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ANALYSIS OF INDIVIDUALIZED CARE PLANS FOR FRAIL ELDERLY PEOPLE IN PALLIATIVE CARE

Análise de planos de cuidados individualizados de idosos frágeis em cuidados paliativos

Análisis de planes de atención individualizados para personas mayores frágiles en cuidados paliativos

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RESUMO

Objetivo: analisar o potencial das informações que compõem o plano de cuidados individualizados (PCIs) para o acompanhamento compartilhado do indivíduo idoso frágil pelas diferentes equipes envolvidas no apoio matricial. **Metodologia:** estudo qualitativo, em que foram analisados 9 PCIs de pacientes idosos frágeis em cuidados paliativos, acompanhados por um programa de apoio matricial, em Belo Horizonte. As informações foram submetidas a Análise Documental. **Resultados:** foram observadas fragilidades como a falta de sistematização entre os planos e a ordenação dos elementos, a ausência da definição de metas terapêuticas e as intervenções de caráter médico centrado e generalizadas. Em contrapartida, o genograma e o ecomapa estão estruturados de forma a favorecer a contextualização social e familiar do idoso. **Conclusão:** os PCIs cumprem o papel de proporcionar a continuidade do cuidado entre as diferentes equipes de saúde, mas aperfeiçoamentos podem ser realizados para potencializar sua funcionalidade.

DESCRITORES: Cuidados paliativos; Saúde do idoso; Equipe de assistência ao paciente.

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ABSTRACT

Objective: to analyze the potential of the information that makes up the individualized care plan (ICP) for the shared monitoring of frail elderly individuals by the different teams involved in matrix support. **Methodology:** qualitative study, in which 9 ICPs of frail elderly patients in palliative care, monitored by a matrix support program, in Belo Horizonte, were analyzed. The information was submitted to Document Analysis. **Results:** weaknesses were observed, such as the lack of systematization between the plans and the ordering of the elements, the absence of the definition of therapeutic goals and the interventions of a medically focused and generalized nature. In contrast, the genogram and the ecomap are structured in a way to favor the social and family contextualization of the elderly. **Conclusion:** the ICPs fulfill the role of providing continuity of care among the different health teams, but improvements can be made to enhance their functionality.

DESCRIPTORS: Palliative care; Health of the elderly; Patient care team.

RESUMEN

Objetivo: analizar el potencial de la información que compone el plan de cuidados individualizado (PCI) para el seguimiento compartido del anciano frágil por los diferentes equipos implicados en el apoyo matricial. **Metodología:** estudio cualitativo, en el que se analizaron 9 ICP de pacientes ancianos frágiles en cuidados paliativos, acompañados de un programa de apoyo matricial, en Belo Horizonte. La información fue enviada a Análisis de Documentos. **Resultados:** se observaron debilidades como la falta de sistematización entre los planes y el ordenamiento de los elementos, la ausencia de definición de metas terapéuticas y las intervenciones de carácter médico-enfocado y generalizado. En cambio, el genograma y el ecomapa están estructurados de forma que favorecen la contextualización social y familiar de las personas mayores. **Conclusión:** los PCI cumplen el rol de dar continuidad asistencial entre diferentes equipos de salud, pero se pueden realizar mejoras para potenciar su funcionalidad.

DESCRIPTORES: Cuidados paliativos; Salud del anciano; Grupo de atención al paciente.

INTRODUCTION

Population aging is a global reality. In Brazil, since the 1970s, a demographic transition has been observed, characterized by the growth of the elderly population alongside a decline in the percentage of children, related to increased life expectancy and reduced birth rates.[1]

Concomitant with aging, there is the onset of illness in this population, due to chronic diseases, whose low treatment effectiveness tends to lead to functional loss and consequent frailty among older adults.[2] Frail older individuals are those who present reduced homeostatic reserve or ability to adapt to biopsychosocial stressors and, because of this, are subject to increased vulnerability, as well as functional decline and its consequences.[3]

In this scenario, Palliative Care (PC) practices become relevant, as they provide individuals with life-threatening illnesses and their families with comfort and symptom relief, avoiding futile procedures and promoting quality of life and dignity in the face of illness.[4] PC encompasses measures such as the prevention and early identification of signs and symptoms like pain, nausea, and dyspnea, as well as analgesia, reduction of suffering, and other psychosocial and spiritual symptoms.[4]

For PC goals to be achieved, the work of a multidisciplinary health team is required, with a comprehensive view of the patient.[5] Thus, each professional contributes specific knowledge and technical skills so that care can be provided in a broad and diversified manner, considering all aspects of the patient.[5] Moreover, it is essential that the team prioritizes bonding and effective communication among professionals, between professional/patient, and with family members.[6] The team must understand the meaning of comfort specific to each patient and plan care individually, ensuring therapeutic effectiveness.[7]

In this context, matrix support (MS) in the care of frail older adults in PC is an innovative strategy that combines continuous care and educational services within the Unified Health System (SUS).[8] MS is the communication between Health Care Network (RAS) teams from different points of the system, in order to guide patient care through information sharing and case discussions.[9] It involves Primary Health Care (PHC) reference teams and matrix support teams composed of specialized professionals,[8] so that PHC teams receive specific theoretical-clinical support related to the conditions of frail older patients.[9]

The final product of MS is the construction of the Singular Therapeutic Project (STP), also called the Individualized Care Plan (ICP). The ICP is a tool composed of a set of

therapeutic proposals, organized in an articulated manner with the reference team, specialized team, patient, and family, considering the frailties and social context of the individual, and can be applied at different levels of care.[10] In the frail elderly scenario, the ICP is based on risk stratification, multidimensional diagnosis, definition of therapeutic goals and proportionality of interventions, including curative, rehabilitative, palliative, and end-of-life care. Epidemiological, nutritional, and family support aspects are also considered.[10]

The matrix support model in the care of frail older adults in PC is still under development in the country and responds to health service needs. Due to its easy operationalization, MS is a useful tool for reference teams in assessing and monitoring older individuals.[8]

In May 2024, the National Palliative Care Policy (PNCP) was established through Ordinance GM/MS No. 3,681. The PNCP pillars are: focus on the multidisciplinary team, dissemination of knowledge and health education about PC, and access to the necessary materials for promoting care.[11] To this end, the PNCP proposes the creation of more than one thousand trained multidisciplinary teams across the country, which will be divided into matrix support teams and care teams, to manage services and serve the population, respectively.[11]

In this context, the ICP assumes great relevance, as it constitutes a communication tool among health teams, through the coordination of care by the reference team and the longitudinality of patient care within the RAS.[10] Thus, the ICP is the communication channel, the link that will serve as the basis for managing individualized care for patients. In the literature, studies on the ICP are mostly focused on the field of Mental Health,[12] with a gap in knowledge regarding its use in other areas of health care. Therefore, this study is justified as it contributes to the development of knowledge about tools used in MS in PC, particularly the ICP. Accordingly, the following question arises: What is the potential of the information contained in the ICP for the shared follow-up of frail older adults by the different teams involved in matrix support?

This study aims to analyze the potential of the information contained in the ICP for the shared follow-up of frail older adults by the different teams involved in matrix support.

METHODOLOGY

This study is a subproject of the Research Project entitled "Repercussions of matrix support in palliative care for frail older adults at home from the perspective of family caregivers." It is a qualitative study, which has among its premises the understanding and interpretation of a situation that cannot be comprehended and analyzed solely through the operationalization of variables, but instead works with meanings, reasons, and values that explain why something happens.[13] In this study, the aim is to understand the information contained in the ICPs of frail older individuals in PC and how such information may contribute to the continuity of shared care among different professionals within the RAS.

The Matrix 10 program was the study setting. The program was created in 2021 by specialist professionals from the Geriatrics and Gerontology outpatient clinic at the University Hospital of UFMG (HC-UFMG), as a matrix support program for frail older patients at the end of life. The Program's team is composed of geriatricians, gerontological nurses, medical residents, and nursing residents, forming a multidisciplinary team. It was designed to ensure specialized support in the management of complex cases, with the objective of monitoring clinical conditions through regular contact with the patient's PHC reference team, either remotely or in person. The Program also provides health education for older adults' family caregivers through weekly virtual meetings. Furthermore, there is a permanent support group for caregivers, coordinated by a professional from the Geriatric Social Service at HC-UFMG, which organizes meetings for bereaved family members of older adults who die while engaged in the Program's activities.

Older adults are classified according to their degree of vulnerability, with frail older adults of high complexity being those who may achieve functional improvement through specialized care, being followed up on an outpatient basis until discharge, which may occur after functional recovery or due to the progression of frailty to lower complexity.[3] These individuals, who progress in their degree of frailty with functional loss and are discharged, are the frail older patients monitored by the Matrix 10 program. They present fragile conditions and require PC at home, being referred to their PHC reference team, with an ICP that includes the definition of therapeutic goals and proportionality, in addition to palliative interventions. The ICP of these older adults is the object of this study.

As this study derives from a larger project, the sample is consistent with that of the original project, which included 9 family caregivers of frail older adults followed in the Matrix 10 Program. In the original research, semi-structured interviews were conducted with the caregivers, field observations were carried out, and the 9 ICPs of the older adults were analyzed, applying inclusion criteria until sample saturation was reached. For this study, the sample consisted solely of the 9 ICPs of older patients monitored by the Matrix 10 Program in 2024.

The ICP consists of information related to: risk stratification assessed using the Clinical-Functional Vulnerability Index, overall functionality, functional systems (cognition, mood, mobility, communication), genogram, ecomap, comorbidities, health needs, definition of therapeutic goals, therapeutic proportionality, palliative interventions, pharmacological and non-pharmacological treatment.

The data were extracted from the ICPs and organized into a data extraction sheet in Excel with the following variables: risk stratification, multidimensional diagnosis, definition of therapeutic goals and proportionality, curative, rehabilitative, palliative, and family support interventions.

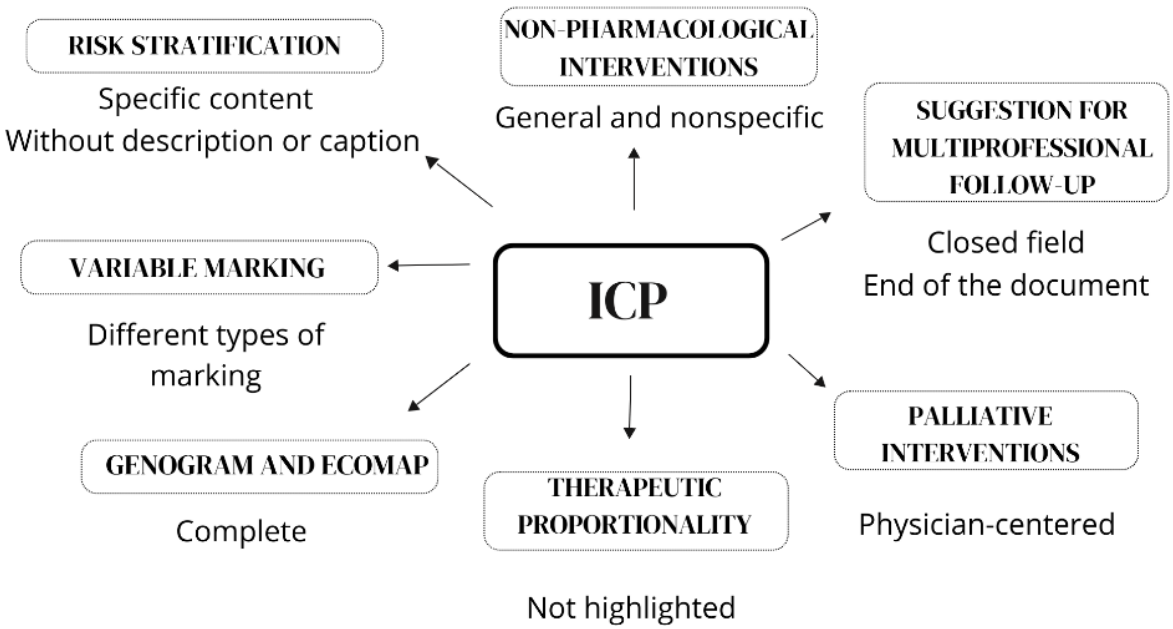
The data collected were submitted to Document Analysis, a method in which data are derived from documents, with the aim of extracting information in order to understand a phenomenon. Documents are communication tools produced for a purpose, and it is important to understand who produced them and with what intent.[15] Document analysis requires the researcher to select, process, and interpret the information contained in documents, with the goal of understanding its relationship with the context in which it was collected.[16] The analysis was conducted through the following steps: document selection (ICPs), document characterization, coding, data recording, categorization, and critical analysis.[15]

The project was submitted for approval to the Research Ethics Committee of UFMG (COEP), under opinion number 6.683.249, as provided for in Resolution 466/2012 of the National Health Council. All participants in the original project signed the Free and Informed Consent Form (FICF). The analysis of the Individualized Care Plans was carried out upon signing of the Data Use Commitment Form (DUCF) by the service manager.

RESULTS

The study sample consisted of 9 ICPs of frail older adults in PC, assisted in the Matrix 10 Program. The ICPs were analyzed, and their data were compiled and organized in an Excel spreadsheet. In this spreadsheet, the ICP information was organized according to the data contained in the ICPs: Determinant Condition, Risk Stratification, General Data, Multidimensional Diagnosis, Comorbidities, Therapeutic Proportionality, and Palliative Interventions. Based on the information contained in the ICPs, a mind map (Figure 1) was developed to illustrate how this information was arranged and how it was filled in.

Figure 1 - Mind map: ICPs information



The older patients for whom the ICPs were developed were between 78 and 96 years old, with 5 women and 4 men. All presented Alzheimer's disease as the determining condition of frailty, and additionally, two of them also had a diagnosis of Parkinson's disease. On the Visual Frailty Scale, in which older adults are classified from 1 to 10, with 1 being the highest level of vitality and 10 the highest level of frailty, the patients were classified as 9 (able to feed themselves) or 10 (completely dependent for activities of daily living).[3] They also presented degrees of immobility ranging from II, in which the individual is unable to walk and transfer from one place to another without assistance, to IV, in which, in addition to the level II incapacities, the person is unable to remain seated or change position in bed.[3] All presented edentulism, as well as urinary and fecal urgency or incontinence; seven had dysphagia and six had constipation.

All patients had five palliative interventions in common, namely: pain management, skin care, constipation management, infection management, and oral care. Regarding therapeutic proportionality, in eight of the nine ICPs, the wishes of the patients and their caregivers regarding which invasive interventions should not be performed were recorded.

When analyzing the ICPs, it is observed that they do not follow a standardized pattern of information, despite being produced by professionals from the same institution. Some contain more information, such as instructions for the care of older adults, and are more detailed regarding palliative interventions. The information contained in the ICPs was compiled in Table 1.

Table 1 – Information contained in the PCIs

ICPs	Age	Gender	Determining condition	Risk stratification	Immobility	Genogram and Ecomap	Comorbidities	Secondary Condition	Therapeutic proportionality	Palliative Interventions
CP1	92	F	Alzheimer's dementia	EVF 10	Grade II	Marital status: widow; Caregiver: daughter; Supplementary income: yes	Femur fracture, **chronic neurological problems**, depression, and hemorrhoids	Parkinson's disease, **edentulism**, dysphagia, urinary incontinence, and fecal incontinence.	yes	**Pain management, skin care, constipation management, infection management, oral care**, blood pressure control, glycemic control, behavioral symptom management, and mental health management.
CP2	78	F	Alzheimer's/Mixed Dementia	EVF 9	Grade II	Marital status: widow; Caregiver: daughter; Supplementary income: necessary.	Hypertension, **chronic neurological problems**, nighttime restlessness and chronic anemia, chronic dyspepsia, and osteoporosis.	Schizophrenia, **edentulism**, urinary incontinence, and fecal incontinence, attempted suicide	yes	**Pain management, skin care, constipation management, infection management, oral care**, blood pressure control, blood sugar control, encouragement of leisure activities, and nausea/ vomiting management.
CP3	96	M	Alzheimer's dementia	EVF 9	Grade IV	Marital status: stable union; Caregiver: daughter and professional; Supplementary income: necessary; Conflicts: occasional	Hypertension, **Chronic Neurological Problems**, Type II Diabetes Mellitus, Cardiovascular Problems, Chronic Kidney Disease, Chronic Injuries, Fractures, and Hypothyroidism	Recurrent Urinary Tract Infection, Sarcopenia, Dysphagia, **Edentulism**, Urinary Incontinence, and Fecal Incontinence	yes	**Pain management, skin care, constipation management, infection management, oral care,** blood pressure control, and blood sugar control.
CP4	93	F	Alzheimer's dementia	EVF 10	Grade IV	Marital status: widow; Caregivers: daughters and granddaughter; Supplementary income: needed. No conflicts.	Hypertension, Hypothyroidism, **Chronic Neurological Problems**.	Fecal incontinence, **edentulism**, depression, behavioral and psychological symptoms of dementia (BPSD), dysphagia, and sarcopenic obesity.	no	**Pain management, skin care, constipation management, infection management, oral care**, dysphagia management, family guidance, management of uncomfortable symptoms, referral to services, sleep quality, and
CP5	89	M	Mixed Dementia (Alzheimer's + Vascular)	EVF 10	Grade III	Marital status: widow; Caregiver: daughter; Supplementary income: necessary.	Hypertension, **Chronic Neurological Problems**, CKD, Chronic Lung Disease, Hypothyroidism.	Depression, Reflux, Dysphagia, **Edentulism**, Fecal Incontinence, and Urinary Incontinence.	Yes	**Pain management, skin care, constipation management, infection management, oral care,** blood pressure control, glycemic control, dysphagia management, uncomfortable symptom management, sleep quality.

ICPs	Age	Gender	Determining condition	Risk stratification	Immobility	Genogram and Ecomap	Comorbidities	Secondary Condition	Therapeutic proportionality	Palliative Interventions
CP6	88	F	Alzheimer's Dementia Cognitive Impairment Caused by Lifelong Mental Illness	EVF 10	Grade III	Marital status: widow; Caregiver: daughter-in-law; Supplementary income: necessary.	**Chronic Neurological Problems.**	Schizophrenia **Edentulism**, Fecal Incontinence, and Urinary Incontinence.	Yes	**Pain management, skin care, constipation management, infection management, oral care**, blood pressure control, glycemic control, and management of uncomfortable symptoms.
CP7	93	F	Alzheimer's dementia	EVF 10	Grade III	Marital status: widow; Caregiver: children; Supplementary income: not reported.	Hypertension, Type II diabetes, cardiovascular problems, **chronic neurological problems**, depression, chronic subdural hematoma, ischemic heart disease, and vitiligo.	Psychological Behavioral Symptoms of Dementia (BPSD), **Edentulism**, Fecal Incontinence, Urinary Incontinence, and Dysphagia.	Yes	**Pain management, skin care, constipation management, infection management, oral care**, blood pressure control, glycemic control, management of uncomfortable symptoms, sleep quality, and dysphagia management.
CP8	88	M	Alzheimer's dementia, mixed dementia.	EVF 10	Grade IV	Marital status: divorced; Caregiver: daughter; Supplementary income: not reported.	COPD, femur fracture, nighttime agitation, daytime hypersomnolence, and **chronic neurological problems.**	Dysphagia, Aggression, Delusions, **Edentulism**, Fecal Incontinence, and Urinary Incontinence.	Yes	**Pain management, skin care, constipation management, infection management, oral care,** blood pressure and blood sugar control, sleep quality, dysphagia management, behavioral symptom management, and mental health management.
CP9	82	M	Dementia associated with Parkinson's disease Alzheimer's dementia	EVF 10	Grade IV	Marital status: married; Caregiver: wife; Supplementary income: necessary.	Chronic Neurological Problems.	Parkinson's disease, partial **edentulism**, sarcopenia, fecal incontinence, and urinary incontinence.	Yes	**Pain management, skin care, constipation management, infection management, oral care**, blood pressure control, glycemic control, dysphagia management, management of uncomfortable symptoms, referral to services, mental health management, and disease prevention.

Source: Prepared by the author

The information present in all plans has been highlighted in bold.

DISCUSSION

When analyzing the 9 ICPs, it was observed that they follow a pre-established outline, divided into closed fields, to mark the characteristics present in each individual, in addition to open fields, for the professional's free writing. The closed fields are: risk stratification (visual frailty scale), global functionality, cognition, mood, mobility, communication, and diagnosis of health needs.

The open fields are: genogram (family structure), ecomap (family and community resources), comorbidities, therapeutic proportionality, palliative interventions, pharmacological and non-pharmacological treatment. However, the document does not include, in its structure, a definition of therapeutic goals, with a determined timeframe and the responsibilities of each professional. In an integrative review study, aimed at analyzing the characteristics of ICPs in mental health care, the absence of therapeutic goal definition was also identified, and in those that included such definition, the scheduling of goals was unclear. The definition of therapeutic goals and scheduling with the corresponding responsibilities was identified as a difficulty for professionals in the elaboration of ICPs.[12] The lack of therapeutic goal definition by professionals results in actions and activities that do not necessarily address the demands and needs of patients.[17]

Risk stratification, represented by the visual frailty scale, is highlighted in the plan, being the first information, although there is no legend or description. In this regard, it should be noted that, as this is a scale specifically used in geriatrics and gerontology, it is possible that other professionals, when viewing it in the ICP, may have difficulty understanding what it represents. A study identified the same limitation in ICPs related to mental health, in which the use of specialized language hindered effective communication among network professionals and resulted in fragmented care.[12]

In the ICPs analyzed, the contents of the closed fields were not filled in uniformly by the professionals. Some were marked with an "x" in very small font, in black like the rest of the text, without emphasis and difficult to see. This lack of clarity in markings may hinder the understanding of professionals unfamiliar with the ICP format and compromise or delay care. Other forms of signaling used included a red circle or highlighting the selected option in color. The latter two options gave greater emphasis to the information, which streamlined professionals' reading of these plans.

A study conducted with 58 mental health professionals in the state of Goiás identified that, although professionals understood the ICP as a strategy for care planning and care coordination within the RAS, it was not carried out in a systematic and standardized manner. The strategy of having a script for ICP elaboration proved effective; however, its use could be enhanced through the standardization of completion and the arrangement of information in a way that is easily understandable for non-specialist professionals.[17]

The open-field content of the ICPs, intended for data entry regarding the ecomap and genogram, was fully completed. The genogram included the names of family members, their ages, with whom the older adult lived, and family interactions. In the ecomap, it was possible to identify family relationships, responsibilities regarding the care of the older patient, the main caregiver, and the social support networks available and their use by the family. These tools are important for identifying risk factors in family dynamics and for understanding social, family, and health support networks. This information is also necessary for health care planning and for designing singular actions and interventions within the intrafamilial context.[18]

Information regarding therapeutic proportionality was presented in the middle of the ICPs, without any emphasis. Given its relevance, this information should appear earlier in the document and with emphasis, as it defines treatment in PC, whose main objective is not to prolong life, but to make it as comfortable and meaningful as possible. In this sense, it is not only a matter of treating or not treating the disease, but of choosing the most appropriate treatment, according to therapeutic proportionality. However, this specificity requires knowledge of proportional measures, as well as treatment decisions, which are complex, as they take into account technical parameters and personal conceptions of what gives meaning to the lives of patients and their families. Thus, well-defined specifications in the ICP support professionals' decisions in providing care within the RAS and reduce the choice of inappropriate interventions.[19]

The records of palliative interventions, which are therapeutic measures without curative intent aimed at reducing the negative repercussions of the disease on patients' quality of life,[20] were predominantly medically centered, focusing on pharmacological prescriptions for symptom relief, with few non-pharmacological actions and those related to spirituality and leisure. Only one ICP included interventions directed toward leisure and spirituality. From this perspective, studies have shown the verticality and centrality of medical knowledge, with little exchange of knowledge among professionals in the elaboration of the ICP.[21,17]

Finally, the ICPs include, in the closed fields, suggestions of interventions, follow-up with the multidisciplinary team, and by which category. However, this field is not sufficient to encompass the actions and guidance necessary for the patient to be assisted in a multidisciplinary way. This hinders biopsychosocial understanding, which is the basis of the subject-centered conception proposed for the construction of an ICP.[22]

With regard to non-pharmacological measures, they were the same in all plans, being general and not specific or individualized. An example of this is that all plans included records of interventions for changing position in bed, even when the patient was not bedridden. All plans also included interventions for dysphagia control, even for those without dysphagia. A similar situation was observed in a study that analyzed the challenges in the operationalization of ICPs, in which professionals planned activities that did not correspond to patients' needs, in addition to the absence of therapeutic goal definition, which is one of the causes of this phenomenon,17 corroborating the findings of the present study.

FINAL CONSIDERATIONS

The ICPs analyzed in the study contain information with the potential to enable shared follow-up of frail older adults by the different teams involved in matrix support. From this document, professionals can become familiar with the patient's social context, health status, degree of frailty, therapeutic proposals, as well as the health interventions suggested by the specialized team caring for frail older adults in PC. In this way, the ICP provides access to information compiled in a single document and fosters communication among the teams involved in matrix support within the RAS.

However, there are structural issues that could be improved, such as the order in which the elements are presented, the lack of systematization among the plans, and the way in which information is highlighted. In addition, the plans did not include the definition of therapeutic goals or the assignment of responsibilities to the respective professionals. With regard to content, the plans rely on specific geriatric concepts, which may be difficult for other professionals to understand.

The interventions had a physician-centered character, and some were described in a generic way, encompassing the individuality and uniqueness of the patient. On the other hand, the outlining of the family and socioeconomic structure provided in the Genogram and Ecomap was complete, with robust information, which facilitates patient contextualization. The plans also followed a pre-established template, designed to make it easier for professionals to complete and, likewise, to analyze.

This study may contribute to reflections on PC practices for frail older adults within the RAS and on the management of care among health teams.

Finally, as a limitation of the study, it is worth noting that Document Analysis is a method in which only the data present in the documents are examined, without exploring the perspective of the individuals involved in their formulation.

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