

Identifying patients for palliative care in primary care in Brazil: Project Estar ao Seu Lado's experience

Identificando pacientes para cuidados paliativos na atenção primária no Brasil: experiência do Projeto Estar ao Seu Lado

Identificando pacientes para cuidados paliativos en atención primaria en Brasil: la experiencia del Proyecto Estar ao Seu Lado

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Abstract

Objective: To present the process of identification of palliative care patients in a Family Health Strategy's team in Brazil. **Methods:** The identification process occurred 1) using the system of work of a Family Health Strategy Team and the principles of primary care and 2) by applying the SPICIT, a tool to help identify patients who might benefit with palliative care. **Results:** Twenty-three patients were enrolled in the palliative care program at the beginning of the project. By the end of the 12 month period, we had identified 38 patients. Six patients died during the time period. Thus during 2015, 38 people were identified with palliative needs from a total population of 3,000 (1.2% of the practice population). Of these 58% (n=22) were women, 63% (n=24) over 65 years, 74.7% (n=28) reported white ethnicity. The most frequent major diagnoses were cancer (39.5%), psychiatric disease (18.4%), cardiovascular disease (15.8%), frailty (10.5%), dementia (10.5%), and respiratory disease (7.9%). Multimorbidity was higher in patients over 65 years (t-test, p=0.009) with a median of four diseases. The most prevalent conditions among those suffering multimorbidity were cardiovascular disease (73.7%), psychiatric disease (65.8%), cancer (50%), frailty (39.5%), diabetes mellitus (31.6%), and respiratory diseases (23.7%). **Conclusion:** We applied a tool for identifying patients who would benefit from palliative care in primary care in a community of Rio Grande. It was practical and feasible. Its further refinement, implementation and evaluation in Brazil is indicated at community centres of Family Health Strategy, specifically taking account of social and economic factors.

Keywords:

Primary Care
Palliative Care
Family Health Strategy
Public Health

Resumo

Objetivo: Apresentar o processo de identificação de pacientes de cuidados paliativos em uma equipe de Estratégia de Saúde da Família no Brasil. **Métodos:** O processo de identificação ocorreu 1) utilizando o sistema de trabalho de uma Equipe de Estratégia de Saúde da Família e os princípios da atenção primária e 2) aplicando o SPICIT, uma ferramenta para ajudar a identificar pacientes que poderiam se beneficiar com cuidados paliativos. **Resultados:** Vinte e três pacientes foram inscritos no programa de cuidados paliativos no início do projeto. Ao final do período de 12 meses, identificamos 38 pacientes. Seis pacientes morreram durante o período. Assim, durante 2015, 38 pessoas foram identificadas com necessidades paliativas de uma população total de 3.000 (1,2% da população de prática). Destes, 58% (n=22) foram mulheres, 63% (n=24) com mais de 65 anos, 74,7% (n=28) relataram etnia branca. Os diagnósticos principais mais frequentes foram câncer (39,5%), doença psiquiátrica (18,4%), doença cardiovascular (15,8%), fraqueza (10,5%), demência (10,5%) e doença respiratória (7,9%). A multimorbidade foi maior em pacientes com mais de 65 anos (t-test, p=0,009) com uma mediana de quatro doenças. As patologias mais prevalentes entre os que sofrem de multimorbidade foram doença cardiovascular (73,7%), doença psiquiátrica (65,8%), câncer (50%), fragilidade (39,5%), diabetes mellitus (31,6%) e doenças respiratórias (23,7%). **Conclusão:** Aplicamos uma ferramenta para identificar e gerenciar pacientes que se beneficiariam dos cuidados paliativos na atenção primária em Rio Grande. Sua aplicação é prática e viável. Seu aperfeiçoamento, implementação e avaliação no Brasil é indicado nos centros comunitários de Estratégia de Saúde da Família, levando em conta especificamente fatores sociais e econômicos desse país.

Palavras-chave:

Atenção Primária
Cuidados Paliativos
Estratégia Saúde da Família
Saúde Pública

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Resumen

Objetivo: Presentar el proceso de identificación de pacientes de cuidados paliativos en un equipo de Estrategia de Salud de la Familia en Brasil. **Métodos:** El proceso de identificación se realizó 1) utilizando el sistema de trabajo de un equipo de Estrategia de Salud de la Familia y los principios de atención primaria y 2) aplicando el SPICT, una herramienta para ayudar a identificar los pacientes que podrían beneficiarse con el cuidado paliativo. **Resultados:** Veinte y tres pacientes fueron inscritos en el programa de cuidados paliativos al inicio del proyecto. Al final del período de 12 meses, habíamos identificado a 38 pacientes. Seis pacientes murieron durante ese período de tiempo. Durante 2015, 38 personas fueron identificadas con necesidades paliativas de una población total de 3.000 (1,2% de la población de la práctica). De estos, 58% (n=22) eran mujeres, 63% (n=24) mayores de 65 años, 74,7% (n=28) reportaron etnia blanca. Los diagnósticos principales más frecuentes fueron cáncer (39,5%), enfermedad psiquiátrica (18,4%), enfermedad cardiovascular (15,8%), Fragilidad (10,5%), demencia (10,5%) y enfermedad respiratoria (7,9%). La multimorbilidad fue mayor en pacientes mayores de 65 años (t-test, p=0,009) con una mediana de cuatro enfermedades. Las enfermedades más prevalentes entre los que padecían múltiples enfermedades fueron enfermedad cardiovascular (73,7%), enfermedad psiquiátrica (65,8%), cáncer (50%), fragilidad (39,5%), diabetes mellitus (31,6%) y enfermedades respiratorias (23,7%). **Conclusión:** Se aplicó una herramienta para identificar y administrar pacientes que se beneficiarían de los cuidados paliativos en atención primaria en Rio Grande. Fue práctico y factible. Su mayor refinamiento, implementación y evaluación en Brasil está indicado en los centros comunitarios de Estrategia de Salud de la Familia, tomando en cuenta específicamente los factores sociales y económicos de este país.

Palabras clave:

Atención Primaria
Cuidados Paliativos
Estrategia de Salud Familiar
Salud Pública

Introduction

Brazil is a vast country of over 200 million people with 18% below the poverty line.¹ The national health system is based on the principles of universality, equity and integrality.² Brazil invests in the health of its citizens USD 512 per capita,³ which corresponds to 8% of the GDP.⁴

In 2012, over 1.3 million people died in Brazil.⁵ The main causes of death were non-communicable disease (NCDs) including cardiovascular disease, cancer, respiratory diseases and diabetes.⁶ Approximately 70% of patients who die and their families in Brazil could benefit from palliative care, the majority of whom could be cared in primary care. However, it is estimated that only 0.3% of people who die in Brazil receive palliative care.⁷ Despite recent laws for pain control and palliative care, Brazil was ranked in 42nd place among 80 countries in the ranking of the Quality of Death Index in 2015.⁷

In 2014, the World Health Assembly (WHA) unanimously adopted a palliative care resolution calling on governments to take the necessary steps to ensure that palliative care was provided early in the course of disease, with emphasis on community centers, thus improving access to patients in need while at the same time using resources more efficiently.⁸ However, palliative care in Brazil is mostly available in higher levels of care.⁹

In 2011 the Federal Government implemented the Strategic Action Plan to Tackle Noncommunicable Diseases (NCDs) in Brazil from 2011-2022,¹⁰ which includes palliative care as a component of the cancer control plan. That plan aims to train primary care professionals in palliative care. This would enable the 40,000 active primary care teams of the Family Health Strategy that cover 60% of the national population¹¹ to integrate palliative care into their care of chronically ill people.

Since 2014, the project “Estar ao Seu Lado – Cuidados Paliativos na Atenção Primária” (roughly translated We are by your side- primary palliative care) offers palliative care in a community center in Brazil.¹² The team is composed of six community health workers, two nurse technicians, one nurse and one physician. The team provides outpatient consultations and home visits to patients with palliative care needs. In addition, the team also enrolled in the global initiative of “community of care”, which seeks to create compassionate communities.¹³

The project is part of the Family Health Strategy of the municipality of Rio Grande, state of Rio Grande do Sul and provides palliative care to a population of about 3,000 people, divided into 3 districts with different socio-economic characteristics.

This study describes this innovative intervention to systematically identify those patients who would benefit from palliative care from a population of 3000 patients served by a particular primary care team, over the course of 12 months during the year of 2015.

Methods

Palliative patients who live in the territory covered by the team are identified in the following ways: 1) by the local knowledge of the Community Health Workers (CHW) from monthly professional visits to the homes of their families under their care; 2) when the diagnosis of the disease and its potential as a life limiting disease is made at the community center (also called basic health unit); 3) when the family member or the patient moves to our territory and contacts the community center directly; 4) when the diagnosis was made by a specialist (eg. oncologist), and 5) when the sick person starts receiving a monthly visit from the CHW or seeks equipment directly from the community center.

Patients were screened using the SPICT tool to identify those who may benefit from palliative care.¹⁴ This tool is available in Brazilian Portuguese for free on <http://www.spict.org.uk/the-spict/spict-br/>. A thorough analysis of the potential patients was performed by the primary care team. This included a review of clinical records, clinical evaluations and home visits, after which inclusion in the program was decided. The records of patients who entered the program from January to December were included in this audit. The Project "Estar ao Seu Lado - Cuidados Paliativos na Atenção Primária" has been registered on SIGPROJ of the Federal University of Rio Grande (FURG) with the registration number 60708.186073.864.97221.18112015.

Analysis

Sociodemographic (age, sex, marital status), clinical (main pathology, comorbidity) and psychosocial (economic problems and family) data were extracted from medical records. Psychosocial data (economic problems and family problems) were recorded, if the patient reporting problems about these matters at any appointment or home visit. The Karnofsky Performance Scale Index (KS),¹⁵ Mini Mental Examination State,¹⁶ Katz Index¹⁷ were recorded when the patients were identified.

The data were anonymized and recorded in an Excel version 2007 (Microsoft) table. Data were then exported into IBM SPSS for Windows (Version 21), where descriptive and bivariate analysis was performed. The t test was used for continuous data, and the χ^2 test for categorical data. The Fisher test was used instead of the chi squared test because at least one cell in the array contained less than five occurrences". Let me know if this is not acceptable and we will see. This is a clinical service audit, ethics approval for this study was not required.

Results

Twenty-three patients were enrolled in the palliative care program at the beginning of the project. By the end of the 12 month period, we had identified 38 patients. Six patients died during the time period. Thus during 2015, 38 people were identified with palliative needs from a total population of 3,000 people (1.2%

of the practice population). Of these 58% (n=22) were women, 63% (n=24) over 65 years, 74.7% (n=28) reported white ethnicity, 34% (n=13) were married or had a partner, 32% (n=12) were widowed, 84% (n=32) had children and 97.4% (n=37) had informal caregivers. Nearly all (92.1%) were not working-of these 71.1% (n=27) were retired. Most (n=25; 65.8%) did not complete primary schooling, and 23.7% (n=9) of patients were without literacy. The prevalence of cigarette use was 44.7% (n=17). Nine patients (23.7%) reported regular alcohol use and two people (5.4%) reported using illicit drugs.

The most frequent major diagnoses were cancer (39.5%), psychiatric disease (18.4%), cardiovascular disease (15.8%), frailty (10.5%), dementia (10.5%), and respiratory disease (7.9%). Multimorbidity was higher in patients older than 65 years (t-test, $p < 0.01$) with a median of four diseases. The most prevalent conditions among those suffering multimorbidity were cardiovascular disease (73.7%), psychiatric disease (65.8%), cancer (50%), frailty (39.5%), diabetes mellitus (31.6%), and respiratory diseases (23.7%). Being older than 65 years was statistically significantly associated with cardiovascular disease (χ^2 , $p < 0.01$) and frailty (χ^2 , $p < 0.01$).

Most patients (47.4%) had a Karnofsky score (KS) of 50% (KS range 20%-80%) when identified, with different levels of dependency. According to the Katz Index 9.5% were independent in their daily activities, while 23.7% were dependent for all activities. The Mini Mental State Examinations of this population were median 23.5 (percentile 25th was 18 and percentile 75th was 26) with 4 four patients with 0 at the time of evaluation by their advanced clinical situation presented.

Most patients (68.4%) reported family problems such as children being drug users, family conflicts with their children, disappearance of a child, and mistreatment and violence of elderly. Family problems were statistically associated with the presence of psychiatric illness (χ^2 $p < 0.01$). Further, 28.9% reported economic difficulties. Economic problems were statistically associated with being younger than 65 years (Fisher Test $p < 0.01$).

Discussion

Summary of the main findings of the study

This study describes the population served during 2015 by the project *Estar ao Seu Lado - Cuidados Paliativos na Atenção Primária*, a program which provides palliative care in primary care as part of the Family Health Strategy in the community in the municipality of Rio Grande, state of Rio Grande do Sul, south of Brazil. Less than half of the patients identified for palliative care were diagnosed with cancer, while dementia syndromes and frailty were common. Multimorbidity was more prevalent in people over 65 years, with an average of four diseases. The existence of multiple conditions demands particular care, coordination and management, with continuous risk and benefit assessment of implementing any new or continuing treatments.¹⁸

Strengths and limitations of the study

A previously validated tool was used to determine the likelihood that a person was progressing towards death. This allowed patients to be identified on the basis of need, rather than on what their diagnosis was. End of life care is not a problem exclusive to cancer patients. We believe we have identified nearly all of those who require end of life care in the twelve month period.

Our catchment population may not reflect other Primary Health Services in Brazil, and other areas may have greater or smaller patient loads compared with ours. The proportion of patients needing palliative care will vary according to the characteristics of population of an area. The high percentage of older people in the area studied is directly related to the presence of chronic multimorbidity and need for palliative care. In areas with other age distributions, morbidity may also vary and therefore the number of people needing palliative care.

The characteristics of the population living in a specific area may also change over time. A recently published epidemiological study of another area in Brazil identified similar groups of diseases to ours, but probably with different cultural, economic and social characteristics.¹⁹ In spite of these differences, it does imply that we identified about the right proportion of people at risk of dying in the foreseeable future.

This study did not elaborate on the relationship of social and economic problems with needs and suffering. As this was a service audit, we could not interview patients about this relationship, and could not apply a measure of suffering as this was not done as part of routine care. Internationally, 80% of people needing palliative care live in developing countries²⁰ where economic and social problems can be pervasive.²¹ These problems can contribute to the suffering and the presence of unmet palliative care needs. We need more research to this in Brazil, a country with 18% of population living in poverty.

Comparison with existing literature

The 38 people identified had demographic characteristics consistent with the data in the literature, with a high proportion of people needing palliative care being older than 65 years.^{19,20} The population served was mainly women, which is consistent with the gender distribution in the country.²² A population based study estimated that 1-2% of the general population may be in need of palliative care at any one time¹⁸ and this number corresponds to the population we identified.

The morbidity reports are also consistent with previous reports describing a high prevalence of NCDs, with cardiovascular disease the most frequent.²⁰ Patients with advanced heart failure may benefit from advance planning and palliative care in primary care.²³ However, the national NCD strategy includes palliative care focused mostly on the cancer control program.¹⁰ Furthermore, it is estimated that by 2020 nearly 55 thousand new cases of dementia syndrome per year on people over 60 years in Brazil.²⁴

Mental health conditions constitute 30% of the country's morbidity and generate a significant burden on primary care professionals.²⁵ This situation indicates the need for better care for mental health, evaluating its relation with palliative care directly when it is a main diagnosis and indirectly, when is part of major context of multimorbidity. Methods of providing palliative care for people with psychiatric illness still need to be developed globally.²⁶

People with dementia and frailty require care from their families, sometimes for many years.²⁷ Caregivers need support to manage the associated psychological, economic and social problems besides the new context of clinical difficulties that will appear during the process of disease.²⁸ There is a need to advance on best care for patients with dementia finding solutions to solve the huge demand of care of them and their families including by the costs for the Health Care System. The burden and costs of dementia for the Health Care were already proved²⁹ and it is necessary to act in advance in a country with an ageing population like Brazil.

In Brazil, there is no strategy in place for the identification of patients with palliative care needs. The SPICT tool is a well-validated instrument in the UK, and it is easy to apply.¹⁴ It seems to be adequate for the Brazilian primary care context, without adding additional burden to the consultation. It would be extremely useful if the 40,000 active teams in the national Family Health Strategy started using it as a screening tool. Early identification of patients may help professionals plan ahead^{30,31} and help them meet their personal goals.

The provision of high quality palliative care requires appropriate resources, and the creation of an environment that considers the patient and his or her family as the unit of care. Participation of children and caregivers in the care is necessary in the context of primary health care, and more so for people in the Latin American culture who need palliative care.³² The need for support and planning of interventions and support of carers and families who care for the elderly has already been described in Brazil.³³ However, the involvement and support of the caregivers at the primary care level in Brasil needs further consideration.

Economic problems were reported by 28.9% of the sample. Lack of financial resources to purchase medications, supplies (such as diapers), food, and conduct examinations when needed were some of the situations identified. To remedy this situation, these patients should be recognized by the system as a priority and insured benefits should be extended to them.

Implications for research and professional practice

We applied a tool for identifying and managing most patients who would benefit from palliative care in primary care in Brazil, and it appears to work effectively. Its further refinement, implementation and evaluation in Brazil is indicated at community centres, specifically taking account of social and economic factors.

The Family Health Strategy has immense potential to identify people with palliative care needs and provide palliative care at a basic level in primary care, taking into account the needs of patients and their families as a central aim. To improve the situation, primary care professionals requires better preparation in the core competencies of palliative care.³⁴⁻³⁶ This would potentially enable the 40,000 program active teams of Family Health Strategy be more effective and efficient. The consulting time that these patients require is one of the main barriers to providing palliative care in primary care.³⁴ Discussions about developing primary palliative care in Brazil have already started and are very timely.¹³

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