, and a salvation.

Another complexity is where participants described how a person with a psychosocial condition in crisis can paradoxically consent to involuntary care and see the benefit of it despite initially refusing. Researchers such as Kevin Iversen et al. have referred to something similar as "uncoerced involuntary" treatment.<sup>35</sup> Such a paradoxical situation

would account for why some participants in our study encourage people with psychosocial conditions to recognize their impaired decision-making and embrace involuntary care despite some discomfort surrounding limitations to their autonomy. These instances also show participants' perception that involuntarily certification does not mean that people in involuntary care lack agency to deliberately rebel or comply in different degrees, despite their status as lacking sufficient mental capacity to make legal decisions.

Additionally, it was difficult to determine the cause of a positive or negative experience or impact on mental capacity—for instance, when one participant described involuntary care as both a cause for and a necessary response to loss and fear. In this circumstance, the participant stated their preference for the use of involuntary care, but it is unclear to what extent this form of care caused the fear that made decision-making difficult. It was also interesting to note that "complying" did not necessarily mean that a person did not feel coerced—and vice versa, that sometimes participants appreciated and did not feel coerced when more assertive, forceful measures were employed. This observation is reinforced by George Szmukler's observation that even the use of "lighter" forms of coercion such as persuasion (rather than threats or physical restraint, for example) does not guarantee that a participant will feel that an interaction is uncoercive or dignified.<sup>36</sup>

On the other hand, there was the instance where police and participants had a mutual understanding and identified their roles as part of a system, and this seemed to foster some solidarity, which one participant seemed to appreciate judging by the light-heartedness of the interaction. And there was another instance where decision-making was voluntarily shared with a relative, which seemed to allow the participant to feel autonomous while also allowing someone else to make a decision on their behalf. Our findings emphasize the phenomenological complexity surrounding coercion, the significance of individual experience, and the range of experiences that can be possible surrounding involuntary care and coercion.

Despite the complexity of these instances, for many participants greater empathy was a defining factor in their views about their care, and this often became as important to people with psychosocial conditions as the question of whether involuntary care should be practiced in the first place. Several participants in our study seconded the view that their experience could be improved by receiving increased levels of empathy, whether before, replacing, or during their involuntary certification. This places emphasis as much on the “how” of care as on the “what” form of care, and greater attention to environmental and interpersonal factors seems critical to the quality of the experience participants had, whether in involuntary or supported care scenarios. There is a particular challenge in that where resources are deficient, it is more likely that people with psychosocial conditions will refuse care, have a negative experience, or fail to receive empathetic provision. Such people also seem more likely to be treated against their will due to a lack of support and sensitive care in unpleasant and under-resourced environments. A lack of support in community and hospital environments may also contribute to the likelihood of participants supporting the use of involuntary care, as well as to the likelihood of their experiencing substituted care as a beneficial response to their condition, despite their unpleasant experiences. Participants’ experiences in South Africa are often ambiguous and contingent, and bifurcated global policy recommendations can sometimes overlook the voice of people with psychosocial conditions in the midst of these challenges.

## Conclusion

The reduction and alleviation of coercive care is an important global agenda that has gained attention in the last decade. Various human rights organizations and committees have debated how to move away from conventional biomedical models of care toward more social and human rights approaches that promote the voice of people with psychosocial conditions, take a community-oriented approach

to rights provision, and eliminate stereotypes that people with psychosocial conditions in crisis require restrictive medical and pharmacological intervention. Strategies toward achieving this are contentious, with professionals, policy makers, academics, and people with psychosocial conditions taking stances both for and against the use of substituted practices.

To better understand and radically empathize with the complex and varied embodied experience of people with psychosocial conditions who have undergone involuntary care, we conducted an analysis of people with psychosocial conditions’ experiences of involuntary care in South Africa. Participants described complex and dialectical experiences of involuntary care where trauma, discomfort, loss, and dislocation often coexisted with support for involuntary care as a practice.

The data and tensions we have described here highlight that issues of autonomy include, but extend beyond, whether involuntary care as a practice should be performed. The complexity of participants’ voices emphasizes that binaries can sometimes be unhelpful and that what people with psychosocial conditions value can depend on a myriad of circumstantial factors. Nevertheless, we felt, based on participants’ accounts, that greater interpersonal empathy could open opportunities for people with psychosocial conditions to feel more satisfied and participative. We also noted that focusing on specific circumstances in the midst of this complexity is important, given that the “how” of provision is often as important as “what kind” of provision.

Based on the data analyzed here, binaries surrounding involuntary care tell only part of the story of the complexity, inter-relationality, and nuance in the experiences of people with psychosocial conditions in diverse contexts.<sup>37</sup> It is critical to consider the voices and experiences of people with psychosocial conditions in the face of contextually complex psychosocial barriers.

Overall, our study has shown the complexity of the issue of involuntary care, as well as many of the embodied possibilities that people with



psychosocial conditions exercise in their engagement with professionals and the wider psychiatric community. There is still much scope to explore new horizons of understanding that can inform the thinking, feeling, and awareness of the community involved in people with psychosocial conditions' decision-making practices.

## References

1. B. Watermeyer, L. Swartz, T. Lorenzo, et al. (eds), *Disability and Social Change: A South African Agenda* (Cape Town: HSRC Press, 2006).
2. Human Rights Council, Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, UN Doc. A/HRC/35/21 (2017).
3. C. Williams and A. Chapman, "Virtual Roundtable: Impact of Human Rights Council Reports on Mental Health," *Health and Human Rights Journal* 24/2 (2022), p. 85.
4. Committee on the Rights of Persons with Disabilities, General Comment No. 1, UN Doc. CRPD/C/GC/1 (2014), para. 27.
5. Williams and Chapman (see note 3).
6. M. C. Freeman, K. Kolappa, J. M. C de Almeida, et al., "Reversing Hard Won Victories in the Name of Human Rights: A Critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities," *Lancet Psychiatry* 2/9 (2015).
7. M. A. Stein, F. Mahomed, V. Patel, and C. Sunkel (eds), *Mental Health, Legal Capacity, and Human Rights* (Cambridge: Cambridge University Press, 2021).
8. Williams and Chapman (see note 3).
9. Ibid.
10. K. Hodal and R. Hammond, "Emaciated, Mutilated, Dead: The Mental Health Scandal that Rocked South Africa," *Guardian* (October 14, 2023), <https://www.theguardian.com/global-development/2018/oct/14/emaciated-mutilated-dead-the-mental-health-scandal-that-rocked-south-africa>; E. Durojaye and D. K. Agaba, "Contribution of the Health Ombud to Accountability: The Life Esidimeni Tragedy in South Africa," *Health and Human Rights* 20/2 (2018).
11. Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106 (2006).
12. M. Burch, "Autonomy, Respect, and the Rights of Persons with Disabilities in Crisis," *Journal of Applied Philosophy* 34/3 (2017); C. de Bhailis and E. Flynn, "Recognising Legal Capacity: Commentary and Analysis of Article 12 CRPD," *International Journal of Law in Context* 13/1 (2017); Freeman et al. (see note 6).
13. Burch (see note 12).
14. L. Berghmans and G. A. Widdershoven, "Ethical Perspectives on Decision-Making Capacity and Consent for Treatment and Research," *Medicine and Law* 22 (2003).
15. Committee on the Rights of Persons with Disabilities (see note 4).
16. Committee on the Rights of Persons with Disabilities (see note 4), para. 13.
17. Ibid., para. 2.
18. E. Kaminskiy, "The Elephant in the Room: A Theoretical Examination of Power for Shared Decision Making in Psychiatric Medication Management," *Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and Practice* 4/2 (2015).
19. E. Rossero, *Care in a Time of Crisis: An Ethnography of Coercive Practices in Italian Acute Mental Health Provision* (London: Palgrave Macmillan, 2023).
20. United Nations General Assembly, Interim Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, UN Doc. A/73/216 (2018).
21. U. M. Read, L. Sakyi, and W. Abbey, "Exploring the Potential of a Rights-Based Approach to Work and Social Inclusion for People with Lived Experience of Mental Illness in Ghana," *Health and Human Rights Journal* 22/1 (2020).
22. C. Lund, "Mental Health and Human Rights in South Africa: The Hidden Humanitarian Crisis," *South African Journal on Human Rights* 32/3 (2016).
23. H. Carel, *Phenomenology of Illness* (Oxford: Oxford University Press, 2016); C. Kong, *Mental Capacity in Relationship: Decision-Making, Dialogue, and Autonomy* (Cambridge: Cambridge University Press, 2017).
24. Ibid.
25. Ibid.
26. Ibid.
27. G. Stanghellini, "Embodiment and Schizophrenia," *World Psychiatry* 8/1 (2013).
28. Kong (see note 23).
29. Ibid.
30. Ibid.
31. Ibid., p. 5.
32. M. Ratcliffe, "Phenomenology as a Form of Empathy," *Inquiry* 55/5 (2012).
33. Carel (see note 23); Kong (see note 23).
34. C. Katsakou and S. Priebe, "Patient's Experiences of Involuntary Hospital Admission and Treatment: A Review of Qualitative Studies," *Epidemiologia e Psichiatria Sociale* 16/02 (2007).
35. K. I. Iversen, G. Høyer, H. Sexto, and O. K. Grønli, "Perceived Coercion among Patients Admitted to Acute Wards in Norway," *Nordic Journal of Psychiatry* 56/6 (2002).



36. G. Szmukler and P. S. Appelbaum, "Treatment Pressures, Leverage, Coercion, and Compulsion in Mental Health Care," *Journal of Mental Health* 17/3 (2008).

37. Human Rights Council (see note 2); World Health Organization, *Guidance on Community Mental Health Services: Promoting Person-Centred and Rights-Based Approaches* (Geneva: World Health Organization, 2021).