A simulation model for predicting palliative care needs and utilization of cancer patients

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October 2016

Abstract

In European countries, the number of cancer patients and of deaths caused by cancer grows each year. This growth is influenced by the ageing of the population and by cancer’s rising incidence within each age group. The same problem affects the Portuguese population. Cancer patients, suffering from a high number of symptoms in their last months of life, may receive Palliative Care (PC), a service designed to alleviate pain and other distressing symptoms in patients suffering from life-threatening illnesses. PC is still in an incipient stage, with limited availability. An expansion of these services is necessary, requiring knowledge of the current and future number of patients benefiting from PC. However, no clear estimation of current and future needs exists, and while methodologies have been developed to predict future health care needs, they have not yet been applied to PC.

The goal of this study is then to determine the current and future number of cancer patients requiring PC, disaggregated by age and gender, through the use of a Markov cycle tree methodology, which also allows the separation of patients across the different service typologies (ambulatory care, home care and inpatient care) according to factors such as phase of disease and income level. Additionally, the benefits associated with PC provision are estimated by comparing the costs associated with these services to the costs of providing those services outside a specialized PC network.

The developed methodology is applied at the small-area level, to the Lisbon county and its municipalities, from the 2016 to 2021 period, confirming that PC needs are expected to increase in coming years, with a clear lack of supply to satisfy those needs.

Keywords: Health Care, Palliative Care, Planning, Demand Prediction, Simulation, Markov Cycle Tree

1. Introduction

With the ageing of the European population, diseases whose incidence rises with age are becoming an increasingly pressing concern to health care providers. One of those diseases is cancer, one of the main causes of death worldwide, whose age-specific incidence has steadily increased over the years. Cancer patients, who usually suffer from a fast decline in health in their last months of life, experience a high number of distressing symptoms, which require alleviation, so the patients can have as much quality of life as possible. An answer to that lies in PC, a holistic approach aimed at the prevention and relief of suffering, whose development only began in the 60s [1]. Its development has been slow worldwide, and even more so in Portugal, where it only began in the 90s [2]. Nowadays, there is a network of PC services in place in Portugal, providing care in ambulatory or inpatient settings, as well as in the patients’ homes. While the number of PC services available in Portugal has been increasing through the years, it is still not enough to meet all the demand, and further expansion of the PC network is necessary.

For that, extensive information is required, both on the total number of patients that currently require PC and their characteristics, and the number of patients that will require it in the future. However, this information is often either unavailable, or incomplete, which makes it more difficult to plan the expansion of the PC network.

Several methods exist to predict future health care needs of a given population, most of which are simulation models. Non-simulation methodologies produce limited results, which often fail to account for changes in population demographics, or in diseases’ incidence or characteristics. Simulation methodologies can be of two types: macrosimulations or microsimulations. Most simulation methodologies used in healthcare
are macrosimulations. These methods analyse cohorts of individuals grouped together by their characteristics (such as age, gender or income), while microsimulation methodologies analyse individual people, families or households [3]. While microsimulation methods yield more detailed information, they also require a higher number of inputs and data, which might explain the much higher number of microsimulation studies found.

Macro simulation Markov chains are a commonly used method to study epidemiological factors and disease trajectories. A Markov chain is a stochastic simulation methodology, which allows the division of a given population into a set of states, according to a set of parameters to be studied [4]. Individuals in each state can move to other states according to different transition probabilities. All transitions in the system are calculated for equal time intervals. Markov chains are considered to be a “memoryless” process, as the distribution of an entire population across different states in any given moment, depends only on its distribution in the previous moment, and not on all the moments that precede it [4].

To the best of our knowledge, no simulation methodology has been developed to estimate current or future PC needs, which might be explained by the pronounced lack of accurate data regarding current need and utilization of PC services. Methods to predict future need of PC based on current usage could not be found either, potentially due to the widely held belief that the current offer of PC services is not enough to efficiently meet all of the demand and the total level of need for PC consequently being difficult to determine. All the studies found focused only on estimating current demand, by determining the number of teams currently required using international rates of number of teams per inhabitants [5] or mortality data [6].

It is within this context that this study is developed. This study proposes a methodology that can estimate current and future demand for PC in a given population, disaggregated by age, gender and type of care required (ambulatory care (AC), home care (HC) or inpatient care (IC)) each month. For that purpose, a Markov cycle tree methodology is developed, which separates patients by type of care according to phase of the disease, level of dependency, income level and presence or absence of an informal caretaker. The methodology also includes the calculation of the costs of providing care to dying cancer patients both within the PC network and outside.

This methodology allows a much more detailed view of the current level of need, by providing estimates disaggregated by factors such as age, gender, type of care and income level, for a smaller time period, and predicts future values. This yields more detailed results in level of need and demand for PC within different population cohorts, which allows a more detailed and thorough planning of the implementation and expansion of a PC network.

2. Background

2.1. Definition of PC

Though the definition of PC has varied through the years, it is currently defined by the World Health Organization as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” [7]. It is based on a set of principles and goals, such as the relief of pain and other symptoms, the affirmation of life and the treatment of death as a natural process and the integration of psychological and spiritual aspects of care[7][8].

Though initially PC was only destined for cancer patients, nowadays the patients receiving PC suffer from other diseases, such as AIDS, advanced organ failure, or degenerative neurological diseases [8] [9]. PC provision is associated with several benefits, improving the end of life (EOL) experience [10], increasing quality of life (QOL), decreasing the incidence of depression and allowing for better symptom control [11]. Several studies also show a marked decrease in costs for PC providers when compared to patients receiving care in an acute care hospital [12]. The potential for cost savings is of remarkable importance in several European countries, such as Portugal, given the recent cuts to the health budget, due to the economic crisis the country has been experiencing and the expected ageing of the population.

2.2. PC provision in Portugal

The modern PC movement is fairly recent in Portugal, having only started in the 90s, due to grassroots actions rather than because of government initiatives. The number of services has been steadily increasing since 1992, with the creation of the Pain Unit of the Fundão Hospital, which would later go on to become the hospital’s palliative medicine service [2]. Nowadays, PC is provided in a PC network, created in 2012 and operating under the tutelage of the National Health Service [13].

In Portugal, PC can be provided in palliative care units, to inpatients, by hospital palliative care support teams, in a hospital environment, and finally by community support teams in palliative care at home, which can provide PC in patients’
3. Methodology

3.1. Overview

The aim of the developed methodology is to predict the number of cancer patients requiring PC in a given region for a certain time period, the type of services those patients require (which might be AC, HC or IC services), and all the costs associated with those services. To determine these needs, it is necessary to study the epidemiological patterns of cancer over time in a population and to observe how patients progress through different phases of the disease, requiring different PC services in the different points of the disease’s trajectory.

Studies have shown that cancer progression can be simplified and more easily studied by separating the disease into different phases [21], i.e., into stable, transitional and EOL. Patients can move repeatedly through these disease states over time. These states are all-inclusive and mutually exclusive, as a patient can only be part of one state at any given time. Markov chains are thus an adequate method to study the evolution of cancer populations over time as patients move through different phases of the disease according to different probability values, showing different symptoms and having different needs.

For this purpose, both a decision tree and a Markov chain model are implemented. The decision tree is used only for the first month of the model, dividing the patients into separate groups. In the following months, a Markov model is used instead.

Initially, the patients are divided according to age and gender. This division is done as cancer affects different age groups and both genders differently. It has been shown that incidence typically rises with age, with older men showing higher incidence values than older women [22].
After that initial separation, patients are separated according to phase of disease. Afterwards, it becomes necessary to separate them according to other characteristics. These characteristics determine which type of care each patient requires, and are as follows:

- **Dependency level**: Patients with cancer and, primarily, cancer patients needing PC, have a high level of needs and the higher their level of dependency, the higher those needs are. A high dependency level is connected to a low ambulation level, which severely hinders the patient’s ability to visit an AC service and makes other types of care necessary [23].

- **Presence/Absence of a caretaker**: Given the high symptom burden of cancer patients in the terminal stages of the disease, a caretaker is usually required, and the absence of one is a criterion used for referral to an inpatient unit [8].

- **Income level**: Receiving PC at home comes with the highest expenditure for the patient or the caretaker, out of all PC services. These costs must be supported either by the patient or the caregiver, if there is one [24].

In the first month, the total number of individuals in each branch of tree depends only on cancer prevalence (number of individuals in a population with cancer at a given time period) and demographic characteristics (i.e., age and gender).

In the Markov model, used for the following months, these values depend on cancer incidence and mortality rates, as well as the dynamic transition between states.

Given the usual short length of life of terminal cancer patients, a time step of one month between each transition was adopted. The methodology has been developed in a generic way, and can be applied in most countries or regions where socioeconomic and demographic data is available, though some adaptation of the methodology might be required.

### 3.2. Short-term Decision Tree

After being separated into cohorts according to age, gender and geographic region, all individuals in a given population are divided into different groups. These groups can be seen in Figure 1.

Initially, individuals are separated into two different groups: the non-cancer group (for individuals who are not cancer patients at the time, making up the NC branch) and the cancer group (for individuals who are cancer patients at the time, the C branch).

Using the classification explained in Section 2.4, the group of cancer patients is further divided into three different groups: stable, transitional and EOL, which are then divided into different branches, as follows:

- **The stable group of patients is further divided into five different branches**: stable 0 (for patients who have been stable for zero years, the S0 branch), stable 1 (for patients who have been stable one year, the S¹ branch), stable 2 (for patients who have been stable two years, the S² branch), stable 3 (patients who have been stable three years, the S³ branch), and stable four (patients who have been stable between four years, the S⁴ branch). Knowing how long a patient has been stable is important since it is assumed that a cancer patient can become a non-cancer patient only after five years spent in the stable state.

- **Patients in the transition group are divided into low dependency patients (corresponding to a PPS score of 60%) and high dependency patients (corresponding to a PPS score of 40 or 50%)**. Transitional patients with low dependency make up the TLD group. The group of patients with high dependency is then divided into patients with or without a caretaker. Patients with high dependency and without a caretaker are part of the THDNCT group. Patients with high dependency and a caretaker are further divided into patients with high dependency and a caretaker who live above the poverty line (THDCTAPL) and patients with high dependency and a caretaker who live below the poverty line (THDCTBPL).

- **For patients in the EOL group**, similar separations into smaller groups are performed. Here the level of dependency isn’t considered as all patients in this group have a high symptom burden, with high needs and a high level of dependency. Like in the transitional group, EOL patients are separated according to the presence or absence of a caretaker. Patients without a caretaker make up the EOLNCT branch. Like in the transitional branch, patients in the EOL branch with a caretaker are further divided into EOL patients with a caretaker who live above the poverty line (EOLCTAPL) and EOL patients with a caretaker who live below the poverty line (EOLCTBPL).

### 3.3. Long-term Markov model

Once individuals are organized into different groups with different characteristics and different needs for the first month of the planning period, it is possible to evaluate how they will progress over time. This evolution is studied with the Markov model summarized in Figure 2.

This model considers the transitions of individuals between 15 different states. 13 of
the states are the same as the branches of the decision tree, while the other two correspond to the death by cancer causes state and the death by non-cancer causes state.

The NCD and CD states are absorbing states (i.e., states from which individuals can’t transition out of), which correspond, respectively, to deaths not caused by cancer, and deaths caused by cancer. All cancer patients can transition to either the NCD or the CD state as they can die both because of cancer and because of other causes. Non-cancer patients can only die from non-cancer causes, thus transitioning only to the NCD state.

Individuals in the NC state can only remain in that state, enter the cancer state by entering the $S^0$ state, or evolve to the NCD state (i.e., die from non-cancer causes).

For cancer patients, transitions between stable, transitional and EOL states are always possible [21] and a cancer patient can, at any moment, transition to the CD or NCD state from one of these states.

While patients in any of the stable states can transition freely to the transitional and EOL states, only some transitions between stable states are possible. It must be noted that since each stable state separates the patients according to length of time spent in the stable state, transitions between them can only happen from stable state $n$ to stable state $n + 1$.

It is only after four consecutive years spent in the stable state that patients can reenter the non-cancer state, so only transitions from the $S^4$ state to the NC state are possible.

Since the division of stable states is meant to separate patients according to how many consecutive years they’ve been stable, the only possible transition to the stable state from the transitional state or the EOL state is to the $S^0$ state.

As patients leaving the NC state to enter a cancer state do so evolving to the $S^0$ state, only individuals who are already cancer patients can transition into the transitional state. For this reason, only transitions from the stable states, the transitional states or the EOL states into the transitional state are considered possible.

For the same reason as the transitional states, only transitions from the stable states, the transitional states and the EOL states into the EOL states are considered possible.

3.4. Service assignment
Once all patients have been divided into different cohorts each month, they must be assigned to an appropriate type of PC service. Since calculating the PC needs of non-cancer patients is outside the scope of this work, it is assumed that non-cancer individuals (NC individuals) do not require a PC service. According to the PPS, stable patients ($S^0, S^1, S^2, S^3$ and $S^4$) don’t have a high symptom...
burden, so it is also assumed they do not need PC services [21].

PC provided in an ambulatory setting comes with lower costs to the NHS than care provided in the patient’s home or in an inpatient unit, and the separation of patients into groups who can receive care in an ambulatory setting and those that cannot, allows for a more efficient utilization of the available resources and a reduction of costs. Thus, it is assumed that patients in the transitional state with low dependency (TLD) receive care in an ambulatory setting, as their level of ambulation isn’t severely hindered by their disease.

According to the PPS, transitional patients with high dependency are patients with a high symptom burden, unable to do any work, who mostly lie and/or sit in bed all day. Without a caretaker present, it is assumed that they cannot receive the care they need as they are not capable of caring for themselves. Since the absence of an informal caretaker is a criterion for admission into an inpatient unit [8], these patients, who belong in the THDNCT group, receive PC in an inpatient unit.

Patients in the transitional state with high dependency and with a caretaker, are assigned to a PC service depending on their income level. Studies show that caretakers of PC patients incur the highest costs when they provide care for patients at home [24]. These costs can be financial, physical and emotional. Additionally, providing informal PC can also signify the loss of opportunities and loss or restriction of employment, since carers spend most of their time taking care of the patient [24]. It is thus assumed that patients who live below the poverty line (those in the THDCTBPL branch), must receive care in an inpatient unit, while those who live above the poverty line, belonging to the THDCTBPL branch, can receive care at home, as that is where most patients desire to receive care and eventually die [25].

For the group of patients in the EOL group, a similar separation between services is performed. Here the level of dependency isn’t considered as all patients in this group have a high symptom burden, with high needs and a high level of dependency. Patients without a caretaker, who make up the EOLNCT group, are immediately assigned to an inpatient unit, whereas patients with a caretaker and who live above the poverty line receive care at home and those with a caretaker who live below the poverty line receive care in an inpatient unit.
4. Case study
4.1. Data Set
The model proposed is applied to each municipality in the Lisbon county, in the 2016-2021 period, for adult individuals.

The data set used was as follows:
- Population [26]: Data from 2011 disaggregated by gender, age, and municipality. Used in the short-term decision tree.
- Mortality [27]: Countrywide data from 2012 to 2014, disaggregated by age and gender. Assumed to remain constant.
- Incidence [22, 28-31]: Data for the Lisbon county from 2002 to 2009, disaggregated by age group and gender. These values were used to estimate future cancer incidence, through a linear regression.
- Prevalence: No data found. Estimated through running an adapted version of the developed methodology retrospectively.
- Dependency level [32]: Estimated using total population dependency. Disaggregated by gender and age group.
- Presence of a caretaker [33]: Estimated using marriage status as a proxy (married individuals assumed to have a caretaker, other individuals assumed not to have one. Data from the 2011 Censos, disaggregated by municipality, gender, and age group.
- Income level [34]: Estimated according to the probability of a given individual living in risk of poverty or social exclusion. Countrywide data from 2014, disaggregated by age group and gender.
- Monthly service costs [12, 35]: Data from 2011 for ambulatory, home-care and acute care settings, and from 2011 for inpatient settings.
- Transition probabilities [21]: Data from a 2013 Canadian study, adapted to fit the Portuguese reality, both for men and women.
- Number of IC beds [36]: Data from 2016. Estimated according the total number of PC units.

4.2. Results
4.2.1 PC needs
Due to the lack of studies in the area giving a detailed estimation of current need, or even a rough estimate of future need, there are no benchmark numbers against which to compare the results obtained here. Quantitative comparisons between the results obtained and the expected results are thus difficult to make. However, qualitatively, the results obtained fall in line with the expected results.

In Figure 3, the evolution of the total monthly number of patients requiring PC over time is shown for the entire Lisbon county from January 2016 to January 2021. It is possible to see that the total need is rising, as well as the need for each individual service, with the highest demand being of AC services, with the number of patients requiring IC being similar to those requiring HC.

As shown, the number of patients requiring each type of service rises each year, a result expected due the rising values of cancer incidence, though it might be overestimated given the assumptions made regarding the possibility of remission, making the expansion of current services being offered even more necessary.

Taking a closer look only at the Lisbon municipality in 2021, it is possible to observe the distribution of PC needs per setting and per gender in Figure 4.

There is a pronounced difference between men and women when it comes to the need for HC, with men requiring this type of service more than women. This can be explained by the fact that older men are more likely to be married than women, which translates into a higher percentage of men having a caretaker. Nevertheless, it must be noted that women require more IC services than HC services, while most studies and experts in the area suggest the expansion of the HC network first. These results, however, suggest that focus should also be placed on IC, so as to provide patients with all the care they require in their last months of life.

Looking at the age distribution of the level of need for men, pictured in Figure 5, it can be seen...
that the need for each service is much higher in older age groups, supported by the higher incidence of cancer in those years. The highest level is for HC, influenced by the number of patients with a caretaker and with high dependency.

Figure 5: Percentage of male patients requiring each type of service per age group in the Lisbon municipality in 2021

4.2.2 Costs

In Table 1, the costs associated with providing PC to all individuals that require it in January of 2016 and of 2021 per service for the Lisbon county are presented. The total costs of providing these services outside the PC network, in an acute-hospital setting, are also presented, as well as the potential savings from providing the services in a specialized PC service.

Table 1: Monthly costs of providing palliative care to all individuals that require it in January 2016 and January 2021 per service for the Lisbon county (euros)

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<thead>
<tr>
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<th>Jan 2016</th>
<th>Jan 2021</th>
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<tbody>
<tr>
<td>AC</td>
<td>116,971.42</td>
<td>131,587.96</td>
</tr>
<tr>
<td>HC</td>
<td>794,049.52</td>
<td>898,954.92</td>
</tr>
<tr>
<td>IC</td>
<td>988,876.80</td>
<td>1,117,428.67</td>
</tr>
<tr>
<td>Total</td>
<td>1,899,897.73</td>
<td>2,147,971.55</td>
</tr>
<tr>
<td>Acute</td>
<td>7,499,253.91</td>
<td>8,455,998.89</td>
</tr>
<tr>
<td>Savings</td>
<td>5,599,356.17</td>
<td>6,308,027.34</td>
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As expected, considerable savings are predicted to happen if PC is provided in a specialized unit, with potential savings of around 420 thousand euros per month.

When the costs of providing PC inside a specialized network are compared to the costs of providing it in an acute hospital, the potential savings thus become evident. This is especially relevant given the current economic context of Portugal, with several budget cuts being experienced by the country. It suggests that although a considerable investment might be required to expand the PC network, it is an important one in a long-term horizon, permitting considerable savings for the NHS.

5. Discussion

5.1. Contributions

With this study, a gap in the literature has been filled. Through the implementation of a Markov Cycle Tree methodology, it was possible to estimate current need for PC based on publicly available data, which can easily be applied to other regions or expanded to include other pathologies, allowing a more detailed view of the current level of need for PC.

The results found yielded a higher degree of disaggregation than any found in the literature, and allowed the assignment of patients to each setting of care, while determining the costs associated with those assignments.

Furthermore, future need for PC services was also determined, using the same demographic variables, allowing health care providers to develop a PC network taking into consideration not only the current, but also future, values of need for PC.

Overall, this study is a valuable contribution in the area of PC, especially in the planning of current and future expansions or implementation of a PC network, allowing the health care service planner to determine the effect demographic factors have on need for PC.

5.2. Limitations

Some limitations are presented in this study, both in the methodology and in the approximations done to the data.

Regarding limitations of the model, it is relevant to mention only monthly needs for PC were calculated. Average length of stay was not determined and information regarding how much time each patient requires each service is

<table>
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<th></th>
<th>IC</th>
<th>Acute care</th>
<th>Savings</th>
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<tr>
<td></td>
<td>693,160</td>
<td>1,112,759</td>
<td>419,599</td>
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not studied, so the annual number of patients requiring PC cannot be determined through this methodology.

Additionally, it is assumed that after five years in the stable state cancer patients reenter a non-cancer state, which might not accurately represent the disease evolution of many cancer patients. This might underestimate the number of remissions, and subsequently overestimate the number of cancer patients, which in turn overestimates the number of PC services required. Additionally, the differences between incidence rates for individuals who'd already been cancer patients in the past and entered a remission state and incidence rates for individuals who'd never had cancer were also not considered, which might underestimate the number of cancer patients each year (and, consequently, the number of cancer patients requiring PC).

Cancer patients are also not disaggregated by pathology (which might have allowed more detailed results, as the incidence of deadlier cancer varies with age) and the need for PC from patients suffering from diseases other than cancer was not determined.

With regard to the application of the model, the main limitations are:

- Some error in the calculation of future cancer incidence, which directly affects the total number of individuals requiring PC.
- The calculation of cancer prevalence was also not ideal, as only cancer patients diagnosed in the past five years were studied, though a patient may show signs of cancer for a longer period, or they might experience remission after a shorter period.
- Transition probabilities between cancer states were assumed to remain constant between age groups, even though cancer affects different age groups differently.
- Dependency was estimated based on the proportion of total population living with dependency, though these numbers might not be the same for cancer patients as cancer is a debilitating disease.

It must be noted that these limitations are not inherently a limitation of the model itself, but rather a limitation due to the scarcity of data available and the rough approximations that needed to be made in order to properly apply the model. Since the model was developed in generic terms, more thorough, detailed data would yield more robust, accurate results.

6. Conclusions

With the ageing of the population and the rising incidence of diseases such as cancer, the importance of a well-developed PC network only grows. However, an efficient, balanced expansion requires detailed information of current and future needs, which was not available at the time of writing. For that purpose, this study was developed, with the aim of estimating the current needs for PC of cancer patients and projecting these values for the future, taking patients’ characteristics into consideration, and determining the need for each type of service, as well as the associated costs.

The application of the methodology developed was severely hindered by the critical lack of data available, and several gross approximations had to be made in order to properly implement the model designed, and to apply it to the small area level, in the Lisbon county, which might negatively affect the quality of the results obtained.

Nevertheless, the results fall in line with what was expected, showing that the current offer of PC services is not enough to provide care to all those patients that require it. Over the years, the model found an increasing need for PC with associated rising costs, more pressing in older age groups, and subject to worsen even more over the years, as the population ages. The need for PC becomes even more evident in the potential savings from providing these services in a PC network. It also becomes clear, however, that the current offer of services is not enough to meet all the demand for it, and an expansion of the PC network is essential, both to improve the quality of life of patients suffering from life-threatening disease, and to lessen the economic burden placed upon health care providers.

Overall, the proposed goal of this thesis was achieved, with a methodology to predict current and future detailed need of cancer patients for PC having been developed, and successfully applied to the Lisbon county and its municipalities, determining both the current and future level of need for PC of cancer patients and the associated costs.

Nevertheless, there are several ways in which additional work can be done and the methodology developed here can be expanded. First and foremost, additional data (especially directly relevant to the Portuguese reality) would allow the determination of more accurate predictions, significantly improving the quality of the results obtained. This is especially relevant in the case of cancer prevalence and remission, which considerably affect the results obtained.

Regarding the methodology itself, it can be expanded to further disaggregate patients across different types of cancer. This allows more exact results, as cancer mortality varies from cancer to cancer. On the same note, it can also be expanded to include different pathologies, accounting for all
the patients that require PC, regardless of whether or not they’re cancer patients.

Another possible expansion is the inclusion of scenario analysis. This way, different policies regarding the implementation and expansion of the PC network could be tested and the efficiency of its implementation could be studied.

An expansion for longer time periods or different regions could also be attempted, ensuring a more thorough, long-term planning of the PC network.

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