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Bioethics and advance directives in psychiatric in the hospital context

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ABSTRACT

Introduction. Mental health services have been a focus of human rights advocates and recent legal reforms in some Latin American countries, which have called for a change from the paradigm of hospitalization to one of accompanying and supporting the person with mental health issues, which make it possible to apply the Advance Directives in Psychiatry (PADs). This change will require time, as well as economic, material, and human resources, and transformations in attitudes, culture, and society, but the implementation of PADs cannot be postponed: they must be used to protect the autonomy of the persons affected, within a bioethical framework. **Objective.** Identify possible bioethical conditions in the prevailing conventional hospital context in Latin America that allow for an implementation of PADs. **Method.** A participant-observer study was carried out in two psychiatric hospital services from June to September 2022. **Results.** A thematic analysis found three themes: 1) clinical care, 2) patient predisposition, and 3) medical-legal questions. This study considered part of theme 2, including the following sub-themes: a) patient self-perception, b) biography/narrative versus diagnostic classification, and c) negotiation. **Discussion and conclusion.** Prominent among the sub-themes discussed are recognition of the values of autonomy and its elements in all of the expressions of the person with mental illness, as well as actions of the physician or health care team in synergy with supported decision-making, a distinctive feature of the anticipatory process of the PAD.

Keywords: Bioethics, advance directives, psychiatry, hospitalization, mental health, autonomy.

RESUMEN

Introducción. La atención de la salud mental se ha visto emplazada por los Derechos Humanos y las recientes reformas legales en algunos países latinos, que instan a cambiar el paradigma asistencial de la hospitalización al del acompañamiento y apoyo en la toma de decisiones de la persona en condición mental, que posibilitan la aplicación de las Directrices Anticipadas en Psiquiatría (DAP). Este cambio implica tiempo, recursos económicos, materiales y humanos, transformaciones actitudinales, culturales y sociales. No obstante, la implementación de las DAP no puede postergarse, deben aplicarse basadas en el respeto a las personas en un marco bioético. **Objetivo.** Identificar las condiciones bioéticas posibles en el contexto hospitalario convencional, imperante en los países de América Latina, que permitan la implementación de las DAP. **Método.** Se llevó a cabo una observación participante en dos servicios de hospitalización psiquiátrica, entre junio y septiembre de 2022. **Resultados.** A través de un análisis temático se obtuvieron tres temas: 1) atención clínica, 2) predisposición de los pacientes y 3) asuntos médicos-legales. Este estudio consideró sólo una parte del tema 2 con sus subtemas: a) Autopercepción de los pacientes, b) biografía/narrativa versus clasificación y c) negociación. **Discusión y conclusión.** En los subtemas discutidos se resalta el reconocimiento a los valores de la autonomía y sus elementos presentes en todas las manifestaciones de la persona con enfermedad mental, se reconoce también el actuar del médico o equipo de salud en sinergia con la toma de decisiones apoyada, que distingue el proceso anticipatorio de las DAP.

Palabras clave: Bioética, directrices anticipadas, psiquiatría, hospitalización, salud mental, autonomía.

INTRODUCTION

The psychiatric advance directive (PAD) is a process by which people with mental disorders determine in advance aspects of their care after they may lack the ability to do so, in order their wishes regarding care and treatment be understood and respected. The PAD is an instrument in the field of mental health that protects patient rights and the legitimacy of their decisions (Mondragón & Guarneros, 2020).

PADs have been introduced within the framework of recognizing fundamental rights under the Convention on the Rights of Persons with Disabilities, approved by the United Nations on December 13, 2006 (United Nations, 2006; Scholten, Weller, Kim, & Vollmann, 2021), as well as in mental health reform legislation in Latin American countries such as Chile (Law 21.331, "On the Recognition and Protection of the Rights of Persons in Mental Health Care") (Ministerio de Salud, 2021) and Mexico ("General Law on Mental Health and Addictions") (Secretaría de Salud, 2022; Marshall & Gómez, 2022). These laws conceptualize PADs as part of the rights of persons to mechanisms of support in decision-making, anticipating their future state of health.

The recent legislation of PADs in coordination with the U.N. Convention is intended to adapt mental health care to the social model of mental diversity; it constitutes a change from a paternalist posture to one of accompaniment in decision-making (Stavert, 2021; Marshall & Gómez, 2022). Self-determination, effective equality of rights, and the participation of persons with potential disorders is made explicit in the provision of care, therapeutic interventions, hospitalization, and other measures.

PADs allow people to specify therapeutic preferences, such as alternatives to hospitalization, restrictions, and confinement (Appelbaum, 2004; Srebnik, Appelbaum, & Russo, 2004; Srebnik & Kim, 2006). Even though, as Marshall and Gómez (2022) note, hospitalization should not be seen as involuntary if it is authorized in advance, PADs provide for it to be considered an "exceptional" measure in persons who experience an episode of acute instability (Amering, Stastny, & Hopper, 2005). The intent of the Convention and related legislation is to eliminate coercive interventions in order to guarantee the rights, the preferences, and the wishes of persons with psychosocial disability or mental illness (Szmukler, 2019; Noguero & Peregalli, 2021; Stavert, 2021; Scholten et al., 2021; Marshall & Gómez, 2022).

Noguero and Peregalli (2021) describe how admissions to closed hospitals with restrictive conditions involve the loss of freedoms, the traumatic experience of confinement, and the possibility of cruel or degrading treatment, with adverse effects on personal dignity. Latin American health systems generally lack alternatives to conventional hospitalization, such as home confinement or open-door acute psychiatric units, that are available in other countries (Cuevas-Esteban et al., 2022). If these alternatives are not developed in the region, the hospital context will continue to be one of paternalism and guardianship in a rehabilitative model, although also a resource, sometimes, compatible with bioethical principles and practices, such as informed consent (Valenti, Giacco, Katasakou, & Priebe, 2014; Martí, 2015).

The form of mental health care put forward by the Convention and the recent legislation in Latin American countries calls for a series of changes: increased budgets, specific resources, and development of alternatives in favor of a social model that would make possible the full implementation of PADs. However, their implementation should not be delayed while these changes are awaited. It should, moreover, be considered within the framework of bioethics. From this perspective PADs are part of an autonomist model that has been developed and accepted in recent years in health care contexts. This model considers the person affected by disorders as an active party, together with the health care team, in the making of decisions about procedures and treatment, including the making of decisions in advance.

Scholten, Gieselmann, Gather, and Vollmann (2019) describe the different aspects of autonomy: 1) instrumental, with which persons can decide which treatment options promote their well-being; 2) inherent, which shape their lives according to their own conception of good; and 3) "service users' positive claim on health professionals to be enabled to make autonomous choices. This grounds a duty on the part of health professionals not only to disclose the information about the consequences of the various treatment options in an understandable way but also to enhance service users' decision-making abilities by means of supported decision making" (p. 4). It recognizes people's right to choose a lifestyle they consider valuable, free, and autonomous, with adequate support to allow for full and effective participation in the construction of their health (Casado & Vilà, 2014).

Changing the paradigm of mental health care in Latin America from one of hospitalization to one of accompaniment and support in personal decision-making is essential, even if it requires time and multiple transformations (United Nations, 2006; Noguero & Peregalli, 2021; Stavert, 2021; Cuevas-Esteban et al., 2022). The implementation of PADs cannot be postponed, and it must take place based on a respect for persons in a framework of bioethics.

The objective of this study was to empirically identify the possible bioethical conditions in the prevailing conventional hospital context in Latin America that would permit the implementation of PADs.

METHOD

Design of the study

This was a qualitative study with simple participant observation (Monje, 2011, p. 153; Mondragón, Romero & Borges, 2008; Larraín, 2008; Castillo, 2018; Bárcenas & Preza, 2019; Granados, 2020, p. 5), carried out with a convenience sample in hospital services in the two major mental health institutions in Chile, from June to September 2022.

Sample

The sample was recruited from three specialized psychiatric units for men and women aged 14 and older. The units were located in hospital services at two different institutions, one public and one private, in the north of Santiago de Chile.

Measurements

Field diary. A field diary was used for observation to record the daily progress of events, experiences, happenings, concrete situations, impressions, statements, and other data. This type of instrument records systematic and detailed observations and information collected in situ (Larraín, 2008, p. 2), accumulating, categorizing, and synthesizing data for interpretation and analysis (Monje, 2011, p. 154; Castillo, 2018, p. 4; Granados, 2020).

Procedure

Participant observation began once approval was received from the Research Ethics Committee. The principal investigator attended the supervisory meetings for the cases of patients admitted to each of the three specialized psychiatric units in the participating institutions, and recorded, facts, objects, events, interactions, ideas, fragments of conversations, perceptions, opinions, and discussions of the treating health care team. The information was recorded in a detailed and systematic manner in a field diary for later evaluation, interpretation, analysis, and description (Monje, 2011; Larraín, 2008; Castillo, 2018; Bárcenas & Preza, 2019).

Statistical analysis

The data analysis compiled the information from the field diary into a single text file with 177 entries. A thematic analysis was performed (Howitt, 2010) to identify broad themes that characterized the content. Although this is a type of analysis used in qualitative research, it is less demanding than other techniques, since it is not closely associated with a particular theory, and is appropriate as a descriptive tool.

A descriptive coding of the data was carried out, with each word, phrase, or statement that referred to a theme assigned a code. During this process, some codes that were unsuitable were subdivided or corrected, and some with overlapping meanings were combined. The process produced 531 codes for the 177 entries. The codes that appeared most frequently (more than four times) were combined, producing 438 distinct codes.

The next step in the analysis was the identification of themes. Constructs connecting with a substantial number of codes were examined, and grouped in terms of similarities and common characteristics, which allowed for an evaluation of whether themes reflected relationships or differences between codes. The themes constructed captured the general meaning of the descriptive coding. Throughout the process of construction of themes, the relevance of each was reviewed with respect to the data as a whole and also among new themes with the entries from the field diary. The grouping of the codes and the development of themes were carried out based on the idea propounded by various authors that themes are not found in the codes themselves, but in the deliberation regarding a particular issue or its emphasis as a process of construction carried out by researchers in relation to a significant narrative (Braun & Clarke, 2006; Michel, Tachtler, Slovak, & Fitzpatrick, 2020).

The final step in the thematic analysis was a literature search regarding PADs and related texts, in order to support interpretation of the codes and themes. To complete the analysis, the entries in the field diary were reviewed once again, this time in light of the themes that had been developed. The importance of each theme was based on its relevance to the purpose of the study.

Ethical considerations

The research protocol was approved the Research Ethics Committee of the Santiago de Chile Metropolitan North Health Service. The study guaranteed the privacy and confidentiality of data. Observations omitted any identifying data regarding participants, patients, or third parties. Before observation began, participants were informed about the research project, the commitments and responsibilities involved in the study, its fully voluntary nature, freedom of participation, and other ethical considerations.

RESULTS

Participant observation is a deliberate and systematic process aimed at capturing the reality of a phenomenon under study (Monje, 2011, p. 153; Mondragón et al., 2008; Larraín, 2008; Castillo, 2018; Bárcenas & Preza, 2019; Granados, 2020, p. 5). The results of the thematic analysis of the observation showed three themes associated with the dynamics of psychiatric hospitalization: 1) clinical care, 2) predisposition of the patients, and 3) legal-medical issues. This study considered only the part of theme 2 that was linked to possible bioethical conditions in the hospital context that could facilitate the implementation of PADs.

Theme 2, the predisposition of patients, was defined in the following way in the observation records: “The self-perception of patients as an indicator of seeking help and voluntary hospitalization, as well an exploration of the patient's life history as a narrative, without a priori classification, in order to understand and explain their illness, with the purpose of negotiating the best treatment recommended by the health care team while respecting the decisions of the person with a mental condition and considering their family." This theme has three sub-themes: a) patient self-perception, b) biography/narrative versus diagnostic classification, and c) negotiation. The results for each were as follows:

Patient self-perception. Patient self-perception is an indicator of seeking help and voluntary hospitalization, when there is an ongoing sensation of decompensation, aggression, and impulsivity.

Admission of a patient. This patient mentions that he is being voluntarily admitted, that he is admitting himself because he is decompensated, which for him means that he started being very aggressive with his family, mainly with his mother, [and] also because he feels it. [Entry 18]

Another patient seeks pharmacological help, and the doctors think that is a good symptom, and congratulate him, while the patient doesn't understand why they are congratulating him. [Entry 114]

Biography/Narrative Versus Diagnostic Classification. The biographical details of the patient are given preference over any classification in terms of diagnosis or treatment. In addition to the clinical chart, the health care team focuses on exploring the patient's history, compiling a narrative of the case and symptoms, in order to arrive at a more general diagnosis of the complexity and context of the illness and provide more personalized treatment.

Admission of a patient. After the interview, the team begins to discuss the case; they mention aspects of the [patient's] biography, focusing on the part about the patient's social life. They say that the boy didn't have attention from his parents, although the father provided a lot of information about his life. [Entry 68]

They [the psychiatrists] tell him [the resident or intern] to explore the patient's history in order to know more and find out the causes of his use. [Item 160]

Negotiation. Addresses the need to arrive at an agreement with the patient and sometimes their family about the clinical recommendations of the health care team, such as continuing hospitalization, the best treatment, or at least the most appropriate treatment for the patient. This is a process that is carried out by means of the clinical case description (technical) and the interview (biographical listening), with non-classificatory narrative elements that allow for diagnosis and treatment. The objective of the meeting is to analyze and improve the patient's quality of life and respect their decisions.

There is a negotiation about the follow-up treatment before they discharge the patient, since this person says that this (the hospitalization) is a social experiment and is insisting that they discharge him, but he is very aggressive. [Item 56]

The professionals are divided over presentation of a case because the patient uses drugs, and presents other complaints such as chronic pain and factors related to antisocial acts, so he cannot be treated with a stimulant. Other professionals say that his treatment must be a stimulant. The disagreement is whether he should be discharged or not with stimulant medication. The question is what purpose it serves to keep him hospitalized longer, what benefit it would bring to him, and they answer and agree that it is necessary to learn more about the patient's life in order to offer him appropriate treatment with management of the controlled medication, that it not be abused. In the end they arrive at a negotiation to address more information with his family and see how much the patient can commit to change his use, so he will remain under observation for a while longer before he is discharged. [Item 75]

The treatment for the patient to be discharged and his willingness to follow up his care is important. One patient wants to leave the hospital to continue with his studies, but the team know that for now his social environment would make it impossible to manage his marijuana use, so they agree to negotiate with the patient and his treating physician, where they will highlight or emphasize as central the decisions the patient should make, so that there is an insight. If the patient decides to pursue his studies, they will ask him to go to follow-up treatment or another alternative that the psychiatrists are thinking of recommending. [Item 163]

DISCUSSION AND CONCLUSION

The first finding of this study concerned the patients' self-perception regarding feelings of decompensation, aggression, and impulsivity that lead them to seek help through hospitalization. This can be recognized as an autonomous act on their part, insofar as their consciousness of themselves and their decision-making ability, apart from the cognitive elements, includes their preferences and wishes, which allow them to recognize their symptoms and express an intention, such as asking for help or requesting voluntary hospitalization (Mondragón, Monroy, Ito & Medina-Mora, 2010; Szmukler, 2019).

Self-perception is not always a characteristic of people with mental disorders. Some people ignore or are not conscious of experiencing the first symptoms of an acute episode and thus do not seek help or present themselves as patients. This could call into question the instrumental or inherent value of their autonomy, not only in the sense of self-consciousness, but above all as a patient's ability to make decisions or declare their preferences. According to Hiu, Su, Ong, and Poremski (2020), this is one of the reasons PADs have not enjoyed widespread adoption (Scholten et al., 2019; Szmukler, 2019; Gloeckler, Ferrario, & Biller-Andorno, 2022).

This finding could thus be linked to the "combined supported decision-making model" of Scholten et al. (2019, p. 2), who note that the support of decisions in this model involves "substitute decision making in cases where a person's functional decision-making capacities remain below the threshold of competence despite the provision of support," as well as the evaluation of functional capacities of health choices. This model makes the objectives of the PAD compatible with accompaniment in decision-making for people with mental illness, as in the self-binding directives also known as Ulysses contracts (Potthoff et al., 2022).

Patients' self-perception of the symptoms preceding an acute episode and their request for voluntary hospitalization also appears to be related to safety or risk reduction. This finding is consistent with the results of Valenti et al. (2014), in their study of the values most important to patients who had been involuntarily hospitalized in England. They report that patients consider hospitalization as a form of risk reduction arising from their symptoms and illness, and that they justify their stay in the hospital as being in a safe place. Potthoff et al. (2022) also found that people perceive involuntary intervention, anticipated in a directive, not as a form of coercion, but as help and treatment. The interpretation of voluntary hospitalization as providing a clinical environment for the benefits of treatment in terms of risk reduction (Valenti et al., 2014) allows for a consensus between the physician and the patient at the moment of making a specific decision. Involuntary hospitalization is a very different situation, which the results of the current study do not examine.

Autonomy that emphasizes patients' preferences and desires, with respect to caring for themselves or perceptive self-care, is an essential bioethical principle in the implementation of PADs (Szmukler, 2019). The way in which to make this principle concrete is a still unresolved question requiring further investigation. Patients' search for help and voluntary hospitalization are acts that require physicians' support and accompaniment, that recall the duty to respect a person's decisions and act for their benefit, reducing the risks and increasing the benefits of treatment such as confinement and the patient's safety. Doing so allows the person labeled as a patient to play an active part in decision-making, together with the health care team, as implied by the respect for autonomy and the beneficial intent specified in PADs.

Another finding of this study was that of putting elements of the patient's history or biography ahead of any diagnostic classification in treatment. The approach through case narrative, symptoms, and diagnosis provides a concrete interpretation to the complexity and context of the illness and results in a more personalized treatment. This type of psychiatric approach allows for an implementation of PADs from a bioethical perspective that is more hermeneutic and more centered on the person, according to the development of their abilities for full participation (Casado & Vilà, 2014).

The importance of knowing the history or biography of people with mental illness as part of their care is consistent with the results of Hiu et al. (2020), who studied opinions and interests in the application of directives between persons diagnosed with psychotic disorders and care providers in Singapore. They found that patients had a greater interest in discussing non-clinical preferences, such as financial or dietetic concerns, or notification of their employers in order to obtain sick leave, and suggest that these preferences could improve their personal autonomy. They recommend that care providers recognize such information that can be added to PADs, that they value the document for more than its clinical content. PADs reflect the values and opinions that support people's lives, and for this reason non-clinical preferences should also be included (Hiu et al., 2020).

The second finding of this study, regarding biography or narrative versus diagnostic classification, supports the psychiatric and bioethical perspective that can provide utility, value, and meaning to PADs. Knowing a patient's history could also provide appropriate support or accompaniment for clinical and non-clinical decision-making that patients consider valuable, and important to their full participation in PADs. Plans for anticipated care should thus be reoriented to people's daily lives (Nicaise, Lorant, & Dubois, 2013; Casado & Vilà, 2014; Hiu et al., 2020; Stavert, 2021).

The third result of this study regards negotiation. At times it is necessary to come to an agreement with a patient and their family about the clinical recommendations of the health care team, such as whether to continue hospitalization or how to determine appropriate treatment, in order to consider and improve the patient's quality of life and respect their decisions about their health. According to Noguero & Peregalli (2021), hospital admissions can affect people's trust in health care personnel, with negative effects on the therapeutic process. However, hospital admissions and the care received can also be the focus of negotiation. Our results show that an agreement is made between people with mental illness and health care professionals about the most appropriate treatment. Negotiation is focused more on follow-up treatment and care plans that are consistent with people's daily lives (Nicaise et al., 2013).

This type of negotiation is not separate from that required for implementation of PADs. Nicaise et al. (2013) conducted a systematic review that considered PADs as multi-step interventions, including the drafting of the document, its finalization, and access. They found that 1) the drafting and content of the PAD are negotiated among the patient, physicians, and third parties; 2) PADs are created to strengthen the autonomy of people with mental illness or psychosocial disability, but the approval by physicians is critical to their effectiveness; and 3) support for PADs is greater if physicians and the health care team participate in the production of the document, especially in cases involving refusals of treatment. Scholten et al. (2019) found that 66% to 77% of the users of community mental health services in the U.S. would want a PAD if they were provided support, a figure comparable to those reported for New Zealand, the U.K., and India.

The negotiation carried out in the hospital context could be a model for deliberation, based on bioethics, in implementing PADs. It recognizes the ability of persons with mental illness to choose in advance their treatment, therapeutic measures, and circumstances associated with interests, preferences, and values in daily life for the moment in which they can no longer do so. It also involves a respect on the part of the physician and health care team that motivates shared decision-making (Nicaise et al., 2013; Szmukler, 2019). The results obtained here show that this context includes the bioethical considerations that could allow for the implementation of PADs. Each of the issues discussed here highlights the need for recognition of the values of autonomy and the issues in all the circumstances surrounding the person with mental illness, but the actions of the physician and the health care team are also recognized as a synergy in decision-making, in the form of support or as part of the combined supported decision making model (Scholten et al., 2019), considerations that characterize an anticipatory process. These issues are consistent with those found in the literature on PADs, noting that although PADs have been designed to increase the patient's autonomy, they turn out to be most effective in maintaining the therapeutic alliance (Nicaise et al., 2013; Scholten et al., 2019; Szmukler, 2019; Noguero & Peregalli, 2021; Gloeckler et al., 2022).

For the implementation of PADs in Latin America, it will be necessary not only to reconsider autonomy from a synergetic perspective, but also to address the challenges faced by some of the countries in the region, not only in the domain of clinics or health systems, but also in adaptation to viable and culturally congruent practices, such as mental health education and the identification and reduction of economic and structural barriers (Amering et al., 2005; Scholten et al., 2019; Szmukler, 2019; Gloeckler et al., 2022; Potthoff et al., 2022).

Biothics can play a fundamental role in the implementation of PADs, but further research will be needed. The findings of this study include some limitations, but they also demonstrate practices in the hospital context that allow for an approach to bioethical conditions that may be necessary for the implementation of PADs.

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Conflicts of interest

The authors declare they have no conflicts of interest.

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