



Identification of resources and skills developed by partners of patients with advanced colon cancer: a qualitative study

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Abstract

Purpose Family caregivers play an important role in caring for patients with advanced cancer. To become competent, individuals must draw on and mobilise an adequate combination of resources. Our goal was to identify the skills developed by caregivers of patients with advanced cancer and the associated resources mobilised. We chose to do it with partners of patients with colon cancer.

Methods The study used a cross-sectional qualitative design based on 20 individual interviews and a focus group. Partners were recruited from patients treated in three hospitals of France. Semi-structured interviews were conducted until data saturation was achieved. Each interview was transcribed verbatim, and thematic analyses were performed to extract significant themes and subthemes.

Results Results from the individual and focus group interviews showed that the skills implemented by the partners (in domains of *social relationships* and *health, domestic, organisational, emotional and well-being* dimensions) were singular constructs, dependant on if resources (*personal, external and schemes*) may have been missing and insufficient. In addition, partners may have had these resources but not mobilised them.

Conclusion The identification of the skills and associated resources could allow healthcare professionals better identifying and understanding of the difficulties met by partners in taking care of patients. This could enable them to offer appropriate support to help the caregivers in their accompaniment.

Keywords Caregivers · Skills · Cancer · Qualitative

Introduction

In many countries, family caregivers play an important role in caring for patients with advanced cancer [1, 2]. They have to thus face the psychological demands of care due to distress, but also physical demands such as housework, and basic

medical care [2, 3]. Caregiving is generally unplanned and most caregivers must adapt their behaviour, modify their role and help according to the evolution of the disease, the health state and feelings of the patient [4].

To be able to support the patients, caregivers are obliged to build their own skills [5]. In the field of cancer, Schumacher et

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al. developed a conceptual framework of the family caregiving skill, taking for context the situation of patients treated with chemotherapy. The authors identified nine dimensions of caregiving (monitoring, interpreting, making decisions, taking actions, making adjustments, accessing resources, providing hands-on care, working together with the ill person and negotiating the health care system) and confirmed that caregivers had to be regarded as involved in a learning process during the disease trajectory [4]. In their work, the authors did not develop a grounded study. However, other authors consider that to become competent, individuals must draw on and mobilise an adequate combination of resources in a particular context [6–8]. These resources can be *personal resources* such as 1—theoretical, environmental and procedural knowledge; 2—operational, cognitive and relational know-how and 3—emotional and physiological resources. They can also be *external resources* such as the ability to mobilise a relational network, to manage time and finances, and “*schemes*” which can be compared to a mode of action and/or thought, or to a logic that is built on experience [7].

At the moment, to our knowledge, no studies have provided data on the skills developed by caregivers of patients with advanced cancer and the associated resources mobilised. Published studies either analyse the concept of the “sense of skills” [9, 10] or focus on specific skills [9–11], and when a larger analysis of skills was carried out, the question of resources was not identified [12]. Moreover, these studies focused on the whole population of caregivers and none concerned the field of oncology. Thus, it seems relevant to us to identify all the skills developed by caregivers and the type of resources required in caregiving. We chose to do it in a specific population of caregivers and patients with colon cancer. Indeed, family caregivers are generally considered as a whole and include partners and relatives. Nevertheless, partners have been shown to be the primary informal caregivers [13–16]. Focusing on colon cancer is important because of the increased incidence of this disease in western countries [13]. Compared with other digestive or non-digestive tumour locations, it is associated with a balanced sex ratio [14] and can last for several years with several lines of treatment associated with various side effects [15]. In this context, the aim of this work was to conduct a qualitative study among partners of patients with colon cancer to identify the resources mobilised and the skills they developed during the treatment of this disease.

Methods

Design

The study used a cross-sectional qualitative design based on individual interviews and a focus group. The aim of the interviews was to understand the impact of the disease on the

everyday life of caregivers and to identify the types of resources they mobilised and the skills they developed. The aim of the focus group was to confirm findings from the interviews, but also to add new information thanks to the interactions between caregivers in similar situations.

Settings and recruitment

Interviews

Caregivers were recruited from patients treated in one of the three following hospitals of the Burgundy region (France): Dijon University Hospital, the Cancer Center and Chalon-sur-Saone Hospital. They were chosen because of their potential differences in terms of patients’ profiles. We included patients who were (1) able to understand written and spoken French, (2) had a diagnosis of stage 3 or 4 and had been treated in one of the three centres with adjuvant or first-line palliative chemotherapy and (3) agreed to his/her partner participating in the study. Patients were not included if (1) they had a previous history of cancer, (2) they were being treated for another cancer at the time of the study and (3) they had severe comorbidities or disease-generating disabilities. Partners were included if (1) they were able to understand written and spoken French, (2) they were living with the patient at home and (3) they agreed to participate in the study. Caregivers with comorbidities or disease-generating disabilities were not included because it could modify their perception of the caregiving work.

The study was presented to the patient/partner dyad by the clinician during a medical consultation. Eligible patients were those who had undergone their first-line chemotherapy. Our idea was to include “naive” caregivers to understand the changes generated by the disease and to identify the skills developed to cope with this new situation. After acceptance of the dyad, the partner was contacted by phone by the sociologist in order to fix the date and the place for the interview. Caregivers were purposely recruited to obtain various profiles in terms of age, gender, place of residence, socio-economic status and patient’s cancer stage and until no new participants were thought to bring new relevant information.

Focus group

Following the interviews, six different caregivers for patients treated either at the Dijon University hospital or at the Cancer Centre were recruited. The decision not to include the Chalon-sur-Saone Centre was justified by the fact that we had to spare caregivers from a long journey from their home to Dijon. Included caregivers were partners of patients who experienced several lines of chemotherapy. By including more experienced caregivers with a longer history of the disease, our goal was to obtain feedback from participants on the findings of the interview and to add new information given the assumption that

caregiving work can be considered a learning process. The suggestion to participate to the focus group followed a procedure similar to the individual interviews.

For the interview and the focus group, ethical approval was obtained from the Person Protection Committee (CPP). In compliance with the French law, oral consent consisted of approval from each participant (patient and caregiver). No written consent was required as no biomedical intervention was performed.

Procedure

Interviews

One flexible, face-to-face semi-structured interview was conducted with each of the caregivers. The interview guide, which had not previously been tested, was prepared by a male doctoral student in sociology, managed by a female senior sociologist. Both had strong experience in the field of health and care. The interviews were conducted by the junior sociologist alone, in most cases at the caregiver's home without the presence of the patient. Before each interview, data concerning the general health state of the patient at the time of the consultation (WHO Performance Status), the date of diagnosis and the tumour stage and data concerning the chemotherapy and the caregiver (occupation, academic level) were collected and provided to the sociologist to help him understand the context. Each interview was audio-recorded and lasted between 1 and 2 h. The sociologist also took notes during the interviews. Four main open-ended questions associated with relaunching questions were asked during the interview (Appendix 1). After the analysis of 20 interviews, it was decided that data saturation had been reached.

Focus group

A neutral but comfortable place was found at the Faculty of Medicine of Dijon. The focus group was led by the senior sociologist. The junior sociologist took a back seat, took notes and, when necessary, asked additional questions and tested the consistency of the results from the verbatim transcripts of the interviews to be sure that the participants' own meanings were represented and not curtailed by the sociologist's knowledge. Because the focus group was video-recorded, a computer engineer was in charge of managing the camera. He was positioned in the back of the room and never changed his place during the discussion so that his presence went unnoticed. The aim of the video-recording was to facilitate the analysis of the discussions and allow the capture of nonverbal communication of the participants. The interview guide for the focus group centred on the resources and skills identified in the verbatim transcripts of the individual interviews (Appendix 2, Fig. 1). None of the caregivers knew either the junior or

the senior sociologist before the focus group meeting. Before the start of the discussion, both researchers presented themselves and the objectives of the focus group. The only data the sociologists had concerning the caregivers were their name, gender, age, occupation, place of residence, cancer stage of their partner and date of the first treatment with chemotherapy.

Data analysis

Interviews

All interviews were transcribed in their entirety. They were subsequently coded using a thematic analysis. This type of analysis aims to identify and categorise the different themes occurring in the body of a text in a cross-sectional manner. Each theme was then considered as a meaningful independent unit of the discursive language. After a careful first reading of the text of each participant, the different themes that arose during the interview were recorded and classified as major themes and secondary themes. Two types of triangulation were used: first, multidisciplinary triangulation with the two sociologists and the public health researcher coordinating the study was performed with the aim to identify the types of resources and skills that caregivers employed in everyday life activities. Second, another triangulation was performed to allow analyses from the first triangulation to be checked by the participants of the focus group. Finally, four successive meetings were organised with the senior sociologist and two other researchers (the coordinator of the study and an epidemiologist, specialised in questions for quality of life questionnaire) to precisely formulate the items representing these resources and skills. Discussion lasted until consensus was reached concerning the choice of dimension and the meaning given to each word.

Focus group

The focus group interview was analysed by the research team to check the findings from the individual interviews. Two meetings were organised to complete and modify the list of items identified after the analysis of the transcripts of the interviews. No findings were modified but additional information was included.

Results

Population

Between June 10, 2014 and June 1, 2015, 20 caregivers accepted to participate in the individual interviews. Those who refused did so because of the absence of time and difficulty to talk about the disease. Between January 1 and May 31, 2016, six caregivers accepted to participate in the focus group. The

reasons for declining the invitation were as follows: concerns of privacy, distance to the hospital, planned holiday or surgical intervention. The characteristics of the patients and their caregivers are described in Table 1.

Findings

Skills implemented by the partners

The results showed that the partners had adopted skills in the following domains of everyday life. In the *domain of social relationships*, they communicate, i.e., they express their thoughts and feelings. Communication can take verbal or non-verbal forms [16]: the partners could decide to speak about the disease and its treatment, but they could also adopt other attitudes such as not passing on information, or filtering information, or hiding or simplifying it. The partners could also choose to avoid speaking about or focus on certain subjects

Table 1 Characteristics of caregivers and patients (interviews and focus group)

Caregivers	Interviews (n = 20)	Focus group (n = 6)
Age (mean, SD)	59.41 (± 9.20)	59.17 (± 8.68)
Gender (n, %)		
Male	7 (35%)	1 (17%)
Female	13 (65%)	5 (83%)
Occupation (n, %)		
Employed	8 (40%)	4 (67%)
Retired	11 (55%)	2 (33%)
Unemployed	1 (5%)	0 (0%)
Highest educational level (n, %)		
< A level	12 (60%)	4 (67%)
> A level	8 (40%)	2 (33%)
Patients		
Age (mean, SD)	59.80 (± 7.41)	61.41 (± 7.59)
Gender (n, %)		
Male	13 (65%)	5 (83%)
Female	7 (35%)	1 (17%)
Cancer staging (n, %)		
Stage II	5 (25%)	0 (0%)
Stage III	9 (45%)	2 (33%)
Stage IV	6 (30%)	4 (67%)
Chemotherapy (n, %)		
Adjuvant	17 (85%)	5 (83%)
Palliative	3 (15%)	1 (17%)
Time since diagnosis (n, %)		
< 1 year	18 (90%)	4 (67%)
1–3 years	1 (5%)	2 (33%)
3–5 years	1 (5%)	0 (0%)

SD standard deviation

of everyday life or let the patient speak. We found all or part of these forms of communication with regard to close relatives and friends, acquaintances, colleagues and employers. With the healthcare professionals, the partners indicated that they themselves sometimes asked questions to the doctor who followed the patient, asking for explanations, or they could avoid asking questions. They could also encourage the patient to speak directly to the doctor or even let the patient manage communication with him without interfering at all.

In the domain of health, several skills were implemented: partners could let the patient carry out certain tasks (getting dressed or care-related tasks); they could help the patients do these tasks or do the tasks themselves or delegate the tasks to healthcare professionals who came to their home. Two other skills were also identified: the management of disease follow-up and treatment (e.g. preparation of medical treatments, going to the pharmacy) and ensuring the mental well-being of the patient (e.g. speaking to the patient about positive subjects, reassuring, trying to organise projects they could do together, providing encouragement to take part in activities together and protecting him/her from the hassle of everyday life).

In the domestic dimension, the partners declared that they had to manage new domestic tasks (e.g. administrative tasks, home organisation and meal preparation). *In the organisational dimension*, the interviews showed that the partners had to modify the organisation of their own professional and personal lives to devote a part of their time to the patient and to preserve their life as a couple. Moreover, although time was an important component, availability was also frequently mentioned by the partners because the illness was always on their mind. Finally, *in the emotional and well-being dimension*, the partners had to bring into play several skills, the first corresponding to coping with their emotions, by expressing them, by speaking about them or by hiding them. The interviews showed that the partners attempted to preserve their well-being by setting aside time for themselves, without the patient or the disease (time devoted to leisure activities, to rest, to their professional life).

The skills are summarised in Table 2 and illustrated by several transcripts from the individual interviews.

Resources brought into play

Both the individual and focus group interviews showed that the skills implemented by the partners were “singular constructs” (i.e. the construction of skills is partner-dependent and highly linked to their life trajectory), dependant on if resources may have been missing and insufficient (Table 3). In addition, partners may have had these resources but not mobilised them.

Personal resources included not only the partners’ theoretical knowledge of the disease and its treatment, and the information they had on the subject, but also the representations that they had of the disease, of their own emotions and of their

Table 2 Illustrations of the skills developed by partners from transcripts of the individual interviews and the focus group meetings

Dimensions and skills	Illustrations
Social dimension	
1. Communication with the partner and the relatives:	
Speaking about it	<p>“I tried to find out more but he said: ‘because I said it, that’s what it is!’ Afterwards, I leave him alone because if I don’t he loses his temper. (...) We often have rows, or stop talking to each other because him, he never learned to speak about things. Me, I’ve always talked a lot with my children, all that. He had to learn how to do that, talk about his feelings, when something is bothering him, talk about it (...). It was hard for him at the beginning, but little by little, he’s getting there. It’s been hard work.” (Ms D, 44 years old)</p> <p>“And then I talked to my children about it. It had to be done. We need to, I think. All alone with the explanations of the doctors, for me it’s not enough.” (Ms R, 65 years old)</p>
Hiding it	<p>“We also spoke about the consequences, things like that, quite easily. But on the other hand for the effect it’s having on me, it isn’t taboo but I avoid talking to him about it because I don’t want to give him something more to worry about; it’s to protect him.” (Ms L, 46 years old)</p>
Avoiding speaking	<p>“We can’t speak about it all the time. I avoid it. Yes, I avoid it... Of course we talk about it, but I do try to avoid it so as not to rub salt in it all the time.” (Mr M, 67 years old)</p>
Filtering the information	<p>“We had lots of calls. That did a lot of good, because we thought great our friends are phoning to get our news. At the start, they spoke to me first, because at the beginning, because he was tired, I filtered the calls so that he wouldn’t have too many.” (Ms B, 48 years old)</p>
Simplifying the information	<p>“I don’t go into details about his illness and the treatments... simple things that everyone can understand.” (Ms C, 58 years old)</p>
Not passing on information	<p>“It’s true that there are some things I don’t tell the children. It’s difficult enough as it is for them to see their father like that without making it worse.” (Ms D, 44 years old)</p>
Focusing on matters of everyday life	<p>“We try to speak about everything, not just about the illness. I often turn the conversation around to everyday matters, people I meet when I’m out shopping and talk about any old thing.” (Mr Z, 64 years old)</p>
2. Communication with the healthcare professional:	
Speaking with healthcare professionals	<p>“As his illness made him weak, I started to go with him, to look after his treatments, to talk with the doctors when things weren’t going very well, call the doctor if there were any problems. I did all of that. I’ve been in the spotlight for quite some time.” (Ms E, 66 years old)</p> <p>“Me, I like to anticipate things, so I need to know where I’m going, so it doesn’t frighten me. I have to know and that reassures me. I suppose it’s to reassure me. It’s certain.” (Ms V, 53 years old)</p>
Letting the patient manage the communication	<p>“most of the time, he asks the questions to the doctor, the nurses. I’m there just to be with him, but not to speak for him.” (Ms P, 61 years old)</p>
3. Communication with colleagues and employers:	
Health dimension	
1. Taking care of physical well-being:	
Helping the patient with care	<p>“Until now, he always got undressed on his own and he put his hands under the hot water. But yesterday for the first time he said: Help me take off my coat, I can’t take it off. He didn’t manage to undo the buttons because his hands and toes are sort of frozen.” (Ms D, 44 years old)</p>
Doing things that the patient could do	<p>“It’s me too who takes care of the equipment (the colostomy bag) because he doesn’t want to do it.” (Ms T, 59 years old)</p>
Getting help	<p>“It’s the injections that the nurse comes to do every evening. He wanted me to do it but the problem is that you have to measure the dose and I didn’t really want to do that. So the nurse comes and that’s fine.” (Ms L, 46 years old).</p>
2. Managing follow-up of the disease:	
Prepare the medical treatments	<p>“I keep an eye on the treatments. He was still in pain, but he hadn’t taken it... all the same I check in the evening. He gives me his anti-inflammatory pills. I always ask him if he’s taken his pills. I just keep an eye on things, because he does it himself really.” (Ms D, 44 years old).</p>
Checking	<p>“It’s especially when he’s tired and I know it. I can see it”. (Ms N, 71 years old).</p>
Accompanying the patient	<p>“It’s the ninth course, and there are 12 altogether. I go with him every time, it’s a choice. The thought of going by taxi never crossed his mind. For every consultation, I take him. He counts on me.” (Ms B, 60 years old)</p>
Doing things instead of the patient	<p>“Everything that’s medical she can handle. Me, I go to get her treatments. Now, I can see fairly well... She guides me too.” (Mr Z, 64 years old)</p>

Table 2 (continued)

Dimensions and skills	Illustrations
3. Taking care of mental well-being:	
Reassuring	“He takes the initiative. He says let’s do this, let’s do that, and I just let him say it.” (Ms B, 48 years old).
Encouraging to take part in activities	“We don’t go out much, not much at all. Mainly because she doesn’t want to. Even then, we’ve had almost two months of sun, and that didn’t encourage her to go out into the courtyard. She won’t move, she’s in too much pain. When I see her like that, I try to persuade her but it doesn’t work. It’s a shame, I mean. But what’s the point, you can’t force her. It’s frustrating sometimes.” (Mr M, 67 years old)
Encouraging to go out, to speak	“I want him to go out; I don’t want him to stay inside all the time. As soon as I have to go out for whatever reason, I tell him to come with me to force him to go out a bit.” (Ms N, 71 years old)
Household dimension	
1. Managing domestic tasks:	“I mow the lawn when it has to be done and I’ve even learned how to use the cultivator!” (Ms Y, 48 years old)
2. Managing administrative tasks:	“All the paperwork, the appointments, the taxes, I look after all that. Before, we shared the work but I preferred to take care of everything a few months ago.” (Mr B, 53 years old)
3. Organising the home:	“We emptied out the small bedroom downstairs and fitted it out, so that she didn’t have to climb the stairs every evening for the night, and the toilet is just next door. It’s much more practical for her like that.” (Mr K, 78 years old)
4. Looking after the meals:	“I started to buy organic stuff. Today, I bought some organic strawberry jam, just to try it. He thought it was nice. Yes, we had to make a few changes. It’s a bit more expensive.” (Ms Y, 48 years old) “Today, I’ve changed everything. I steam almost everything. He eats fish one day and red meat the next. On Friday, he has his chemotherapy and on Sunday, I say to myself that I’ll have to buy a nice piece of red meat so that he’ll get his protein. I cook spinach, things like that which are good for him. So that he won’t be too tired to continue with his chemo. It’s all I think about.” (Ms I, 60 years old)
Organisational dimension	
1. Limiting the amount of time:	“Cancer is something that drops on you like a ton of bricks. You always think it happens to other people. I think you have to take control, you have to anticipate for the treatments, for everything, you have to see where you’re going, you mustn’t let yourself be overwhelmed.” (Ms T, 59 years old)
2. Modifying your rhythm:	“For me, I used to paint, things like that and I stopped everything. Not only for my husband’s sake, but for me. I think I didn’t want to do it any more, but it’ll come back.” (Ms E, 66 years old).
3. Adapting your work rhythm:	“A week ago, when I took Wednesday and Sunday off. The second week, if he’s got his chemotherapy, I take Saturday and Sunday. Like that, it makes two days and I can look after him. This is new, because in the restaurant business you can’t take Saturday off. It’s very hard, so I spoke with the boss. I’ve given a lot to him too. I’ve worked 16 h a day.” (Ms V, 53 years old).
Emotional and well-being dimension	
1. Coping with your emotions:	
Expressing your emotions	“OK, caregivers, the doctors think they are great when they need them, but otherwise, it’s true, we are not that important.” (Ms P, 61 years old)
Hiding your emotions	“At the first chemo session, he was very bad. That frightened me to death. I wasn’t feeling very well and I could not stop crying. I went down into the cellar. I never showed it. Never. I kept it inside. I went down into the cellar to cry (...). I did not want to show him that I was crying, because I did not want him to worry. I always want to show him that I am strong.” (Ms Y, 48 years old)
Getting reassurance	“I went to see my son-in-law for a chat and he said ‘Do not worry, chemotherapy has that effect’. He reassured me.” (Ms E, 66 years old)
2. Preserving your well-being:	“I tried to go to the swimming pool once or twice a week. Two or three of us go together. I am trying to carry on with that. At the moment it’s not easy. I try to do that or I go out on my bike. A little bike ride if the weather’s OK. Things like that, I try all the same. You have to set aside time for yourself, but sometimes, it’s not easy. It’s not easy because you have to be there all the same.” (Mr S, 52 years old)

Table 3 Potential, present or missing resources: illustration from the transcripts of individual interviews

Resources	Illustrations
1. Personal resources	
Information/knowledge relative to the disease and the treatments	“For me, I’ve got more to worry about; it seems complicated because I don’t see how it spreads. The fact of opening it up, you cut it; you’ve got particles all over the place and I wonder about these particles. What is it? and how do you follow the evolution? Because, afterwards, you know it when it starts. With the blood tests, I don’t know if you can see something, and now they talk about markers... me, I don’t know what they are... and even at the beginning, how did this cancer happen? Because it was everywhere, but what started it? So you ask yourself, is it the food you’ve been eating? the stress?” (Mr Z, 64 years old).
Emotions	“At work, two or three times, I just broke down (...). One of my colleagues lost her husband last year, lung cancer. He was 48 years old. It all happened so fast.” (Ms D, 44 years old). “And even now I’m still frightened. It’s a disease you don’t recover from. One day or another, it’s going to happen to him. The most difficult is the waiting and the uncertainty.” (Ms T, 59 years old)
Representation of the disease	“I don’t push him too hard either because I know he’s tired. I’d really like to do things. But, well, we tell ourselves this is just a temporary thing. We tell ourselves that it’s going to last six months and no longer, we hope.” (Ms P, 61 years old).
Technical knowledge	“You don’t know how to manage at the beginning. The fatigue, is it normal? When do you have to start worrying? I’m always afraid of not knowing how to cope if anything goes wrong with the treatments.” (Ms I, 60 years old)
Practical know-how in everyday life	“I do the shopping say an hour or 45 min, and then after the meal, it depends on what we do. Then the bed has to be made, the floor cleaned. It’s true, it builds up fast. The evening just flashes past! I can’t do much else in the evening. That’s the priority, that’s how it should be.” (Mr B, 53 years old)
2. External resources	
Healthcare professionals	“What I find difficult to understand is why doctors try to hide things from us. At the beginning, they didn’t even want me to speak to my husband about it.” (Ms N, 71 years old)
Time	“I do everything: breakfast, the meals... lunch, I prepare everything in the evening for the next day. I do the shopping for the week. I go past every evening on the way back from work, so it doesn’t bother me too much because I finish at four in the afternoon. Otherwise, I would have needed help, but so far, I haven’t needed any.” (Mr B, 53 years old) “Every time he goes to the hospital, I don’t go because I have to work. Since he started his chemotherapy, he always sees the doctor on his own, so I don’t know if he tells me everything. He says he tells me everything, but...” (Ms V, 53 years old)
Financial resources	“All the alternative medical stuff: homeopathy, mesmerism... She sees a mesmerist every week before she has the chemo session. She’s open to all that stuff. She also takes essential oils. I encourage her to do these kinds of things. (...) it’s not a major expense but it all adds up.” (Mr S, 52 years old) “It’s this, plus this, plus this... Automatically it costs money. I had €180 and now I’ve got nothing left. I’m going down to the job centre to apply for some help and I’ll see what they might be able to give me. It’s a pile of expenses that came (with the disease). We were already in the red. It’s my parents who helped us out.” (Ms B, 48 years old)
Support from the patient	“When he came home, he sent messages to his children. I wanted him to speak about it.” (Ms D, 44 years old) “Me, I wanted him to take his time, not to go till 3 o’clock so that he could rest more, but no.” (Ms Y, 48 years old)
Getting support from family and friends	“I’ve got illnesses too, so I have to go to the hospital myself. So, I don’t have much time. It also means that in the week she was in the clinic, I had to ask my brother, who lives in Paris. I asked him to come here.” (Mr Z, 64 years old) “As he was in hospital earlier than we expected, right away, mum came with my sister-in-law... there were lots of people, with my parents, we’re very close. We get lots of support from the family and it’s true it’s a great help. It meant I could go to the hospital to see my husband.” (Ms D, 44 years old)
Support from alternative medicine	“I made another appointment for him to see the acupuncturist because I said to myself that it couldn’t do any harm. The man had said that he could do something for people being treated with chemotherapy, if only to strengthen the immune defences.” (Ms B, 48 years old)
Support from external services	“Let’s say that we can’t get around so easily. It’s true. We’re getting help so that we can live normally, with the housework, the garden. We don’t go on holiday, so we’re always at home and so we don’t want the garden to look like a jungle. And then the housework, I didn’t want to tire myself out more than I had to.” (Ms N, 71 years old)
Support with equipment	“She didn’t want to until then, but when she was in hospital, I decided to order a wheelchair, which is here. Thanks to that, I’ve got more time.” (Mr M, 67 years old)

Table 3 (continued)

Resources	Illustrations
	“As for equipment, there’s the walker, but I was given that, so it didn’t cost us anything. The wheelchair didn’t cost anything either because our health insurance paid for that. There are dietary supplements, she pays for that. They’re not covered.” (Mr H, 61 years old)
3. Schemes	
Aptitude of the partner to adopt a way of communicating depending on the information about the disease and its treatment	“Sometimes, I don’t tell him everything. There are certain points I prefer not to talk about straight away. There’s a time for everything... We’ll wait till the end of the course and we’ll see afterwards.” (Ms D, 44 years old) “I let him do it; he asks the questions to nurses or when he sees the doctor. Afterwards, we can talk about it together, if he wants to. It’s whatever he wants.” (Ms P, 61 years old)
Aptitude of the partner to develop strategies on how to do things or get the patient to do things for the good of the patient	“I said to myself: I’ll have to be strong for him. I’ll have to be there to look after him. I’ll have to do all that I can so that he feels OK. I’ll have to take care of him.” (Ms Y, 48 years old).
Aptitude of the partner develop adaptation strategies for the good of the patient and life as a couple	“It’s true, we sleep much less. As we sleep together and if she doesn’t feel well during the night, I don’t sleep much, and it builds up. OK, I catch up at the week-end. Days are more tiring, yes. It was really physical fatigue. And doing something else; that does you good. We’re not so old, we manage to recover.” (Mr R, 68 years old)

couple. Other personal resources such as technical or practical know-how seemed to play an important role, but only to implement skills in the health and domestic dimensions. *External resources* included tangible elements such as the time available to the caregiver, the available financial resources or the existence of outside care services, and material means, as well as recourse to religion. The patients themselves, healthcare professionals and close friends and family were also important external resources the partner could count on if necessary. External resources also included more intangible elements, such as the experience and habits of the couple. These resources were mobilised in different ways depending on the dimension concerned. For example, for the domestic, health and organisational dimensions, tangible external resources were mobilised to a greater extent than was the case for the social relationship dimension. Finally, partners had to implement *schemes* allowing them to organise and structure their action in a given situation. The interviews showed that above all, they had to think about how to communicate depending on their level of understanding of information related to the disease and its treatment, to develop strategies on how to do things or how to get the patient to do things for the good of the patient and to improve their aptitude to anticipate and to project into the future.

Discussion

Today, the important role played by informal caregivers, and notably partners of patients, in the healthcare system has been clearly established, whatever the medical specialty concerned [17]. In this context, the aim of this study was to identify in a pragmatic manner the skills developed by caregivers of patients treated for colon cancer and the associated mobilised resources.

There are relatively few data on the subject of skills and the associated resources. Most studies in oncology have investigated the objective and subjective burden perceived by caregivers [2, 18–27]. The few studies that have concerned the concept of skills were carried out in other medical fields [9–12, 28–30] and with no pre-established conceptual framework. These studies concerned either specific skills, such as communication [10], or skills related to the physical well-being of the patient with regard to nursing care or technical care [9, 11, 12]. The domains of emotion and social relationships [12] have also been identified. The results of our study, which did not aim to target any type of skill in particular, are in keeping with these studies. With regard to the concept, the study closest to ours was that done by Schumacher et al., above all because it concerned the therapeutic management of cancer. They distinguished between nine levels of skills: “monitoring, interpreting, making decisions, taking action, adjusting to changing needs, comforting with hands-on care (direct care), accessing resources, working with the ill person and negotiating the health care system” [4]. Our results spontaneously correspond to these levels, even though the dimension “negotiating the health care system” was rarely raised in our study.

However, our study brought to light a new dimension as we tackled the concept of resources that were mobilised to implement these skills and we identified Weberian ideal types [31]. Moreover, our study was conducted within the confines of a pre-established conceptual framework [7]. This was important as it allowed us to escape from a purely factual analysis. The fact that we conducted our study in the framework described by G Le Boterf explains why the definition given by Schmacher et al. of skills, such as the “ability to engage effectively and smoothly” in the nine processes, could be challenged [4].

We could criticise the fact to have studied the only context of colon cancer. But the sex ratio in this disease allowing us to

include caregivers of both sexes and the relatively long life expectancy of patients place the partner in a process of skill acquisition, which is not possible for some other cancers.

Several limits need to be pointed out. In this study, patients from different care centres were included to take into account various profiles of patients and partners. However, in the focus group, there was a bias because there was only one male partner. One could also criticise the fact that caregivers of patients with a more advanced stage of cancer were included in the focus group. However, even at this stage, caregivers are still in a learning process, thus confirming once again the idea that the caregiver function necessarily changes to adapt to an evolving situation as shown by Schumacher et al. [4].

The major difficulty associated with this study was our ability to take into account elements of information, often tacit, in the discourse of the partners. We think that, despite the long list of concrete, tangible and observable skills we identified, the emotional dimension was transversal and implicated in all of the dimensions: the partners expressed their worries and their emotions (such as being afraid to leave the patient alone, fear of the disease, of death, of absence, the fear of making a mistake, the fact of not wanting to continue, of thinking about something else, of denying themselves things). Moreover, certain resources could not be captured directly, such as the story of the couple, which is a resource in itself and implicit in the different items. It gives the partner a specific place in the familial and social organisation and a role potentially different compared to other caregivers.

The partners thus let the patient do various things, because they knew that he/she could do it. This resource could not be captured because the study concerned partners whose relationship with the patient was the normal relationship of a couple.

A skill consists in the mobilisation of a set of various resources depending on the complexity of the task to accomplish. However, the skill is always implemented in different situations, meaning that it involves a process either of adaptation or of transfer from one situation of life to another. This process of adaptation takes time. This study was not able to follow the process for each particular partner because the interviews were conducted at a given moment and not repeated over time. Repeating interviews over time would have allowed us to show the adaptation and learning processes necessary for the construction of skills.

Conclusion

There are no models of caregiving. This study promotes the skills and resources mobilised by the partners to help the patients treated for a cancer. These results have to be considered as the first step of a more ambitious study aiming at constructing a questionnaire which could be used to identify vulnerable partners and could be generalised to other cancer locations.

Indeed, the identification of the skills and associated resources could allow healthcare professionals better identify and understand the difficulties met by partners in taking care of patients. This could enable them to offer appropriate support to help the caregivers.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in the study involving human participants were in accordance with the ethical standards of the CPP (French protection person committee. All participants (here patients and their caregivers) were informed about the purpose and nature of the study. In compliance with French law, oral informed consent was obtained from each participant (patients and caregivers) for whom information is included in this article.

Appendix 1 Interview guide

Background: Could you present yourselves, speak to me about you, your couple?

- Studies, profession
- Retrace the construction of the couple (meeting, children...)
- Retrace the different activities/centres of interest whether shared or not in the couple
- Way of life (before the diagnosis)

Could you run me through the history of your partner’s illness?

- Your worries (first symptoms, doubts about the disease)
- Announcement of the diagnosis (who was present?)
- Announcement of the treatment
- What role did your doctor play at the time of the diagnosis? (Usual role of the GP/specialist)

- What was the role of the specialist?
- Who did the doctors speak to? (Your partner, you alone, both of you, other people in your family)
- What were your thoughts about the illness? What did it mean to you (representations of the disease) (death, handicap, transition/temporary period...)
- Did you speak to your family and friends about the illness? What reactions? (Usual role of family and friends)
- Did it affect your life in any way? (Lifestyle changes, adaptations, projection into the future, focus on life/activities around the disease)

Could you tell me how your partner has been followed since the discovery of the illness?

- Who is managing the illness?
- How often do you see the doctor/nurses?

How do you organise your everyday life?

- With your partner
- When he/she is in hospital
- With regard to the day-to-day care
- In everyday tasks
- With regard to your work
- With regard to leisure activities (travel, holidays, journeys, etc.)
- With regard to your personal life, going out
- Has the illness (its treatment) modified your everyday habits? Yours personally? Your life as a couple? In what way?
- Financial aspects (additional expenditure, purchase of equipment, etc.)

How are you experiencing this illness?

- With your partner
- And you personally?

Appendix 2

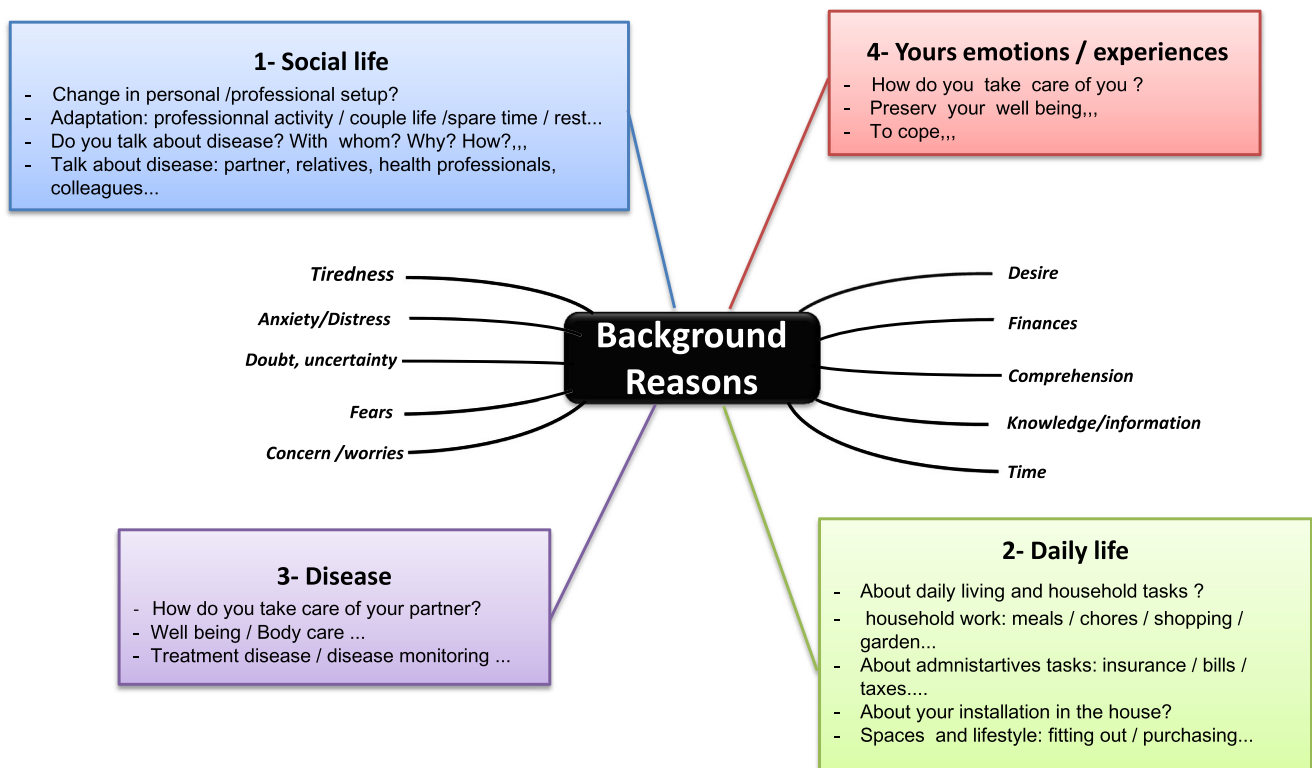


Fig. 1 Interview guide for the focus group: mental card structured in four topics: social life, everyday life, disease and feelings

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