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Research Article

The Moral Dimensions of Family Caregiving for Patients with Advanced Cancer: A Qualitative Study

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Background. Family caregivers in charge of patients with advanced cancer play an essential role. The psychosocial cost of these caregiving activities has been studied, and psychosocial interventions have been developed to improve the quality of life of family caregivers. A deeper understanding of caregivers' burden is essential in order to enhance the benefits of these interventions. The aim of this study was to explore the socioeconomic and cultural factors responsible for shaping the complex personal experience of family caregiving and to analyse the moral dimensions of the caring experience so as to understand its effects on family caregivers more clearly. **Materials and Methods.** A qualitative study based on in-depth interviews was conducted with patients with advanced cancer ($n = 20$) and their family caregivers ($n = 19$) from 2017 to 2020. These interviews were analysed using an inductive approach and an iterative procedure. A thematic analysis was then performed using Tronto's "ethic of care" framework in order to identify the various levels of responsibility and the relationships and effects involved. **Results.** Providing patients with advanced cancer with informal care is highly valuable work requiring various moral qualities, including attentiveness, responsibility, competence, and responsiveness. The mental load resulting from the moral aspects of care results from the cumulative effects of carers' attentiveness and the responsibilities they have taken on. **Conclusion.** The present findings could guide healthcare professionals to develop best practice resources and guidelines in order to alleviate the hitherto underestimated effects of caring and promote a coordinated public health approach addressing the needs of caregivers. These efforts are particularly important as contemporary health policies tend to promote the shift from inpatient to outpatient treatment, which increases the importance of informal caregiving and the burden involved.

1. Introduction

It is now widely recognised that family caregivers looking after patients with advanced cancer play an essential role by helping them meet both their medical and nonmedical needs [1–10]. Family caregivers' experience has been studied mainly from the perspective of the psychosocial cost of caregiving to a family member living with a patient with

advanced cancer [10–15]. Family caregivers' quality of life usually deteriorates [16–18], as does their physical and mental health [19–25]; they also suffer financially, professionally, and socially and experience occupational problems [26, 27]. To alleviate the burden of caregiving, as well as caregivers' loneliness [28], several psychosocial interventions designed to improve the quality of life of adults with cancer and their family caregivers have been developed

during the last few decades [29–37]. Some of them have targeted various forms of psychosocial support for family carers in charge of palliative care patients, including psychoeducation, psychosocial support, symptom management, family meetings, and training in carer coping and means of improving sleep [38–41]. A deeper understanding of caregivers' burden is essential in order to enhance the benefits of these interventions.

It was therefore proposed to complement and extend previous findings on caregivers' burden by analyzing more closely the content of what has been called “the soul of care” [42] and the moral dimension of this interpersonal experience. This qualitative study based on an anthropological approach to lived experience [43] was conducted in France with patients with advanced cancer and their family caregivers. We adopted the definition for experience proposed by Kleinman and Seeman [44]: “the intersubjective, felt flow of events, bodily processes, and life trajectory which always take place within a social setting.” The aim of this study was to explore the socioeconomic and cultural factors responsible for shaping the complex personal experience [9] of family caregiving, the meaning given to these caregiving practices [45] by the caregivers and the patients, as well as the hitherto undervalued visible and invisible aspects of family caregiving, especially the various skills and moral qualities required.

For this purpose, we used Tronto's “ethic of care framework” [46], in line with previous authors in the field of health research [47, 48]. According to Tronto, caring is a practice and a process consisting of four interrelated phases: caring about (recognising a need for care); caring for (taking responsibility for meeting that need); care giving (the actual physical work of providing care); and care receiving (assessing how well the care provided has met the patient's needs). Each of these phases requires moral qualities: caring about requires attentiveness (awareness of and attention to the need for care); caring for involves responsibility (taking responsibility for meeting a need that has been identified and for organising and marshalling resources); care giving requires competencies that are not only technical issues but also moral ones; and care receiving requires responsiveness on the part of the recipient of the care.

It was therefore proposed to analyse both patients' and carers' lived experience of informal home care using Tronto's “ethic of care framework” as a guide to identifying the various levels of responsibility, the relationships and effects at work, and the moral dilemmas with which primary caregivers have to cope in order to provide appropriate quality informal home care.

2. Methods

2.1. Study Design. In this qualitative study, in-depth face-to-face interviews were conducted with patients and family caregivers from October 2017 to March 2020 with the approval of the French Institute of Medical and Health Research Ethics Committee (IORG0003254, FWA00005831) and the Institutional Review Board (IRB00003888) (Opinion number 16-318). All the participants gave their written

informed consent to the procedure after receiving both oral and written information about the study. Designing and reporting of this study strictly followed the SRQR checklist [49] (see supplementary material S1).

2.2. Sample. Based on a purposive sampling strategy, 20 patients and 19 primary caregivers were interviewed (Table 1). The enrolment process stopped when data saturation was reached [50].

The patients were recruited with the help of oncologists and palliative care specialists at two comprehensive cancer centers in the South of France. They were all treated with first-line chemotherapy for locally advanced or incurable metastatic cancer, age ≥ 18 years, life expectancy ≥ 1 month, and performance status (OMS) ≤ 2 . Fourteen of them had been referred to outpatient palliative care services. Family caregivers were defined here as any family member or friend who usually took care of these patients and provided them with help and moral support. They were designated by the patients interviewed. The main exclusion criterion adopted for both patients and caregivers was the presence of severe cognitive impairments.

In-depth face-to-face interviews were carried out with 15 caregiver/recipient dyads either separately (in 10 cases) or both together (in 5 cases). In addition to these dyads, 5 patients and 4 caregivers were interviewed who were involved in caregiving relationships but not with each other (Table 1). None of the patients subsequently refused to participate in the study, withdrew their consent, or dropped out. However, a few caregivers refused to participate.

2.3. Data Collection. The interviews were conducted in French by an experimented medical anthropologist (ASE). The respondents chose the place where the interviews were to take place: the patient's room, a neutral hospital setting, or their own homes. The carers' interviews lasted 43 minutes on average (range: 22–90 minutes). The patients' interviews lasted 33 minutes on average (range: 17–42 minutes).

All possible precautions were taken when discussing painful situations with patients and carers to avoid upsetting them. We applied the ethical principles of research in the field of social science, namely, guaranteeing the anonymity of the data collected, the informed consent of the respondents, the possibility of ending the interview whenever they wished, and presenting them with the results of the study.

The semistructured interview guide used here covered the following topics: respondents' knowledge and understanding of the disease and its prognosis; patients' care pathway since the onset of the disease; the various tasks involved in informal caregiving; and the reasons why these caregivers undertook these tasks. In addition to these themes, the interviews with caregivers covered topics relating to the caregivers' psychosocial burden: the significance of looking after an ailing relative; what aspects of the caregivers' everyday lives were affected by this work; and the effects on caregivers' own well-being, mood, quality of life, financial resources, and family relationships.

TABLE 1: Participants' characteristics.

Patients' gender	<i>n</i> = 20
M	8
F	12
Caregivers' gender	<i>n</i> = 19
M	6
F	13
Patients' age	<i>n</i> = 20
<40	0
40–50	2
51–60	2
61–70	8
71–80	5
>80	1
Caregivers' age	<i>n</i> = 19
<40	1
40–50	3
51–60	4
61–70	4
71–80	6
>80	1
Patients' cancer site	<i>n</i> = 19
Pancreas	15
Breast	1
Sarcoma	1
Leukaemia	1
Lymphoma	1
Ovary	1
Patients' cancer site (according to caregivers interviewed alone)	<i>n</i> = 4
Breast	2
Leukaemia	1
Ovary	1
Caregivers' relationship with their patient	<i>n</i> = 24
Partner	12 (7 females, 5 males)
Child	8 (5 daughters, 3 sons)
Parent	2
Friend	1
Uncle	1

The interviews were audio-recorded and transcribed. All personally identifiable details were removed from the transcripts. In the excerpts from interviews quoted here, patients were coded P plus a number, whereas carers were coded C plus a number. These excerpts have been translated by a professional translator (Dr Jessica Blanc).

2.4. Data Analysis. An inductive thematic approach and an iterative process [50] were used to analyse the interviews. The first step was to code the interviews. The transcripts were coded manually by two coders (an anthropologist and a psychologist) working independently; the coding of each transcript was compared, and any discrepancies between the two were discussed until the final coding scheme was consolidated. The data were managed with Excel software.

We applied the following strategies to assure the rigour of the analysis [51]: saturation, reflexivity, and a peer review. Data collection and analysis were conducted simultaneously and until no further news items emerged (theoretical

saturation was reached) [50]. Core categories and themes (the content of informal care, its impact on caregivers' quality of life, and caregivers' needs) were discussed at interdisciplinary team meetings (including an anthropologist, a sociopsychologist, and a palliative specialist physician) and examined in relation to the existing literature in order to spot any inaccuracies and misinterpretations. Preliminary results were presented at two research conferences (the EAPC 2020 World Congress and the SFAP 2020 Congress) to obtain feedback from peers.

The last step of the analysis was to refine the thematic findings using Tronto's "ethic of care" framework [46]. Tronto's four moral qualities required for caring (attentiveness, responsibility, competence, and responsiveness) were associated with each category of task (logistic assistance, psychological support, nursing tasks and monitoring activities, and accompanying patients on medical check-ups or for treatment) identified during the first stage of the coding process. Figure 1 represents these associations.

3. Findings

3.1. Attentiveness to and Empathy with Patients' Experience. Family caregivers provided logistic assistance with the aspects of daily life with which patients could no longer cope themselves or only with difficulty, such as cooking, housework, shopping, and administrative tasks. Attentiveness, i.e., attending to their loved ones' need for care and anticipating their medical and nonmedical needs, was frequently mentioned as a means of improving the patient's living conditions, as well as providing emotional support:

"I help him psychologically as well as doing the shopping and the housework, disinfecting everything and keeping him clean (. . .) I actually help him all day long (. . .) When he perspires, I bring him a damp cloth, and when he vomits, the bucket is full so I go to empty it in order to get rid of the smell, then I disinfect it (. . .) It's just improving his everyday living conditions. (C5)"

Psychological support could take many forms: accompanying patients in activities such as walking, distracting them from their disease by engaging in relaxing activities, and staying by their side in their everyday lives and their medical care to show that they are not alone and not abandoned. This presence ("being there") was perceived by caregivers as a means of alleviating the patients' anxiety and emotions to make them feel better. Almost all the interviewees mentioned the emotional support involved, which was perceived by both patients and caregivers as being the most important and most valuable aspect.

3.2. Downside of Attentiveness. According to Tronto [46], attentiveness requires suspending one's own goals, ambitions, plans for life, and concerns in order to meet the needs of others. This is what the family caregivers interviewed did. The time devoted to informal care was taken at the expense of the carers' own professional, family, and leisure activities.

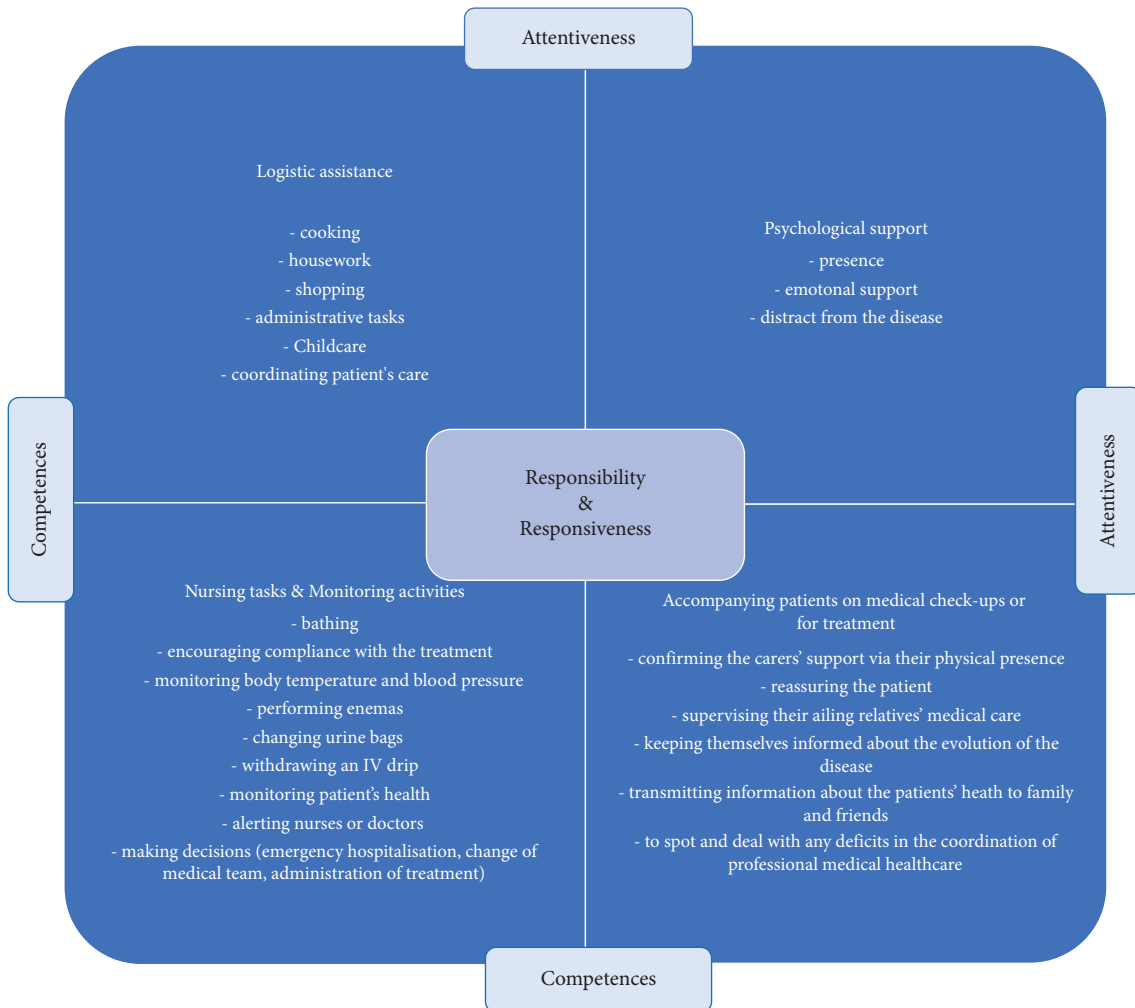


FIGURE 1: Thematic analysis.

Some caregivers were obliged to reorganise their working, social, and family lives. As one caregiver said, "I have put my life on hold" (C17). Although most of them did not complain, some of them expressed the feeling that their lives had been invaded.

Among the 19 family caregivers interviewed, 13 were unemployed or had retired by the time of the interview and 6 were still working. Only three of them were able to reduce or postpone the periods spent at work. The other three stopped their occupational commitments and devoted their time entirely to their ailing relatives.

However, although informal caregiving was a time-consuming activity, some respondents perceived informal care as an opportunity to spend more time with a parent whose life expectancy was shrinking:

"[Caregiving is] helping her with her formalities, accompanying her to see the doctor, taking her to the hospital, enjoying the time left to her, that's it . . . Yes! It's important to be with her, yes! I feel I am lucky despite my misfortune because I can enjoy being with her now, before she passes away! (C13)"

Some caregivers declared paradoxically that this time of care was a "lucky opportunity" to stay with their loved ones during their last few weeks or months of life.

3.3. Taking Responsibility for Patients' Health. Family caregivers took on the responsibility for meeting the patient's identified needs, especially the health-related ones, by coordinating various tasks as well as ensuring continuity of care and fitting patients' and medical professionals' time-schemes.

In addition to making medical appointments, almost all the carers questioned said that they often accompanied their loved ones on medical visits, at admission to hospital or for chemotherapy sessions. Although the cost of patients' transport from their homes to hospital for the latter reasons is entirely covered by the French public health insurance system, some caregivers preferred to drive the patients to hospital themselves. Even when the patients travelled by ambulance or cab, the caregivers stayed with them. Their presence on these occasions mainly meant giving the patients physical and emotional support.

Support of this kind gave these carers an additional facilitating role in the management of their relative's disease, by informing the hospital doctors about the patient's state of health and about any after-effects of the drugs prescribed, as well as making up for any forgetfulness on the patient's part. Staying with the patient during chemotherapy sessions also gave caregivers an opportunity to spot and deal with any deficits in the coordination of their medical care:

"The last time (. . .), we didn't have the right prescriptions for the blood tests, the right nurse, or the right drugs (. . .) First I went to see the dispatcher, who referred me to a nurse, who sent me all over the place. . . In the end, there was no solution and I had to go and see the head nurse! (. . .) How do people manage when they are all alone? (C13)"

It is worth noting that this study was conducted before the implementation of biosecurity measures due to the COVID-19 pandemic. Patients must have missed this important form of support during the COVID-19 pandemic because family caregivers were not allowed into French hospitals or medical consultations at that time. Family caregivers are still not admitted to chemotherapy sessions.

By supervising and coordinating the whole treatment plan, primary caregivers contribute actively to the management of their relatives' care. But ensuring continuity of care and supervising the timing of medical interventions to meet the patient's needs are burdensome tasks:

"I am thinking about Mummy's appointments, I am thinking about keeping house for her. That's the problem, thinking all the time about doing the shopping, always wondering whether her blood tests have been done in time, remembering to print out the results, thinking about. . . hundreds of things which need to be thought about, all of which relieve her, but put me myself in a state of stress. (C17)"

These cumulative responsibilities and tasks imposed a mental load on some of them.

3.4. A Responsibility Shaped by Cultural and Societal Norms.

The notion of responsibility also carries the idea of obligation or duty that is embedded in a set of cultural practices [46]. In this study, informal caregiving was found to be shaped by social norms based on the moral contract between spouses ("Yes, it's important to accompany him! It's my duty as his wife" C8) and solidarity within families and between generations. When the patient was the carer's father or mother, the commitment to help also responded to a wish for reciprocity, i.e., to repay to a parent the help and love received during childhood or at least to show their gratitude:

"I only do what's normal. What children ought to do for their parents. Parents have brought up their children during their whole lives, at least up to the time when they left home, and even then, some parents are still there for

them. So it's sort of up to the children to repay them. (C22)"

Several caregivers expressed a sense of purpose in accomplishing their duty, as explained by one caregiver:

"I do it because she's my mother, and then I do it in order to have a clear conscience. I want to be able to say, "I have done what I had to do." Personally, I have done what I had to do. Nobody will be able to say one day, "Ah, but you didn't do this or that for your mother," or "you didn't stand by your mother" . . . (C7)"

Although our sample of caregivers was not intended to be representative, we noted that the proportion of women (13/19) was much higher than that of men (6/19). Some respondents mentioned the cultural tradition of allocating the work of care to women, as illustrated by this person who was caring for her mother and could not delegate any of her tasks to her brother:

"I have a brother who lives near Mummy's home (. . .) But he's a male and he's not very useful. Neither am I, but I do my best! I too often feel scared, but what can you do? (...) I can't rely on him, no, no, no, not at all. I actually asked him to help, but he said, "I can't handle the enemas the way you do, I couldn't stand seeing Mummy like that. . ." (C22)"

As in many other cultural settings, caring is shaped in French society by the gender-based distribution of domestic work.

3.5. Developing Competences. Most of the informal care work provided required experiential knowledge and specific skills, such as the ability to perform general nursing tasks (bathing, encouraging compliance with the patients' treatment, monitoring their temperature and blood pressure, performing enemas, or changing urine bags). The carers interviewed often carried out these basic nursing tasks in order to reconcile the timing of the health professionals' interventions with the patients' requirements as suggested by this carer: "the nurses come in three times a day, but they don't always come when we need them most" (C17). In addition, their daily presence enabled them to monitor their ailing relatives' health and to warn the nurses or doctors when their condition deteriorated.

Some of these primary informal caregivers have had to make decisions about an emergency hospitalisation, making a change of medical team, or even administering treatment, as explained by one woman who decided to administer oral chemotherapy to her mother without the oncologist's approval because of the poor communications with the hospital team:

"For three weeks they kept me waiting, three whole weeks! And when we went along for an appointment (. . .), it so happened that we did not see my mother's own

oncologist, but a different one. Then they scolded me for having given her the next (oral) chemo without consulting them first. So I said “Listen here, I called you on the phone! (...) I asked to be called back and told what to do ... you should just have answered! I looked at the results of her latest blood tests and I saw they were the same as the time before, so I took the responsibility of giving my mother her chemo. Nobody answered my calls and I didn’t know whether I should do it or not!” (...) I felt really all on my own (C22).”

As this excerpt suggests, efficient informal home caregiving requires building a dialogue and trust between professionals and carers so as to alleviate carers’ responsibility and strengthen their self-esteem.

3.6. Responsiveness: Primary Caregiving as a Lucky Opportunity. The patients interviewed recognized the help received and expressed their gratitude to their caregivers. The carer’s presence was regarded as a token of affection:

“The main thing is not feeling alone. Because the most important part of the care received is the other person’s presence and affection... (...) It’s knowing that one is loved which is the most important thing. (P5)”

Many of the patients interviewed said that they were lucky to have somebody to help them meet their daily needs and break the social isolation into which their illness had plunged them:

“I am sorry for people with serious illnesses who have no caregivers! Well frankly! Nobody to deal with the housework, the shopping, the doctor’s prescriptions, providing psychological support and all that, it must be very, very hard! (...) I mean, caregivers play an essential role (...) And having somebody coming in every single day is wonderful too! (P11)”

However, most of the patients interviewed were aware of the impact of their illness and the burden placed on the caregivers’ health and well-being. They often expressed moral awareness of this burden and wanted to protect their caregivers from having too much work, as explained by this patient whose caregiver was a friend:

“She has just turned 89 but she is a wonderful woman. (...) now I try to protect her a little bit (...) even so, I do protect her (P3).”

4. Discussion

The present qualitative study helps in understanding how informal care is carried out in practice. The concept of care developed by Tronto [46] provides a useful analytic framework for documenting carers’ experiences of caregiving. It takes us beyond the caregivers’ daily life and lifestyle changes, their perception of their role, and their

difficulties and needs, and it highlights the mental load resulting from the moral dimension of care, resulting in particular from the cumulative effects of the attentiveness devoted and the responsibilities assumed.

Providing informal home care means showing concern for patients and constantly making sure that all their basic and care needs are met. This attentiveness is required to improve the patient’s living conditions, as well as providing psychological support. In line with previous reports [2, 6], the most important and most valuable part of family caregivers’ work described by the respondents was the emotional support and presence they provided. Kleinman has described presence (“being there”) as being central to caregiving [52] and constituting “the soul of care” [42]. However, this presence disrupts caregivers’ everyday lives [10], imposes several restrictions, and leads to a form of “emotional devastation” [53], which often affects their own physical and mental health.

Taking responsibility for meeting these needs leads family caregivers to perform a multitude of tasks that pile up, often on the same day. The present findings also show that caregiving is a socially and culturally situated activity. It has been shaped by societal norms in the moral contract between spouses and the solidarity within families and between generations, especially placing women in the role of wives, mothers, and daughters. The moral responsibility for home care certainly rests on women [54, 55], especially when the work involved is belittled because it is “dirty work” [56].

Like those in previous qualitative studies [5, 10], the present respondents took on the responsibility for monitoring their ailing relatives’ health at home and alerting the medical team when their health was deteriorating. They also dealt with planning and coordinating the patients’ care. These tasks facilitated the management of patients’ cancer care and palliative home care and made family caregivers full partners in treatment of patients experiencing advanced cancer. Caregiving gave them the feeling of contributing actively to the patient’s management [10, 57] and helped them cope with the suffering caused by a close relative’s illness and their own helplessness to deal with its evolution [58].

However, this involved mobilizing their experiential knowledge of coordination, monitoring, and care planning as well as skills about how to dispense basic nursing care. As described by McDonald et al. [4], these primary caregivers had undergone an active process of learning via the health professionals encountered during the patients’ disease and had thus acquired the essential skills required for this job. However, previous studies have suggested that caregivers felt they had inadequate information and preparation [14] and had important caregiver learning needs [59]. As previous authors have suggested [60], those of our respondents who had some professional experience of caregiving had greater ability to provide home care and navigate within the healthcare system, which “highlights a potential inequity of access to service and resources between caregivers” [60] (p.431). Moreover, in line with previous reports [59], our respondents needed to be reassured about their ability to care at home for their loved one by being supported by the

healthcare system [59], especially by enhancing direct communication with clinicians [61].

The last topic analyzed here was responsiveness, which refers to how recipients respond to the care provided. The patients interviewed expressed the feeling that the presence of a caregiver and the assistance provided were of great importance, and they qualified this accompaniment as “a lucky opportunity.” As previously reported, social support from family and friends has positive effects on patients’ quality of life [62]. This raises the issue of patients’ potentially unequal access to informal caregiving, especially in the case of socially isolated patients or those whose family ties have weakened. Healthcare professionals could help correct these inequalities by paying special attention to socially isolated patients.

However, responsiveness requires balancing the needs of care receivers with those of their caregivers [47]. As noted in previous surveys, informal caregiving reinforces the bonds of affection and trust between patients and their caregivers [57, 63, 64]. “Caregiving is an existential action affirming a moral commitment” [42] that satisfies caregivers’ need to fulfil their marital or filial moral duty, thus also enhancing their self-esteem [14, 27, 58, 65, 66]. As care is a gift-sharing process [42, 67], caregivers expressed gratitude for being able to spend time with their loved ones [68] and “to take advantage of the time that still remains.” This feeling may have been perceived more deeply when the patient was suffering from a cancer with a rapid progression that altered their quality of life, such as pancreatic cancer which affected fifteen of the patients in our sample.

4.1. Study Limitations. The authors acknowledge the limitation that the study was conducted in the French context and that there may exist significant differences from one country to another. Despite these limitations, the fact that the present findings are consistent with previous reports certainly suggests that our conclusions are also applicable to other national contexts.

5. Conclusion

The concept of care developed by Tronto [46] makes it possible to think of the care provided by family caregivers in charge of persons with advanced cancer as valuable work and not simply as an activity restricted to private spheres, involving qualities such as altruism and compassion. In line with the political stand taken by Tronto, whose aims included denouncing the relegation and discrediting of care, the present study sheds light on the moral dimensions of caregiving on the basis of caregivers’ own personal experience and shows the important social contribution made by them.

The present findings could serve to guide healthcare professionals as a means of developing best practice resources and guidelines to support family caregivers and promoting a coordinated public health approach to address the needs of caregivers [23]. These efforts are particularly important as present health policies tend to promote the

shift from inpatient to outpatient treatment, which increases the importance of family caregiving and the burden it involves. Future research could pay particular attention to this last point in order to assess the possible increase in the burden of home care and, in particular, the increase in the responsibility and mental workload of family caregivers.

5.1. Implications for Practice. In their treatment plans, healthcare professionals should place greater stress on the value of informal care work [42]. They should also be made aware of the underestimated effects of caring in order to alleviate these effects. Supporting family caregivers is certainly a key aspect of palliative care and family medicine. Healthcare professionals should be aware of the risk of caregiver burnout and be able to provide multidisciplinary support. However, the support provided should not be only psychological [3]; caregiver burnout also results from the piling up of the tasks involved in informal care. Although this study was conducted in a European welfare state context, health professionals everywhere should be made aware that informal primary caregivers must be able to delegate some of their tasks and have their own respite times [61].

Data Availability

All the data sets on which the results of the study were based are available on request from the corresponding author.

Conflicts of Interest

The authors declare that there are no conflicts of interest regarding the publication of this paper.

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Supplementary Materials

Table S1. SRQR checklist: The Standards for Reporting Qualitative Research, a checklist for how we reported the research. (*Supplementary Materials*)

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