

Chapter #3

INCEPTION OF AN INSTRUMENT ON HEALTH CAPABILITY OF FAMILY CAREGIVERS

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ABSTRACT

The health capability of family caregivers has already been studied through eight factors: physical and psychological functioning, lifestyle value, self-efficacy towards health services, family support, social capital, socio-economic conditions and access to health services. Our aim was to identify new factors. Family caregivers of stroke victims living at home were recruited in the Lorraine region (France; n=8) and Luxembourg (n=6). Semi-structured interviews about their health statuses, how they currently take care of their health, and the internal resources they need to achieve optimal health were conducted face-to-face. Verbatim transcriptions were open-coded and grouped into new factors of health capability. Items reflecting the main idea of the categories were formulated. Seven women and seven men (age 63.6±10.1) participated. Statements were regrouped together into new ways, giving rise to seven new emergent factors: health knowledge, health self-efficacy, health value, life skills, health decision-making, motivation, and attitude towards the future. Of them, 76 items were generated, 51 reflecting generic abilities while 26 being specific to family caregiving. Content analysis of these factors first allows guiding the preparation of innovative supports to promote health capability. Second, this list can serve as a basis to elaborate a guide to which clinicians can refer to, in orienting family caregivers according to their needs. Further research is needed to complete the validation of the HCFC instrument.

Keywords: health capability, family caregiving, stroke, qualitative approach.

1. BACKGROUND

Demographic changes (increased life expectancy), a declining economic outlook (increasing social inequality), and the current way of managing chronic diseases call for intergenerational solidarity and yet they act to undermine the health of family caregivers. As shown by two meta-analytic studies family caregivers have a higher risk of developing problems with their physical health, compared to non-caregivers (Vitaliano, Zhang, & Scanlan, 2003) and to suffer from stress and depression (Pinquart & Sörensen, 2003).

Health capability defines the capacity to achieve one's optimal health (Ruger, 2010b). Adapted from the capability approach (Nussbaum, 2011; Sen, 1992), the health capability paradigm aims to conceptualize a right to health. The approach assumes that it is the duty of the society, on the one hand, to create environments which are favorable for the health of the individual, and, on the other hand, to develop personal health-related skills. In this framework, a 'capable' person is able to make informed health choices. Health capability is a complex capacity which requires a set of simpler capabilities (Venkatapuram, 2011) such as those defined in Ruger's paradigm: having sufficient health-related knowledge, a health-oriented attitude, benefitting from social networks to help in everyday life, or living in a safe environment, and in a country where

health care systems are enabling (Ruger, 2010a). Despite the need to understand the capacities required to develop health capability among family caregivers who daily support relatives with chronic diseases (Bucki, 2014), little psychological research has based their works on this approach, to date.

Identifying the main factors of health capability and their content is also needed to help construct a measurement instrument relying on the capability approach. The strength of such an innovative instrument would be to enlarge the classical spectrum of analysis (quality of life, health-related quality of life) to aspects not directly related to health variables (Al-Janabi, Keeley, Mitchell, & Coast, 2013).

Based on the correspondence between this paradigm and the content of a national survey conducted among family caregivers in Luxembourg, eight factors of health capability have already been identified (Bucki, 2015): physical health, psychological functioning, lifestyle value, self-efficacy towards health services, family support, social capital, socio-economic conditions and access to health services. This first eight-factor model has been operationalized by 20 items (HCFC-8 factors) with satisfactory psychometric properties (Bucki, 2015). The analyses showed that the factors which impacted health capability the most, were physical functioning and lack of family support; i.e. fatigue and feeling abandoned by the family impeded health capability the most. The 8-factor model covers psychological, social, and environmental aspects. However, in reference to Ruger's internal dimensions of the paradigm, psychological aspects seem to be under-represented. A deeper knowledge is thus needed to understand what intrinsically contributes and impedes the health capability of family caregivers.

Operationalizing health capability in a unique instrument of measurement has also become a need to the development and applications in this field (Al-Janabi et al., 2013). The challenge is to make the instrument illustrate the large spectrum of concepts covered under "health capability", while taking into account the specifics of the family caregivers' lifestyles, yet not being too long for respondents.

2. METHODS

2.1. Study design, sample and recruitment

After being informed about the survey, family caregivers were invited to participate in a face-to-face interview at their homes:

- In the Lorraine region (France) –Family caregivers aged 45-80 years and caring for a stroke victim living at home for at least one year, were contacted by two local associations: '*France AVC Lorraine*' and the '*Ecole des Parents et Educateurs de Moselle*'.

- In Luxembourg - Family caregivers who participated in a national survey, four years earlier, about life two years after a stroke were recontacted. A preliminary verification of deaths having occurred among the stroke patients and family caregivers was made at the Luxembourgish death registry.

2.2. Procedure

Informed consent was obtained from family caregivers willing to participate. Semi-structured interviews were held between February and May 2013 at the homes of the participants. The interviews focused on their health statuses, how they take care of their health (including what helps/impedes a better agency), and the internal resources they would need to achieve their optimal health. Three researchers trained in qualitative methods

conducted the interviews, so that diverse individual sensitivities were represented, thus avoiding an interviewer-related bias. Interviews were recorded and transcribed.

2.3. Data analysis

Analysis was conducted with the help of Nvivo 8 software. In the first step, verbatim from the transcripts were open-coded and similar ideas grouped together to form categories related to the aim of the study. Verbatim were selected in accordance with the categories originally formulated in Ruger's paradigm. Verbatim which seemed not to belong to this generic classification, especially if related to specific experiences of family caregivers, were inserted into new categories. This method allowed developing a stepwise theoretical interpretation grounded in the collected data. In the second step, the content of the categories was refined and adjusted by two researchers, thus guaranteeing the quality criteria of reliability (Mays & Pope, 1995). The third step consisted of formulating items that would potentially be integrated into the new version of the HCFC instrument. To form the items, the most relevant and comprehensible statements emerging from the participants were selected within each identified factor and were validated by consensus with an expert group.

3. RESULTS

3.1. Socio-demographic profile of the participants

Seven women and seven men (age 63.6 ± 10.1) volunteered to participate. They cared for the stroke victims for an average of 7.3 years (± 2.9). Twelve were the partners of the stroke victims, one cared for her mother and another accompanied her daughter. While most were retired, three caregivers were employed at the time of the survey (table 1).

Table 1. Characteristics of the participating family caregivers.

	Country	Sex	Age	Relationship	Working	Time since stroke	Last position
A.01	Fr	F	64	Spouse	No	3 years, 6 months	Schoolteacher
A.02	Fr	F	61	Spouse	No	8 years	Housewife
A.03	Fr	M	66	Spouse	No	8 years, 4 months	Laboratory technician
A.04	Fr	F	80	Mother	No	4 years, 9 months	Typist
A.05	Fr	M	79	Partner	No	2 years, 4 months	Director
A.06	Fr	F	65	Spouse	No	9 years	Officer at the Post
A.07	Fr	M	67	Spouse	No	15 years	Paper delivery person
A.08	Fr	M	48	Spouse	Yes	6 years, 2 months	Foreman
A.09	Lux	F	64	Daughter	No	7 years, 8 months	Secretary
A.10	Lux	M	45	Spouse	Yes	7 years, 1 months	Teacher
A.11	Lux	F	70	Spouse	No	7 years, 9 months	Accountant
A.12	Lux	M	64	Spouse	No	7 years, 4 months	Mechanic
A.13	Lux	F	51	Spouse	Yes	7 years, 6 months	Sales assistant
A.14	Lux	M	66	Spouse	No	7 years, 3 months	Airline pilot

3.2. Analysis of the transcriptions

The following section details the categories identified by their items and illustrated by a selection of verbatim.

3.2.1. Health knowledge

Three items related to health knowledge emerged.

The first regrouped the causal relationships between behaviors or lifestyle and health. While several caregivers declared e.g. "*You cannot really influence your health, either you*

have it, or you do not" (A.06), others cited a varied range of physical, recreational activities and nutritional behaviors that help maintain their health.

Second, the causal attribution of symptoms like pain, sleeping problems and fatigue was mentioned by all the participants. Discourses ranged from "*I don't really know where my pain comes from*" (A.08) to "*anyway I am sometimes a little more tired than normal because [...] I must do eight hours*" (A.05), reflecting that some symptoms directly derive from being a caregiver.

Third, TV, journals and internet were described as the means to acquire health-related information and knowledge.

3.2.2. Self-efficacy and health-related skills

Self-efficacy has been mentioned as one of the contributors to achieving an optimal health status: "*What's important is that I feel capable of being in better health*" (A.10). Other skills comprise the implementation of healthy behaviors "*now I pay attention to what I eat, I am a very good cook*" (A.05), adapting installations in the house in order to be relieved, and the ability to adopt protecting behaviors: "*By car, I was a little...I loved to drive very fast, very... I calmed down [...] telling me I have no right to accident*" (A.01).

3.2.3. Health value

The value of health emerged as an essential part of health capability in two ways.

The first was general, as mentioned by A.01: "*I attach great value to health*" or conversely by A.04: "*I am not concerned about my health*".

Second, according to some participants, the value placed on health was directly influenced by becoming a caregiver. Either health became more important: "*now I have to take care of her so I am more careful*" (A.03), either less of a priority: "*I should now go to the physio for a problem of sciatica etc. As my husband goes to the hospital every morning, I realize that my back problems are not the priority*" (A.01).

3.2.4. Life skills

The participants mentioned a set of skills to manage everyday life.

The ability to manage personal situations is put to the test, as shown by the following statements: "*Friends who drifted away after the stroke, I threw them out*" (A.05), "*I feel torn between him and others*" (A.06).

The aptitude to call for someone to solve problems or for relief from the caregiving role was considered as beneficial to maintain their health: "*Given my health, I asked a nurse to come for his personal hygiene*" (A.01) or conversely "*I won't bother anyone*" (A.06).

The aptitude to get arrangements from health services was expressed in statements which reflected their capacity to express their needs: "*Sometimes it was necessary to grumble for information*" (A.05) or "*I am the one who asked to place her in a nursing home because it was becoming more difficult [...] and after 10 years, I could not make her stand anymore*" (A.09).

The capacity to express their needs and limits to the relatives for whom they were caring was also cited by the caregivers as facilitating: "*He knows that on Thursday mornings, don't ask me anything!*" (A.01) and is also well illustrated by the following statement from A.06: "*it was already a habit not showing when I am sick, unless I'm lying on the ground*".

Finally, three coping strategies were mentioned for attempting to cope with the situation: denial, as shown by the following statement "*It's been more than ten years or*

fifteen years, anyway I always ignored that and that's all, it does not exist" (A.05). Others illustrated their acceptance of the situation as *"I say to myself, it is like that, some will experience it earlier, some later, it is like that"* although A.07 stated the contrary: *"I have never accepted my wife's disease"*. Finally, some caregivers tried to put things into perspective by reinterpreting their situation positively: *"it is not something that has been proposed to us and we think it could have been worse"* (A.06) or *"other relatives have more important health problems"* (A.13).

3.2.5. Health decision-making

This domain regroups the aptitude to identify health problems and to pursue an efficient prevention or treatment. This pattern was especially emphasized when speaking about doctor consultations. *"I go to see my doctor every three months"* (A.04; A.05) or on the contrary: *"I go to see my doctor when it goes wrong. I don't go for prevention"* (A.13).

Other contexts of decision-making were cited, as the prevention of back pain (*"I have serious back problems so I try to go slowly. Gardening, not more than one hour at a time"*; A.06), trying to eat better (*"I eat less, I hardly drink anything"*; A.10), taking medicines for prevention (*"if I stay here, I don't necessarily take my painkiller but if I go to my daughter for example twice a week, I always take it before leaving"*; A.04), and deciding to do activities outside the caregiving role. These activities mainly consist of walks, physical activities and yoga, but it can sometimes also consist of activities like: *"At the moment, I avoid a little bit [about visiting her mother] because [...] I want to protect myself"* (A.02).

3.2.6. Motivation

Two types of motivation emerged from the analyses: the motivation to maintain health and the motivation to be a caregiver.

The sources of motivations to maintain health were diverse: material reasons (*"I earn the most money so it is not very romantic, but be it only for money, it is very important that I am in very good health"*; A.05), extrinsic motivation (*"my daughters, they say 'don't force mom, stop, we need you to stay healthy'"*; A.06) or the responsibility of being a caregiver (*"in those moments, his presence allows me not to let go, because I have to act for me and for him"*; A.06). Some caregivers were motivated by the desire to be here for their grandchildren: *"I want to see my grandchildren grow up [...] to often see them, play with them, all that, it motivates me and it gives me strength"* (A.06) and others were just intrinsically motivated *"it has to be your own choice. It's like you don't stop smoking because somebody tells you to. You stop smoking because you want it yourself"* (A.14).

The motivation to be a caregiver was particularly present among French participants with statements like *"I was advised not to visit him every day, but if I don't I just feel guilty"* (A.02). The reasons to care ranged from internal reasons like the *"need to see"* (A.02) the relative or love *"This is all about love. I think if I did not care about my wife, I would have gone"* (A.07) to a perception of the duty to care *"I'm not separated from my wife because I got engaged, I must hold on"* (A.07).

3.2.7. Attitude towards the future

Two types of attitudes towards the future were expressed: perspectives about health, and perspectives about one's personal life. Health perspectives were, on the one hand, optimistic. Some caregivers said they felt *"positive"* (A.06) or, as A.10 about reaching his optimal health, *"I think it is still feasible and I'm sure next year will be close"*. And on the other hand, some caregivers felt concerned about the recurrence of a disease that had already occurred in the past, such as depression or cancer.

Regarding the perspectives about their personal life, caregivers explained they make efforts to think about the present rather than worrying about the future “*I decided that I won’t ever worry about olden days*” (A.01). Whether optimistic or pessimistic about their future life, they feel that the most important for the future would be that the situation stabilizes: “*that’s all I’m asking for, that it won’t get worse*” (A.06). Anxiety is present for some respondents, as A.09 who said “*Now it’s over, I have had enough [...] an anguish of the future*”. Finally, some envision the future with projects, but this view is tempered by the constraints associated with the state of the stroke patient such as new habits to take, or lack of time: “*we have projects, but what we need is time*” (A.10).

3.3. Item generation

In total, 76 items were generated (table 2); of them, 51 reflect generic abilities and 26 are specific to family caregivers.

Table 2. List of 76 potential items completing the instrument of Health Capability of Family Caregivers.

Health knowledge
<i>Causal relationships between behaviors / lifestyle and health status</i>
1. One cannot really influence one’s own health. 2. According to me, physical activity really contributes to good health. 3. According to me, eating well really contributes to good health. 4. Going on holiday is good for my health.
<i>Causal attribution of fatigue, pain, and sleep disorders</i>
5. I do not really know where my pain comes from. 6. I do not really know where my sleep problems come from. 7. I do not really know where my weight problems come from. 8. Some symptoms (fatigue, pain) come directly from the fact that I am a family caregiver.
<i>Means of acquiring health-related information and knowledge</i>
9. When I need information, I sometimes go and look on my computer. 10. I regularly read articles / books on health. 11. I made material changes at home by adapting what is done in institutions. 12. I usually read the package leaflets.
Health-related beliefs, skills, and self-efficacy
13. I feel able to be more physically fit. 14. Since I am a family caregiver, I developed new behaviors to protect my health. 15. To keep me healthy, I take the example of people I admire. 16. I do not feel so necessary for my (sick / invalid /) relative. 17. I inherited my temperament from my parents. 18. I feel strong enough to be a family caregiver. 19. I sometimes exaggerate when I make efforts for my health. 20. Since I became a family caregiver, I have acquired skills which I try to keep.
Health value and health goals
<i>Value of health and healthy behaviors</i>
21. I attach great value to my health. 22. I am not concerned about my health.
<i>Value of health conditioned by the caregiving role</i>
23. As all depends on me, I pay more attention to my health since I became a family caregiver. 24. Since I am a family caregiver, my health comes second to others. 25. Since I am a family caregiver, I do not have time to take care of my health.

Table 2. List of 76 potential items completing the instrument of Health Capability of Family Caregivers. (cont.)

Motivation
<i>Motivation to maintain health</i>
58. Being able to work in order to support us motivates me to be healthy.
59. Not being sick is enough of a reason to motivate me to stay healthy.
60. Seeing my grandchildren grow up and taking care of them motivates me to stay healthy.
61. I need to be healthy to take care of my relative; it motivates me to stay healthy.
62. No one else could (can?) take care of him/her, I must stay healthy.
63. I do not feel especially motivated to take care of my health.
<i>Motivations to care</i>
64. I would feel like I abandoned him/her if I did not take care of him/her – I would feel guilty.
65. I need his/her presence.
66. Taking care of him/her is a duty.
67. I take care of him/her because I love him/her.
68. I want him/her to have the most enjoyable life.
69. I do not want to disappoint him/her.
Expectations, perspectives, attitudes towards the future
<i>Health perspectives</i>
70. When I imagine my health status in one year, I am positive.
71. I am afraid of the recurrence of a disease (depression, cancer...).
<i>Personal life perspectives</i>
72. I try to live in the present, and not to think about the future.
73. All I am asking for is that my life does not get worse.
74. Even if I do not really believe it will, I hope the future will be better.
75. I fear the occurrence of a new problem.
76. We are positive people, we have projects.

4. DISCUSSION

Seven new factors of health capability have emerged: health knowledge, health self-efficacy, health value, life skills, health decision-making, motivation, and attitude towards the future. The aim of this exploratory study was to complete the first eight-factor model of health capability of family caregivers (HCFC) with new facets based on internal skills. Together, the HCFC completed model contains 15 factors which take into account psychological as well as social and environmental aspects.

Stroke was an event that forced family caregivers to test how they cope with situations. Some refer to leisure activities; others appeal to their social networks or use their ability to express their needs to the victims.

Most motivations to maintain own health were intrinsic; this finding is encouraging since the studies based on self-determination theory (Ryan & Deci, 2000) show that self-determined motivation promotes the adoption of healthy behaviors. However, an ambivalence towards the value accorded to health persists. Indeed, on the one hand, health is not the family caregivers' priority anymore since they have to care for their relative's well-being. But on the other hand, they feel a duty to stay in good health in order to fulfill their caregiving role, and thus preserve themselves. Motivational interviews (Miller & Rollnick, 2012) may help to clarify this ambivalence so that they can act according to the actual place of health in their lives. Besides, most motivations to keep caring refer to a sense of duty. This finding confirms the influence of the altruistic norm of

our societies (Schwartz, 1977) that may impede their capability of making the informed choice to be and remain a family caregiver, as they are partly guided by this caregiving norm.

The participants evoked in detail, the preventive behaviors they adopt for themselves, which represents the health decision-making category. However, literature about health decision-making among family caregivers mostly analyses the decision-making process occurring during transitional phases such as a relative's institutional placement (Mamier & Winslow, 2014; Ducharme, Couture & Lamontagne, 2012) or end of life (Edwards, Olson, Koop, & Northcott, 2012). Our finding reinforces the need to enlarge research to health decision-making that allows focus to be placed on how family caregivers make decisions about their own health while caring for someone else

The study revealed that self-efficacy towards health was a contributor of health capability. Among family caregivers, self-efficacy is shown to guard against the perception of burden (Gonyea O'Connor, Carruth, & Boyle, 2005), and to promote psychological well-being and vitality (van den Heuvel, de Witte, Schure, Sanderman, & Meyboom-de Jong, 2001). Thus, actions promoting health capability could contain modules on self-efficacy reinforcement.

Our findings highlight the necessity to implement interventions that will help family caregivers develop diverse aspects of their health capability. For example, improving their knowledge of the causal relationships between lifestyle or behaviors and health status can influence their decision-making process. Increasing their intrinsic motivations to maintain health can improve their health value. Since our sample size was limited and did not reach saturation, a second wave of interviews will be conducted to complete and adjust the content of the list.

To date, 76 potential additional items reflecting seven new factors have been selected (Bucki, 2015). Among them, 51 reflect generic capacities such as the ability to cope with personal situations, health perspectives, knowledge about causal effects between behavior/lifestyle and health, and motivation to maintain one's health; and 26 refer to aspects directly related to caregiving conditions such as the motivation to care and the ability to seek help or relief from caregiving tasks. In order to strengthen the conceptualization of health capability of family caregivers, it would be beneficial that this study be made by more research teams.

5. FUTURE RESEARCH DIRECTIONS

Together, the model of HCFC contains 15 factors (8 previously identified + 7 new potential factors). The relevance of each new factor will be verified: Modes of response will be selected for the 76 newly created items. The complete list (76 new items + 20 first formulated) will be administered to a new and independent sample of family caregivers. A procedure of item reduction (Goetz et al., 2013) will be conducted, combining content validity and psychometric properties. This will allow the adaption of a more complete (exhaustive / inclusive) model and to operationalize HCFC in a final validated measurement instrument. . Afterward, the relationships between the different factors of the completed model of HCFC will be determined.

The HCFC instrument would have several topical utilities. First, it would guide the preparation for innovative support systems to promote health capability, and second, could serve as a basis to elaborate a guide which clinicians can use to orient family caregivers according to their health capability needs. Finally, it can be used among other indicators to assess the efficacy of complex health interventions.

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