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A translational approach to design effective intervention tools for informal caregivers of dependent cancer patients

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ABSTRACT

Objectives: Caregivers of terminal patients often report a higher prevalence of unmet needs than cancer survivors. However, very few interventions have been carried out to support caregivers of patients in advanced stages, and, in most cases, they have not been rigorously designed and evaluated. The ultimate aim of this research was to obtain specific information about the sociodemographic characteristics, the different types of care provided, the symptoms due to burdens, the impact of caring on the quality of life, and the unmet needs of informal caregivers of dependent patients with cancer. This is to design effective intervention programs that can be implemented from the hospital setting itself and therefore, to improve their quality of life and prevent the deterioration of their health.

Study design: A cross-sectional design and survey methodology were used for descriptive purposes.

Methods: The sample was composed of 132 informal caregivers of dependent patients with cancer, from a public hospital in Valencia, Spain, who were identified through the patient database of the oncology service, over the 4-month data collection period. Self-administered questionnaires were combined with personal interviews: Interview Protocol for the main caregiver, Questionnaire ICUB97, and survey of hospital quality.

Results: The most frequently provided types of care included the following: keeping the patient company, acting as an intermediary between them and healthcare workers, and helping them to do basic daily life activities. The main negative consequences caregivers reported were the following: feeling more tired, having less free time, changing their daily routines, and having fewer social relationships/interactions and various emotional and physical symptoms. Many of the needs of informal caregivers were not being met: resolution of doubts about illness, training in the care they should provide to the patient, and psychological help.

Conclusions: Recommendations for the development of effective intervention programs are offered: increasing the psychological services provided in oncology units, training medical

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staff in communication skills, facilitating access to information about the disease through different means, training for informal caregivers in care techniques, coping and communication skills, self-care, and organization of time. On the one hand, implementing effective intervention programs for informal caregivers will reduce the amount withdrawing from their care duties and on the other hand, the proliferation of what are known as secondary patients.

Introduction

Despite the significant advances made in cancer treatment, this disease is one of the leading causes of death in developed countries.[1] The advanced stages of this disease are characterized by intense suffering and a high need for care. At this point, the family becomes particularly important. In most cases, relatives become informal caregivers owing to the demands produced by the disease itself or by the patient's treatment. Carers should address a wide range of issues, including the following: physical problems (such as pain, fatigue, or insomnia), emotional problems (such as anxiety or depression), and problems of a practical nature (such as financial or legal difficulties). However, the caregiver's needs are largely unmet,[2–5] which can considerably worsen the intense emotional climate produced by the impact of the disease and the anticipation of the loss of a loved one.[6]

Some empirical studies reveal that informal caregivers of patients with end-stage cancer have greater anxiety and symptoms of depression than the patients themselves, which affects their quality of life.[7–9] The findings of these studies suggest that main caregivers should not be treated merely as care partners but also as possible secondary and future patients. In addition, informal caregivers also manifest different needs at the physical, social, and psychological levels (e.g., see[10–13]). A recent review[5] classified the unmet needs of partners and caregivers of adults diagnosed with cancer into six categories: comprehensive cancer care, emotional and psychological, partner or caregiver impact and daily activities, relationship, information, and spiritual needs. They found that the main unmet needs across a number of studies included managing their own and the patient's emotional distress and, consequently, the need for specific training in coping skills. Regarding information needs, Adams et al.[14] carried out a systematic review of empirical studies that assessed these needs in partners and/or family members of adult patients with cancer. They found that most of the studies focused on the diagnosis and initial treatment phase but did not assess the needs of the more advanced phases of the disease. Moreover, only some of them distinguished between met and unmet needs, concluding that caregivers were more likely to have unmet needs for information about supportive care than for medical information.

As a recent meta-analysis pointed out, although interventions have small to medium effects, they significantly relieve the burden and improve coping skills, self-efficacy, and quality of life.[15] More specifically, a systematic review of community intervention models for dependent people and their caregivers concluded that some respite care positively affects caregivers' physical and mental health while lowering their perceived burden.[16] Types of services studied included the following: day care, host family, in-home, institutional, and video respite. The formal health support services are also called respite services because their purpose is to relieve the caregiver, on a regular or temporary basis, of responsibility and caregiving demands. Clearly, it is important to act early to improve the quality of life of informal caregivers because unmet needs not only compromize caregivers' quality of life but also have an adverse effect on the quality of care provided to patients.[3,17]

The unique contribution of this work is that, following the basic principles of translational research, it gathers empirical data from informal caregivers of dependent patients with cancer that can be used to design effective intervention programs and to prioritize resources.[18] Recent conceptualizations of translational research emphasize its multidisciplinary and multidirectional character to reduce the incidence and prevalence of psychological, behavioral, and physical disorders.[19,20] It also points out the need to reduce the gap between the scientific and service communities, to design effective interventions into typical care settings and disseminate them to as many consumers as possible.[21] In this line, we propose the implementation of empirical knowledge–based intervention programs from the hospital setting, to facilitate accessibility for all the agents involved: patients, informal caregivers, and medical staff.

Therefore, the specific objectives of this article were to describe and quantify the following: (i) the sociodemographic characteristics of typical informal caregivers of dependent patients with cancer; (ii) the different types of care provided by informal caregivers; (iii) the symptoms due to burdens and their impact on the quality of life perceived by the informal caregiver as a result of providing care; and (iv) the unmet needs presented by informal caregivers. The study included informal caregivers of dependent patients with cancer, regardless of their diagnosis, treatment, or age, because they all have similar care demands. In fact, a recent systematic review found that caregivers of palliative care or terminal patients often report a higher prevalence of unmet needs than cancer survivors.[5] However, very few interventions have been carried out to support caregivers of patients in advanced stages, and, in most cases, they have not been rigorously designed and evaluated.

Methods

A cross-sectional design and survey methodology were used for descriptive purposes. In collecting the data, self-administered questionnaires were combined with personal interviews.

To achieve the objectives proposed in the introduction, different analyses were carried out. Information about sociodemographic characteristics of typical informal caregivers of dependent patients with cancer were collected through the Interview Protocol of the main caregiver, and a frequency analysis was carried out for each of the variables. The different types of care provided by informal caregivers were evaluated through part 1 of the Questionnaire ICUB97, and a frequency analysis of the responses was also carried out. The information about the symptoms due to burdens and their impact on the quality of life, as well as the unmet needs, was obtained through two different instruments. First, a list of symptoms and needs was compiled through the answers to the open questions of the second part of the Interview Protocol of the main caregiver. Then, from the answers to the second part of the Questionnaire ICUB97, the percentage of participants who had suffered different symptoms and consequences derived from the care was calculated. Finally, through the answers to the survey of hospital quality, we calculated the percentage of participants who had different unmet needs.

Participants

All procedures performed in studies involving human participants were in accordance with the ethical standards of the research committee of the 'Hospital General Universitario de Valencia' (CPMP/ICH/135/95) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study. The sample was composed of 132 informal caregivers of dependent patients with cancer from the University General Hospital of Valencia, Spain, (hereinafter HGUV). The eligible participants were identified through the patient database of the oncology service, over the 4-month data collection period. All eligible caregivers were contacted, and after verifying that they met the inclusion criteria, they were invited to participate in the project. Specifically, informal caregivers had to meet the following criteria: they had to be first- or second-degree relatives of the cancer patient, aged at least 18 years, and live with the patient or visit them at least 6 times a week with the purpose of applying specific care related to the disease. In the case of the cancer patients, they had to be older than 18 years, have received the diagnosis at least 6 weeks before filling out the questionnaires, present significant symptoms that would require specific and frequent attention, and obtain a score between 0 and 75 in the Barthel Index,[22] a test that assesses the level of patient independence with respect to the performance of basic activities of daily living. The scores should be interpreted as follows: 0–20, total dependence; 21–60, severe dependence; 61–90, moderate dependence; 91–99, slight dependence; and 100, independence. The exclusion criteria for informal caregivers were the following: previous psychological or psychiatric disorders and other known health and/or social problems that could be confused with the symptoms stemming from their caregiver role. All participants had a level of knowledge of Spanish that allowed them to complete the assessment instruments without difficulty.

Each survey was filled out in the oncology ward of the HGUV by one of the members of the research team while the patient was hospitalized or on the days when he/she came to receive chemotherapy treatment. We also made telephone contact with informal caregivers of patients whose state of dependence made it impossible for the caregiver to visit the hospital.

Instruments

Interview Protocol of the main caregiver

The interview of the main caregiver was drawn from a doctoral thesis[23] and had two parts (see Appendix A). In the first part, sociodemographic data (name, age, gender, education level, and relationship with the patient) were collected. Knowing the sociodemographic characteristics of habitual caregivers makes it possible to design intervention programs that are more suitable for the target population. In the second part, caregivers had to answer open questions about the current situation of the disease. This interview provided an initial approach to informal caregivers, established rapport, and facilitated subsequent evaluation through the closed questionnaires. In the first place, the identification and sociodemographic data were collected to confirm that they fulfilled the inclusion criteria and to find out the basic characteristics of the interviewees. Thus, the interview was contextualized by adapting the duration, the language used, and the degree of direction and structuring to the caregiver's characteristics. The other objective of this interview was to compose a list of needs and symptoms experienced by at least one subject from the sample as a result of his/her caregiver role.

Questionnaire ICUB97

We used the Spanish version[24] of this questionnaire that has two parts:

Part one: care provided by the caregiver. It contains 48 items related to the care given to the dependent person to satisfy his/her 14 basic needs, according to the conceptual framework by Henderson:[25] breathing, nutrition, elimination, movement, rest and sleep, dressing and undressing, thermoregulation, hygiene, avoiding dangers, communication, living according to their own beliefs and values, working and achieving fulfillment, recreation, and learning.

Part two: impact of caring on the caregiver. It contains 42 items referring to the impact of the care provided on the informal caregiver. It stems from the same theoretical framework as part one,[26] but it evaluates how the care provided by the informal caregiver can affect the satisfaction of his/her own 14 basic needs. Items in both parts are dichotomous (yes/no).

The questionnaire has been shown to be valid and reliable. The validation study of the original content was based on Henderson's model,[25] equating health with independence in

basic life necessities. A consensus task among experts was carried out to ensure the adequacy of the theoretical model. Reliability was calculated by using the test-retest technique, obtaining an alpha coefficient for the first part of 0.78 and 0.86 for the second part.

Survey of hospital quality

The survey of hospital quality was developed for this research by adapting the survey of pediatric patients' opinions[26] and the survey of patients with cancer.[27] This questionnaire collects subjective data about the quality perceived by cancer patients' caregivers regarding the treatment received from the medical staff at the hospital, as well as the information and training provided about the disease and the necessary knowledge related to it. We selected questions about different aspects of interest for the present study: information, training, humanity, and the team's knowledge. The ultimate purpose of this survey was to find out to what extent the hospital met some of the caregiver's needs and what the main unmet needs were.

Results

Of the 166 eligible caregivers, 132 agreed to participate. The participation rate was approximately 80%. It must be taken into account that the required sample size to estimate the population proportion for a 5% margin of error was 116. No response bias was found between participating caregivers and non-participants with respect to age, gender, and relationship with the patient.

Sociodemographic characteristics of caregivers

Caregiving women (77.28%) were more prevalent than men (22.72%), with an average age of 45 years (range 23–82) and a medium socio-economic status. About half of them had a

Table 1 – Care provided by caregivers, sorted by frequency.

Type of care	%	Type of care	%
Keeping the patient company (C)	85.93	Overseeing the management of patient medication (A)	35.93
Being the intermediary between the patient and the healthcare workers (C)	81.25	Making decisions for the patient (W)	35.93
Supervizing the patient's personal and household hygiene (H)	76.93	Changing the patient's diaper (E)	34.37
Buying food (N)	75	Helping the patient to move inside the house or from bed to chair (M)	34.37
Cooking (N)	75	Curing the patient's skin lesions (H)	32.81
Accompanying the patient to healthcare services (M)	65.62	Monitoring the patient so that he does not have an accident (A)	32.81
Cutting the patient's toenails (H)	60.93	Helping the patient to live according to his/her beliefs and values (B)	32.81
Watching the patient while resting (S)	59.37	Preparing a special diet for the patient (N)	29.68
Helping the patient to choose the proper clothing and footwear (D)	59.37	Administering sleep medication to the patient (S)	29.68
Adapting the home conditions (A)	57.81	Teaching the patient how to improve his/her health and well-being (L)	25
Performing the patient's hair and/or foot hygiene (H)	56.25	Using non-verbal communication to communicate with the patient (C)	23.43
Performing all the patient's hygiene (H)	53.12	Adapting home conditions (O)	21.87
Listening to the patient's concerns (C)	51.56	Administering medication and/or enemas to the patient, to regulate his/her intestinal transit (E)	21.87
Taking the patient for a walk (R)	50	Helping the patient to use the bedpan (E)	20.31
Helping to dress and undress the patient (D)	48.43	Administering medications to the patient to regulate his/her temperature (T)	20.31
Dressing and undressing the patient (D)	46.87	Administering the treatment to the patient (O)	18.75
Administering medication to the patient (A)	46.87	Adjusting the patient's body temperature (T)	17.18
Providing the patient with entertainment (R)	45.31	Managing the patient's material resources (W)	17.18
Performing the patient's oral hygiene (H)	43.75	Helping the patient to practice his/her hobbies (R)	15.62
Preventing injuries on the patient's skin (H)	43.75	Teaching the patient how to manage his/her disease (L)	15.62
Feeding the patient (N)	39.06	Feeding the patient by gavage (N)	14.06
Accompanying the patient to the toilet (E)	37.5	Providing learning resources to the patient (L)	09.37
Changing the patient's position (M)	37.5	Helping the patient to distribute his/her time (W)	06.25
Monitoring the patient's body temperature (T)	35.93	Helping with or providing the patient with respiratory rehabilitation (O)	03.12

O, oxygenation; M, movement; T, thermoregulation; C, communication; R, recreation; N, nutrition; S, rest and sleep; H, hygiene and skin protection; B, living by beliefs; L, learning; E, elimination; D, dressing and undressing; A, avoiding dangers; W, working and achieving fulfillment.

primary school education, while the other half also had a secondary education. As for the relationship with the patient, most of the informal caregivers were their children (45.45%), followed by spouses (22.72%).

Types of care provided by caregivers

Table 1 shows the care provided by informal caregivers to satisfy the 14 basic needs of the patient. The most frequent types of care provided by informal caregivers to the dependent patients with cancer (more than 80%) were keeping the patient company and acting as an intermediary between them and healthcare workers. Other types of care frequently provided were intended to help perform basic activities in daily life (37%–77%): performing or supervizing the hygiene of the patient and the household, dressing and undressing them, buying and cooking food, feeding them, and accompanying them to the toilet. In addition, the disease adds new tasks and responsibilities that must also be taken care of by the informal caregiver (34%–65%): accompanying the patient to health services, watching them while resting, adapting home conditions, supervizing or administering medication, preventing skin injuries, making postural changes, monitoring the patient's body temperature, and changing the patient's diaper. Table 1 also shows other types of care that are less frequent and, in many cases, more specific.

Symptoms due to burdens and their impact on the caregiver's quality of life

Through the answers to the open questions of the Interview Protocol of the main caregiver, the informal caregivers reported that at some point they had experienced or currently experienced: anxiety, depression, disappointment, fear, worry, despair, discouragement, anger, lack of memory and concentration, thoughts about the anticipation of death and the progression of the disease, and concerns about the care of the family and their future personal life. In addition, from the answers of the second part of the Questionnaire ICUB97, we calculated the percentage of caregivers suffering from various symptoms and negative consequences on their life, as a result of providing care. Table 2 shows that most of them reported feeling more tired and having less free time (73%–75%). Many of them (50%–70%) also reported emotional symptoms, specifically, they felt the following: nervous, helpless, anxious, irritated, and depressed. Very often (31%–73%), the role of caregiver involved significant changes in lifestyle and daily routines. Caregivers had modified their activities, had fewer social relationships and engaged in less physical activity, slept/rested less, ate at odd times, spent less time on personal care, and ate isolated from their family. Moreover, a considerable number of caregivers (31%–42%) also experienced physical symptoms such as back pain (even taking analgesics for pain), weight loss/gain, loss of appetite, waking up often, and a feeling of breathlessness. A noteworthy result was that, owing to the type of care they provided, informal caregivers (58%) reported that they needed more knowledge and/or skills to provide the care. Table 2 also shows less frequent effects on lifestyle, organization of time, physical and emotional health, and even work and the economy.

Unmet needs of caregivers

First of all, a list of needs was compiled through the answers to the open questions of the second part of the Interview

Table 2 – Impact of caring on the caregiver, sorted by frequency.

Effects	%	Effects	%
You are more tired (S)	75	You have difficulty expressing your feelings (C)	28.12
You have less free time (R)	75	You have poor digestion (N)	26.56
You have modified your daily routine (R)	73.43	Your sex life has been altered (C)	23.43
You feel nervous (A)	70.31	Your economy has shrunk (W)	23.43
You feel helpless (A)	65.62	Your feet/legs swell (M)	21.87
You have fewer social relationships (C)	62.5	You have difficulty satisfying your need to learn (L)	21.87
You practice less physical activity (M)	60.93	You feel disinterested in your environment (A)	20.31
You feel anxious (A)	59.37	You take sleep medication (S)	18.75
You feel irritated (A)	57.81	You take medicines (A)	18.75
You need knowledge and/or skills to provide care (L)	57.81	You smoke more (O)	17.18
You eat at odd times (N)	51.56	Your bowel habits have been alterated (E)	17.18
You sleep/rest less (S)	50	Your beliefs and/or values have changed (B)	15.62
You are depressed (A)	50	You work less time outside the home (W)	15.62
You have back pain (M)	42.18	You have adapted your work outside the home to take care of your relative (W)	14.06
You have lost/gained weight (N)	35.93	Your menstrual cycle has been altered (E)	12.5
You take pain killers (M)	35.93	You have difficulty dressing like you used to (D)	09.37
You have lost your appetite (N)	34.37	You have left your job (W)	07.81
You spend less time on your personal care (H)	34.37	You take laxatives (E)	06.25
You wake up often (S)	32.82	You have difficulties promoting at work (W)	06.25
You eat isolated from your family (C)	32.81	You take self-protection measures (A)	04.68
You have a feeling of breathlessness (O)	31.25	You drink more alcohol (N)	03.12
You have difficulty distributing your time (W)	29.68	You have difficulty maintaining your body temperature (T)	01.56
Your family life has been altered (W)	29.68	You have started smoking (O)	0

O, oxygenation; M, movement; T, thermoregulation; C, communication; R, recreation; N, nutrition; S, rest and sleep; H, hygiene and skin protection; B, living by beliefs; L, learning; E, elimination; D, dressing and undressing; A, avoiding dangers; W, working and achieving fulfillment.

Table 3 – Responses to the survey of perceived quality by caregivers about the care provided by health personnel, arranged according to the frequency of negative responses (N = 128).

Question	Yes (%)	No (%)
Do you know the name of the nurse who was treating you?	25	75
Were you informed of the existence of the hospital's psychology unit?	25	75
Do you know the name of the doctor who usually attended to you?	65.62	34.37
Has anyone explained what you should do with the medication that your relative was taking before admission to the hospital?	56.25	6.25
Has anyone explained what to do and how to alert the medical staff if your relative needs anything?	93.75	6.25

	Well (%)	Barely adequately (%)	Poorly (%)
Has anyone explained the phases that you and your relative will go through during the illness?	0	3.12	93.75
Has anyone explained how to do the daily personal care of your relative?	6.24	3.12	81.25
If your relative cannot perform movements alone, have you been taught which exercises he/she should practice and how to do them?	3.12	3.12	78.12
Has anyone explained how to avoid the appearance of pressure sores?	3.12	9.37	71.78
If you have felt jittery, uncontrolled or desolate, have you received help from the healthcare personnel?	12.5	9.37	68.75
Has anyone explained how to perform postural changes on your relative?	3.12	15.62	65.62
Has anyone explained whether you must give your relative a special diet and how to prepare it?	3.12	12.5	62.5
Has anyone explained what you can do to make the treatment the best possible (how to care for your relative, what precautions to take, etc.)?	9.37	28.1	59.37
Has anyone explained what special attention you should pay to the patient's wounds, if he/she has them?	12.5	28.1	56.25
Has anyone explained clearly enough if there are treatment options?	40.62	15.62	43.75
Has anyone explained what kind of care or precautions you should take with medication once at home?	37.5	25	31.25
Have you had the feeling that the healthcare personnel listened and took into account what you said?	21.85	45.87	28.12
Have you been able to ask and answer all your questions about your relative's illness and treatment?	56.25	25	18.75
If your relative has felt severe pain, have you received enough information about what to do?	62.5	12.5	15.62
Has anyone explained the advantages and disadvantages (possible risks and complications) of the treatment that your relative would receive?	75	12.5	9.37
Have you had the feeling that the medical staff knew the history of your relative?	75	12.5	9.37
Has anyone explained the possible evolution of the disease?	68.75	25	6.25
Has anyone explained clearly enough the treatment, medical tests, or surgery your relative received in the hospital?	87.5	12.5	0

	1[a]	2[a]	3[a]	4[a]	5[a]
Compared to what you expected, how was the health care received from the onset of the disease?	12.5	37.5	46.87	3.12	0
Indicate your overall level of satisfaction with the health care received	Average = 3.39				

[a] 1, much better; 2, better; 3, more or less equal; 4, worse; 5, much worse.

Protocol of main caregiver. They mainly requested information about the disease and treatments received by patients during hospitalization and about specific testing times and training related to patient care. They also noted the need for the hospital to hire more healthcare workers, pay for systematic support for the care of the dependent patient during the work day and/or at night, and improve the comfort of the facilities. In addition, through the answers to the survey of hospital quality, we calculated the percentage of participants who had different unmet needs and their perception of the quality of the care provided by the healthcare staff. Table 3 reveals that most of the informal caregivers reported having received enough information about the treatment, medical tests, or surgery that their relative was undergoing in the hospital (87%), and about the evolution of the disease (69%) and the advantages and disadvantages of the treatment (75%), but only 56% had been able to effectively resolve other doubts about the disease. For example, none of the caregivers reported being correctly informed about the phases that their relative would go through during the illness. Moreover, most of the informal caregivers (56%–81%) claimed that they had not received any training or specific information from the healthcare personnel about care to be provided and precautions to be taken with the patient: carrying out the daily personal care, trying to promote appropriate physical exercise, avoiding pressure sores, performing postural changes, preparing a special diet, taking precautions to make the treatment as good as possible, or taking care of wounds.

In terms of the quality of the relationship and the communication with the health personnel, although 75% of caregivers had the feeling that the medical staff knew the history of their relative, only 22% of them had the feeling that health personnel listened and took into account what they said. Moreover, 67% said they had not received help from healthcare workers in the case of having experienced lack of control, distress, or anxiety. Similarly, only 31.25% of the respondents had been informed of the existence of the psychology unit, sometimes stating that they knew about this service for the patient but not for the family.

Discussion

Several previous studies have shown that the care of cancer patients hinders the organization of work, social relationships, leisure activities, and even self-care, causing stress and exhaustion at both the physical and psychological levels (see[13], for a recent review). Although most caregivers have anxiety and depression symptoms (e.g., see[7–9]), as well as different physical, social, and psychological needs (e.g., see[10,11]), they have very few resources to address these issues (e.g., see[2–4]). In fact, after reviewing the current status of the aid offered by different organizations to the main caregivers of cancer patients, important shortcomings are confirmed. The resources that family members can access are often scarce and incomplete, focusing mainly on aid at a physical level, usually through respite services.

Based on a translational approach, our research provides novel empirical results that support the design of effective interventions into typical-care settings, i.e. hospitals. The ultimate purpose is to prevent diseases and improve the quality of life of a population with a high prevalence of unmet needs, the dependent patients' informal caregivers. In the following section, we propose some lines of intervention, derived from the results.

First, many informal caregivers reported that they needed more information about the phases that their relatives would go through during the illness and training or specific information about the care they should provide to the patient. These results are consistent with those reported by Adams et al.,[14] who concluded that caregivers were more likely to have unmet needs for information about supportive care than for medical information. Therefore, an effective support program must definitely include greater access to information about the disease and the available resources for patients and their families, through different channels, such as a basic guide. Given the widespread use of the Internet today, it could also be used as a powerful support tool, through the creation of a website that contains both written and audiovisual information. The results of a recent systematic review, that evaluated the availability and characteristics of instructional cancer pain management videos on YouTube, showed that most videos were directed toward a clinical audience rather than toward informal caregivers.[28]

Additionally, the types of care most frequently provided by informal caregivers included the following: keeping the patient company, accompanying them to health services, mediating between them and healthcare workers, helping or performing basic activities in daily life, nursing them, listening to the concerns of the patient, and providing them with entertainment. Consequently, support programs should also include specific training of informal caregivers through workshops on the care they must provide to patients (techniques and resources), coping skills, and communication skills with patients and medical staff. Personal interactions between caregivers, medical staff and psychologists should also be improved by increasing availability and providing training, through workshops, of all medical staff.

Finally, the main symptoms and negative consequences reported by informal caregivers were: feeling more tired, having less free time, changing their daily routines (sleep, eating, physical activity, and personal care), having fewer social relationships/interactions, and various emotional and physical symptoms (such as helplessness, anxiety, depression, back pain, loss of appetite, insomnia, and so on). Moreover, many of them had not received help from healthcare workers in the case of having experienced lack of control, distress, or anxiety, and had not been informed of the existence of the psychology unit. This leads us to conclude that intervention programs need to involve: changes at the organizational level with the role of the psychologist becoming more prevalent; psychological support through individual and group sessions to relieve emotional symptoms; and specific training, through workshops, on self-care, and organization of time for family sustainability.

The analysis of sociodemographic characteristics reveals that the intervention should be adapted by using simple and accessible language and materials. Regarding the possibility of generalizing the results, the study was carried out with a sample of caregivers of patients from a public hospital in Valencia. In compliance with the requirements of the Law of Cohesion and Quality of the Spanish National System,[29] public hospitals in Spain have similar characteristics in terms of services and resources. However, a rigorous methodology would require new studies that included samples from different autonomous communities to generalize the results to the entire national territory.

Although the implementation of intervention programs for informal caregivers can have a high economic cost, it must be kept in mind that attending to caregivers will reduce the amount of caregivers withdrawing from their care duties, on the one hand, and the proliferation of what are known as secondary patients, on the other, thus producing benefits for the community in the medium term. The present results are a good starting point, based on empirical data, for designing effective intervention programs in the hospital setting, where medical treatment is given to cancer patients, to facilitate informal caregivers' access to help.

Author statements

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the research committee of the 'Hospital General Universitario de

Valencia' (CPMP/ICH/135/95) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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Competing interests

The authors declare that they have no conflicts of interest.

Data statement

The authors have full control of all primary data and agree to allow the journal to review them if requested.

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Appendix A. Interview Protocol for main caregiver (Barahona, 2013).

Name:	
Age:	
Gender	
Education level	No schooling completed
	Primary education
	Secondary education
	Higher education
Socio-economic level	Middle-high
	Middle
	Middle-low
Kinship	Spouse
	Parent
	Son/daughter
	Others
How do you feel about the current situation of your relative?	
What is going through your head?	
Are you worried about something in particular?	
Do you receive any financial aid?	
Have you had to change your usual routine to take care of your relative?	
Do you have help from other people to care for your relative?	
What do you think the hospital could do to help you care for your relative?	