



ARTIGO DE REVISÃO SISTEMÁTICA/SYSTEMATIC REVIEW ARTICLE

Planeamento Antecipado de Cuidados para Pessoas com Esquizofrenia e em Situação de Fim de Vida: Uma Revisão Sistemática Qualitativa

Advance Care Planning for People with Schizophrenia and an End-of-Life Situation: A Qualitative Systematic Review

JOSÉ PALMA GÓIS^{*1,2}

1. Psychiatry Service, Hospital do Espírito Santo, Évora Portugal
2. Polytechnic Institute of Castelo Branco, Castelo Branco, Portugal

Resumo

Introdução: As pessoas com esquizofrenia têm um risco acrescido de mortalidade ao mesmo tempo que recebem menos cuidados paliativos, dos quais o planeamento antecipado de cuidados é um componente essencial. O objetivo desta revisão é reunir as provas disponíveis relativamente ao planeamento antecipado de cuidados em contexto paliativo em pessoas com esquizofrenia, os seus obstáculos e as boas práticas a serem seguidas.

Método: Revisão sistemática da literatura qualitativa ao longo dos últimos 20 anos relativamente à utilização de planeamento antecipado de cuidados em cuidados paliativos ou de fim de vida em pessoas com esquizofrenia.

Resultados: Sete artigos foram incluídos na revisão. Por análise temática foram identificados cinco temas, nomeadamente, a capacidade de decisão em doenças mentais graves, as particularidades do planeamento antecipado de cuidados na pessoa com esquizofrenia, as características da esquizofrenia que afetam o planeamento antecipado dos cuidados, comunicação e formação, e a multidisciplinaridade e continuidade de cuidados.

Conclusão: É urgentemente necessária mais investigação nesta área. Os pacientes enfrentam obstáculos relacionados com a sua doença mental, desconforto e dúvida por parte dos profissionais de saúde e falta de figuras de apoio. Uma abordagem multidisciplinar e colaborativa, a formação e o reconhecimento da capacidade inerente dos pacientes para fazerem escolhas e terem discussões eficazes sobre o seu estado de saúde, facilita o processo de planeamento antecipado de cuidados.

Abstract

Introduction: People with schizophrenia suffer a higher risk of mortality and at the same time receive less palliative care, of which advance care planning is a key element. This review aims to gather available evidence regarding the use of advance care planning in palliative care in people with schizophrenia, its obstacles and the best practices that should be followed.

Methodology: A systematic review of the literature over the past 20 years, with a qualitative focus, on the use of advance care plans for people with schizophrenia and in end-of-life or palliative situations.

Results: Seven articles were included in the review. Five themes were identified from the thematic analysis, namely decision capacity in severe mental illness, peculiarities of advance care planning in people with schizophrenia, characteristics of schizophrenia that can affect advance care planning, communication and training, and multidisciplinary and continuity of care.

Conclusion: More research in this area is urgently needed. Patients face obstacles related to their mental illness, discomfort and doubt from health professionals, and lack of supportive figures. A multidisciplinary and collaborative approach, training and recognition of patients' inherent ability to make choices and to have effective discussions about their health status, facilitate the process of advance care planning.

Recebido/Received: 2020-07-10

Aceite/Accepted: 2020-09-29

Publicado / Published: 2020-11-27

*Autor Correspondente/Corresponding Author: José Palma Góis | josegois66@gmail.com | Psychiatry Service, Hospital do Espírito Santo, Évora Portugal | Largo do Sr. da Pobreza, 7000-811 Évora
© Author(s) (or their employer(s)) and SPPSM Journal 2020. Re-use permitted under CC BY-NC. No commercial re-use./
© Autor (es) (ou seu (s) empregador (es)) e Revista SPPSM 2020. Reutilização permitida de acordo com CC BY-NC. Nenhuma reutilização comercial.

Palavras-chave: Cuidado Terminal; Cuidados Paliativos; Esquizofrenia; Planeamento Antecipado de Cuidados

Keywords: Advance Care Planning; Palliative Care; Schizophrenia; Terminal Care

INTRODUCTION

a. Rationale for the review - theoretical and practical relevance

Advance care planning (ACP) can be defined as a process that supports patients in understanding and establishing goals, plans and preferences for their future, with regard to decisions on medical treatment and health care, compatible with their life choices and values.¹ This process can be initiated at any stage of life, regardless of health status, and may include the naming of other people meaningful to the individual who may in the future participate, or replace the individual, in the decision-making process.² Advance care planning implies discussing choices and objectives with health professionals, family, and caregivers, and may have its ideal timing when the patient's health status worsens; all decisions should be recorded.³

Advance care planning can include, but goes beyond, the concept of the advance directive (AD), which is a document with legal value, defining specific orders of treatment and medical intervention (e.g. orders not to resuscitate).^{4,5} Advance care planning is a key element of integrated palliative care provision,⁶ allowing the patient to decide, while still having the capacity to do so, on treatments and other future choices, including those related to his death.⁷ Early decisions avoid unnecessary end-of-life interventions and value individual patient choices and preferences.^{8,9} The respect for, and the early integration into the palliative process of, the wishes and choices of patients and their families is, together with the individual adaptation of care and the integration of the palliative approach into health systems, one of the three key themes of the palliative approach identified by Sawatzky and colleagues in a recent literature review.¹⁰ The research we present next shows that people with schizophrenia receive less, and worse, palliative care compared to their peers without schizophrenia. However, the specific issue of advance care planning *per se* is often not directly addressed in the literature.

Schizophrenia affects about 0.75% to 1% of the population.¹¹ Recent data indicate a median lifetime prevalence of 7.49 per 1000 of the population suffering from primary psychoses.¹²

Schizophrenia is a chronic, disabling and incurable disease that results in a decrease in the life expectancy of patients by as much as 10 to 20 years.¹³ The causes of mortality in these patients are suicide¹⁴ and physical diseases such as cancer, cardiovascular, respiratory, liver and endocrine diseases.¹⁵⁻¹⁸

These patients tend to remain on the margins of health care and exhibit risky behaviors such as smoking, substance abuse, poor diet and sedentariness.¹⁹⁻²³

Studies show that these patients seek between two and three times less physical health care, have difficulty in making

lifestyle changes, do not value their health problems and experience little collaboration between their mental and physical care providers.²⁴⁻²⁷ Faced with an equivalent risk of cancer, patients with schizophrenia are less screened for cancer, die more and receive less chemotherapy, radiotherapy and palliative care than the general population.^{18, 28}

The fact that they are often isolated from society and health services makes it difficult to identify the need for palliative care at the end-of-life or in the face of chronic progressive and disabling illness.²⁹ Canadian studies show that these patients tend to die in nursing homes rather than hospital services, and are less likely to receive end-of-life care, be followed by specialists (other than their psychiatrists) or receive appropriate analgesia.³⁰

People with schizophrenia at the end-of-life are about half as likely to receive palliative care as other patients and are generally not considered fit to make advanced end-of-life decisions, even when in fact they are.^{31,32} A recent Australian study found that in a population of patients who died of cancer, only 27.5% of those with schizophrenia had access to community palliative care, versus 40.4% of those without.³³

There are several factors that make it difficult for a patient with schizophrenia to access palliative care. Relyea *et al* mention the stigma of mental illness and the tendency to attribute physical symptoms to the schizophrenia, difficulties in understanding the diagnosis, difficulties in making decisions, social isolation of the patient, and difficulty in being admitted to a palliative or medical service when one has a mental illness.³⁴

Factors such as being homeless, having little family or caregiver support, difficulties in establishing trusting relationships with unfamiliar health professionals, and symptoms of the psychotic illness can make it difficult both to access and to accept palliative care.³⁵

Best practice implies the collaboration between various medical specialties, psychiatry, social services, and caregivers, as well as the early initiation of palliative care.³⁶

Psychosocial interventions, complex pharmacological management, interdisciplinary and family collaboration, and setting of care goals are best practices identified for these patients.³⁴

The inability of these patients to make decisions in a palliative context should not be presumed. An inclusive multi-specialized approach that addresses the physical and mental illnesses, lifestyles, and substance use, should be used.²⁹

Patients with schizophrenia may be able to decide on analgesia and end-of-life care preferences.^{32,37} Foti *et al*³² conclude that patients with severe mental illness generally choose the same options for themselves as they would for others in hypothetical palliative settings, and therefore care planning and future options using imaginary situations may facilitate the patient's reflection. However, the

expression of these decisions by psychiatric patients is rare. In a study of a small group of 150 severe psychiatric patients, 66% of whom had schizophrenia, only 27% of patients had thought of advance care planning for future medical situations, and only 5% had discussed it with a doctor.³⁷

Cai and colleagues,³⁸ in a quantitative study of residents of nursing homes in the United States show that only 57% of residents with severe mental illness (schizophrenia and other psychoses and bipolar disorder) had any kind of advanced directive, as opposed to 68% of those who did not have mental illness. The authors concluded that the most likely reason was a bias by health professionals who presumed a basic incapacity of patients with mental illness to discuss these issues.

OBJECTIVES

In view of these data, it seemed pertinent to study the use of advance planning of care in this population at risk. We pretended to identify factors that may be barriers to advance care planning and gather indications of best practices for their use.

STARTING POINT

What evidence is there about the use of advance care planning for people with schizophrenia who are at the end of their life, or receiving or being referred for palliative care, due to physical, advanced, incurable and progressive illness?

a. Specific objectives

To synthesize the existing evidence on the use of advance care planning in people with schizophrenia and in palliative situations

To identify the obstacles that may exist to the use of advance care planning in these patients

To identify the best practices to be followed for the use of advance care planning in patients with schizophrenia and in palliative situations

METHODS

a. Search Descriptors

A comprehensive search was conducted of the following databases: b-On, Polytechnic Institute of Castelo Branco Bibliographic Catalogue and Scientific Repository, ClinicalKey, Cochrane Database of Systematic Reviews, Directory of Open Access Journals – DOAJ, OAIster, Open Grey, Prospero, PubMed and PubMed Central, Open Access Scientific Repository of Portugal – RCAAP, Scopus, and Web of Science – all data bases, including Medline.

The b-On, Scopus and Web of Science databases were accessed on the EBSCO platform through the library of the Polytechnic Institute of Castelo Branco (IPCB), where the author is a master's degree student in palliative care. The PROSPERO and Cochrane databases were searched

with the purpose of confirming if a similar review work existed.

The selected articles from the database searches were also searched manually, and bibliographic references considered potentially relevant were obtained.

The search was anchored to the following three search terms/concepts: “Palliative care; advance care plan; schizophrenia”.

For each of these terms the following English language synonyms or equivalent terms were also added:

1. palliative care OR end-of-life care OR terminal care OR dying OR hospice OR end-of-life
2. advance care plan OR acp OR advance-care plan OR end-of-life plan OR terminal care plan OR end-of-life plan OR terminal-care plan
3. schizophrenia OR psychosis OR psychoses OR psychotic disorder OR schizophrenic disorder OR severe mental illness

The automatic search was done for the 20-year period from 1999 to 2019. In databases where it was not possible to define the time period, the entire database was searched. An additional search on the Google search engine was done up the end of March 2020. Appendix 1 provides further details of the search methodology used.

d. PICOD (population, intervention, comparison, outcome, study design)

i. Population

Inclusion: The population of interest were adults with schizophrenia or related diseases such as schizoaffective disease or primary delusional disorders (but not dementia, not affective diseases, not substance related), and who were receiving or had indication for palliative care, or who were at the end of their lives (last 12 months of expected life) due to the presence of an advanced, incurable and progressive physical illness.

Exclusion: Minors under 18, psychiatric illnesses other than schizophrenia or related diseases.

ii. Intervention

The objective was to identify factors that influence the use or not of advance care planning, and the best practice for its use in this population.

Inclusion: Studies in which *advance care planning* was explicitly addressed in adults in end-of-life/palliative care and those with schizophrenia or related illnesses.

Exclusion: Studies where *advance care planning* is not explicitly addressed.

iii. Comparison

Does not apply.

iv. Outcome

Practices, processes and interventions addressing advanced care planning in palliative care for people with schizophrenia; obstacles to these processes, opinions, experiences and practices of patients, caregivers and health professionals.

v. Design

The emphasis was on qualitative studies, but grey literature and other relevant scientific publications with a qualitative focus would also be considered.

f. General inclusion and exclusion criteria

Inclusion: qualitative focus studies, on adults over 18 years of age, diagnosed with schizophrenia or diseases of this spectrum; in English or Portuguese. Studies or papers with available abstract or accessible full text.

Exclusion: all other mental illnesses. In the case of dual pathology, where substance dependence is the main diagnosis. Studies where the palliative approach is for the mental illness itself and not because of a physical, advanced, incurable and progressive illness. Non-qualitative works or without a qualitative component capable of direct analysis.

g. Data Collection

After searching the databases all citations were uploaded to the EndNote Web programme (<https://access.clarivate.com/login?app=endnote>) and duplicates and irrelevant results eliminated. The remaining titles and abstracts were sorted based on the inclusion and exclusion criteria.

The review followed the PRISMA flowchart process (<http://www.prisma-statement.org>), illustrated in Fig. 1. The data extracted were the identification of the study/article, the principal author, year of publication, country of origin, biographical characteristics of patients and diagnosis, type of study, approaches identified in the use of advance care planning, obstacles identified to the use of advance care planning, and best practices suggested for advance care planning.

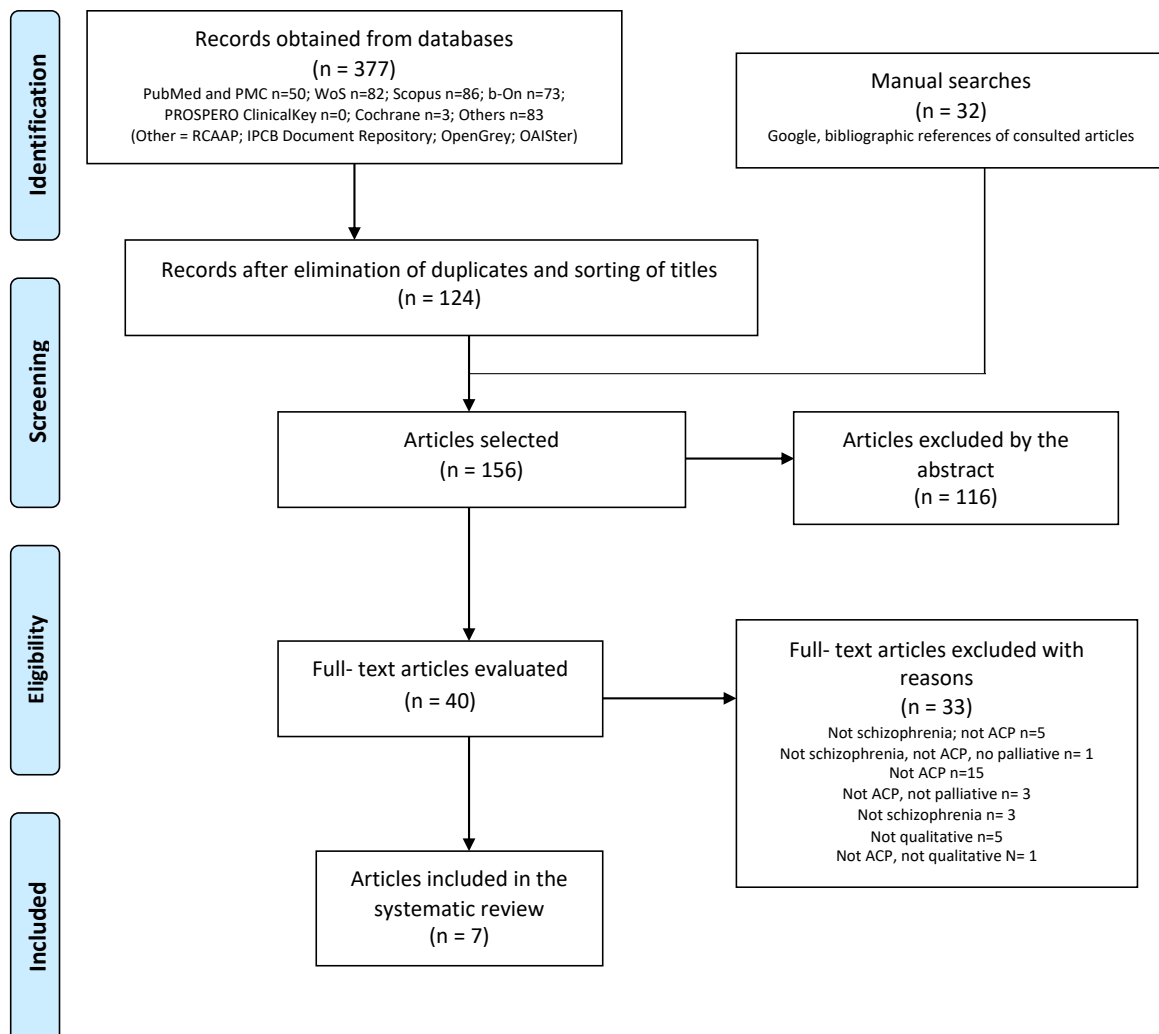


Figure1. Flowchart based on the PRISMA model

h. Risk of bias assessment (quality assessment)

All selected papers were evaluated using the CASP - Critical Appraisal Skills Programme for Qualitative Research (<https://casp-uk.net/wp-content/uploads/2018/01/>

CASP-Qualitative-Checklist-2018.pdf), and CASP - Critical Appraisal Skills for Systematic Review (https://casp-uk.net/wp-content/uploads/2018/01/CASP-Systematic-Review-Checklist_2018.pdf), depending on the nature of the paper.

We chose to evaluate non-systematic reviews with the CASP – Review, since in our opinion, even without systematization, this was the most appropriate instrument to use. Each item was rated on a scale from 0 to 20, and each was assigned a low (0-6) medium (7-13) or high (14-20) quality score. The individual scores are presented in Appendix 2. We recognize as weaknesses and risk of bias in our paper there being a single author doing the screening, the selection of papers and the data analysis. We recognize as a weakness of our study not having access to the EMBASE database, although this is partially mitigated by the fact that the Scopus and ClinicalKey databases are from the same publisher, Elsevier, and share some data sources with EMBASE.

i. Data Analysis

The qualitative data was summarized using a thematic approach. The overarching themes were determined by

inductive method following the analytical and careful reading of the selected papers and studies.

RESULTS

a. Characteristics of studies

Seven studies^{29,36,39-43} were selected for inclusion in the systematic review, whose characteristics are presented in Table 1. Of the 156 articles obtained by database searches and manual search, 40 were selected for full text analysis. Of these, 33 were excluded for not meeting eligibility criteria, the most frequent cause being not directly addressing advance care planning (n=15). See Fig. 1.

Of the seven final articles, two are systematic reviews,^{39,40} two are non-systematic reviews,^{36,43} one is a qualitative study with thematic analysis,²⁹ one is a mixed qualitative - quantitative paper⁴¹ and one is a *case report*.⁴²

Table 1. Descriptive characteristics of the articles included in the analysis

Article	Country	Population	Main results	Design	Limitations	CASP Score
McNamara <i>et al</i> , 2018	Australia	End-of-life schizophrenia	Vulnerable population, especially at the end-of-life Social factors make end-of-life care difficult. Difficulty with decisions and self-care. Late diagnosis of palliative needs. Need for representatives, / caseworkers to fight for the patient. Need for multidisciplinary teamwork. They receive less and worse palliative care.	Qualitative study. Interviews with professionals with experience of people with schizophrenia at end-of-life.	Located in a territory of Australia. Small number of subjects (16).	19
Hanan, Lyons, 2020	USA	Severe persistent Mental Illness (SPMI)	Absence of a representative, difficulties or doubts with decision capacity interfere with hospice care. Discussions on ACP should be early.	Systematic review.		18
Woods <i>et al</i> , 2008	Canada	SPMI	Need for more research. Four critical areas: capacity to decide and ACP, access to care, care provision, vulnerability. SPMI factors make care difficult. Difficulty of palliative care professionals in establishing relationships with patients. SPMI can make decisions and participate in ACP. A consensus approach is necessary.	Systematic review.	Not exclusively schizophrenia.	18

Article	Country	Population	Main results	Design	Limitations	CASP Score
Shalev <i>et al</i> , 2017	USA	End-of-life schizophrenia	Patients do not inherently lack decision-making ability. Difficulty in treating these patients can in fact increase the value of ACP, for medical and psychiatric contingencies. ACP must be early and frequent.	Short qualitative review.	Not systematic.	15
Foti, 2003	USA	Institutional caregivers and mental health professionals working with SPMI and PAC, family groups of SPMI patients	65% of stakeholders thought that assistance with ACP is positive for people with SPMI. Increased advance directives and ACP completed from 1 in 344 cases (before the project started) to 45 in 961 cases over the 3 years of the project.	Mixed qualitative and quantitative. SPMI palliative care educational project. Assessment of knowledge and training needs.	Located in an area of Massachusetts, USA. No evaluation of change in all interventions No distinction within the SPMI group.	13
Toor, 2019	Canada	2 cases with schizoaffective disorder	Do not assume inability to decide. Do not equate psychiatric symptoms with inability to decide. Importance of support from mental health teams and relevant people for patients. Adjusting times, schedules and space of patient consultation to their needs.	Qualitative case report.	Case report, 2 cases.	11
Baker, 2005	USA	SPMI	Lack of investigation. Importance of addressing end-of-life issues in SPMI. ACP is generally not carried out.	Non-systematic review.	Not exclusively schizophrenia.	9

b. Quality of articles

Of the seven articles, three were of medium quality, and four of high quality. See Table 2.

Table 2. Evaluation of the quality of selected articles

Article	Type	CASP Checklist	Quotation	Quality
McNamara <i>et al</i> , 2018	Qualitative with thematic analysis	CASP-qualitative	19	high
Hanan, Lyons, 2020	Systematic review	CASP-review	18	high
Woods 2008	Systematic review	CASP-review	18	high
Shalev <i>et al</i> , 2017	Non-systematic review	CASP-review	15	high
Foti 2003	Mixed qualitative and quantitative	CASP-qualitative	13	medium
Toor 2019	Qualitative <i>case report</i>	CASP-qualitative	11	medium
Baker 2005	Non-systematic review	CASP-review	9	medium

c. Overview of data

In-depth inductive analysis of the seven articles revealed five overarching themes relating to palliative care advance care planning in people with schizophrenia.

d. Decision-making capacity in severe mental illness

Issues relating to the ability of patients to decide were raised by four articles.^{36,39,40,42} All stressed that it should not be assumed *a priori* that mental illness implies an inability to decide, and state that this ability is generally present. Toor⁴² warns of the risk of interpreting the symptoms of mental illness as an indication of an inability to make decisions.

Nevertheless, the possibility of psychotic illness or its decompensation, with the presence of psychotic symptoms hindering or preventing the ability to make decisions, is a concern that palliative care professionals see as an obstacle to advance care planning.^{36,39,40,42}

The existence of a representative or decision-maker who helps the patient or eventually replaces him/her with decisions, is considered to be of the greatest utility.^{29,39,40} The absence of an advance care plan and/or representatives puts patients at risk of being subjected to unwanted procedures⁴⁰ and excessive invasive interventions at the end-of-life.³⁹

A particular issue is when there are legal limitations imposed on the patient with schizophrenia, which limit his or her decision-making autonomy.⁴¹

e. Characteristics of advance care planning in this patient population

Advance care planning must be early, repeated throughout the palliative process and happen before the critical phases of the terminal illness.^{36,39}

Woods⁴⁰ emphasizes the use of appropriate methods and processes for early planning and decision making for people with psychotic illnesses, referring to the central work of Foti,^{32,37,40,41} using hypothetical scenarios of end-of-life situations and structured questionnaires to assist in decision making.

The link between early directives for psychiatric treatment and early directives for physical treatment in the palliative context is mentioned. Shalev and colleagues refer to the usefulness of having advanced directives that spell out not only the choices of psychiatric but also physical treatments that the patient agrees to in the future.³⁶ However, even when there are practice protocols that indicate the obligatory discussion of advance plans or advance directives, these discussions do not take place with mental patients⁴¹ and the low rate of implementation of advanced psychiatric directives corresponds to a low implementation of anticipated medical directives.⁴³

The role of mental health professionals who know the patient and have an established relationship of trust with him/her is fundamental in palliative care planning.^{29,42} They should help patients create future care plans for both their mental and physical illness.⁴³

f. Characteristics of schizophrenia that can affect advance care planning

Hospitalization is often a disturbing period for patients with psychoses and may not be the best time to have

discussions about advance care planning and decisions about the future,³⁹ hence the importance of having these discussions early in the clinical course and taking advantage of periods of stability of the psychiatric illness.⁴⁰

There is also (unfounded) fear among palliative care professionals that discussions about end-of-life situations may cause decompensation of the psychiatric illness.^{40,41}

Shalev *et al* raise concerns that the possibility that psychotic patients may come to need physical restrictions or sedation in the management of decompensation of their disease, and this may pose ethical questions in palliative care and prevent the creation of advance plans and directives.³⁶

Among the characteristics of schizophrenia that can impede advance planning are the disorganization of thinking that is part of the disease, especially in situations of acute decompensation or symptomatic chronicity,³⁹ and the difficulty people with schizophrenia have in adhering to treatment plans and complying with medical instructions and appointments.⁴⁰

People with schizophrenia have difficulty in establishing trusting relationships and therapeutic alliances, not only in general, but especially with new health care professionals.^{39,40} Hence the importance of including the mental health team in advance care planning, who are familiar figures and have an established relationship with the patient.^{29,41-43}

The frequent breakdown of relations between patients with schizophrenia and their relatives, with the absence of caregivers or representatives, and social isolation, is seen as an obstacle to advance care planning.⁴¹ It is therefore essential attend to the social and cultural particularities of the schizophrenic patient.⁴²

g. Communication and training

The importance of communication seems to be implicitly present in every article, in the issues of decision-making capacity and in the importance of having a representative, a family member or other caregiver involved. Its importance in the dialogue with the patient and relevant persons is explicitly mentioned as a facilitator of advance care planning in two articles.^{29,42}

Foti makes the point that there is a need for effective and regular communication between all mental health and palliative care workers involved in patient care, joint case discussions, and the greater need for cross-training, with mental health professionals generally lacking palliative care training and palliative care specialists lacking mental health training.⁴¹

Multidisciplinary and continued care

The authors stress the need for mental health professionals who treated the patient previously to be involved in care planning and not to break the already-existing therapeutic relationship.^{41,42} The involvement of all health professionals and social services should be of a collaborative nature, including both the patient and caregivers.²⁹

Multidisciplinary implies good working relations between palliative and mental health teams, joint case discussion and collaboration in care planning.^{29,41-43}

DISCUSSION

h. Data Summary

The five themes taken from the revised articles - decision making capacity, particular features of advance care planning in people with schizophrenia, the impact of schizophrenia on advance care planning, communication and training, multidisciplinary and continuity of care - inform us what obstacles and facilitators of advance care planning in these patients exist, and what best practices should be followed.

The identified obstacles include the preconceived ideas of these patients' inability to make important decisions about treatment and not being able to understand or deal with information about their terminal illness. Added to this is the fear that emotionally charged conversations may cause worsening of the mental illness. Equally present is the tendency to equate psychotic symptoms with an inability to decide. However, periods of hospitalization due to worsening physical illness and times of worsening psychiatric illness are obstacles to the process of creating an advance care plan. The absence of a representative or caregiver and the breakdown of family relationships, are seen as fundamental obstacles to the creation of an advance care plan. The lack of advanced psychiatric care planning or psychiatric advance directives is also associated with the absence of an advance care plan or medical advance directives. Another obstacle identified is the discomfort that mental health teams feel in dealing with the palliative needs of their patients and, in parallel, the discomfort of palliative care teams in dealing with patients with severe mental illness.

Patients with schizophrenia find it difficult to establish relationships of trust with health professionals, have difficulty in joining treatment programmes and may be subject to legal measures that limit their autonomy, which make it difficult to create an advance care plan.

Facilitating elements of advance care planning for the schizophrenic patient in palliative care are the early recognition that in general these patients have the same ability to decide about future treatments and options as any other patient. The existence of a representative or significant figure for the patient is of the utmost importance, and here the role of the mental health team that knows the patient well and with whom there is a prior bond of trust, is highlighted. The existence of advance directives or advance planning for psychiatric illness, and the addressing of palliative issues by the mental health team, facilitates the creation of advance medical plans. The stabilization phases of mental illness should be used as ideal times for discussions about advance care planning.

Training in both palliative care and mental illness for the health teams treating the patient, such as joint case discussions and effective communication between all professionals and specialties, facilitates discussions on palliative care with the patient and the creation of advance care plans.

Best practice for the schizophrenic patient in palliative care should include early and repeated discussion of future end-of-life decisions and plans, the participation of representatives and caregivers, and the proactive participation

of the mental health team in discussions on advance care planning.

Joint monitoring between palliative care and mental health professionals and maintaining the patient's therapeutic link with his mental health team is desirable, as is continuous and cross-training between palliative care and mental health teams. These teams should maintain optimal working and collaborative relationships and joint discussion of cases, between themselves and with the patient.

Ideally, advance care plans should be comprehensive and holistic and encompass the care of both mental and physical illnesses.

i. Limitations of the revision

Qualitative studies do not emphasize generalizing their data, but rather seek to identify and validate existing ideas and concepts in current practice.

Even so, our review contains important limitations that need to be considered. First, it results from small number of articles - seven. All of them are from English-speaking countries; one Australian, two Canadian and the rest from the United States, which limits the applicability of the results to other countries, cultures and health systems. For example, in Portugal, the use of advanced psychiatric directives or advance planning of psychiatric care, along the lines of palliative care practice, is not common practice.

Foti's work in this area appears in several of the articles, namely Hanan *et al.*,^{32,37,41} Shalev *et al.*,^{32, 37} and Woods *et al.*^{32,41} There are also cross references between articles - Shalev *et al* cites Mcnamara *et al.*, and Toor and Woods *et al* cite Baker. This situation causes considerable endogamy among the articles that should advise caution to the reader. The dearth of studies dedicated to patients with schizophrenia means that only two of our seven articles deal exclusively with schizophrenia.^{29,36} Toor described two patients with chronic schizoaffective disorder, who nevertheless have a very similar disorder. The remaining four articles dealt with patients with severe persistent mental illness (SPMI), a definition that encompasses several pathologies. However, in all the articles there was specific mention of including people with schizophrenia in their SPMI definition, and it was possible to assess the authors' specific findings pertaining to these patients, giving us some confidence in our analysis. It is estimated that 90% of patients classified as SPMI have schizophrenia.⁴⁴

j. Implications for future research

Qualitative research on care planning for schizophrenic and palliative patients is very scarce. It seems urgent to us that this area be investigated, both to determine the most appropriate processes to make advance care planning the norm for this population, and to identify the obstacles and facilitators to this goal. Generally, advance care planning for these patients is approached only indirectly in the literature, through considerations of decision-making capacity. However, there is a lack of studies directed at process factors, obstacles, facilitators, and best practices to be adopted, specific to early planning of care for the end-of-life patient with schizophrenia.

It is important to investigate the role of mental health professionals at this stage of their patients' lives, so that there is no breakdown in the therapeutic relationship, as they may be the ones in the best position to initiate the care planning process. It is necessary to investigate how to cross-train mental health and palliative care teams to best deal with these patients.

It should be a priority to include people with psychiatric illnesses, particularly schizophrenia, whether or not they be in a palliative situation, in investigations, and to hear what their needs and difficulties are.

Although the diseases included in the group of severe persistent mental illness have many clinical similarities among themselves,^{45,46} it is still a heterogenous group in which joint analysis may not be appropriate.⁴⁷ The definition of SPMI is highly dependent on the degree of dysfunction and duration of the disease^{46,48} rather than disease type., [Estimating the number of adults with severe and persistent mental illness who have complex, multi-agency needs]

and may not take adequate account of the clinical and psychological specificities of the person with schizophrenia with respect to an end-of-life and palliative care situation. We believe that there is a need for research aimed exclusively at patients with schizophrenia.

CONCLUSION

Advance planning of care for patients with schizophrenia and palliative care needs faces obstacles resulting from the characteristics of mental illness, social and relational factors, and difficulties of health professionals in dealing with these patients. Mental health professionals may be in a privileged position to initiate and facilitate this whole process. There is an urgent need for training and collaboration between all professionals who accompany the patient in this phase of life, and to not neglect this fundamental element of quality palliative care provision.

Responsabilidades Éticas

Conflitos de Interesse: Os autores declaram não possuir conflitos de interesse.

Suporte Financeiro: O presente trabalho não foi suportado por nenhum subsidio o bolsa ou bolsa.

Proveniência e Revisão por Pares: Não comissionado; revisão externa por pares.

Ethical Disclosures

Conflicts of Interest: The authors have no conflicts of interest to declare.

Financial Support: This work has not received any contribution grant or scholarship.

Provenance and Peer Review: Not commissioned; externally peer reviewed.

References

- Rietjens J, Korff I, Taubert M. Advance care planning: the future. *BMJ Support Palliat Care*. 2020;bmjcare-2020-002304. doi:10.1136/bmjcare-2020-002304
- Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, et al. Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. *J Pain Symptom Manage*. 2017;53:821-32.e1. doi: 10.1016/j.jpainsymman.2016.12.331.
- Rietjens JAC, Sudore RL, Connolly M, van Delden JJ, Drickamer MA, Droger M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol*. 2017;18:e543-e551. doi:10.1016/s1470-2045(17)30582-x
- Lei n.º 25/2012 de 16 de julho, Diário da República n.º 136/2012, Série I de 2012-07-16 3728-3730 (2012). [Accessed 07-02-2020]. Available from: <https://data.dre.pt/eli/lei/25/2012/07/16/p/dre/pt/html>
- Medline Plus. Advance Directives. Webpage. US National Library of Medicine. [Accessed 11-06-2020]. Available from: https://vsearch.nlm.nih.gov/vivisimo/cgi-bin/query-meta?v%3Aproject=medlineplus&v%3Asources=medlineplus-bundle&query=advance+directives&_ga=2.109397894.2024106621.1591814538-1549090681.1591814538
- den Herder-van der Eerden M, Ewert B, Hodiamont F, Hesse M, Hasselaar J, Radbruch L. Towards accessible integrated palliative care: Perspectives of leaders from seven European countries on facilitators, barriers and recommendations for improvement. *J Integrated Care*. 2017;25:222-32.
- Karver SB, Berger J. Advanced care planning-empowering patients for a peaceful death. *Asian Pac J Cancer Prev*. 2010;10:23-5.
- Agarwal R, Epstein AS. Advance Care Planning and End-of-Life Decision Making for Patients with Cancer. *Sem Oncol Nursing*. 2018;34:316-26.
- Lynn J, Goldstein NE. Advance care planning for fatal chronic illness: avoiding commonplace errors and unwarranted suffering. *Ann Intern Med*. 2003;138:812-8. doi:10.7326/0003-4819-138-10-200305200-00009
- Sawatzky R, Porterfield P, Lee J, Dixon D, Lounsbury K, Pesut B, et al. Conceptual foundations of a palliative approach: a knowledge synthesis. *BMC Palliat Care*. 2016;15:5. doi: 10.1186/s12904-016-0076-9.
- Saha S, Chant D, Welham J, McGrath J. A systematic review of the prevalence of schizophrenia. *PLoS Med*. 2005;2:e141. doi:10.1371/journal.pmed.0020141
- Moreno-Küstner B, Martín C, Pastor L. Prevalence of psychotic disorders and its association with methodological issues. A systematic review and meta-analyses.

- PLoS One. 2018;13:e0195687. doi:10.1371/journal.pone.0195687
13. Laursen TM, Nordentoft M, Mortensen PB. Excess early mortality in schizophrenia. *Annu Rev Clin Psychol.* 2014;10:425-48. doi:10.1146/annurev-clinpsy-032813-153657
 14. Palmer BA, Pankratz VS, Bostwick JM. The lifetime risk of suicide in schizophrenia: a reexamination. *Arch Gen Psychiatry.* 2005;62:247-53. doi:10.1001/archpsyc.62.3.247
 15. Olfson M, Gerhard T, Huang C, Crystal S, Stroup TS. Premature Mortality Among Adults With Schizophrenia in the United States. *JAMA Psychiatry.* 2015;72:1172-81. doi:10.1001/jamapsychiatry.2015.1737
 16. Simon GE, Stewart C, Yarborough BJ, Dixon D, Lounsbury K, Pesut B, et al. Mortality Rates After the First Diagnosis of Psychotic Disorder in Adolescents and Young Adults. *JAMA Psychiatry.* 2018;75:254-60. doi:10.1001/jamapsychiatry.2017.4437
 17. Bitter I, Czobor P, Borsi A, Fehér L, Nagy BZ, Bacskai M, et al. Mortality and the relationship of somatic comorbidities to mortality in schizophrenia. A nationwide matched-cohort study. *Eur Psychiatry.* 2017;45:97-103. doi:10.1016/j.eurpsy.2017.05.022
 18. Irwin KE, Henderson DC, Knight HP, Pirl WF. Cancer care for individuals with schizophrenia. *Cancer.* 2014;120:323-34. doi:10.1002/cncr.28431
 19. Cerimele JM, Katon WJ. Associations between health risk behaviors and symptoms of schizophrenia and bipolar disorder: a systematic review. *Gen Hosp Psychiatry.* 2013;35:16-22. doi:10.1016/j.genhosppsych.2012.08.001
 20. Berti L, Bonfioli E, Chioffi L, Morgante S, Mazzi MA, Burti L. Lifestyles of Patients with Functional Psychosis Compared to Those of a Sample of the Regional General Population: Findings from a Study in a Community Mental Health Service of the Veneto Region, Italy. *Community Ment Health J.* 2018;54:1050-6. doi:10.1007/s10597-017-0223-7
 21. Buhagiar K, Parsonage L, Osborn DP. Physical health behaviours and health locus of control in people with schizophrenia-spectrum disorder and bipolar disorder: a cross-sectional comparative study with people with non-psychotic mental illness. *BMC Psychiatry.* 2011;11:104. doi:10.1186/1471-244x-11-104
 22. Dickerson F, Schroeder J, Katsafanas E, Fehér L, Nagy BZ, Bacskai M, et al. Cigarette Smoking by Patients With Serious Mental Illness, 1999-2016: An Increasing Disparity. *Psychiatr Serv.* 2018;69:147-53. doi:10.1176/appi.ps.201700118
 23. Onyeka IN, Collier Hoegh M, Naheim Eien EM, Nwaru BI, Melle I. Comorbidity of Physical Disorders Among Patients With Severe Mental Illness With and Without Substance Use Disorders: A Systematic Review and Meta-Analysis. *J Dual Diagn.* 2019;1-15. doi:10.1080/15504263.2019.1619007
 24. Vasudev K, Martindale BV. Physical healthcare of people with severe mental illness: everybody's business! *Ment Health Fam Med.* 2010;7:115-22.
 25. De Hert M, Cohen D, Bobes J, Cetkovich-Bakmas M, Leucht S, Ndeti DM, et al. Physical illness in patients with severe mental disorders. II. Barriers to care, monitoring and treatment guidelines, plus recommendations at the system and individual level. *World Psychiatry.* 2011;10:138-151. doi:10.1002/j.2051-5545.2011.tb00036.x
 26. van Hasselt FM, Oud MJT, Loonen AJM. Improvement of care for the physical health of patients with severe mental illness: a qualitative study assessing the view of patients and families. *BMC Health Serv Res.* 2013;13:426. doi:10.1186/1472-6963-13-426
 27. Hahm HC, Segal SP. Failure to Seek Health Care Among the Mentally Ill. *Am J Orthopsychiatry.* 2005;75:54-62. doi:10.1037/0002-9432.75.1.54
 28. Mo PK, Mak WW, Chong ES, Shen H, Cheung RY. The prevalence and factors for cancer screening behavior among people with severe mental illness in Hong Kong. *PLoS One.* 2014;9:e107237. doi:10.1371/journal.pone.0107237
 29. McNamara B, Same A, Rosenwax L, Kelly B. Palliative care for people with schizophrenia: A qualitative study of an under-serviced group in need. *BMC Palliat Care.* 2018 27;17:53. doi: 10.1186/s12904-018-0309-1.
 30. Chochinov HM, Martens PJ, Prior HJ, Kredentser MS. Comparative health care use patterns of people with schizophrenia near the end of life: a population-based study in Manitoba, Canada. *Schizophr Res.* 2012;141:241-6. doi:10.1016/j.schres.2012.07.028
 31. Candilis PJ, Foti MEG, Holzer JC. End-of-life care and mental illness: A model for community psychiatry and beyond. *Community Ment Health J.* 2004;40:3-16. doi:10.1023/B:COMH.0000015214.24404.cc
 32. Foti ME, Bartels SJ, Van Citters AD, Merriman MP, Fletcher KE. End-of-life treatment preferences of persons with serious mental illness. *Psychiatr Serv.* 2005;56:585-91. doi:10.1176/appi.ps.56.5.585
 33. Spilsbury K, Rosenwax L, Brameld K, Kelly B, Arendts G. Morbidity burden and community-based palliative care are associated with rates of hospital use by people with schizophrenia in the last year of life: A population-based matched cohort study. *PLoS One.* 2018;13:e0208220. doi:10.1371/journal.pone.0208220
 34. Relyea E, MacDonald B, Cattaruzza C, Marshall D. On the Margins of Death: A Scoping Review on Palliative Care and Schizophrenia. *J Palliat Care.* 2019;34:62-9. doi:10.1177/0825859718804108
 35. Shalev D, Brewster K, Arbuckle MR, Levenson JA. A staggered edge: End-of-life care in patients with severe mental illness. *Gen Hosp Psychiatry.* 2016;44:1-3. doi:10.1016/j.genhosppsych.2016.10.004
 36. Shalev D, Brewster KK, Levenson JA. End-of-Life Care for Patients with Schizophrenia #332. *J Palliat Med.* 2017;20:787-8. doi:10.1089/jpm.2017.0164

37. Foti ME, Bartels SJ, Merriman MP, Fletcher KE, Van Citters AD. Medical advance care planning for persons with serious mental illness. *Psychiatr Serv.* 2005;56:576-84. doi:10.1176/appi.ps.56.5.576
38. Cai X, Cram P, Li Y. Origination of Medical Advance Directives Among Nursing Home Residents With and Without Serious Mental Illness. *Psychiatric Serv.* 2011;62:61-6. doi:10.1176/appi.ps.62.1.61
39. Hanan DM, Lyons KS. Hospice Use Among Individuals With Severe Persistent Mental Illness. *J Am Psychiatric Nurs Assoc.* 2020:1078390320910482. doi:10.1177/1078390320910482
40. Woods A, Willison K, Kington C, Gavin A. Palliative care for people with severe persistent mental illness: A review of the literature. *Can J Psychiatry.* 2008;53:725-36. doi:10.1177/070674370805301104
41. Foti ME. "Do It Your Way": a demonstration project on end-of-life care for persons with serious mental illness. *J Palliat Med.* 2003;6:661-9. doi:10.1089/109662103768253830
42. Toor H. Palliative care in patients with severe mental illness. *Can Fam Phys.* 2019;65:799.
43. Baker A. Palliative and End-of-Life Care in the Serious and Persistently Mentally Ill Population. *J Am Psychiatric Nurses Assoc.* 2005;11:298-303. doi:10.1177/1078390305282209
44. McCasland LA. Providing Hospice and Palliative Care to the Seriously and Persistently Mentally Ill. *J Hospice Palliat Nurs.* 2007;9:6.
45. Trachsel M, Irwin SA, Biller-Andorno N, Hoff P, Riese F. Palliative psychiatry for severe persistent mental illness as a new approach to psychiatry? Definition, scope, benefits, and risks. *BMC Psychiatry.* 2016;16:260. doi:10.1186/s12888-016-0970-y
46. Whiteford H, Buckingham B, Harris M, Diminic S, Stockings E, Degenhardt L. Estimating the number of adults with severe and persistent mental illness who have complex, multi-agency needs. *Aust N Z J Psychiatry.* 2017;51:799-809. doi:10.1177/0004867416683814.
47. Carlsson IM, Blomqvist M, Jormfeldt H. Ethical and methodological issues in qualitative studies involving people with severe and persistent mental illness such as schizophrenia and other psychotic conditions: a critical review. *Int J Qual Stud Health Well-being.* 2017;12:1368323.
48. Ruggeri M, Leese M, Thornicroft G, Bisoffi G, Tansella M. Definition and prevalence of severe and persistent mental illness. *Br J Psychiatry.* 2000;177:149-55. doi:10.1192/bjp.177.2.149