

Research Article





# Ethical issues in access to palliative care in primary health care in a Brazilian municipality

#### **Summary**

Goal: Identify ethical issues related to access to Palliative Care (PC) in Primary Health Care (PHC), from the experience of managers, nurses and eligible users to PC.

**Methodology:** Descriptive, qualitative study conducted in the municipality of Divinópolis, Minas Gerais, Brazil. We used the methodological framework for Bardin content analysis and the theoretical framework of Justice Norman Daniels for discussion. The ATLAS IT 7 software was used for data organization.

**Results:** Emerged the following thematic categories: Perceptions of physical access to palliative care; Meanings attributed to theoretical and practical about the PC domain; Feelings and experiences outside the host of health facilities and reflections about the inequalities in the distribution of materials and medicines.

**Final considerations:** The PHC of the city studied is not prepared for the attention to PC. It is necessary to organize a structured network for this care and invest in training in the subject.

**Keywords:** bioethics, nursing, palliative care, primary health care, access to health services

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**Abbreviations:** PC, palliative care; PHC, primary health care; NCD, chronic non-communicable disease; KPS, karnofsky performance scale; WHO, world health organization; COPD, chronic obstructive pulmonary disease; AIDS, acquired immune deficiency syndrome; REC, research ethics committee; HU, health unit; NHP, national humanization policy; CHA, community health agents; BHU, basic health units

#### Introduction

The chronic non-communicable disease (NCD) are now responsible for most deaths in many countries of high, medium or low socioeconomic status, and in Brazil disproportionately affect the poorest and accounted for 72.0% of mortality 2011. The rapidly changing demographical and epidemiological profile of the population, with an evident increase in the number of adults and the elderly, has caused the increased prevalence of these diseases.<sup>1</sup>

Concurrently with the changing population profile, there are great advances in medical and biological sciences, such as the many supporting technologies, able to increase the life expectancy of people. However, such advances have led to the emergence of important ethical challenges such as the issue of access to services and health care. In this context, it becomes relevant discussions about the ethical issues involving access to palliative care (PC).

The term 'palliative care' is used to indicate the care offered to patients out of therapeutic possibilities, ie, those patients with incurable diseases who have no treatment dressing.<sup>3</sup> Highlights, therefore, the importance of PC and the reorganization of health services in order to ensure its supply to those in need,<sup>4</sup> since there is some difficulty in maintaining justice and equity in access to such care in health systems.

Thus, there must be a new welfare approach, an investment in the training of professional health<sup>4</sup> and even an incentive for

improvement of PC on Primary Health Care (PHC). The objective of this study was to inventory the ethical issues related to access to the PC in the PHC, from the experience of managers, nurses and eligible users to PC and then discuss them according to the theory of justice proposed by Norman Daniels, American philosopher, ethicist and bioethics. According to Daniels, a theory of justice related to the right to health must address the individual and social responsibilities with regard to the protection and promotion of health, encompassing both the theoretical foundation as responding to real issues.<sup>5</sup>

### **Methodology**

This was a descriptive study of qualitative nature, performed in the county of Divinópolis, Minas Gerais, Brazil. The study included 11 nurses, three managers and eight members eligible for early or immediate PC. The criterion for defining the sample was of convenience, that is, data collection was closed when we got the 'corpus' need for analysis of the reports, which was constituted by the relevance of the statements.

The selection of participants was carried out nurses from a list containing the names of all nurses working in the municipal PHC, sweepstakes being held to recruit them. Participant managers are the total number of managers of municipal PHC. The selection criteria for nurses and managers participate in the research were: minimum of 6 months of experience in PHC, because it assumes that less time that is not enough to know the patients eligible for PC, accepting to participate in the research and not be away from work. As for users, they included those with a score equal to or less than 70% on the Karnofsky Performance Scale (KPS), which was applied using the medical records of all users eligible for PC, according to the World Health Organization criteria (WHO). This scale is used to measure the functional capacity of people affected by any disease. Patients with Karnofsky score on the scale (KPS) less than or equal to 70% have early indication of Hospice Care assistance. As for the WHO criteria,



it is important to say that for a patient to be eligible for PC it has one or more of the following diseases or conditions: Alzheimer's disease and other dementias, cancer, cardiovascular diseases (excluding when cause of sudden death), cirrhosis, congenital anomalies, sequelae of meningitis, hematological and immunological disorders, neonatal conditions, chronic obstructive pulmonary disease (COPD), diabetes, Acquired immune Deficiency Syndrome (AIDS), kidney failure, multiple sclerosis, Parkinson's disease, rheumatoid arthritis and resistant Tuberculosis.<sup>7</sup> Therefore, the selection criteria of the participating members were: over 18 years, be eligible to receive early PC (KPS≤70%) and accept to participate.

Data collection with nurses and managers took place from September to November 2014 and the collection with users took place in June 2015.

At nurses and managers the following questions were asked:

- i. In your opinion, how the (re) knowledge of the concepts and eligibility criteria for PC influences the quality of care provided to this type of patient in the FHS?
- ii. Tell me about your experiences involving access to this type of care in the family health unit where he works. To collect data with users used the following guiding question: Tell me about your experiences involving access to PC in the health unit of the family in his neighborhood, considering the host, physical structure, disponility materials, services your needs, among others.

The reports from the interviews were recorded and later fully transcribed for content analysis.<sup>8</sup>

For the organization of the data we used the computer program ATLAS IT 7.As for the discussion of ethical issues, we used the Theory of Justice proposed by Norman Daniels, which proposes a reflection on three aspects in relation to the health needs:

- i. Whether the health has a special moral significance;
- ii. When a health inequality can be considered unfair;
- iii. How to meet the health needs if it cannot meet all needs.<sup>7</sup>

About the ethical aspects of the study, it is important to say that the participants were identified by numbers, the interviews were conducted in private place and the project received approved by the Research Ethics Committee (REC) of the Federal University of Sao Joao del Rei (UFSJ) through opinion number 812 278.

### **Results and discussion**

In order to know the profile of the participants were collected data focused on the characterization of the same. About nurses found that all participants (100%) are female, with a mean age of 28.5 years and average working time in primary care of 2.5 years, the maximum period of eight years and the minimum time of six months. Regarding users to realize that 4(50%) are female and 4(50%) were male, mean age 65 years, minimum age of 29 years and maximum 94 years. Already managers, 2(66%) are female and 1(34%) were male.

Respondent users had the following diseases / conditions: breast cancer (1; 12.5%), Arthritis Rheumatoid (1; 12.5%), Alzheimer's (1; 12.5%), Sequelae of Cerebral Vascular Accident (CVA) (2; 25%), diabetes and Rheumatism (3; 37.5%). Regarding the scores obtained after application of the KPS in the records, it was found that: 5(62.5%)

had a score of 70% 1(12.5%) and 50% score of 2(25%) 40% score. After knowing it profile of participants transcription and analysis of the speeches was held .Four theme categories were identified as follows:

### Perceptions of physical access to palliative care

Through this theme category you can see that the nurses interviewed pointed out the means of transport as a facilitator of user access to PC, especially for those who are bedridden, live far away or that for some reason cannot reach the unit. It is worth noting that the 11(100%) nurses mentioned this portability.

"We have patients who live far away, but the van has to make home visits, is a facilitator point. If they had the van to take us to go in the patient's home" [E9]. "It is ... the issue of transport, if you need to go in the patient's home and stuff ... we have access, we have a car, and then yes we will, we have a doctor who will not it?!" [E5].

The municipality of Divinópolis offers each health unit (HU) a car that is available to the HU all day. This car is mainly used for carrying out home visits, so this facilitates patient access to care, as noted in the reports. It is important to note that the searched city is privileged to count on this facilitator, since this is not part of the reality of many municipalities.

Professionals only mentioned the ease of transporting the same to the user's home, however, report difficulty in user access to services such as speech below:

Buses also right!? [...] Where we work has no asphalt, so they are more bad bus to take the hit, so accessibility is not entitled to it. So one has to bring the patient here walk, wheelchair, carrying the wheelchair to get here, sometimes for almost an hour's walk right!? Because not always have a car to bring here. "[E1]

Caregivers and patients at the end of elencaram life, in a study conducted in 2013, some weaknesses in the PHC forward to care for their families: lack of resources and support, lack of high cost of medicines and lack of transportation when they need to take your relative services health and need for this help from family members and neighbors.<sup>4</sup>

In most municipalities, the precarious conditions of transport systems and infrastructure have hampered the economic dynamics and the population's quality of life, with regard to urban mobility and accessibility. It is known that the inadequacy in the provision of services in remote areas, in addition to high rates of public transport end up harming the poorest part of the population by restricting access to the same health services. Nurses also pointed to the physical structure of the unit as a point which makes the user access to PC, mainly regarding physical access. All nurses (100%) reported that physical access unit is bad. The report below reflects some of the difficulties listed:

"[...] But here for example here in the unit does not have access for wheelchair right! ? So if a disabled person with disability who does not walk and is in a wheelchair, this is very difficult for him.

In a study conducted with parents of children with cerebral palsy in Belo Horizonte, Minas Gerais, Brazil, environmental barriers were highlighted that hinder the use of the wheelchair. Parents pointed out that in health care environments, either by the provision of securities or the lack of adaptations, equipment handling becomes very difficult.<sup>10</sup>

During the interviews with managers were also reported these difficulties of access for the poor structure of the units. This could be observed in the statements of 3(100%) managers, as exemplified by the reported below:

"In a matter of infrastructure, some Health Strategies Family does not have adequate space to do a job. Usually, it is a job at the residence of the person or sometimes in the group, in community spaces. "[G2]

The Brazilian policy PHC states that the structural aspects of health facilities should be valued, as are items necessary for conducting the primary care activities. Structure criteria for health facilities are also present in Board Resolution 508 and the physical structure of manual primary health units. 11 One can also cite the Cabinet Ordinance of the Ministry of Health 648/2006, which specifies standards infrastructure, human and material resources necessary for the development of the actions of health teams of the family. 12 But even compared to so many regulations in the country also note the existence of structural precariousness of health facilities, as evidenced by the speeches of the professionals interviewed.

The difficulties cited by nurses and managers have also been identified in a study with tutorial monitoring the PHC, which pointed out that the evaluated units operate in rented houses, adapted to operate as a health unit, without inspection of the risks and unhealthy. <sup>13</sup> Another study focused on the evaluation of the health system, held in Natal, Rio Grande do North-Brazil, also said the FHS units operate mostly in rented houses which were adapted, but do not have adequate infrastructure to The operation. Also found that managers recognize the existence of barriers in the PHC which hinder access to care. <sup>14</sup> It is clear, then, that this is still a present reality in different states of Brazil, which needs to be rethought.

From the reports of this category, emerged the following ethical question: how the lack of structure of health facilities interferes with access to PC? The lack of structure of the units for service users eligible for PC can be seen as an ethical issue, since it is related to the commitment of assistance, but it has political implications related to lack of funds for investments in physical infrastructure.

As noted in the statements of nurses and managers, there is often not the appropriate number of rooms for service users, there is the presence of stairs inside the unit, making it more difficult access and even causing embarrassment to professionals and users.

It is understood that in health is important to establish some priorities for improving the quality of services. In this sense, it is mentioned the need for investments in physical infrastructure of health facilities, in order, including the ease of physical access to PC PHC. However, it is noted, according to Daniels, who needs and preferences are not synonymous. The difficulty in addressing the needs is precisely the lack of consensus on what is really needed. It follows, then, to the search for a fair decision procedure for the allocation of resources when there is no consensus on disputes.<sup>5</sup>

# Feelings and experiences outside the host of health facilities

It was noticed during the interviews that all eight users feel satisfied with the way we are welcomed by health professionals. Of course, this reflects the concern of professionals to ensure a better quality of life for these users. Below are some statements that refer to the feeling of satisfaction of users:

"I had no problem. I always go in the post, serve me well, pass me in front of me not to wait because of my health problems even. I get there, I serve well, I take medicine, passes recipe, everything right. I have nothing to complain about "[U1]". They are very attentive to me. Whenever you have something they are doing for me" [U3].

Users mentioned in his speech that the professionals in the host attentive drive way and always try to be resolute in the face of your needs. Home is a guideline of the National Humanization Policy (NHP), which has no place or right time to happen and is not restricted to a specific professional to do it: part of all meetings of the health service. The host is an ethical stance that implies you hear your complaints, to recognize their role in the process of health and illness and accountability for the resolution, enabling knowledge sharing networks. Host is a response of commitment to the needs of citizens seeking the services of health.<sup>15</sup>

Research shows that nurses consider the interpersonal relationship with the patient and their families as an important means of promoting PC because it facilitates the clarification of doubts so that patients explain their anxieties and fears. Finally, evidence of the importance of communication as a fundamental strategy to support clinical nursing practice directed to the patient in PC.<sup>16</sup>

Among the professionals who perform this host, the Community Health Agents (CHA) stood out in the statements of users, as 4(50%) of them mentioned in his speech that the CHA, in fact, are intermediaries between them and other professional units.

"A health worker marks the day and he (doctor) comes here. The agent is always going here to see me, they are very attentive to me" [U3]. "The agent comes here at home and the doctor has the right days to come." [U5]

The role of the CHA is critical in the context of the PHC, as it makes possible that people's needs reach the professional team and, from there, that interventions are made in the community. It is pertinent to remember that the CHA also transmits health information to the population. Besides Brazil, countries like the United States, Kenya, Bangladesh, United Kingdom and South Africa, have entered the CHA in their health systems.<sup>17</sup>

Study in Montes Claros, Minas Gerais- Brazil, pointed out that most of the CHA share with the team of professionals of PHC situations encountered during visits, especially risk situations. In addition, the CHA makes general guidance to families and-schedule appointments and tests for population.<sup>17</sup> The CHA is the link that allows trust and the link between the health team and assisted community, thereby facilitating access to care.

# Meanings attributed to theoretical and practical field about palliative care

This thematic category it shows that nurses recognize the importance of theoretical and practical knowledge of the PC. This category results from the talks of 7(63.7%) nurses and shows how important think to know the eligibility criteria for PC, since from the moment you know who are the eligible users for PC can prepare a plan of care to be provided. It was also noted, as shown below, that nurses care a lot in ensuring able assistance to contribute to improving the quality of life of patients in PC.

"[...] having a diagnosis that user, we will make our action plan on top of what it needs, huh!?" [E3]. "Help you to be able to select their

population who need such care right!? [...] So when you know your people, you know the people you have to meet, you can program is best ... even strategies to be able to reach this audience" [E5].

It is important that nurses are concerned about the issue of planning of actions, especially in the case of patients who need early PC, it is known that the user needs number is directly proportional to the need for care planning. The greater the need for care, the greater will be the planning of actions.

It notes that all nurses (100%) reported in their speeches the importance and necessity of carrying out targeted training for PC, since they never took part in refresher courses or any course that would address the issue. Some nurses said they had studied, in general, PC concepts during the graduation. The desire to be able to provide better assistance to users can be demonstrated by the statements below:

- i. I think even if we needed was recycling right?! Neither was a recycling actually right?! But it was an even training to all network nodes, to be able to improve it right!? To be able to classify these patients even, make a schedule, have a space on our agenda, because often when we program to make visits, something is interpreted wrong, we want to get out of the unit, which is better exit to stay within the unit [E7].
- ii. Today we do not have training; more or less you see in college, so the more knowledge, more training, more improved care. Training we do not have. I think we need to have, not me, but my whole team [E10].

It must be said that the need for training has also been recognized by one (33.3%) of the three managers interviewed. The following report below:

i. In terms of training, unfortunately we even needed a partnership with the university to promote a little more this policy palliative care. [...] The issue of professional by training, I think they have more openness to work more with this methodology (palliative care) [G2].

The fact that nurses have never participated in refresher courses and/or training on PC may be related to the scarcity of courses focused on this issue and also to the limited approach to the subject at the undergraduate and graduate. The professional curriculum of Nursing requires disciplines geared to human finitude because nurses feel unprepared to deal with patients who are dying. Finally, there is a lack of specific training for palliative nurses. Nursing professionals are the ones who invest the most time with patients at the end of life when compared to any other health care professional. However, these professionals do not feel competent or confident to care at the end of life. Palliative care in nursing is to provide comfort, act and react appropriately to a situation before death with the patient, family and with it. 20

From the reports of nurses in this category, it was possible to inventory the following ethical question: what are the implications about the lack of preparation of health professionals to deal with users who require PC? The unpreparedness of professionals to deal with users in PC constitutes an important ethical issue. It is worth mentioning that during the professional practice, nurses can go through issues involving PC with which will not be able to position and therefore can face moments of anguish and anxiety, which can lead directly to the poor quality of service to users. Thus, it highlights

the importance of education in PC, prior to addressing ethical issues of professional practice. According to Norman Daniels education is among the items that make up the determinants of health, so it is important to invest in this area. Thus, it is noted that Daniels does not restrict his theory of justice to resource allocation issues and health services.<sup>5</sup> Rather, Norman also turned his studies for health professionals and recognizes that in addition to seeking to achieve good clinical outcomes of patients, professionals bother to provide equitable service to them.<sup>21</sup>

Finally, it is noted that the reports present in this category can relate directly to the users' access to PC, since when professionals have knowledge of PC, as well as their eligibility criteria, it is possible to for example, an active search these users to communicate their needs and provide assistance. In addition, when professionals these users know certainly take care of them with due particularity.

# Reflections about the inequalities in the distribution of materials and medicines

In this thematic category were included the lines that refer to the influence of material resources in the access to PC, such as gauze, serum, adhesive plaster, bandage for roofing, equip and medicines. It was observed that there was no consensus on the availability or unavailability of materials to be used, that is, it was noted that 6 (54.6%) nurses said they were satisfied with this issue of materials, while 5(45.4%) claimed lack of material.

This inconsistency in the statements allows two inferences:

- i. The inconsistency may be related to how nurses make their monthly planning of inputs, therefore, with a view all HU are inserted in the same municipality, it is understood that the materials are available to all teams equally, that is, when there is request of material, this comes to the unit.
- ii. The inconsistency may be associated with differences in population environment under which the HU is inserted once interviewed nurses working in rural, low-income and interviewed nurses working in urban areas.

A survey conducted in Cuiabá Mato Grosso do Sul-Brazil, with the aim of analyzing the perception of nurses regarding the influence of the infrastructure in their actions, standing out the specific context of basic health units (BHU) also found a lack of traditional consensus among nurses interviewed when asked about availability or otherwise of materials. Some nurses reported that the materials available are sufficient and others expressed contrary to.<sup>22</sup>

It is worth mentioning that the availability or unavailability of materials is therefore reflected in the speeches of users because it was realized during the interviews, that some are receiving the necessary materials in adequate number and not others. The statements presented below refer to the lack of material in the unit pointed out by nurses:

- i. The health of the family helps a lot, but still encounter some problems, missing some stuff, but nothing that interferes directly in bad care [E9].
- Material always missing. It difficulty. When we need specific exam, it is barred. So difficult [E10].

It is known that the lack of materials in HU affect nursing practice because some actions are interrupted. In addition, lack of inputs prevents adequate health care and the development of appropriate clinical care to patients.<sup>22</sup> The lack of material resources was also highlighted by 4 (50%) users. It was noticed that, for the most part, this is related to the lack of medicines, as present in the account below:

i. Lately we have been missing too much medicine at City Hall. They have not replenished the ranks. Often loses the trip. Enough nervous here [U6].

As previously mentioned, they were also found reports which refer to material resources as a positive point for assistance in PC. Below you can see one of the testimonies of the nurses:

i. With regard to the materials we need, especially when it comes to dressing materials and medicine, the NHS provides access to this kind of stuff, so patients have this type of material, monthly applications for these patients. Also in relation to tests to control such care, the NHS also ensures that patients have these tests at home [E4].

This ease of access to the materials was also identified by users. From 8 users surveyed, 4 (50%) are satisfied with the way the materials reach them:

i. I needed to post the material. It's easy to get material. I have nothing to complain about [U8].

Front to ease user access to materials in health facilities is important to draw attention to the need for evaluation of the patient prior to dispensing materials, since this requires a comprehensive care. The delivery of unaccompanied assessment materials can compromise the quality of PC. Remember that users on PC require continuous care, a wide assistance, which meets as a whole, considering it as a bio psychosocial and spiritual being.<sup>23</sup>

The reports identified in this category resulted in following ethical question: the lack of organization and network of health services related to the difficulties of access to medicines and materials required for the PC? The difficulty in access to medicines and materials is an ethical issue that involves the commitment to PC offered to users. It is also known that the unavailability of medicines, such as painkillers, can cause the suffering of users with potential pain increases.

It is important to have conditions that allow the immediate availability of drugs to control symptoms of patients.<sup>24</sup> Note also that the drug consumption program should be designed with a safety margin not to miss medicines, as well; access and continuity of care of patients will be guaranteed.<sup>22</sup> Front inequalities in access to materials and medicines, that is to say that Norman Daniels It argues that these are permitted provided they offer a gain for those who are worse off.<sup>5</sup> Thus, it is suggested, with regard to lack of medicines and material for all eligible users for PC, that managers establish criteria to distribute such inputs.

However, it is important to mention that when establishing criteria for the distribution of materials and medicines, managers should keep in mind the existence of a moral controversy surrounding the creation of beneficiaries and 'impaired' in resource allocation decisions. Such allocation can result in a problem of legitimacy, since demand and answer on conditions in which decision-makers have the moral authority to define the limits imposed by their decisions.<sup>5</sup>

In addition, one must justify the way decisions are taken. Daniels argues that an authority is reasonable as legitimate if it meets a predetermined and debated procedure or process. When there is no

consensus on principles able to resolve disputes about the allocation of resources to health and health care, it is necessary to find a fair trial whose results are accepted as fair or reasonable.<sup>5</sup>

#### Final considerations

From the reports of the participants, it can be observed that ethical issues inventoried are often PHC unpreparedness of reflection for attention in PC and lack of organization of a structured network for this care in the county. Thus, it emphasizes the importance of healthcare policies for the inclusion of PC PHC and training of health professionals in this level of attention for this type of care. It is worth noting the importance of health care networks in the structuring of attention to PC, with a proper structuring of a referral and counterreferral, which sets the levels of care and the different services involved in the provision of care. It is interesting to explore the full potential that the PHC has, for this, in a network, is able to direct all actions to the PC.

Finally, it points out the need for a systematization of guidelines and actions for the implementation of PC in the PHC due to the existing demand this level of attention, accompanied by the changing demographical and epidemiological profile of the Brazilian, who increasingly needs PC at the end of life.

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None

#### **Conflict of interest**

The author declares no conflicts of interests.

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