




Catastrophic financial effect of replacing informal care with formal care: a study based on haematological neoplasms

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Abstract

Informal care is a substantial source of support for people with cancer. However, various studies have predicted its disappearance in the near future. The aim of this study is to analyse the catastrophic effect resulting from the substitution of informal care with formal care in patients with blood cancer throughout the different stages of treatment. A total of 139 haematological neoplasm patients who underwent stem cell transplantation in Spain, completed a longitudinal questionnaire according to the three phases of treatment between 2012 and 2013. The economic value of informal care was estimated using proxy good, opportunity cost, and contingent valuation methods. Catastrophic health expenditure measures with thresholds ranging from 5 to 100% were used to value the financial burden derived from substitution. A total of 88.5% of patients reported having received informal care. In 85.37%, 80.49%, and 33.33% of households, more than 40% of their monthly income would have to be devoted to the replacement with formal care, with monthly amounts of €2105.22, €1790.86, and €1221.94 added to the 40% in the short, medium, and long-term, respectively (proxy good method, value = 9 €/h). Informal caregivers are a structural support for patients with blood cancer, assuming significant care time and societal costs. The substitution of informal care with formal care would be financially unaffordable by the families of people with blood cancer.

Keywords Informal care · Formal care · Economic value · Haematologic neoplasms · Catastrophism

JEL Classification D63 · I0 · I38

Introduction

Universal Health Coverage (UHC) is one of 13 health goal targets of the Sustainable Development Goals (SDGs) established by the World Health Organization for implementation by 2030. The specific target of UHC portends that all people can access the complete range of health services they need

(preventive, curative, palliative...) with sufficient quality and avoid suffering a catastrophic financial situation [1].

Out-of-pocket (OOP) payments are disbursements that individuals pay to access health systems that are not funded by the public sector [2]. OOP payment expenditures are catalogued as catastrophic when they represent a certain percentage in relation to household income (called threshold), for example, 5%, 10%, 20% [3], 30%, 40% [4], 50%, and 60% [5]. The threshold defined depends on the healthcare provision and level of coverage in each country (public or private health care system) [6]. In this sense, Xu et al. identified three key factors associated with catastrophism: healthcare services that require payments, low ability to pay and lack of prepayment of health insurance [7], and they revealed that average catastrophic countries rates vary depending on the each country's level of income [7, 8]. A more recent article found that OOP payments in health care expenditures in the Middle East and North African countries induce catastrophic rates ranging from 7 to 13% [9]; these catastrophic rates oscillate between 1–25% in 12 Latin American and

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Caribbean countries [10] and are especially higher in households with elderly members.

OOP payments have been studied in specific diseases, highlighting the financial burdens derived from the assumption of different types of costs, mainly medical and non-medical costs [11–15]. However, to our knowledge, only one study has briefly analysed the catastrophic incidence of OOP payments in cancer. It was done in South Korea and the catastrophic rate was 39.8% (threshold 10%) [16]. Several studies highlight the need to analyse the financial burden supported by cancer patients, survivors cancer patients and their relatives concerning the catastrophic incidence of OOP payments [17–19], and the need of homogenizing the measures of financial hardship in cancer research [20].

Cancer is one of the four most serious problems affecting society that greatly reduces the quality of life of patients throughout their treatment, making caregiver assistance necessary for daily activities [21, 22], and is the second most common cause of death world-wide (one in six) [23] and the first in Spain (one in four) [24]. Cancer treatment and medical costs are generally supported by the public sector in Europe, although there are direct costs, such as non-medical costs (informal and formal care costs), and psychosocial costs [25] that are assumed by the families [18]. In this way, OOP payments in cancer represent an important financial burden for families [17, 26, 27], even when individuals have overcome the disease [18]. The financial burden can be so high that families become indebted and reduce their assets to take care of their relatives with cancer [28]. The provision of informal care (i.e., a family member or friend who voluntarily assumes their care without specific training and without receiving any economic compensation [29]) means assuming the burden of care (generally women) and giving up hours of work and leisure and even reducing the quality of their own health [30–34]. Likewise, the burden, emotional distress, and quality of life of caregivers are closely interrelated with each other [35], with the financial burden becoming as important [20, 36] and as worrisome as the health burden of the caregivers [37]. However, the incorporation of women into the labour market, together with changes in family structures [38], emphasise the disappearance of the informal caregiver figure in favour of a necessary future demand for professional services [39–42]. Particularly, in Spain, this formal care could be provided publicly or privately. Public provision is mainly financed by the government and the patient pays according to his financial status [43, 44]. However, long waiting lists and high requirement should be met [45]. On the other hand, private provision is fully financed by the patient who acquires the service in the private market [46]. It is easy to get but expensive and it supposes a high economic burden to families [46, 47].

The forecast of the disappearance of informal care would imply that the Supplementary Care Model [46, 48, 49], which

postulates the temporary or circumstantial substitution of informal care with formal care, broadens its definition to the point of a perfect and permanent substitution of informal care with formal care and serves as our study hypothesis. The objective of this study is to quantify the catastrophic financial effect derived from the substitution of informal care with formal care in the case of blood cancer along with its temporal evolution in the different stages of treatment.

We have focused on blood cancer because the phases of the treatment can be easily differentiated; a recent study noted that over 75% of patients diagnosed with blood cancer receive informal care [50], with the informal caregivers acquiring the roles of “advocate”, “protector”, and “symptom monitor” in a relevant manner [51]. The main blood cancer diseases, such as leukaemia, lymphoma, and multiple myeloma, have been estimated to be extremely relevant to the increase in the incidence rate in European regions [52], and stem cell transplant patients are among the most vulnerable and acutely ill cancer populations [53, 54].

Materials and methods

Data

To conduct this study, we used the results obtained in a previously published study, in which the economic value of informal care was estimated in people diagnosed with haematologic neoplasms. Detailed information on this study can be found elsewhere [55, 56]. To summarise, a descriptive and longitudinal questionnaire was developed to obtain sociodemographic or/and clinical information relative to patients and their primary informal caregiver during different phases of treatment (available in Ortega–Ortega [56]). Eligible patients included adults (≥ 16 years) diagnosed with acute leukaemia, Hodgkin lymphoma, non-Hodgkin lymphoma, multiple myeloma, and other less common malignant haematological diseases (myelodysplastic syndrome, chronic myeloid leukaemia, and chronic lymphocytic leukaemia, among others) who underwent stem cell transplantation between 2006 and 2011 at the University Hospital Virgen de las Nieves in Granada and the University Hospital Virgen del Rocío in Seville (Spain) and who, at the time of survey, had survived the disease; both hospitals are reference hospitals for malignant haematological diseases in southeast and southwest Spain, respectively. The Clinical Research Ethics Committee and Haematology Department of each health centre approved the study.

The information was obtained between January 2012 and December 2013. All of the patients ($n=299$) were contacted by telephone. Patients who responded to the first or second call, randomly ($n=230$), were informed and invited to participate in the study by sending a questionnaire by mail. Patients completed the questionnaire, providing information

on their sociodemographic and clinical characteristics (the latter were corroborated with their clinical histories). In addition, they were asked to identify their primary informal caregiver during their illness and to answer the questions related to him or her and the number of hours and months of informal care they received from their informal caregiver.

To analyse the process of temporal evolution when receiving informal care, the three sequential phases of treatment were differentiated according to the medical protocol [57]. Phase 1, or short-term, corresponds to the pre-transplant phase, understood as the period of time between the initial treatment protocol and the transplantation. It includes the administration of the different cycles of chemotherapy and/or radiotherapy prior to transplant and the consolidation and maintenance of the patient until the transplant takes place. We limited the time of care to a maximum of 24 months when the time of care reported exceeded this figure. Only five patients reported times of more than 24 months in this phase. Phase 2, or medium-term, corresponds to the first year after the transplant. By the medical protocol, phase 1 may lead to a new phase characterised by a haematopoietic stem cell transplant (HSCT) because it is the most suitable clinical choice and the most effective therapy to extend the survival of patients whose clinical conditions indicate such a treatment [58, 59]. This process requires a period of close to a month of hospital isolation for the infusion of the haematopoietic stem cells and adequate medical control, given the treatment's complexity. Finally, phase 3, or long-term, covers the second to the sixth years after the transplant. The months and years following the transplant, taken up by the recovery of the patient, are an especially vulnerable time and shape the complete remission of the disease, which is itself capable of becoming a prolonged process. All of the patients who were in any of the years corresponding to phase 3 prospectively answered the questions referring to phase 3, but retrospectively answered the questions referring to phases 1 and 2 based on the recall method [60].

Economic valuation of informal care

The number of months and hours per day of informal care received in each of the three phases was quantified. The intensity of informal care received during each period was measured by an ordinal categorical group variable (< 2 h/day, 2–4 h/day, 4–8 h/day, and > 8 h/day). The midpoint of each ordinal group was used as the value of time. For the group of > 8 h/day, the midpoint was set at 12 h/day, following the truncation that other authors have given, restricting the maximum to 16 h/day of care [61, 62]. Due to the retrospective nature of our study, we could not request disaggregated information on basic and instrumental activities of daily living.

To estimate the informal care value (ICV), the monetary value of informal care hours received by the patients was quantified. As there is no market price for informal care, it was necessary to allocate a shadow price for the valuation of these hours. The economic valuation of this time was achieved by following certain preference methods, i.e., the proxy good method (PGM) and the opportunity cost method (OCM), as explained and displayed in the results in our previous study [55]. In sum, the PGM values the time devoted to informal care at the market price of the nearest substitute asset. Care-giving hours were valued using the cost of the reference Home Help Service published in the Official Bulletin of the State of Spain because care services are offered by professional and trained caregivers (14 €/h, 11.5 €/h, and 9 €/h) [63]. OCM values informal care as the informal caregiver's benefit forgone due to spending time providing informal care and was calculated according the circumstances of each caregiver. A third method has been added in this study, the contingent valuation method (CVM) [64], which values informal care based on the willingness for compensation that a caregiver should receive when providing 1 h or more of care so that the caregiver's wellbeing is not altered. For this valuation, the monetary value of €6.40/h was used, representing the minimum symbolic cost for which a family member would be willing to provide care to their family member [65]. All costs are given in Euros as of 2012.

Statistical analysis

Following the approach by Wagstaff and van Doorslaer [4], a dummy variable E_i is defined that takes a value of 1 when the ICV_i of household i , as a proportion of the equivalent household income (x_i), exceeds the normative threshold (z_{cat}), that is, when $(ICV_i/x_i) > z_{cat}$; otherwise, the value is 0. The equivalent household income is calculated by dividing the household income between the equivalent members of the household. To do this, we used the OECD modified equivalence scale [66], which assigns a value of 1 to the first household member; 0.5 to each household member aged 14 or over; and 0.3 to each member aged 13 or under. The household's ICV_i is defined as catastrophic when the expenditure incurred by the household exceeds the normative threshold. The catastrophic payment headcount ratio (H) quantifies the incidence of ICV_i and is defined as follows (n is the sample size):

$$H_{cat} = \frac{1}{N} \sum_{i=1}^n E_i = \mu_E. \quad (1)$$

It also defined the gap between the dependency-related ICV_i and the normative catastrophic threshold (z_{cat}) as the catastrophic *overshoot* (O_i), equal to $(ICV_i/x_i) - z_{cat}$ if $E_i = 1$;

otherwise, the value is 0. The global average that measures the size and intensity of the gap of the catastrophic payments (O_{cat}) is defined as:

$$O_{\text{cat}} = \frac{1}{N} \sum_{i=1}^n O_i = \mu_O. \quad (2)$$

A new measure has been proposed that complements the previous one, the catastrophic absolute overshoot (AO_i), which shows the difference gap or excess due to disbursement of ICV_i , equal to $ICV_i - z_{\text{cat}} \times x_i$ if $E_i = 1$; otherwise, the value is 0. In this case, the global average represents the intensity of the gap of the catastrophic absolute payments (AO_{cat}) and is defined as:

$$AO_{\text{cat}} = \frac{1}{N} \sum_{i=1}^n AO_i = \mu_{AO}. \quad (3)$$

The global catastrophic absolute overshoot (GAO_i) of ICV_i is defined as:

$$GAO_{\text{cat}} = \sum_{i=1}^n AO_i. \quad (4)$$

Therefore, while H measures the proportion of households that surpass certain threshold levels, O indicates the average amount by which the chosen threshold levels are exceeded. The expenditure thresholds most common in the literature (z_{cat}) of 10%, 20% [3, 67], 30% [4, 10], 40% [7, 68], 50%, 60% [5] were investigated, along with two new thresholds (80% and 100%), which to our knowledge, have never been reported in the literature.

Results

A total of 139 questionnaires were received (60.43% response rate), of which 123 patients reported having received informal care at some phase during their treatment (88.49% of survey respondents). The percentage of population who receive informal care in phase 1 is 82.73%, 79.14% in phase 2, and 41.05% in the last phase (more information in [50]). Table 1 shows the sociodemographic information of the sample. Half of the individuals were men (51.22%), and the average age was 46.42 years (SD 13.93). The marital status of with a partner (69.92%) and a low level of education (37.40%) predominated. Regarding the clinical variables, a slightly higher incidence of lymphoma was observed (32.52%), followed by multiple myeloma (29.27%), and almost two of every three transplants performed were autologous (63.41%). In addition to this, formal care was present for 12 (8.63%) of the patients during the pre-transplant

period, 11 (7.91%) during transplant period and 9 (6.47%) (detailed information in [50]).

Table 2 shows the daily and monthly times and the monthly value of informal care estimated according to the methodology. The average numbers of estimated months of care were approximately eight during the short-term and seven during the medium-term. From the sample, 52.03% and 39.02% of respondents reported receiving more than 8 h of care daily in the pre-transplant and first-year post-transplant phases, respectively, with significant reductions in the last stage, where two out of three people reported receiving less than 2 h of care daily.

The catastrophic effect derived from the substitution of care for the phase 1 or pre-transplant stage is shown in Table 3. It is observed that 85.37% of households would devote at least 40% of their income to formal care (H_{cat}) according to the PGM, a percentage that drops to 82.93% according to the OCM and CVM. Taking the PGM as a reference with a value of €9/h, families would have to devote 414.83% of their monthly income, i.e., €2105.22 (SD €1050.51), which, added to the 40% corresponding to the set threshold, equals a total of 454.83% of their income. This expenditure would represent an annual gap of €2.65 million per year for the sample presented. According to the method used, the minimum and maximum intervals for the same threshold of 40% would be those revealed by the CVM and PGM (with a value of €14/h), respectively, whose amounts, when added to 40% of their income, would be 292.17% and 642.67%, and, in monetary terms, would be €1441.04 and €3342.00.

These percentages and amounts decrease as the thresholds used increase. However, it is striking that households that would have to devote more than 100% of their income would amount to 73.17% for the PGM (value €9/h) (66.67% for both methods, CVM and OCM). In monetary terms, this would mean that in addition to 100% of the household income, it would be necessary to devote an additional 419.76% (297.99% for the CVM and 281.19% for the OCM) of income, that is, €1924.87 more per month above their total income (€1293.15 for the CVM and €1231.64 for the OCM).

Table 4 shows the results for phase 2, which, although with moderate reductions, offers very similar amounts and patterns of behaviour compared to the first stage of chemotherapy treatment.

It is in the last phase of the analysis, phase 3, as shown in Table 5, that the incidence and intensity rates are significantly reduced: 33.33% of households would spend more than 40% of their income on formal care, with an added percentage of their resources of 312.48%, that is, €1221.94 for the PGM (€9/h). The intervals are again made up of the OCM and the CVM, with percentages of resources added for this threshold of 215.40% and 235.38% (€878.28 and

Table 2 Hours and months of informal care received

	Stage 1: pre-transplantation (%)	Stage 2: 1 year after transplantation (%)	Stage 3: 2–6 years after transplantation (%)
Informal care hours received (h/day)			
<2	12.19	17.89	66.67
2–4	13.82	24.39	12.19
4–8	17.89	14.63	9.76
>8	52.03	39.02	7.31
Missing data	4.07	4.07	4.07
Informal care months received [mean (SD)]	7.92 (5.72)	7.33 (4.68)	–
Value of informal care			
Proxy good method (9 €/h) [mean (SD)]	2192.03 (112.35)	1791.61 (118.14)	701.69 (109.46)
Proxy good method (11.5 €/h) [mean (SD)]	2800.93 (143.55)	2289.28 (150.96)	549.15 (85.67)
Proxy good method (14 €/h) [mean (SD)]	3409.83 (174.76)	2786.95 (183.78)	854.24 (133.26)
Opportunity cost method [mean (SD)]	1505.18 (91.85)	1223.24 (95.41)	393.79 (68.25)
Contingent valuation method [mean (SD)]	1495.42 (90.43)	1222.24 (92.87)	374.64 (65.27)

Value of informal care according to different methods

SD Standard deviation

€881.19 in absolute value) according to the two methods, respectively. Finally, it should be noted that, again, the percentages and amounts are reduced as the thresholds used increase: in this sense, the percentage of households that would spend more than 100% of their income to pay for formal care in the remission stage would be 25.20%, with a monthly average catastrophic gap of €1173.35 (SD €436.21), according to the PGM (€/h).

Discussion

In high-income countries, access to most of the health services required is covered in the face of inherent financial risks [8], given that the countries have developed ad hoc mechanisms to avoid such financial risk [7]. However, in low- and middle-income countries, the absence of formal health coverage leads to a struggle in the capacity of households to pay, especially for the lower income percentiles, who often sink into poverty [69]. For this reason, given that medical costs are covered in Spain, informal care would be one of the main potential factor of impoverishment for families in the event of the disappearance of informal care.

This paper provides information on the financial implications arising for households to replace informal care with formal care in patients with haematologic malignancies during different phases of treatment. Following our results, if

informal care disappear in a future, more than 90% of families with a cancer patient should pay formal care generating an important economic impact and catastrophic situation. High average numbers of hours of informal care are received by patients throughout the different stages of treatment, ranging from more than 8 h of care in more than half of the patients in the first stage to less than 2 h in the final stage. This investment would result in a significant financial burden for families that would mean having to assume disbursements of more than 414.83% above 40% (total 454.83%) of the household's monthly equivalent income in the first stage [total 322.17% CVM—682.67% PGM (€14/h)]. These amounts represent the approximate monetary values that these relatives would have to face if they had to resort to hiring a formal caregiver instead of an informal one. Therefore, a significant financial hardship on household finances is observed of which health decision-makers must be aware.

A decrease in the disbursement can be observed in the next stages. Particularly, in the transplant phase, the proportion of household that would dedicate more than 40% of income is reduced from 85.37 to 80.49%, and the correspondent monthly gap decreases to 392,11% (above 40%), while in the post-transplant stage this values are reduced to 33.33% and 312.48% (above 40%), respectively (PGM €14/h). These results are especially higher in the first two phases due to the extraordinary large number of hours of informal care received and the lower value of the equivalent

Table 3 Catastrophic incidence of substitution of informal care to formal care of patients with hematologic malignancy

	Threshold						
	10%	20%	30%	40%	60%	80%	100%
Proxy good method (9 €/h)							
Headcount (H_{cat})	89.43%	88.62%	86.99%	85.37%	82.11%	81.30%	73.17%
Overshoot (O_{cat}) (%) (SD)	424.94 (420.00)	418.86 (420.00)	416.78 (420.00)	414.83 (420.20)	411.29 (420.56)	395.48 (420.68)	419.76 (422.26)
Absolute overshoot (AO_{cat}) (€) (SD)	2264.59 (1102.83)	2197.79 (1090.79)	2151.44 (1067.95)	2105.22 (1050.51)	2015.32 (1029.49)	1877.36 (1051.01)	1924.87 (957.76)
Global absolute overshoot (GAO _{cat}) (€)	2,989,254	2,874,708	2,762,443	2,652,577	2,442,565	2,252,834	2,078,863
Proxy good method (11.5 €/h)							
Headcount (H_{cat})	89.43%	89.43%	88.62%	86.99%	84.55%	82.11%	81.30%
Overshoot (O_{cat}) (%) (SD)	545.75 (536.66)	535.75 (536.66)	530.77 (536.69)	530.89 (536.79)	526.42 (536.97)	522.21 (537.38)	507.56 (537.54)
Absolute overshoot (AO_{cat}) (€) (SD)	2917.77 (1409.14)	2830.90 (1410.67)	2769.90 (1396.32)	2734.70 (1366.29)	2639.97 (1336.82)	2547.78 (1322.22)	2416.15 (1338.74)
Global absolute overshoot (GAO _{cat}) (€)	3,851,454	3,736,788	3,623,023	3,511,357	3,294,685	3,087,914	2,899,382
Proxy good method (14 €/h)							
Headcount (H_{cat})	89.43%	89.43%	88.62%	88.62%	85.37%	84.55%	82.11%
Overshoot (O_{cat}) (%) (SD)	666.57 (653.32)	656.57 (653.32)	652.67 (653.36)	642.67 (653.36)	647.52 (653.65)	633.90 (653.71)	633.12 (654.02)
Absolute overshoot (AO_{cat}) (€) (SD)	3570.95 (1715.65)	3484.08 (1716.12)	3428.31 (1696.27)	3342.00 (1702.35)	3293.97 (1630.62)	3154.58 (1640.69)	3080.25 (1615.22)
Global absolute overshoot (GAO _{cat}) (€)	4,713,654	4,598,988	4,484,323	4,371,337	4,150,405	3,936,914	3,733,262
Opportunity cost method (OCM)							
Headcount (H_{cat})	89.43%	86.99%	85.37%	82.93%	76.42%	70.73%	66.67%
Overshoot (O_{cat}) (%) (SD)	285.63 (310.70)	283.76 (311.39)	279.32 (311.87)	277.76 (359.24)	281.23 (315.58)	283.98 (318.09)	281.19 (320.35)
Absolute overshoot (AO_{cat}) (€) (SD)	1527.78 (935.50)	1483.45 (910.48)	1425.35 (898.68)	1383.43 (883.06)	1331.46 (855.5)	1290.83 (822.63)	1231.64 (803.24)
Global absolute overshoot (GAO _{cat}) (€)	2,016,671	1,904,744	1,795,944	1,693,312	1,501,883	1,347,623	1,211,936

Table 3 (continued)

	Threshold						
	10%	20%	30%	40%	60%	80%	100%
Contingent valuation method (CVM)							
Headcount (H_{cat})	89.43%	86.99%	84.55%	82.93%	78.86%	71.54%	66.67%
Overshoot (O_{cat}) (%) (SD)	299.29 (298.66)	297.71 (298.74)	296.36 (298.84)	292.17 (299.00)	287.08 (299.60)	296.50 (300.37)	297.99 (300.89)
Absolute overshoot (AO_{cat}) (€) (SD)	1,585.28 (784.72)	1,541.39 (758.19)	1,498.11 (738.32)	1,441.04 (737.07)	1,351.91 (727.12)	1,337.35 (672.19)	1,293.15 (641.45)
Global absolute overshoot (GAO_{cat}) (€)	2,092,566	1,979,148	1,869,643	1,763,833	1,573,621	1,412,243	1,272,455

Pre-transplant or first phase

H_{cat} is the proportion of households that dedicate more monthly equivalent household income than threshold to replace informal care with formal care

O_{cat} is the average amount dedicated above the threshold of monthly equivalent household income (%)

AO_{cat} is the average amount dedicated above the threshold of monthly equivalent household income (€)

GAO_{cat} is the global amount dedicated above the threshold of monthly equivalent household income (€)

household income. It reveals that the financial hardship is concentrated in first and second phases.

This paper is the first to analyse the catastrophic risk for families facing non-coverage of informal care and its possible disappearance; therefore, its comparison with other papers is not possible. However, to put the magnitude of the results obtained into context, a comparison can be made based on the catastrophic incidence ratios in OOP payments for access to health systems. Thus, low-income countries show ratios of catastrophic incidence ranging from 3.1% [8] to up to 10.45% in countries in transition, such as Vietnam, or 10.27% in Brazil [7]; in developed countries, ratios of 13.50% in Portugal [70] and 9.75% in Greece [71] have been observed (a 40% threshold was used in all of these studies). However, none of these studies shows ratios as high as those obtained in this paper.

This paper provides a complementary measure to assess the impact of informal care in terms of the financial budget of families, taking a step further than in the traditional methodologies of informal care assessment [64], which reveals problem of the financial burden inherent to informal care by means of the measure used [4]. Similar to what has been previously reported in the literature in the OOP payments inherent in access to health systems [7, 8, 69] or in different diseases [11–16], the use of this measure is proposed, though not applied until now, in direct medical costs [17] and the rest of the inherent costs of the disease [18].

In 2006, Act 39/2006 of 14th December on the Promotion of Personal Autonomy and Assistance for Persons in a Situation of Dependency, called the Dependence Act, was approved in Spain [72]. This Act covers the needs of individuals who cannot perform the basic activities of daily living in an autonomous and independent way; however, it automatically excludes individuals in chemotherapy or radiotherapy from its coverage [73], despite the important care burden that has been revealed in this and other papers [50, 55, 62, 74–77]. The design of this Act ignores the situation of not only individuals with cancer, but also of their caregivers, in terms of financial hardship, by not recognising their work. The temporary provision of home nursing or home help services developed by the Dependence Act would contribute greatly to mitigate the financial hardship of household in pre-transplant and transplant phase.

Our results may be relevant for the design of further social policies in Spain and other countries regarding the recognition and attention of informal care in people with cancer, specifically blood cancer. First, the need to develop constructs to evaluate the financial hardship in cancer must include, in addition to labour productivity losses or psychosocial costs [20], informal care because otherwise, the

Table 4 Catastrophic incidence of substitution of informal care to formal care of patients with hematologic malignancy

Threshold		10%	20%	30%	40%	60%	80%	100%
Proxy good method (9 €/h)								
Headcount (H_{cat})	86.18%	83.74%	82.93%	80.49%	75.61%	71.54%	64.23%	
Overshoot (O_{cat}) (%) (SD)	394.48 (461.08)	396.14 (462.95)	390.11 (463.59)	392.11 (465.72)	397.58 (470.13)	400.69 (473.76)	427.80 (479.73)	
Absolute overshoot (AO_{cat}) (€) (SD)	1910.12 (1202.72)	1881.60 (1186.29)	1818.49 (1188.82)	1790.86 (1180.63)	1742.40 (1171.74)	1700.42 (1152.16)	1763.48 (1072.22)	
Global absolute overshoot (GAO _{cat}) (€)	2,429,665	2,325,652	2,225,837	2,127,542	1,944,515	1,795,645	1,671,778	
Proxy good method (11.5 €/h)								
Headcount (H_{cat})	86.18%	85.37%	82.93%	82.93%	78.86%	75.61%	71.54%	
Overshoot (O_{cat}) (%) (SD)	506.83 (589.16)	501.75 (589.93)	506.80 (592.36)	496.80 (592.36)	502.65 (596.98)	504.69 (600.72)	514.21 (605.37)	
Absolute overshoot (AO_{cat}) (€) (SD)	2464.12 (1534.13)	2403.63 (1532.52)	2391.29 (1509.34)	2310.10 (1521.22)	2261.99 (1506.16)	2201.10 (1503.3)	2187.74 (1470.07)	
Global absolute overshoot (GAO _{cat}) (€)	3,134,365	3,028,572	2,926,937	2,827,562	2,632,955	2,456,425	2,310,257	
Proxy good method (14 €/h)								
Headcount (H_{cat})	86.18%	85.37%	83.74%	82.93%	80.49%	77.24%	75.61%	
Overshoot (O_{cat}) (%) (SD)	619.18 (717.23)	615.18 (718.18)	617.33 (720.14)	613.50 (721.14)	612.18 (724.45)	618.21 (729.00)	611.79 (731.31)	
Absolute overshoot (AO_{cat}) (€) (SD)	3018.13 (1865.68)	2962.20 (1861.57)	2935.99 (1955.41)	2882.89 (1841.25)	2803.87 (1832.73)	2755.97 (1821.88)	2659.81 (835.04)	
Global absolute overshoot (GAO _{cat}) (€)	3,839,065	3,732,372	3,628,877	3,528,662	3,330,995	3,141,805	2,968,337	
Opportunity cost method (OCM)								
Headcount (H_{cat})	85.37%	82.93%	78.05%	73.17%	66.67%	56.10%	53.66%	
Overshoot (O_{cat}) (%) (SD)	260.17 (318.52)	257.98 (320.10)	264.42 (323.47)	272.39 (326.92)	279.22 (331.52)	312.21 (338.45)	306.46 (339.93)	
Absolute overshoot (AO_{cat}) (€) (SD)	1289.72 (1005.54)	1245.10 (1003.06)	1240.55 (995.51)	1246.80 (983.49)	1226.78 (959.69)	1313.18 (901.74)	1244.98 (891.61)	
Global absolute overshoot (GAO _{cat}) (€)	1,625,051	1,524,002	1,429,116	1,346,545	1,207,148	1,087,316	986,020	

Table 4 (continued)

	Threshold						
	10%	20%	30%	40%	60%	80%	100%
Contingent valuation method (CVM)							
Headcount (H_{cat})	85.37%	82.93%	80.49%	76.42%	65.04%	59.35%	54.47%
Overshoot (O_{cat}) (%) (SD)	280.37 (328.31)	278.74 (329.66)	328.67 (418.79)	282.27 (333.78)	311.35 (340.68)	320.92 (343.63)	329.56 (345.83)
Absolute overshoot (AO_{cat}) (€) (SD)	1,347.04 (851.79)	1,303.98 (843.72)	1,260.84 (842.32)	1,246.22 (833.83)	1,309.44 (762.35)	1,297.70 (713.52)	1,280.61 (669.93)
Global absolute overshoot (GAO_{cat}) (€)	1,697,274	1,596,067	1,497,881	1,405,735	1,257,059	1,136,782	1,029,609

First-year post-transplant or second phase

H_{cat} is the proportion of households that dedicate more monthly equivalent household income than threshold to replace informal care with formal care

O_{cat} is the average amount dedicated above the threshold of monthly equivalent household income (%)

AO_{cat} is the average amount dedicated above the threshold of monthly equivalent household income (€)

GAO_{cat} is the global amount dedicated above the threshold of monthly equivalent household income (€)

total costs of the disease would be underestimated [77], thus biasing any evaluation that one may wish to perform. Second, all of these evaluations take place in an environment in which demographic and social perspectives suggest that an important part of informal care may be unsustainable in the future and should be replaced by professional care [39–42], with no definite decisions made about whether the funder should be public, private, or mixed. Finally, the design of care policies for people with dependencies requires the best coordination of socio-health and family resources with the one in existence [24], which permits meeting the needs of these people with assurance, efficiency, and quality, resulting in significant externalities for society.

This paper has the following limitations. First, the analysis was performed on patients diagnosed with haematologic neoplasms who had undergone stem cell transplantation as a minimum in the previous year. This selection was made with the aim of analysing the informal care received not only at the phase of chemotherapy, but in the transplantation phases, which are characterised by health complications. Second, the hypothesis of the substitution of all informal care with formal care can be very radical because families would foreseeably make the substitution not for the full value of the informal care obtained in the valuation results, but for the minimum indispensable value that would permit balancing the budget of the home and the coverage of care needs. In this sense and in the absence of more information, we understand that formal care would be used to temporarily or circumstantially replace informal care [48] or for those tasks that require formal professional services, combining this attention with the support of the informal caregiver [78]. Finally, another limitation has to do with the use of the “recall method” based on patients’ memory due to the design of the study. Consequently, there could be a bias inherent in the methodology and disaggregated information on basic and instrumental activities of daily living could not be requested.

Future lines of research should be aimed at analysing the impoverishing effect on other types of cancer and other diseases, taking into account not only informal care, but also other health costs, such as labour productivity losses due to temporary or permanent disability.

Table 5 Catastrophic incidence of substitution of informal care to formal care of patients with hematologic malignancy

	Threshold						
	10%	20%	30%	40%	60%	80%	100%
Proxy good method (9 €/h)							
Headcount (H_{cat})	42.28%	36.59%	35.77%	33.33%	30.08%	30.08%	25.20%
Overshoot (O_{cat}) (%) (SD)	269.86 (386.82)	302.62 (401.49)	299.79 (406.57)	312.48 (410.27)	327.26 (419.51)	307.26 (419.51)	349.50 (436.21)
Absolute overshoot (AO_{cat}) (€) (SD)	1160.88 (1062.05)	1250.33 (1055.59)	1205.62 (1049.17)	1221.94 (1049.17)	1215.25 (1038.27)	1087.63 (1050.88)	1173.35 (1042.08)
Global absolute overshoot (GAO _{cat}) (€)	724,389	675,177	636,566	601,194	539,571	482,909	436,486
Proxy good method (11.5 €/h)							
Headcount (H_{cat})	42.28%	39.84%	35.77%	35.77%	31.71%	30.08%	30.08%
Overshoot (O_{cat}) (%) (SD)	347.60 (494.27)	359.16 (502.31)	391.39 (515.67)	381.39 (515.67)	411.62 (530.15)	414.83 (536.04)	394.83 (536.04)
Absolute overshoot (AO_{cat}) (€) (SD)	1507.03 (1353.2)	1509.11 (1361.34)	1601.07 (1344.95)	1528.40 (1351.56)	1578.44 (1333.65)	1531.55 (1328.21)	1403.93 (1340.99)
Global absolute overshoot (GAO _{cat}) (€)	940,389	887,357	845,366	806,994	738,711	680,009	623,346
Proxy good method (14 €/h)							
Headcount (H_{cat})	42.28%	42.28%	36.59%	35.77%	33.33%	30.08%	30.08%
Overshoot (O_{cat}) (%) (SD)	425.34 (601.72)	415.34 (601.72)	471.85 (624.54)	473.00 (627.77)	488.30 (638.20)	508.00 (648.95)	502,4652.56
Absolute overshoot (AO_{cat}) (€) (SD)	1853.19 (1644.46)	1767.91 (1658.59)	1953.16 (1641.39)	1923.85 (1639.36)	1915.96 (1631.01)	1925.06 (1618.64)	1847.85 (1618.26)
Global absolute overshoot (GAO _{cat}) (€)	1,156,389	1,103,177	1,054,706	1,015,794	942,651	877,829	820,446
Opportunity cost method (OCM)							
Headcount (H_{cat})	40.65%	36.59%	31.71%	30.89%	27.64%	24.39%	19.51%
Overshoot (O_{cat}) (%) (SD)	186.40 (260.79)	197.78 (267.61)	219.31 (276.08)	215.40 (277.47)	221.40 (283.98)	232.45 (290.83)	273.21 (301.17)
Absolute overshoot (AO_{cat}) (€) (SD)	840.75 (909.20)	857.50 (916.36)	917.88 (918.16)	878.28 (914.38)	855.11 (911.18)	848.01 (911.72)	932.05 (920.97)
Global absolute overshoot (GAO _{cat}) (€)	504,447	463,050	429,567	400,494	348,883	305,283	268,431

Table 5 (continued)

	Threshold						
	10%	20%	30%	40%	60%	80%	100%
Contingent valuation method (CVM)							
Headcount (H_{cat})	42.28%	35.77%	33.33%	30.08%	26.83%	21.14%	20.33%
Overshoot (O_{cat}) (%) (SD)	189.01 (275.07)	214.51 (286.98)	220.65 (291.75)	235.38 (298.32)	243.48 (306.13)	290.24 (318.82)	282.16 (320.46)
Absolute overshoot (AO_{cat}) (€) (SD)	800.88 (759.52)	867.02 (750.54)	858.32 (746.86)	881.19 (737.27)	847.83 (740.31)	941.96 (712.49)	868.39 (719.65)
Global absolute overshoot (GAO_{cat}) (€)	499,749	457,785	422,294	391,250	335,739	293,893	260,518

Second-sixth year post-transplant or third phase

H_{cat} is the proportion of households that dedicate more monthly equivalent household income than threshold to replace informal care with formal care

O_{cat} is the average amount dedicated above the threshold of monthly equivalent household income (%)

AO_{cat} is the average amount dedicated above the threshold of monthly equivalent household income (€)

GAO_{cat} is the global amount dedicated above the threshold of monthly equivalent household income (€)

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Compliance with ethical standards

Conflict of interest The authors of this manuscript have no conflicts of interest.

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