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Involuntary hospitalization for treatment purpose; an act of caregiving? Perspectives and experiences of patients diagnosed with schizophrenia

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ABSTRACT

Background: Coercive methods in psychiatry are still a matter of debate, raising ethical challenges ranging from liberal to paternalistic approaches. Involuntary hospitalisation (IH) for treatment purpose is a major intervention not yet fully examined from patients' perspectives.

Aim: To examine at discharge the views and experiences of patients diagnosed with schizophrenia involuntarily hospitalized in a psychotic state for treatment purpose.

Method: We examined nine patients with semi-structured interview concerning their views on IH in general, their own admission, and ways to prevent such situations.

Results: None of the patients considered their IH necessary in its entirety or viewed their condition as psychosis. They did not consider IH as an act of care and believed that community support could have prevented IH in their case. They stressed that psychiatric patients should be able to refuse treatment as somatic patients are.

Discussion: We discuss the patients' experiences and negative view of IH, the concepts of psychosis and insight, possibilities of acute outpatient intervention and ethical issues.

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Involuntary hospitalization;
insight; psychosis;
schizophrenia;
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Introduction

Coercive methods in psychiatry have been discussed for many years among patient-associations, medical professionals, and scholars in the humanities and are still a matter of intense public debate within a Danish context and internationally (de Almeida, 2019; Høyer, 2000; Saks, 2010; Sz mukler, 2019). Several issues are being discussed ranging from absolute respect for a person's free will to a paternalistic attitude. The World Psychiatric Association declared that coercive methods should always be the last resort (Lovbekendtgørelse, 2019; Tingleff et al., 2017; UN, 2006; WPA, 2020). One of the most debated interventions is involuntary hospitalization (IH) whose frequency is increasing in several countries including Denmark (Rains et al., 2019). IH results in social stigmatization and fosters public debate over patients' rights (Wasserman et al., 2020). According to the Danish Mental Health Act (Lovbekendtgørelse, 2019), persons in a psychotic state can be hospitalized involuntarily if they are 1) imminently dangerous to themselves or others or 2) for the purpose of treatment. In Denmark, only medical doctors have legal permission to write a certificate of IH, and it must be validated by a legal attorney of the police. The police are thus obligatorily involved

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in the hospitalization process. Application of IH for the purpose of treatment is only permitted if there is a prospect of recovery, of a substantial and crucial amelioration, or of prevention of grave disability. The main purpose of the treatment-criterion is to provide care for not imminently dangerous individuals, who, during psychotic episodes, are not able to take care of themselves and at risk of significant deterioration (Kallehauge, 1986). The effects of IH remain inconclusive due to methodological issues and differences in legislations between countries. It is interesting to notice that there is no distinction in the empirical literature between IH motivated by an imminent dangerousness to self or others and by only a need for treatment (Diseth & Høglend, 2014; Giacco et al., 2018; Høyer et al., 2002; Katsakou & Priebe, 2006). The patient's point of view on her own hospitalization is rarely systematically examined and typically studied using structured questionnaires. Studies using e.g. Consumer Satisfaction Rating Scale (UKU-ConSat) (Bø et al., 2016) or Client Satisfaction Questionnaire (CSQ 8) (Smith et al., 2014) showed satisfaction in the majority of patients (Gardner et al., 1999; Priebe et al., 2010; Wynn & Myklebust, 2006). The few studies using qualitative interviews found that autonomy, feeling cared of, and keeping a sense of identity contributed to positive experiences of IH. However, the patients asked had divergent opinions about the necessity of their hospitalization and its impact on their condition. Some considered IH a protection and recognized a long-term benefit, others experienced it as unfair and even harmful because of the violation of their autonomy. Several patients did not find the treatment helpful and felt dehumanized (Katsakou & Priebe, 2006, 2007; Katsakou et al., 2012; Priebe et al., 2010; Smith et al., 2014). Other studies underline the decisive role of communication between patients and staff (Larsen & Terkelsen, 2014; Tingleff et al., 2017). The knowledge of psychopathology has proven to be essential in the management of situations involving coercion (Poulsen & Engberg, 2001). In view of the general scarcity of qualitative studies and particularly the lack of studies concerning IH for treatment purpose, we have conducted an empirical naturalistic study in a group of patients diagnosed with schizophrenia, involuntarily hospitalized for the purpose of treatment (with no imminent dangerousness) to address the following questions:

- (1) What are the views of the patients on involuntary hospitalization for treatment purpose in general?
- (2) Do the patients feel that their own involuntary hospitalization is justified?
- (3) Do the patients experience improvement of their condition during the hospitalization?
- (4) Do the patients consider their involuntary admission an act of care?
- (5) What are their proposals for alternatives to involuntary hospitalization?

Methods

The study was conducted at the Psychiatric Centre Glostrup, a university-affiliated department of psychiatry situated in Copenhagen with a catchment area of 300.000 inhabitants. IH is prohibited in private psychiatric facilities in Denmark.

Design

The study is an explorative qualitative study researching patients' experiences of IH. IH begins with a disagreement over the need for hospitalization between the patient and the surrounding carers. To gain more nuanced insight into this disagreement we explore the patients' experiences and opinions on IH from a first-person perspective and invite them to reflect on descriptions from third-person perspectives (relatives, mental health care professionals) in their charts. A qualitative approach is chosen to capture the patients' viewpoints in depth.

Sample

Given the qualitative and therefor time-consuming design of the study, we aimed to include 10 patients. Among the contacted patients, three declined to participate. One patient was ultimately excluded because of doubts concerning his legal status. The final sample of nine patients, five women and four men, with a median age of 42 (range 18–61), underwent the full examination. Four patients were recruited during their first admission, the remaining five had previously experienced IH. All the patients received antipsychotic medication at discharge (see [Table 1](#) for sociodemographic data). A summary of the medical reasons for IH for treatment purpose is provided in [Table 2](#). The case number of the patients in [Table 2](#) corresponds to the number of vignettes in the results. During the six months of inclusion, all patients meeting the inclusion criteria were contacted by the staff of the wards (for ethical reasons). The research was designed as an explorative study, giving precedence to the recruitment of participants interested in sharing their perspectives over the use of a formal selection method. We have no information about the three patients who declined to participate.

Exclusion criteria: IH due to dangerousness or forensic cause and suffering from organic brain disorder.

Inclusion criteria: Patients involuntarily hospitalized for treatment purpose, no longer under measures of coercion, approaching discharge and diagnosed with schizophrenia according to ICD-10. ICD-10 diagnoses were established by senior psychiatric consultants involved in the treatment of the patients. We verified the diagnosis through the examination of the patient's chart.

Table 1. Sociodemographic data.

Gender	Female: 5 Male: 4
Age	Median: 42 (range: 18–61)
Education	Primary school: 3 High school: 4
Occupational status	University students: 2 Disability pension: 3 Sick leave from study: 2 Unemployed: 4
Previous psychiatric hospital experience	First hospitalization: 4 Previous hospitalization (all previous experience of IH): 5
Medication	Antipsychotic medication at discharge: 9

Table 2. Patients' condition as described in the chart at the time of admission.

Case	Description in chart
1	Auditory hallucinations commanding him to suffer, stop antipsychotic medication and quit contact to psychiatric system.
2	Aggression towards neighbors, knocking and kicking loudly at their doors, destroyed the door to his own apartment. Believed neighbors were watching him with cameras.
3	Delusional beliefs about the police stealing her underwear, verbally aggressive behavior in the outpatient clinic, incoherence of thought and speech.
4	Locked herself outside, standing outside barefoot in cold weather, stopped speaking, and made unconventional movements.
5	Declining level of functioning, became homeless, refused help from social system, persecutory thoughts about persons working in social system.
6	Noisy in the staircase and verbally aggressive towards neighbors, persecutory thoughts about neighbors, incoherence of thought and speech.
7	Controlling behavior of his girlfriend, kicking doors, smashing things in their home, verbally aggressive towards girlfriend and a neighbor.
8	Locked herself out from her apartment, persecutory thoughts about her neighbor and different religious institutions, disturbances of thought and speech.
9	Declining level of functioning, became homeless and was on sick leave from studying, several somatic delusional beliefs, thought broadcast, incoherence of thought and speech.

Interview

We prepared a semi-structured questionnaire for this study. The first draft was created by the authors, reflecting our aims, and including results from the literature on IH. One of the authors (AUP) has many years of clinical experience with coercive measures in a closed ward. The questionnaire was revised through discussion between the authors and clinical colleagues until consensus was reached. The structured element of the interview covered the questions addressed in the study: 1) What are the views of the patients on IH for treatment purpose in general? 2) What are the views of the patients on their own IH for treatment purpose and its justification? 3) Do they experience improvement of their condition during the hospitalization? 4) Do they consider their IH an act of care? 5) What are their proposals for alternatives to IH?

Apart from the need to cover all domains, the interviews were conversational and gave the patients a chance to express themselves freely and to spontaneously add other topics (Nordgaard et al., 2013). The interviewer was a MD, trained in psychiatry, who had no role in the patients' admission and treatment.

The interview with each patient comprised two parts. The purpose of the first part was to explore the patient's experiences from his/her own perspective. Therefore, to avoid being influenced by prior knowledge of the patient, the interviewer (SKL) had no information about him/her or the process of hospitalization. The purpose of the second part was to engage the patient in reflection on other people's perspectives (e.g. the doctors', the relatives') on his/her condition. It was conducted after the interviewer had read the patient's chart, which enabled the interviewer to invite the patient to relate his/her own experience to the descriptions given by others. The participants were also presented with a constructed vignette describing a situation similar to their own at the time of admission. Thus, each patient was able to give a third person's perspective on a situation roughly resembling his/her own. The duration of the interviews was between one and three hours.

Data analysis

The analysis was carried out by the authors as a thematic analysis according to the principles described by Kvale and Brinkmann (Kvale & Brinkmann, 2009) and outlined in more detail by Braun and Clarke (2021): The interviews were audio recorded and transcribed verbatim by the first author. The transcripts were read and re-read by both authors and initial analytic ideas noted. The data was coded, and the codes were clustered in initial themes by each author and reviewed by both authors, until the themes adequately reflected our aims, the coded extracts, and the full dataset. The themes were refined with intent to capture their essence (main themes correspond to our five research-questions and sub-themes are listed as subcategories of each main theme in results). Key extracts belonging to the themes were chosen, and the themes were related to our aims.

Ethical issues

All participants gave written consent. The study was accepted by the relevant local ethic committee (Regional Committee on Health Research Ethics Copenhagen, Denmark, ref.nr.: 22019761) and carried out in accordance with the appropriate data protection legislation and the Declaration of Helsinki.

Results

What are the views of the patients on involuntary hospitalization for treatment purpose in general?

IH because of Dangerousness

All patients agreed that if a person in a psychotic condition is dangerous to themselves or others, it justifies IH.

Case 2: "People shouldn't be involuntarily admitted unless they are completely insane and dangerous".

Respecting the free will

There were divergent views on IH under the treatment criterion. Seven patients considered "free will" fundamental. They disagreed that the social community should interfere with how you live your life if you do not harm others.

Case 1: "I think people should be allowed to live their lives the way they want to, after all it's a free choice, as they say, so I don't think it's cool to hospitalize people against their will if they want to keep on living as they do".

Most patients judged it "unfair" that people suffering from psychiatric illnesses do not have the same right to refuse admission and treatment as patients with somatic diseases.

Case 9: "If I had cancer, say, then many people they say no to chemotherapy, and I would probably say no too, so telling me: 'you have to stay here because we think this chemotherapy will be very beneficial for you', and it is just poison you get injected into your body, I would still have the right to say: 'No, I don't want this'".

Others in need of help

Six patients still thought that some cases could justify IH. They described possible situations - consistently different from their own conditions - as e.g. the risk of harming oneself, not providing food, suffering from dementia, or humiliating behavior.

Case 7: "I think involuntary hospitalization for the purpose of treatment is reasonable if the person isn't prepared to seek help, in such cases I understand, for those patients just saying: 'I am not sick and I don't need any help'".

Case 9: "If someone is running around naked on the street or calling themselves 'Lord Voldemort' or something like that, I find it fair that the police intervene".

Do the patients feel that their own involuntary hospitalization is justified?

Justification, necessity, and duration of IH

Four patients recognized some necessity for their IH but thought their stays lasted too long. Only one participant was satisfied with the admission and its duration; she would not be opposed to a potential future IH. However, she described that she was feeling well before and during the hospitalization and did not find her admission and treatment necessary at all.

Four participants found their IH unfair and did not understand the reason for admission. Some did not agree with the doctor's descriptions of their condition and behavior at the time of entry; others partly agreed but did not think that it necessitated or justified IH.

Case 2: "They thought I had kicked down my own door, but I haven't, and that I had been kicking on some neighbors' doors, but it's not true (...) If I had been kicking on other people's doors, then I think I have the right to a fair trial. I have been imprisoned before, so I think it is better to appear before a judge and get sentenced to prison instead of being kept here [in hospital] where they say all kinds of things about you that aren't true".

Case 6: "I was speaking loudly and I said some terribly nasty things (...) but they didn't listen to what I said, they just thought: 'Now she has gone raving mad, she is shouting in the staircase' (...) I was downstairs kicking at the door to the women's association's room to tell them that at ten o'clock they should be quiet, at that time I was indeed unbalanced (...) but I don't think it justifies an involuntary hospitalization, if I had been standing in the street with a gun or a knife, but I wasn't".

Difficulties in understanding the term “psychosis”

The majority of the interviewed did not understand what the doctors meant by the word “psychotic” or recognized that they had suffered from a psychotic episode. Some used terms as “stressed” or “angry” when describing their condition. Others thought they never had suffered from psychiatric problems.

Case 6: “If the diagnosis is as it is then I was psychotic, but I wasn’t insane as she [the doctor] has written in the medical record (. . .) I hadn’t any delusions or anything like that or hallucinations (. . .) but I was terribly angry”.

Case 9: “I also think that the expression “psychotic” is used rather at random because when you look “psychosis” up on the internet it comes up with schizophrenia, mania, depression, it comes up with 10.000 things, so it’s just such a broad spectrum that you can’t do anything yourself, because if you say that I’m psychotic then how do I get better”

Case 2: “The first time I spoke to a doctor, he thought that I was psychotic. I had only spoken to him very briefly (. . .) And the second time I spoke to that other doctor, she thought that I had paranoia and now that I’m here [in another ward], they say ‘you have psychosis’, so it is just three different things they are telling me all the time”.

Relating their own experience to descriptions from others

Some patients considered their own hospitalization unjustified but thought that other persons with similar behavior as their own (as told by the interviewer in a hypothetical scenario) could seem odd and possibly need help.

Interviewer: “The doctor worried about you because you had been standing outside barefoot and had locked yourself out”.

Case 4: “But I knew it was no problem, there was nothing wrong, I knew there was a purpose in it, I had to do the qigong (. . .)”.

Interviewer: “But if you saw someone standing barefoot outside in the month of February, would you then be worried?”

Case 4: “Then I suppose I would ask if I could do anything to help, if there was anything, I could do for them, I would probably do that”.

Case 8: Interviewer: “But what if you get worried about someone you pass on the street?”

Case 8: “Some years ago, there was a woman outside our door, she was berating herself, so I called the police”.

Interviewer: “If somebody thought that you were berating yourself violently or behaving strangely, would you then find it reasonable that they called the police so you could get help?”

Case 8: “Yes, I would, but I don’t act like that”.

Do the patients experience improvement of their condition during the hospitalization?

Improvement independent of hospitalization and medication

Six patients described improvement in their conditions. They reported feeling less stressed or angry but did not attribute this improvement to the hospitalization or the treatment and disagreed that the medication could play a role in their recovery. Four of these thought that they could have improved just as well without admission or treatment by relaxing at home or being taken care of by family and friends.

Case 8: “I am no longer so stressed-out. I was suffering from stress when I arrived here [the hospital]”.

Interviewer: “Do you also think that the medication has been helpful, has it been a part of getting better”

Case 8: "No, not at all".

Case 6: "I could have achieved the same at home by following my daily routines of singing in the choir, going to The Salvation Army and the second-hand store ... but I have gotten better, I have learned a lot, I have met interesting people".

Positive social interaction during hospitalization

Five patients found that positive contact and interactions with some fellow patients and staff members contributed to improvement of their conditions.

Case 3: "It probably gets a little better. But it's also because there are so many good people here ... the staff and the patients".

Do the participants consider their involuntary admission an act of care?

IH contains elements of care

None of the patients considered their involuntary admission in its entirety to be an act of care, though some perceived elements of it as caring (e.g. informal contact with the staff and other patients, the daily routine on the ward).

Not feeling the need to be cared for

Three patients, who did not feel mentally ill when admitted, found the question of "improvement" and "care" irrelevant, or felt that they had deteriorated during the admission.

Case 5: "What should make me feel better when I haven't had anything? I was very surprised that you could have your freedom robbed just like that, by the way you're not allowed to go outside, you're not allowed to go to the garden with the others, you're not allowed to go for a walk, I don't understand, should I have gotten better that way? You could also end up getting worse if this continues, but then they will certainly have a solution for that too".

What are their proposals for alternatives to IH?

Possibility to choose and refuse

All patients agreed that the social community should play an active role in caregiving, and the majority appreciated that persons suffering from mental illnesses receive help. They would call it an act of care if it were possible to choose between different treatment options, e.g. outpatient psychiatric clinics, assertive psychiatric teams, or general practitioners, including the possibility of refusal of treatment.

Case 6: "Yes, I wish the doctor had said: "It sounds like you could need some help, I don't consider it necessary to admit you involuntarily, but I think it would be a good idea for you to get in contact with the outpatient psychiatric clinic (...)".

Treatment options in the outpatient clinic

Five patients were interested in receiving psychiatric care after the IH. They thought that conversations with doctors, psychologists, or nurses were helpful.

Case 7: "But there are things that I already know, and they are things that I'm trying to work on, and that's why I want to receive help from here [the outpatient clinic], to get some tools".

IH as a reason for refusal of further contact with the psychiatric system

Three patients never wanted any contact with the psychiatric system again.

Case 9: "I don't think that I ever want to be involuntarily admitted again . . . It has been the worst time of my entire life; I don't think I'll ever ask for help from the public system again".

Discussion

Strengths and limitations

A major limitation of the study is the small sample size, naturally preventing generalization. The study concerns only patients involuntarily hospitalized on the treatment-criterion of the Danish Mental Health Act. However, the study concerns a patient sample difficult to obtain, given the legal constraints on research on involuntarily admitted patients. The interview was very comprehensive, and the data analysis carefully conducted. Some studies suggest that patients' views tend to be more positive towards IH at follow-up interviews months after discharge (Katsakou & Priebe, 2006; Priebe et al., 2010). Interviewing at the time of discharge could influence the results with more negative views but, on the other hand, increase the possibility of reaching a broader variety of viewpoints from patients who would drop out from follow-up. A second interview after discharge, uninfluenced by hospitalization status, would have been desirable.

Discussion of results

The most striking result was the complexity of the participants' reflections and experiences. They all agreed that IH could be necessary in case of dangerousness but cannot be justified in the same way under the treatment criterion as discussed in another study (Diseth & Høglend, 2014). None of the participants thought that their hospitalization was necessary in its entirety. They did not perceive being taken by the police and placed in a psychiatric ward as an act of care. This finding contrasts with the results of a large study (Priebe et al., 2010), reporting that 1 month after IH 55% (and 3 months after 63%) of the patients thought their admission was right. A diagnosis of schizophrenia was, however, significantly associated with viewing the IH as wrong, which is in line with our findings. The study does not distinguish between reasons for IH (dangerousness or treatment purpose). The patients in our study all agree that dangerousness justifies IH and it is possible that patients involuntarily hospitalized because of acute dangerousness retrospectively more often find their IH justified. The patients of the study of Priebe et al. rated their IH on an 11-point Likert scale (0: entirely wrong – 10: entirely right). Answers distributed throughout the whole scale indicate more nuances which corresponds to the patients of our study who acknowledged elements of the hospitalization as caregiving and presented more complex, even sometimes paradoxical, views. None of the patients mentioned medication as a meaningful treatment. In our study, the violation of autonomy and free decision making appeared to be the most negative aspects of IH as emphasized in other studies (Katsakou & Priebe, 2006; Priebe et al., 2010; Smith et al., 2014). Four patients acknowledged that their condition improved during the IH, and several felt better at discharge. For many patients, the beneficial dimensions of IH consisted in the daily ward routine and the interpersonal exchanges with staff members and other patients. These findings cohere with other studies' results demonstrating that the experience of improvement is associated with the staff's maximal attempts to preserve the patient's autonomy (Bonsack & Borgeat, 2005; Katsakou et al., 2010; Plahouras et al., 2020). A sub-theme of the analysis has pointed to the ambiguous and unhelpful status of the concept of psychosis. First, the patients did not recognize themselves in the multifarious terms of medical descriptions with words as paranoia, psychosis, thought disorders, etc. They could not find a clear definition of psychosis and disagreed that their condition at the IH, which according

to themselves consisted of emotional turmoil, anger, and stress, corresponded to atomistic terms as delusions or hallucinations as described in their charts. This is in accordance with empirical research demonstrating that the first psychiatric contact of patients with schizophrenia is motivated by complains of anxiety, stress and suicidal ideation (Mølstrøm et al., 2020; Yttri et al., 2020). Thus, the issue of defining psychosis is extremely important when a psychotic state is the primary legal requirement for IH.

This leads to the question of insight into illness in schizophrenia. According to DSM-5 insight into illness is defined as “an awareness of the illness, its symptoms and consequences”. It has been pointed out that this medical definition of insight is rarely applicable to schizophrenia due to the complexities of subjective experience and disorders of selfhood (Henriksen & Parnas, 2014; Parnas et al., 2021). Moreover, the DSM-5 and ICD-10 do not truly define the concept of psychosis, but only list a number of apparently independent symptoms considered as psychotic (Parnas, 2014). The participants of the study did not consider themselves psychotic but recognized severe mental disorders requiring intervention in the vignettes of other people with similar conditions to their own. This indicates that it is easier to attribute a psychotic state to someone else violating the tacit rules of social conduct (Bovet & Parnas, 1993). In accordance with other studies (Lloyd-evans & Johnson, 2019; Plahouras et al., 2020), most participants in our study thought that the optimal help should come from the community and network outside of the hospital. The act of caregiving, described by Kleinman, implies an interpersonal relation and mutual influence between the caregiver and the person cared for (Kleinman, 2012). It is always a difficult process to integrate the viewpoints and values of both parties. According to several philosophers (Gadamer, 2013; Levinas, 1969; Løgstrup, 1956), it is impossible to establish an interpersonal relation without influencing each other’s lives. Such interpersonal encounters may imply making a decision on behalf of the other in their best interest as an act of care. The relationship between the caregiver and the cared for is extremely complex and convoluted at IH because the parties involved start with a disagreement. In contrast, Mill defends the fundamental right to make free decisions over one’s life. He argues that every person has the right to live their life as they wish, as long as it does not harm anybody or deprives others of their freedom (Mill, 1859). The participants emphasized the disparity of human rights between a person suffering from a somatic illness, who may generally refuse treatment, and a person with a mental illness, who can be obliged to be treated. United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) recommends that patients receive optimal support in making decisions about their treatment, respecting their autonomy, will, and preferences. When speaking of their own IH the patients in this study agreed with UNCRPD and with Mill’s thoughts, emphasizing a total freedom for a person to decide for herself. The recommendations of UNCRPD correspond to the patients’ view that the psychiatric and social system should offer multiple options of caregiving and treatment in the community, but also the right to refuse any or all of them.

Conclusions

First, our study indicates that increasing treatment options, including acute outpatient intervention in the community, may be one avenue to reduce IH for treatment purpose. Second, it seems that a better psychopathological insight into the patient’s condition and subjective lived experience may provide a foundation for the doctor-patient discussion of future paths and possible interventions in the case of critical situations. Third, we believe that the concept of psychosis, as used in the context of IH for treatment purpose, needs a clarification consistent with the phenomenological view of psychosis as radical irrationality affecting the whole person (Parnas, 2014). Such a description would most likely fit better with the self-description of the patients.

Finally, the psychiatric and social systems must be adequately funded and developed to provide the necessary framework to support the decision-making process and limit the use of coercive methods. However, even if all these conditions could be optimally met, the decisive question is unresolved, i.e. whether the use of coercive methods would, nevertheless, remain indispensable to

avoid the abandonment of individuals confined in their psychotic world and not able to care for themselves during some periods of their life.

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