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RESEARCH ARTICLE



Coping strategies of family caregivers in spinal cord injury: a qualitative study

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ABSTRACT

Purpose: To identify the coping strategies used by family caregivers of persons with spinal cord injury (SCI) in Switzerland in order to develop tailored support programs.

Materials and methods: Purposive sample of >18 years participants, speaking an official Swiss language fluently, being family caregivers of persons with SCI for at least 4 years, and perceiving either a high or low burden in relation to caregiving. Data were collected through face-to-face semi-structured interviews ($N=22$). Thematic analysis was performed.

Results: Four main coping strategies were identified: reappraisal, active acceptance, setting limits to the caregiver role, and seeking support. These strategies can be used one at a time or combined, and at different times of a caregiver pathway. Our analysis highlighted that caregivers need skills to implement these strategies (e.g., self-evaluation skills).

Conclusions: Caregivers of persons with SCI develop cognitive coping strategies to make sense of the situation and establish a “new normal” and problem-focused coping strategies to deal with their new tasks and role. These strategies do not seem to be typical only of SCI caregivers. Hence, interventions that worked for caregivers in other fields could be adapted. Rehabilitation centers should systematically integrate programs targeted to caregivers into their offerings.

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► IMPLICATIONS FOR REHABILITATION

- Healthcare systems need to develop educational and support measures for both persons with a health condition and their caregivers.
- Caregivers should become long-term partners in rehabilitation and a regular and structured needs assessment should be offered.
- Interventions that worked for caregivers in other fields can be adapted to support also caregivers in SCI.
- Educational and support programs dedicated to caregivers should teach not only how to perform caregiving tasks but also how to balance between responding to the care recipient's needs and their own needs.

Introduction

An informal caregiver is an “unpaid individual (a spouse, significant other, family member, friend, or neighbor) involved in assisting others who are unable to perform certain activities on their own” [1]. Informal caregiving is a fundamental part of healthcare provision. In the United States, 16.6% of Americans provide care to adults with a disability or illness [2]. In Europe, it is estimated that the number of informal caregivers ranges from 10% up to 25% of the total population [3]. In Switzerland, more than a hundred thousand family members assist others with activities of daily living and/or medical tasks [4].

The number of informal caregivers is destined to grow. Demographic changes coupled with societal behaviors (e.g., tobacco and alcohol use, poor nutrition, lack of physical activity) and the advancements in medicine and supportive technologies contribute to increasing life expectancy, often associated with an

increment of chronic health conditions [5,6]. Because chronic conditions require constant management in daily life, many individuals affected receive support from their family members. In the case of complex chronic conditions, such as spinal cord injury (SCI), the support of family caregivers is particularly precious because the condition affects many aspects of human functioning [7], including body functions and structures [8–10], activities and participation in society [11,12].

Caregiving is not always without consequences for the family members. A study comparing family caregivers to the general population suggests that the caregiver role is associated with poorer health and psychological wellbeing compared with their non-caring counterparts [13]. Moreover, family caregivers are more likely to work less and have lower household incomes, when compared with non-caregivers [14]. In the field of SCI, caregiving has been associated with caregiver burden and several negative outcomes including poor general health, depression and

anxiety, relationship and financial strain, stress and a lower overall quality of life [15–18].

The engagement in caregiving can also have positive effects on informal caregivers. Studies have shown that caregiving might enable the learning of new skills and an increase in self-efficacy, but also a sense of fulfilment, the feeling of being rewarded, and an enhanced relationship with the care recipient [19–21].

These effects of caregiving could possibly be explained by the way caregivers themselves cope with it. Studies in different fields have shown that coping strategies are significant predictors of adjustment in caregivers. For instance, in caregivers of people with dementia, greater use of coping strategies was related to higher life satisfaction and self-reported health [22]. Similarly, psychological wellbeing was enhanced thanks to coping strategies in caregivers of people affected by advanced cancer [23], and a higher number of coping strategies predicted better psychosocial adjustment as well as better quality of life in caregivers of people with Parkinson disease [24]. Coping strategies are defined as “an action, a series of actions, or a thought process used in meeting a stressful or unpleasant situation or in modifying one’s reaction to such a situation” [25].

The aim of this article is to present the coping strategies used by family caregivers of persons with SCI in Switzerland. In light of the need to develop interventions to reduce caregiver burden and support those caregivers who have more difficulties in dealing with their role, our study offers a first insight into the coping strategies already adopted by caregivers.

Materials and methods

Recruitment

This qualitative study is the second part of a larger project. The first part of the project consisted of a nationwide survey (conducted between August 2016 and July 2017) which aimed to investigate the living situation of primary family caregivers of persons with SCI in Switzerland. This study (August–November 2017) was conducted with a subgroup of survey participants.

To recruit the caregivers for the survey, we contacted the persons with SCI included in the address lists of the national longitudinal survey (SwiSCI, the Swiss Spinal Cord Injury Cohort Study [26,27]), cross-referenced with the membership database of the Swiss Paraplegic Association and patient databases of the four SCI-specialized clinics in Switzerland. Persons with SCI were then asked to hand over the enclosed survey to their primary family caregivers. The caregivers who completed the survey ($N = 717$) could indicate in the informed consent form their availability to take part in an interview.

Among those people who indicated their availability, we recruited a purposive sample of participants. The sampling strategy was based on factors which might affect the experience of caregiving [28–31] and ensured the recruitment of a heterogeneous sample of interviewees, which in turn allowed a wide range of perspectives to be captured.

The interviewees fulfilled the following inclusion criteria: over 18 years old and speaking an official Swiss language fluently; providing at least ten h/week of care to a family member with SCI who is a wheelchair user for at least four years, and perceiving either a high burden or a low burden in relation to caregiving. Caregiver burden was defined as the perception of a negative impact of caregiving on their own life and health as well as of a lack of support as measured with a shortened version of the COPE (Carers of Older People in Europe) Index (Table 1). The four-point Likert scale was dichotomized into either “Always” or

“Often” versus “Sometimes” or “Never” for each item and used to calculate a burden score for each participant through a Rasch model. As a result of this analysis, respondents were classified into three groups: low-burden, high-burden, and neutral, based on an equal split of the ordered Rasch scores into thirds. Participants in the low- and high-burden groups were then divided into two groups each depending on paraplegia vs tetraplegia. For each group, clusters were built based on single-linkage with Gower distances in order to select interviewees from heterogeneous clusters. The following parameters were considered: gender and age (for caregiver and care recipient), linguistic region (German, French, Italian), family relationship between caregiver and care recipient (spouse, sibling, descendant, forebear), financial expenditures due to caregiving, and the number of years of caregiving. From each cluster within the low-burden groups, the participant with the highest number of care hours was selected. From each cluster within the high-burden groups, the participant with the highest-burden, according to the Rasch burden score, was selected.

Data collection

Data were collected through face-to-face semi-structured interviews. Preliminary data analysis was conducted in parallel, and the recruitment of participants was stopped when inductive thematic saturation was reached (i.e., when new data did not lead to the development of new themes) [32]. All interviews were conducted by two researchers, in the preferred language of the interviewees and a place of their choice. This study was conducted in accordance with the ethical principles for medical research involving human subjects [33]. It obtained a clearance declaration from the assigned national ethics body (ref. EKNZ 2016-00863). Participation in the study was on a voluntary basis, and full written consent was obtained from all interviewees.

The questions explored the participants’ experience of caregiving in general and focused on its positive and negative aspects in particular, as well as their ways of dealing with challenging or unexpected situations. Three pilot interviews were conducted to test the interview topic guide. No major changes were made to the questions, but the wording was improved to avoid misunderstandings. Sample questions are presented in Table 2.

Data analysis

The interviews lasted 70 min on average ($SD = 33$) and were digitally audio-recorded to enable verbatim transcription. Contextual and personal information which could lead to the identification of the participants were removed from the transcripts to ensure confidentiality.

Table 1. Shortened version COPE Index.

Do you feel you cope well as a caregiver?
Do you find caregiving too demanding?
Does caregiving cause difficulties in your relationships with friends?
Does caregiving have a negative effect on your physical health?
Does caregiving cause difficulties in your relationship with your family?
Do you feel trapped in your role as a caregiver?
Do you find caregiving worthwhile?
Do you have a good relationship with the person you care for?
Do you feel well supported by health and social services? (for example, public, private, voluntary)
Do you feel that anyone appreciates you as a caregiver?
Does caregiving have a negative effect on your emotional well-being?
Overall, do you feel well supported in your role of caregiver?

Answer options: Always, Often, Sometimes, Never.

Table 2. Sample questions from the interview grid.

Topics	Leading questions	Additional questions
Freedom of choice	What factors influenced your decision to care for [care recipient]?	<ul style="list-style-type: none"> Was professional care considered?
Skills	Which are in your opinion the most important skills a caregiver in your situation would need?	
Role / Self-efficacy	How do you feel in your role of caregiver?	<ul style="list-style-type: none"> Do you feel confident? At ease? Why? What helps you deal well with this activity?
Impact of caregiving on personal life	How has your life changed since you took on caregiving?	<ul style="list-style-type: none"> Which aspects of your life have been affected by this activity? Where is the main impact?
Positive aspects of caregiving	What are the positive aspects of being a caregiver?	
Negative aspects of caregiving	What do you think are difficult aspects of being a caregiver? Why?	<ul style="list-style-type: none"> Difficult tasks Organization private and professional life with the caregiving Time for yourself
Coping strategies	How are you coping with the responsibilities of caregiving?	<ul style="list-style-type: none"> How do you deal with practical problems related to caregiving that you encounter in daily life?
General support	Overall, how do you feel supported in your role of caregiver?	<ul style="list-style-type: none"> From whom? Which kind of support? What helps you most? Why?
Professional support	What about professional support for yourself?	<ul style="list-style-type: none"> Are you aware of the possibilities for support? Are you using any of them?
Needs and suggestions	Is there anything that could help you better deal with your caregiving tasks?	<ul style="list-style-type: none"> Information Wishes?
Needs and suggestions	How do you feel when looking at the future?	<ul style="list-style-type: none"> Fear or worry for yourself/the care recipient?

The interviews were analyzed following the principles of thematic analysis, an approach used to identify and interpret patterns within a dataset [34]. Our approach combined a deductive and an inductive phase. First, the interviews were coded by relying on codes derived from the interview topic guide. Then, they were coded inductively based on emerging topics. The codes were revised and merged into themes in an iterative process. To ensure that all excerpts within a theme reflect the same aspect, the excerpts were compared continuously among each other and with those of other themes. As suggested by Patton [35], we used analyst triangulation to enhance the quality and consistency of our analysis. The first author developed preliminary codes and a second researcher reviewed the coding of half of the interviews (i.e., accepting the coding as performed by the first author, suggesting a new code for the same excerpt or new codes for additional excerpts). The regular discussions between researchers were useful for generating and examining possible interpretations of the data, and, consequently, for revising the coding structure [36,37]. Both coders are experienced researchers in social sciences, in particular in the conduction of qualitative studies.

The interviews were analyzed in the original language. Relevant quotes were translated to support and present the findings in scientific publications. The software MAXQDA™ (Release 12.2.0) was used to organize and store data.

Results

The final sample included 22 participants: Sixteen women and six men with a mean age of 61 years ($SD = 10.4$). They were caregivers for 18 years on average ($SD = 13.5$) and were mostly life partners of the care recipient ($n = 15$). Ten of them reported in the questionnaire a high subjective burden, of which five reported taking care of a person with paraplegia and five of persons with tetraplegia. Twelve caregivers reported a low subjective burden, of which five reported taking care of a person with paraplegia and seven taking care of a person with tetraplegia. Participants' characteristics are presented in Table 3.

Four main coping strategies were identified in the interviews: reappraising the caregiving experience, actively accepting the

situation, setting limits to the caregiver role, and seeking support (Figure 1). The first two are purely cognitive coping strategies, whereas the last two are action oriented. These strategies can be used one at a time or combined, and at different times of a caregiver pathway. Reappraising the caregiving experience and setting limits to the caregiver role are used by the majority of our interviewees. In our sample, accepting the situation is applied mostly by caregivers with lower burden, while seeking support by caregivers reporting a higher burden.

Reappraising the caregiving experience

A first coping strategy is reappraising the experience of caregiving. This consists of a thought process that changes their views on a topic or situation. The analysis showed that the caregivers mostly used two ways of reframing the caregiver experience: one way is to present caregiving or caregiving tasks as a "normal" situation or activities (see subtheme "Normalizing" below) and another way is to stress the positive aspects of caregiving (see subtheme "Looking at the bright side" below). Thanks to this coping strategy, the participants explained why caregiving is acceptable in their eyes and even why they prefer it to other solutions. Exemplar quotes are presented in the text; for more examples, please refer to Q1–Q8 in table 4 in the Supplemental material.

Normalizing

The interviewees reappraised the experience of caregiving by emphasizing its "normality". Caregiving tasks are considered part of the household chores (Q1).

I would say that what I take over is part of the family tasks. (INT21, Life partner)

In some cases, the responsibilities of caregiving are compared with other family responsibilities, referring to traditional role perceptions and expectations (Q2).

How do I deal with this responsibility? So I feel responsible for the family, somewhere out of the traditional view in which the man is expected to provide for the family. This view is part of me. (INT21, Life partner)

Table 3. Participants' characteristics.

ID	Age	Years of caregiving	Gender	Relationship to the care recipient	Care recipient's lesion level	Caregiving burden
INT01	73	6	F	Life partner	Paraplegia	low
INT02	76	10	M	Life partner	Paraplegia	low
INT03	64	22	F	Parent	Paraplegia	low
INT04	65	11	M	Life partner	Paraplegia	low
INT05	53	42	F	Child	Paraplegia	low
INT06	58	7	F	Parent	Tetraplegia	low
INT07	70	5	M	Life partner	Tetraplegia	low
INT08	50	16	F	Life partner	Tetraplegia	low
INT09	48	23	M	Life partner	Tetraplegia	low
INT10	66	39	F	Life partner	Tetraplegia	low
INT11	72	27	F	Parent	Tetraplegia	low
INT12	35	13	M	Life partner	Tetraplegia	low
INT13	47	11	F	Life partner	Paraplegia	high
INT14	57	5	F	Parent	Paraplegia	high
INT15	77	5	M	Life partner	Paraplegia	high
INT16	63	17	F	Life partner	Paraplegia	high
INT17	69	47	F	Life partner	Paraplegia	high
INT18	57	6	F	Parent	Tetraplegia	high
INT19	63	19	F	Sibling	Tetraplegia	high
INT20	60	41	F	Life partner	Tetraplegia	high
INT21	54	24	F	Life partner	Tetraplegia	high
INT22	59	5	F	Life partner	Tetraplegia	high

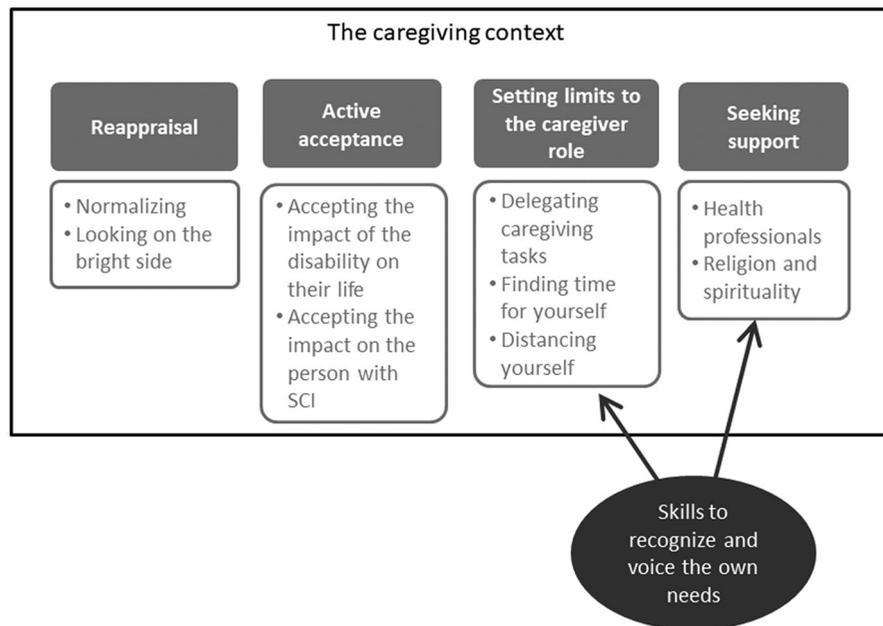


Figure 1. Visualization of the findings.

Other ways of normalizing caregiving were to compare it to a regular job, in which there are difficult moments and tough days, or to downplay their tasks or time investment as a caregiver (Q3).

It's a job, sometimes I do it like a job, like a 50% job. For me, for the partner. So far I'm actually satisfied. Of course, there are days when you say: "Today it's a little bit too much". But I think it's like this everywhere, no matter what you do, it's a bit like that. (INT09, Life partner)

Some partners also normalized caregiving by stressing that it does not interfere in their relationship. They described their relationship with the care recipient as an ordinary, balanced relationship based on reciprocity, and they attribute the problems encountered to aging, for instance, and not caregiving (Q4).

She does the bookkeeping for my company [...] I appreciate what she does very much, I'm so happy, she does it for me. So even if once I don't feel like taking care of her, then I also think that she also does so

much for me. It's giving and receiving. [...] [This] also contributes to our well-being. (INT12, Life partner)

Looking at the bright side

Some interviewees also reframed the experience of caregiving by stressing the positive aspects. Indeed, some caregivers claimed that, although caregiving can sometimes be demanding, taking care of everything has clear advantages, first of all more freedom in the organization of the activities and privacy (Q5).

The people who support my husband and I need to be a good fit with us. And you can handle it a little better if you do everything on your own. First of all you learn and secondly you can also organize yourself as you like. (INT01, Life partner)

Moreover, despite the efforts, some caregivers value the fact that the partner can still live at home instead of in a nursing home (Q6).

I don't complain. Sometimes my mood is a bit down, but I always tell myself that my wife is here with me. She is at home. Because I may be too sentimental, but imagining her alone in her wheelchair in a nursing home ... (INT20, Life partner)

Two participants also positively reframed the change in their professional life: giving up a leading position was balanced by retraining at the university and the fact of reducing the working time to 50% was appreciated because of the freedom it offered in the organization of the day (Q7).

It has an impact, yes. But I don't find it too negative now. The life I had before was good. The life I have now is good. I can or may or must work only 50%, I can be at home, I like being at home, I like that, I can organize my time and my job, it also works out financially. Of course there is also a loss, but well, money is not everything. So, it has an impact, but it doesn't have to be a negative one, does it? (INT09, Life partner)

In addition, many participants seemed to (have learnt to) look on the bright side of the situation, switching their focus from the loss to what life still offers (e.g., less but stronger friendships, spending time with the grandchildren) (Q8).

Thank God it happened when we were already old. When I look around and see how many young people are in this situation. [...] But we've already completed two thirds of our lives and lived very well, and that's how we've achieved a certain level of satisfaction, and then it's probably easier. (INT01, Life partner)

Actively accepting the situation

A second coping strategy we identified was actively accepting the situation. Acceptance is a thought process that consists of becoming aware of the impact that the disability has on one's life and on the person with SCI and in changing one's attitude toward the new situation: instead of ruminating on the bad luck or fighting against something that they cannot change, some caregivers take in and move forward. Exemplar quotes are presented in the text; for more examples, please refer to Q1–Q6 in table 5 in the [Supplemental material](#).

The acceptance that things have changed and that what is now cannot be what was before seems to be very helpful for the participants, who considered that acceptance makes life easier (Q1).

Of course I'd prefer if my wife wouldn't need my support at all and could walk like you and me. But that is ... with that we simply had to cope, neither she nor I have ever fought against the fate. We just accepted the fate and the restrictions related to it, we simply accepted it and so it was easier (INT02, Life partner)

Indeed, those caregivers who have accepted the situation tend to be satisfied with what they have and do not have many demands (Q2).

We went in the afternoon, climbed to the top of the mountain and we spent a beautiful afternoon up there, at the restaurant, and so on. For me it was perfect, I felt as if I were at the Caribbean [...] because you have to know how to settle for what you have. (INT19, Sibling)

Furthermore, accepting the situation seems to influence the way in which caregivers set their priorities in life: they can more easily give up an activity or make changes in their life (plans) to facilitate caregiving without having regrets. For instance, some caregivers gave up their hobby because it was too dangerous, some changed their job (e.g., from a management position to a lower position) or reduced their workload, and some renounced having children (Q3).

[...] my first career was actually flying and I actually gave up flying because of her [care recipient], too. First of all because it was a certain

risk, and I didn't want to take this risk anymore. [...] I thought of replacing flying with motorcycling, then my wife said quite clearly that she disagreed because it is also a high-risk sport. I accepted it. (INT21, Life partner)

The acceptance of the situation can also be a basis for finding alternatives to previous habits or activities (Q4).

You can't ski with your friends anymore, can you? Or you can no longer go hiking with your friends. These are the activities to which you have to renounce, and that's a pity. And sometimes you just have to say to yourself "This is how it is now" or "You can do different things now". Or sometimes I do some activities alone with friends and colleagues and then for instance in the evening we come back home, spend the night together at our place, so that my husband can also enjoy the evening together. And that actually works quite well. (INT08, Life partner)

Likewise, accepting the behavior of the care recipient and justifying it in relation to his or her disability and life experience can help overcome some conflicts between caregiver and care recipient. Some participants explained, for instance, the importance of taking a step back and letting the problems roll right off their back, or look the other way and be understanding with the care recipient, or using humor to diffuse the tension (Q5).

It is important to empathize with the care recipient because at the beginning it was quite difficult for her to accept help. She [care recipient] was angry with the home care service and then also not so nice to us [daughters = informal caregivers]. But then at some point, with the time, she calmed down and she's very happy now and she is always happy when we come and always says thank you. (INT04, Adult child)

This can be helpful and needed, especially when the care recipient is in a relationship of dependency with the caregiver, and there are no or few opportunities to have a break from caregiving (Q6).

One of the most important skills is to be able to put some distance, so that not everything becomes your own problem or situation to deal with. (INT08, Life partner)

Setting limits to the caregiver role

To deal with the evolving and impending challenges of caregiving, many caregivers adopted a third coping strategy: setting limits to the caregiver role. The implementation of this coping strategy is reflected in the delegation of tasks (see "Delegating caregiving tasks" below), but also in the efforts caregivers undertake to have some time for other activities (see "Finding time for yourself" below) and social roles (see "Distancing yourself" below). Exemplar quotes are presented in the text; for more examples, please refer to Q1–Q8 in table 6 in the [Supplemental material](#).

At the origin of this coping strategy, there is the awareness that they need time for themselves and activities other than caregiving. Reaching this awareness is, however, often a long way for the caregivers. Indeed, many reported that after SCI onset, the focus of health professionals and family members is on the functional recovery and well-being of the patient and that caregivers tend to forget their own needs (Q1).

I've become more stubborn, more selfish, but that's for my own good. For years I accepted everything and nearly had a nervous breakdown. [...] I simply didn't want to admit it back then ... being selfish, I had to learn it to protect myself. (INT13, Life partner)

Moreover, setting limits to the caregiver role requires from the caregiver assertiveness and the ability to negotiate alternative solutions, a good deal of organization and the ability to delegate without feeling guilty. Simultaneously, it requires from the care recipient some flexibility to accept that someone else takes over

caregiving (e.g., accepting the support of home care providers) (Q2).

I used to feel guilty when my husband and I were away or on holiday or so. What does he [care recipient, son] do? How is he? And now I'm slowly getting to the point where I say he's grown up, he should organize himself and somehow it works. I don't worry so much anymore but it's still difficult and it has taken quite a long time to get to this point. (INT11, Parent)

Delegating caregiving tasks

Many caregivers reported cumulating several and varied tasks in relation to caregiving: from cleaning the house and grocery shopping to basic body care, from helping with transfers to support for bladder and bowel management. One way of setting limits to the caregiver role is to delegate some tasks, in most cases, to professionals. Household chores and administrative work (e.g., counseling service for finances and insurances) were mostly delegated to limit the time invested in caregiving, whereas care was delegated to avoid mixing up the roles of being a partner and being a caregiver (Q3).

So what I then searched for, together with him [care recipient] is help for all legal issues at the Pro Juventute and at the ProCap. They advised us and took over all the legal issues. For instance the thing about the disability insurance. And what is also good, is the support we receive from the Suva [accident insurance]. There is a case manager, he was also very good, he came once per year, he explained and showed. It was very helpful and now things are working well. (INT06, Parent)

Besides delegating to professionals, in some cases, the caregivers also transferred some organizational tasks to the care recipients (e.g., when the caregiver is not available, the care recipient takes over the organization of a replacement) (Q4).

Today, when I want to go away for a few days, I just say: "Listen, I'd like to do this". I used to organize everything, the home care service and other informal caregivers. I used to ask our children who could bring dad to bed. And today I leave it to him [care recipient] to organize and it actually works quite well. But it is ... It's up to me to do it this way. (INT08, Life partner)

Finding time for yourself

The majority of the caregiver interviewed mentioned the importance of setting limits to caregiving by taking some time off and planning activities that "recharge their batteries", such as practicing sports or gardening, going out for a coffee with a friend, taking a walk, painting, reading or having a nap (Q5).

[progressive muscle relaxation] is mindfulness [...]. They are muscle relaxation exercises, you can do them with headphones. [...] I also often check my agenda and see what I can cancel this week or next week, which is unnecessary. These are strategies that I've learned so that I don't land in rough waters again, so that I stay healthy. (INT13, Life partner)

Even work was sometimes mentioned as a compensation or a distraction from the caregiving tasks (Q6).

Although I am retired since May, I always work two-half day, working is my hobby [...] I'm an accountant and there is my kingdom and I feel great. (INT19, Sibling)

Distancing yourself

Two participants emphasized the need for setting limits to the caregiver role by distancing themselves and creating room for other roles. In this process, the professional life offered opportunities. Such a distance might be especially important for those people perceiving a high burden in relation to caregiving, who find in other social roles a means of personal realization (Q7).

Three years ago I found a job that's just right for me. [...] I realized that Tuesday and Friday are the only days in which I don't have a disabled son and in which I'm Mrs. [name]. On Mondays, Wednesdays, Thursdays, Saturdays, Sundays I'm the mother of a disabled child. (INT18, Parent)

Similarly, one participant mentioned that, given the impossibility of pursuing retraining and starting a new professional career, she could find through voluntary work another role that brings her personal satisfaction and for which she feels valued (Q8).

[...] after four, five years [after the accident] one starts to breathe again and, I have to be honest, I struggled to deal with the situation. [...] and then I got involved in other things and I'm very satisfied now. [...] I did some voluntary work and I received recognition. (INT08, Life partner)

Seeking support

The fourth coping strategy identified to better deal with the challenges of caregiving is seeking support. The implementation of this strategy presupposes that the caregivers realize that their resources are not enough to cope with the situation and, therefore, they have to look for help. Exemplar quotes are presented in the text; for more examples, please refer to Q1–Q5 in table 7 in the [Supplemental material](#).

Some interviewees sought support from healthcare professionals to treat their own physical issues (e.g., back pain), sometimes in the long term and sometimes for acute situations (Q1).

I just realized that I have to look after myself. I do some sports, balance a bit, I've been doing physical therapy once a week since the accident of my husband (INT08, Life partner)

Some others sought professional help for psychological concerns, such as for overcoming the shock of the accident. In most of the cases, the participants were satisfied with the outcome (Q2).

What helped me? Psychological support. I saw a psychologist, several of them, until I found someone who made me feel understood. (INT13, Life partner)

Only in one case, the participant reported that the therapy was not helping her and gave up (Q3).

I tried it [psychiatrist] then. During the fifth session I said: "Listen, I stop. I come here to talk to you and I know that's a naive statement, I'm totally aware of that, but one goes to a psychiatrist hoping to feel better, but do you know what happens to me when I leave your practice? XX [care recipient] is still in a wheelchair". Yes, that sounds now totally ... but that's my truth, that's my present. What can bring me to tell him my problems? Then I stopped. (INT18, Parent)

Some participants also mentioned having found support in religion and spirituality (Q4).

[...] we have also been practicing with the Buddhist monk for a long time and this helps us a lot to deal with life disruptions. We are always ready for vicissitudes in life and therefore we can bear this condition. We also practice the art of letting go and therefore, despite my career or our finances, we can live normally, without great suffering. (INT22, Life partner)

As one caregiver reported, seeking support also implies an effort (Q5): not only do caregivers have to recognize their need for support, but they also have to take the initiative and sometimes try out different offers.

I would say that all that you could demand or receive [in terms of support] is more in theory than in practice. There is a certain reluctance to ask for it. It always takes a little energy to accept help, to ask for help, you can only do that to a limited extent. (INT21, Life partner)

Discussion

The analysis helped us to identify four different coping strategies that caregivers of persons with SCI use: reappraising the caregiving experience, actively accepting the situation, setting limits to the caregiver role, and seeking support.

Overall, our findings are in line with existing literature, in that they show that adjustment to the caregiver role and its integration in the caregiver's life is an active process, often involving renegotiation of expectations, priorities and life plans. Studies in the field of SCI show that adjustment requires care recipients and caregivers to shift former social roles and norms, for instance by finding new ways of contributing to the family life and participating in social activities [38,39]. Likewise, Lopez-Espuela and colleagues found that stroke caregivers perceived a biographical disruption and only those who acknowledged the changes and engaged with the transition process developed effective coping strategies [40]. These findings are further corroborated by findings of a recent metasynthesis of the literature in the field of advanced cancer [41]: caregiving is a life disruption at all levels (e.g., roles and relationships, priorities) and adjustment implies that caregivers find ways to redefine their reality, by acknowledging the situation and then connecting to resources and support for themselves. In contrast, those caregivers who are unable to redefine their reality tend to experience anxiety, anger, depression, guilt, and shame [41].

Moreover, our findings add to the current literature by showing that adjustment to the caregiver role is not a one-time adjustment, but a continuing process also reflecting the changes happening in the caregiving context [42]. Indeed, our participants are at different stages in their lives and in their role as caregivers, and they use these coping strategies to face the practical as well as the existential challenges that arise over time.

The four strategies sketched in our findings can be better understood, and their potential for adjustment better evaluated, in light of previous work on coping with stressful situations [43], and on coping in caregiving. Following Hawken et al. [44], our participants mostly use problem-focused and cognitive strategies. The former is used to reduce the burden of care and gain a sense of control. Strategies to set limits to the caregiver role and seeking support belong to this type. The latter includes ways of reappraising the person-environment relationship to keep control over emotions and feelings, such as, in this case, strategies to reframe the caregiving experience and active acceptance. These types of coping strategies have shown to be associated with reduced psychological distress and positive outcomes, and to promote self-efficacy [44–46]. Moreover, problem-focused strategies seem to be a way to gain control over life. If, as reported in other studies [47,48], providing personal care often weakens the couple relationship, setting a limit to the caregiver role by deciding not to take on personal care, can be seen as a way to preserve the couple. Indeed, setting limits to the caregiver role could reduce the emotional strain, which was shown to be associated with higher relationship quality [49]. Similarly, as found by Dickson and colleagues, if caregivers whose life is defined only by caregiving, have an increased dissatisfaction in life [48], then setting a limit to the caregiver role and making space for other roles (e.g., in the professional life) can be seen as a way to preserve their own identity. Indeed, multiple roles can offer protection against the engulfment in the caregiver role and serve as an opportunity for recognition and positive feedback that can enhance self-identity [50]. Multiple roles could, however, also conflict with and negatively affect the caregiver's mental health, vitality and well-being, as shown by Fekete and colleagues [51].

Caregivers in our sample also use cognitive strategies, such as reappraising the caregiving experience or actively accepting the situation. The fact of downplaying their engagement in caregiving and highlighting the reciprocity in their relationship with the care recipient contributes to normalizing their situation and justifying why caregiving is acceptable in their eyes. This strategy is central, especially for couples, because the perception of a power imbalance in the couple due to the many tasks and responsibilities assumed by the caregiver can engender dissatisfaction and conflict [52]. In contrast, greater reciprocity is likely to contribute to well-being and mental health, as well as to satisfaction [53,54], also in caregivers of persons with SCI [49, 55,56]. Also, according to Nakamura and Orth [57], active acceptance is an adaptive strategy when people are confronted with unchangeable and uncontrollable situations, and it is positively related to indicators of mental health. Active acceptance is not characterized by resignation or hopelessness. As shown in our findings, despite the difficulties, the person acknowledges the situation, tries to find meaningfulness in it and still pursues life goals.

Our analysis also adds to the literature about coping strategies by providing an insight into the preconditions to the mobilization of these coping strategies. Indeed, our findings suggest that caregivers need, first, to gain awareness of their situation, of the requirements of the caregiver role and of their own resources. Besides these self-examination skills, in order to apply the problem-focused coping strategies, the caregivers also have to be able to voice their needs, negotiate solutions with the care recipient or identify the adequate interlocutor or source of support. The literature on caregivers' skills primarily focuses on those that caregivers need to perform their daily tasks and contribute to the management of the health condition (e.g., skills to assess and manage patient symptoms) [58–61], but do not involve the skills (e.g., self-examination) that they need to adopt these coping strategies.

The current study has some methodological limitations. It offers a screenshot of the coping strategies used by the caregivers, but it does not show if and how they have evolved over time. Moreover, this study aimed at identifying the coping strategies adopted by caregivers and not the impact that these strategies have on the caregiver burden. Further studies are needed to investigate the casual relationship. Longitudinal studies could monitor the evolution of the coping strategies, for instance examining if some are more used at the beginning and some others later on or in relation to specific life changes, and their impact on the caregiver burden. As pointed out by Kneebone and Martin [62], we need to know not only which strategy is useful in which situation, but also when.

Furthermore, regardless of their level of burden, all our interviewees have used more than one coping strategy in their life. Future studies could explore the experiences of caregivers who gave up their roles to better understand how to avoid this dropout.

Finally, considering that in our sample there are 15 life partners, a few parents and only one sibling and one child, we were unable to perform comparisons among groups, as we did not reach thematic saturation for all groups. Though not being representative of the caregiver population in SCI, the composition of our sample seems to mirror the composition of other study samples, in which most caregivers are spouses [63].

Conclusion

Caregivers of persons with SCI develop cognitive coping strategies in order to make sense of the situation and establish a "new

normal” as well as problem-focused coping strategies to deal with their tasks and role. These coping strategies do not seem to be typical only of caregivers in SCI. Hence, interventions that worked for caregivers in other fields can also be adapted to support caregivers in SCI.

The analysis highlighted that the use of these strategies is dependent on the caregivers’ ability to recognize their needs and voicing them. This suggests that programs targeted to caregivers should also include courses in their training to enhance, among other things, self-examination skills. More broadly, this means that the healthcare system needs to develop a partnership not only with the persons affected by the health condition, but also with their caregivers, and adopt preventive and educational measures for both of them. The empowerment of the caregivers follows a double pathway: caregivers have to learn how to perform caregiving tasks and how to balance between responding to the care recipient’s needs and their own needs. This will allow the caregiver to stay healthy and to take care of their loved ones in the long term.

Practice implications

We encourage the development of educational and support programs dedicated to caregivers aiming at developing not only knowledge and skills in relation to the health condition of the care recipient, but also knowledge and skills to take care of themselves. This is in line with current trends worldwide. Health organizations, such as the World Health Organization (WHO), the National Cancer Institute or the Mayo Clinic, as well as governments (e.g., in Switzerland [64]), are acknowledging the need to better support caregivers in preserving their health and well-being. For instance, the WHO released a manual for caregivers of people with dementia [65]. Although this manual is specific for dementia, it contains valuable inputs for training dedicated to any caregiver, such as a module that teaches self-care (e.g., reducing stress in everyday life, making time for pleasant activities).

Hence, interventions targeted to caregivers should, first of all, raise awareness of their limited resources and highlight the importance of self-care. A regular and structured needs assessment could help in this. Furthermore, an intervention could include the following components. First, the training of a problem-solving technique derived from cognitive-behavioral theory (for instance an intervention based on the Family COPE model), which have shown to increase overall quality of life and decrease the caregiver burden [58, 66]. A second important component would be training to teach caregivers to voice their needs and negotiate solutions with the care recipient [67]. Family, support group or peer-to-peer interventions could also be of value: they were linked to positive outcomes (e.g., reduced isolation and caregiver burden, increased quality of life) [68]. Additionally, social support was generally shown to be a major facilitator in caregiving [69] and to be related to better physical health [70]. Finally, interventions could target the relationship between caregiver and care recipient, as it was shown that the quality of the relationship influences both the perception of subjective caregiver burden and caregiver satisfaction [55].

With regards to the format and delivery method of the intervention, based on the results of a meta-analysis of RCTs testing interventions with family caregivers of cancer patients [71], the intervention should be delivered in face-to-face and only addressed to the caregivers. The intervention could include role-playing and simulations in order to practice the acquired skills in a real-life situation and receive personalized feedback [72]. Role-

playing and simulations are successfully used in the education of healthcare professionals, as they combine direct observation and coaching when responding to challenging situations [73]. Considering that caregivers are often homebound due to their role, the possibility of providing technology-based training should also be explored. Several systematic reviews revealed that available evidence is promising (e.g., acceptance among target population; positive outcomes such as enhanced self-efficacy or mastery, reduced caregiver burden or anxiety), but methodological shortcomings impede drawing firm conclusions [74–77]. Furthermore, as suggested by Montgomery and Kosloski [42], these programs should acknowledge the dynamic nature of the caregiver role as well as the diversity among the caregivers (both in terms of personal characteristics and of what they consider part of their role). Generally, rehabilitation centers and associations for persons with SCI should start to systematically integrate programs targeted to caregivers into their offerings and ensure that they regularly reach out to their target audience.

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References

- [1] Brown RM, Brown SL. Informal caregiving: a reappraisal of effects on caregivers. *Social Issues and Policy Review*. 2014; 8(1):74–102.
- [2] Caregiving in the US. AARP Public Policy Institute and National Alliance for Caregiving; 2015.
- [3] Zigante V. Informal care in Europe. Exploring formalisation, availability and quality. Luxembourg: Publications Office of the European Union; 2018.
- [4] Schweizerische Arbeitskräfteerhebung (SAKE): Modul Unbezahlte Arbeit Neuchâtel Swiss Federal Statistical Office; 2018.

- [5] Suzman R, Beard JR, Boerma T, et al. Health in an ageing world: what do we know? *The Lancet*. 2015;385(9967):484–486.
- [6] World Health Organization. Global action plan for the prevention and control of noncommunicable diseases 2013–2020. Geneva, Switzerland: WHO; 2013.
- [7] Bickenbach J, Biering-Sørensen F, Knott J, et al. Chapter 1: understanding spinal cord injury. In: Bickenbach J, et al. editors. *International perspectives on spinal cord injury*. Geneva: World Health Organization; 2013.
- [8] Brinkhof MW, Al-Khodairy A, Eriks-Hoogland I, et al. Health conditions in people with spinal cord injury: contemporary evidence from a population-based community survey in Switzerland. *J Rehabil Med*. 2016;48(2):197–209.
- [9] Sweis R, Biller J. Systemic Complications of Spinal Cord Injury. *Curr Neurol Neurosci Rep*. 2017;17(1):017–0715.
- [10] Sezer N, Akkuş S, Uğurlu FG. Chronic complications of spinal cord injury. *World J Orthop*. 2015;6(1):24–33.
- [11] Chang FH, Liu CH, Hung HP. An in-depth understanding of the impact of the environment on participation among people with spinal cord injury. *Disabil Rehabil*. 2018;40(18):2192–2199.
- [12] Chhabra H, Batra S. Spinal cord injury and its impact on the patient, family, and the society. *Int J Recent Surg Med Sci*. 2016;2(1):1–4.
- [13] Berglund E, Lytsy P, Westerling R. Health and wellbeing in informal caregivers and non-caregivers: a comparative cross-sectional study of the Swedish general population. *Health Qual Life Outcomes*. 2015;13(1):015–0309.
- [14] Australian Bureau of Statistics. Survey disability, ageing and carers, Australia: summary of findings. Canberra: Australian Bureau of Statistics; 2018.
- [15] Baker A, Barker S, Sampson A, et al. Caregiver outcomes and interventions: a systematic scoping review of the traumatic brain injury and spinal cord injury literature. *Clin Rehabil*. 2017;31(1):45–60.
- [16] Lynch J, Cahalan R. The impact of spinal cord injury on the quality of life of primary family caregivers: a literature review. *Spinal Cord*. 2017;55(11):964–978.
- [17] Maitan P, Frigerio S, Conti A, et al. The effect of the burden of caregiving for people with spinal cord injury (SCI): a cross-sectional study. *Ann Ist Super Sanita*. 2018;54(3):185–193.
- [18] Fekete C, Tough H, Siegrist J, et al. Health impact of objective burden, subjective burden and positive aspects of caregiving: an observational study among caregivers in Switzerland. *BMJ Open*. 2017;7(12):e017369–017369.
- [19] Morrison AK, Schapira MM, Gorelick MH, et al. Low caregiver health literacy is associated with higher pediatric emergency department use and nonurgent visits. *Acad Pediatr*. 2014;14(3):309–314.
- [20] Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. *Am J Nurs*. 2008;108(9 Suppl):23–27.
- [21] Li Q, Loke AY. The positive aspects of caregiving for cancer patients: a critical review of the literature and directions for future research. *Psychooncology*. 2013;22(11):2399–2407.
- [22] Haley WE, Levine EG, Brown SL, et al. Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychol Aging*. 1987;2(4):323–330.
- [23] Walshe C, Roberts D, Appleton L, et al. Coping well with advanced cancer: a serial qualitative interview study with patients and family carers. *PLoS One*. 2017;12(1):e0169071.
- [24] Navarta-Sanchez MV, Senosiain Garcia JM, Riverol M, et al. Factors influencing psychosocial adjustment and quality of life in Parkinson patients and informal caregivers. *Qual Life Res*. 2016;25(8):1959–1968.
- [25] APA Dictionary of Psychology (online edition). 2018. Coping strategy.
- [26] Post MW, Brinkhof MW, von Elm E, et al. Design of the Swiss Spinal Cord Injury Cohort Study. *Am J Phys Med Rehabil*. 2011;90(11 Suppl 2):S5–S16.
- [27] Brinkhof MW, Fekete C, Chamberlain JD, et al. Swiss national community survey on functioning after spinal cord injury: protocol, characteristics of participants and determinants of non-response. *J Rehabil Med*. 2016;48(2):120–130.
- [28] Lai D. Effect of financial costs on caregiving burden of family caregivers of older adults. *SAGE Open*. 2012;2(4):215824401247046.
- [29] Hu X, Dolansky MA, Zhang F, et al. Factors associated with the caregiver burden among family caregivers of patients with heart failure in southwest China. *Nurs Health Sci*. 2016;18(1):105–112.
- [30] Saunders MM. Factors associated with caregiver burden in heart failure family caregivers. *West J Nurs Res*. 2008;30(8):943–959.
- [31] Adelman RD, Tmanova LL, Delgado D, et al. Caregiver burden: a clinical review. *JAMA*. 2014;311(10):1052–1060.
- [32] Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant*. 2018;52(4):1893–1907.
- [33] World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. Adopted by the 52nd WMA General Assembly, Edinburgh, Scotland, October, 2000.
- [34] Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3(2):77–101.
- [35] Patton MQ. Enhancing the quality and credibility of qualitative analysis. *Health Serv Res*. 1999;34(5 Pt 2):1189–1208.
- [36] Johnson RB. Examining the validity structure of qualitative research. *Education*. 1997;118(2):282–292.
- [37] Creswell JW, Miller DL. Determining Validity in Qualitative Inquiry. *Theory into Practice*. 2000;39(3):124–130.
- [38] Dickson A, O'Brien G, Ward R, et al. Adjustment and coping in spousal caregivers following a traumatic spinal cord injury: an interpretative phenomenological analysis. *J Health Psychol*. 2012;17(2):247–257.
- [39] Jeyathevan G, Cameron JI, Craven BC, et al. Re-building relationships after a spinal cord injury: experiences of family caregivers and care recipients. *BMC Neurol*. 2019;19(1):117.
- [40] Lopez-Espuela F, Gonzalez-Gil T, Amarilla-Donoso J, et al. Critical points in the experience of spouse caregivers of patients who have suffered a stroke. A phenomenological interpretive study. *PLoS One*. 2018;13(4):e0195190.
- [41] Duggleby W, Tycholiz J, Holtslander L, et al. A metasynthesis study of family caregivers' transition experiences caring for community-dwelling persons with advanced cancer at the end of life. *Palliat Med*. 2017;31(7):602–616.
- [42] Montgomery R, Kosloski K. Caregiving as a process of changing identity: implications for caregiver support. *Generations*. 2009;33(1):47–52.
- [43] Lazarus R, Folkman S. Stress, appraisal, and coping. New York: Springer-Verlag; 1984.

- [44] Hawken T, Turner-Cobb J, Barnett J. Coping and adjustment in caregivers: a systematic review. *Health Psychol Open*. 2018;5(2):2055102918810659.
- [45] Boerner K, Mock SE. Impact of patient suffering on caregiver well-being: the case of amyotrophic lateral sclerosis patients and their caregivers. *Psychol Health Med*. 2012;17(4):457–466.
- [46] Cheshire A, Barlow JH, Powell LA. The psychosocial well-being of parents of children with cerebral palsy: a comparison study. *Disabil Rehabil*. 2010;32(20):1673–1677.
- [47] Sawatzky JE, Fowler-Kerry S. Impact of caregiving: listening to the voice of informal caregivers. *J Psychiatr Ment Health Nurs*. 2003;10(3):277–286.
- [48] Dickson A, O'Brien G, Ward R, et al. The impact of assuming the primary caregiver role following traumatic spinal cord injury: an interpretative phenomenological analysis of the spouse's experience. *Psychol Health*. 2010;25(9):1101–1120.
- [49] Tough H, Fekete C, Brinkhof MWG, et al. Vitality and mental health in disability: Associations with social relationships in persons with spinal cord injury and their partners [Research Support, Non-U S Gov't]. *Disabil Health J*. 2017;10(2):294–302.
- [50] Skaff MM, Pearlin LI. Caregiving: role engulfment and the loss of Self1. *The Gerontologist*. 1992;32(5):656–664.
- [51] Fekete C, Siegrist J, Tough H, et al. Work and family conflicts in employees with spinal cord injury and their caregiving partners. *Spinal Cord*. 2018;56(1):63–70.
- [52] Pereira HR, Rebelo Botelho MA. Sudden informal caregivers: the lived experience of informal caregivers after an unexpected event. *J Clin Nurs*. 2011;20(17–18):2448–2457.
- [53] Tanji H, Anderson KE, Gruber-Baldini AL, et al. Mutuality of the marital relationship in Parkinson's disease. *Mov Disord*. 2008;23(13):1843–1849.
- [54] Wright DL, Aquilino WS. Influence of emotional support exchange in marriage on caregiving Wives' burden and marital satisfaction. *Family Relations*. 1998;47(2):195–204.
- [55] Tough H, Brinkhof MW, Siegrist J, et al. Subjective caregiver burden and caregiver satisfaction: the role of partner relationship quality and reciprocity. *Arch Phys Med Rehabil*. 2017;98(10):2042–2051.
- [56] Siegrist J, Tough H, Brinkhof MWG, et al. Failed reciprocity in social exchange and wellbeing: Evidence from a longitudinal dyadic study in the disability setting. *Psychol Health*. 2019. DOI:10.1080/08870446.2019.1707826
- [57] Nakamura YM, Orth U. Acceptance as a coping reaction: adaptive or not? *Swiss J Psychol*. 2005;64(4):281–292.
- [58] McMillan SC, Small BJ, Weitzner M, et al. Impact of coping skills intervention with family caregivers of hospice patients with cancer. *Cancer*. 2006;106(1):214–222.
- [59] Given B, Sherwood PR, Given CW. What knowledge and skills do caregivers need? *Am J Nurs*. 2008;108(9 Suppl):28–34.
- [60] Porter LS, Keefe FJ, Garst J, et al. Caregiver-assisted coping skills training for lung cancer: results of a randomized clinical trial. *J Pain Symptom Manage*. 2011;41(1):1–13.
- [61] Schumacher KL, Stewart BJ, Archbold PG, et al. Family caregiving skill: development of the concept. *Res Nurs Health*. 2000;23(3):191–203.
- [62] Kneebone II, Martin PR. Coping and caregivers of people with dementia. *Br J Health Psychol*. 2003;8(Pt 1):1–17.
- [63] Robinson-Whelen S, Rintala DH. Informal care providers for veterans with SCI: who are they and how are they doing? *J Rehabil Res Dev*. 2003;40(6):511–516.
- [64] Federal Office of Public Health. 2019; [cited 2020 May 05]. Available from: <https://www.bag.admin.ch/bag/fr/home/strategie-und-politik/politische-auftraege-und-aktions-plaene/aktionsplan-pflegende-angehoerige.html>. In: 18.10.2019. editor. Plan d'action de soutien et de décharge en faveur des proches aidants
- [65] World Health Organization. 2019; [cited 2020 May 05]. Available from: https://www.who.int/mental_health/neurology/dementia/en/. In: 18.10.2019, editor. iSupport for dementia. Training and support manual for carers of people with dementia
- [66] Bahrami M, Farzi S. The effect of a supportive educational program based on COPE model on caring burden and quality of life in family caregivers of women with breast cancer. *Iran J Nurs Midwifery Res*. 2014;19(2):119–126.
- [67] Ripich DN, Zioli E, Fritsch T, et al. Training Alzheimer's Disease caregivers for successful communication. *Clinical Gerontologist*. 2000;21(1):37–56.
- [68] Dam AE, de Vugt ME, Klinkenberg IP, et al. A systematic review of social support interventions for caregivers of people with dementia: are they doing what they promise? *Maturitas*. 2016;85:117–130.
- [69] Joling KJ, Windle G, Drees RM, et al. What are the essential features of resilience for informal caregivers of people living with dementia? A Delphi consensus examination. *Aging Ment Health*. 2017;21(5):509–517.
- [70] Pinquart M, Sörensen S. Correlates of physical health of informal caregivers: a meta-analysis. *J Gerontol: Series B*. 2007;62(2):P126–P137.
- [71] Northouse LL, Katapodi MC, Song L, et al. Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA Cancer J Clin*. 2010;60(5):317–339.
- [72] Chiu M, Wesson V, Sadavoy J. Improving caregiving competence, stress coping, and mental well-being in informal dementia carers. *WJP*. 2013;3(3):65–73.
- [73] McNaughton N, Ravitz P, Wadell A, et al. Psychiatric education and simulation: a review of the literature. *Can J Psychiatry*. 2008;53(2):85–93.
- [74] Boots LMM, de Vugt ME, van Knippenberg RJM, et al. A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. *Int J Geriatr Psychiatry*. 2014;29(4):331–344.
- [75] Scott JL, Dawkins S, Quinn MG, et al. Caring for the carer: a systematic review of pure technology-based cognitive behavioral therapy (TB-CBT) interventions for dementia carers. *Aging Ment Health*. 2016;20(8):793–803.
- [76] Hopwood J, Walker N, McDonagh L, et al. Internet-based interventions aimed at supporting family caregivers of people with dementia: systematic review. *J Med Internet Res*. 2018; 2018/06/1220(6):e216.
- [77] Ploeg J, Ali MU, Markle-Reid M, et al. Caregiver-focused, web-based interventions: systematic review and meta-analysis (Part 2). *J Med Internet Res*. 2018;20(10):e11247.