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Conceptualizing patient empowerment in cancer follow-up by combining theory and qualitative data

Anna Thit Johnsen^{a,b}, Nanna Bjerg Eskildsen^a, Thora Grothe Thomsen^{c,d}, Mogens Grønvold^{b,e}, Lone Ross^b and Clara R. Jørgensen^f

^aDepartment of Psychology, University of Southern Denmark, Odense, Denmark; ^bDepartment of Palliative Medicine, Bispebjerg Hospital, Copenhagen, Denmark; ^cZealand University Hospital, Roskilde, Denmark; ^dInstitute of Regional Health Research, University of Southern Denmark, Odense, Denmark; ^eDepartment of Public Health, University of Copenhagen, Copenhagen, Denmark; ^fWarwick Medical School, University of Warwick, Coventry, UK

ABSTRACT

Background: Patient empowerment (PE) may be defined as the opportunity for patients to master issues important to their own health. The aim of this study was to conceptualize PE and how the concept manifests itself for cancer patients attending follow-up, in order to develop a relevant and sensitive questionnaire for this population.

Material and methods: A theoretical model of PE was made, based on Zimmerman's theory of psychological empowerment. Patients who were in follow-up after first line treatment for their cancer ($n = 16$) were interviewed about their experiences with follow-up. A deductive thematic analysis was conducted to contextualize the theory and find concrete manifestations of empowerment. Data were analyzed to find situations that expressed empowerment or lack of empowerment. We then analyzed what abilities these situations called for and we further analyzed how these abilities fitted Zimmerman's theory.

Results: In all, 16 patients from two different hospitals participated in the interviews. PE in cancer follow-up was conceptualized as: (1) the perception that one had the possibility of mastering treatment and care (e.g. the possibility of 'saying no' to treatment and getting in contact with health care when needed); (2) having knowledge and skills regarding, for example treatment, care, plan of treatment and care, normal reactions and late effects, although knowledge and information was not always considered positively; and (3) being able to make the health care system address one's concerns and needs and, for some patients, also being able to monitor one's treatment, tests and care.

Conclusion: We conceptualized PE based on Zimmerman's theory and empirical data to contextualize the concept in cancer follow-up. When developing a patient reported outcome measure measuring PE for this group of patients, one needs to be attentive to differences in wishes regarding mastery.

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The concept of patient empowerment (PE) can be defined in several ways [1,2], but a useful initial definition is that patients have the possibility of mastering what is important to them in relation to their health and health care [3,4].

PE has recently gained increasing attention [5–7] and is viewed as important from several perspectives. From one perspective, empowerment is a social right and all people, regardless of who they are, should be supported in gaining power and mastery of their own lives [8,9]. From another perspective, it is argued that PE potentially adds to the patients' quality of life and welfare [4,10]. From a third perspective, PE is viewed as necessary, because of the limited resources in the healthcare system which requires that patients take on more responsibility [10,11], and might become part of a political agenda trying to limit the expanding costs of the health care system [12]. Hence, there are several reasons to focus on the empowerment of patients. However, one needs to be careful when

introducing PE in the health care system as attempts to strengthen PE may also give patients (too much) responsibility [5], favor those with many resources [13] and may not be equally relevant in all contexts [3].

Recently, empowerment and empowerment-related themes, such as patient activation, enablement and involvement, have also been brought into focus in cancer follow-up [10,11,14,15]. In this paper, cancer patients in follow-up are defined as patients who have been through their initial cancer treatment and live with or beyond their illness, but who are regularly followed by the health care system in order to monitor the disease, potential relapse and/or late effects [16]. In Denmark, new follow-up programs were recently introduced, with the explicit aim of making patients more involved in their care plans [16,17].

In order to evaluate the effects of these new follow-up programs for PE and other interventions aimed at increasing

CONTACT Anna Thit Johnsen  atjohnsen@health.sdu.dk  Department of Psychology, University of Southern Denmark, Campusvej 55, 5230 Odense M, Denmark

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PE, a suitable questionnaire for measuring PE as an outcome was required. As empowerment is likely to be context-dependent [1,3] and no patient reported outcomes measures (PROM) have been developed for patients in cancer follow-up [18], a mixed-method study (Empowerment Study) was developed in order to construct a questionnaire. The aim of the present paper is: (1) to present findings from the semi-structured interviews; and (2) to use these and Zimmerman's [3] theoretical model to conceptualize PE, in order to develop a questionnaire that would be relevant and sensitive to cancer patients in follow-up.

Method

Combining theory and data in questionnaire development

Questionnaire development will often use a 'top-down' approach where a theoretical concept is operationalized based on theory [19]. However, the theories of empowerment are quite abstract and can be operationalized in different ways [1,2,4]. To inform the development of the questionnaire and make sure that it was relevant to the target population, we therefore included interviews to contextualize the concept.

Theoretical model of empowerment

To guide our conceptualization of empowerment, Zimmerman's theory of psychological empowerment was chosen [3]. This theory was chosen because it is a comprehensive and well known theory within the field [20] and describes empowerment at a psychological and individual outcome relevant for a questionnaire [1,20]. Furthermore, Zimmerman's definition makes the distinction between empowerment as an outcome and as a process – a distinction that is relevant for the purpose of developing a questionnaire. A questionnaire can measure both – but for our purpose, and as stated in the Introduction, we were interested in empowerment as an outcome. Finally, he describes a 'nomological network' of PE [3], which lends itself to the development of a questionnaire. Zimmerman's theory thus seemed both sensible and relevant. For a review of the context in which Zimmerman developed his theory, see [21].

According to Zimmerman, psychological empowerment is the process by which people gain mastery over issues of concern to them and the outcome is having mastery and or control of these processes [3]. The concepts 'control' or 'mastery' are often central in the definition of empowerment [8,9]. Empowered outcomes are context-specific [3]. However, he makes a model of empowerment that contains three components which are needed in order to become empowered: (1) the intrapersonal component, which is the individuals' perception of their possibility of and motivation for having mastery and is a component that includes self-efficacy and perceived control; (2) the interactional component, which is having adequate relevant skills and knowledge to navigate in the system; and (3) the behavioral component, which is about actions taken to master or influence specific outcomes.

Analysis: linking theory and data

For the Empowerment Study, we wanted to develop a questionnaire that was conceptualized according to Zimmerman's theory. The analysis may be labeled a deductive thematic analysis [22]. First, we analyzed the data to find situations that expressed empowerment or lack of empowerment according to Zimmerman's definition. We then analyzed these situations to explore what abilities they called for and what self-conceptions, motivations and behaviors were relevant. Finally, we analyzed how the data fitted into the three categories of Zimmerman's theory (the intrapersonal, interactional and behavioral components – see the section on theory), carefully paying attention to – and describing – the examples that did not fit the theory [22,23].

Patients and interviews

Sixteen patients were recruited from five different departments (two departments of oncology, one department of surgery, one of urology and one of hematology) at two hospitals (Zealand University Hospital and Copenhagen University Hospital). We used strategic sampling to ensure a diverse population according to age, gender, severity of disease, duration of follow-up and socioeconomic status. Two patients were interviewed twice because we did not have a co-researcher present at the first interview (see below) and we wanted to have co-researchers present at as many interviews as possible. Characteristics of the included patients can be seen in Table 1. The patients were all in follow-up after first line treatment for their cancer, time since diagnosis varied from 6 months to 16 years, ages were between 42 and 88, 10 of the patients had been treated with curative intent and six had incurable cancer.

Interviews took place wherever the patients preferred. Patients had been informed about the purpose of the interview by the first author beforehand and signed a consent form. We used a semi-structured interview guide (see Table 2) that started with broader questions, such as 'Tell us about when you got cancer' and ended with more focused questions, such as 'Tell us about an incidence when you felt you were involved in a decision about your cancer care'. All interviews were transcribed verbatim.

The study was approved by the Danish Data Protection Agency (University of Southern Denmark 15/94453) and it was submitted to The National Committee on Health Research Ethics, who judged that it did not need ethical approval (journal no. H-15000936). It took place from April 2015 to March 2016.

Co-researchers

Nine patients or former patients were involved as co-researchers in the study, acting as representatives of Patient and Public Involvement (PPI). They were involved: (1) in the discussions of the concept and the conceptualization; (2) gave feedback on the interview guide; and (3) participated in carrying out the interviews (always with the first author). As the process and outcomes of PPI is not the focus

of this paper, it is beyond its scope to report all aspects of relevance to the PPI process and outcomes [24] and these will be reported elsewhere.

Results

Analysis of the manifestations of empowerment in cancer follow-up

The content categories of the analysis can be seen in Tables 3 and 4.

Zimmerman's component 1: the perception of and motivation for having mastery and influence

Zimmerman's component 1 consists of one's perception of being capable of having mastery (self-efficacy) and having the ability to influence a situation (perceived control). In addition, this component encompasses motivation. Without the perception that one has the capability to have mastery and without the motivation, no empowerment will take place.

Table 1. Participating patients (n = 16).

Age, years (mean, range)	63 (42–88)
Time since diagnosis, years (mean, range)	4 (0.5–16)
	n (%)
Sex	
Male	9 (56)
Female	7 (44)
Diagnosis	
Breast	3 (19)
Gastrointestinal	5 (31)
Prostate/bladder	3 (19)
Gynecological	1 (6)
Hematological	4 (25)
Primary treatment	
Curative intent	10 (63)
Not curative intent	6 (38)
Occupation	
Retired	10 (63)
In job	6 (38)
Education	
None	2 (13)
Short education/worker	6 (38)
Theoretical education	8 (50)
Marital status	
Married	12 (75)
Single/widowed	4 (25)
Living situation	
Larger city	9 (56)
Countryside	7 (44)

Many patients expressed the importance of having the possibility to have mastery or influence in relation to their health, care and treatment. For example, one woman said: 'The physician needs to be there to help me because he is the expert. But I need to have influence on my life' (Female, 42–59 years). The possibility of mastery and influence manifested itself as the importance of knowing that they had the possibility of saying 'No' to treatment, that one could always contact the health care providers and ask questions, and that one had the possibility of being involved if one wanted to (Table 3, Rows 1, 2 and 3).

The experience that one had the possibility of being involved was most often enabled by the healthcare providers. Patients felt they had the possibility if the health care providers took time with them, listened to their questions and followed up on their concerns, and so forth (Table 3, Rows 1, 2 and 3).

However, it is important to note that some patients felt that in general they had mastery of their lives, without feeling the above. An example of this was the following where a man feels that he has mastery of his life – except when in contact with the hospital system: Interviewer: 'You feel that you have always been able to say what you mean and wanted?' Patient: 'Yes, I have.' Interviewer: 'Also in the conversations you have had with the health care professionals?' Patient: 'No, actually not. That is not how these conversations went at all. They were actually very short conversations ...' (Male, 60–88 years). This means that some patients might be generally empowered, even though they did not feel that they had mastered their health, treatment and care. A questionnaire needs to take this into account.

As stated, most patients wanted the possibility of having a say in relation to treatment and care. Some patients also wanted the health care staff to motivate them to do something (Table 4, Row 4). However, many did not want to engage in empowered behaviors, as will be described below under Zimmerman's component 3.

Some patients had a motivation for mastery, but because it was not made possible by the health care providers, they did not achieve it and gave up. For example, a man said: 'I have asked about the plan, but then they look into the computer and say, "Well, there is no plan"' (Male, 60–88 years). Others did not feel they needed motivation, because the

Table 2. Semi-structured interview guide.

Theme	Sample questions
Patient background	How old are you? How is your family situation? Do you work?
History of cancer	Tell us about when you got cancer. Are you receiving treatment? Where do you consider yourself to be in the disease trajectory?
Life with follow-up	We would like to know some more about being followed up by the health care system. How does this affect your life? Do you often think about being in follow-up? What is important for you when being followed up by the health care system?
Having control	How does having cancer affect your feelings of having control in your life? How is this affected by being in follow-up? What is important for you in order to feel that you have control of your life? Is it important to have control? Have you been involved in any decisions regarding treatment or care during your time with cancer? In follow-up?
Empowerment	What do you think of the concept of empowerment? Can you tell us about a situation where you felt empowered? What was it like? Can you tell us about an incidence where you felt that you were involved in your cancer care?
Strength	Is there something from outside the health care system that helps you being in control of your life?
Last follow-up meeting	Will you tell me in detail about your last follow-up visit? Did you prepare for the conversation? What did you hope to get out of the consultation? What happened in the consultation? Did you ask the questions you wanted to ask? Did you get the information you needed?

Table 3. Manifestations of the empowerment model in the qualitative interviews (n = 16).

Component	Row #	Manifestations	Quotes from interviews
Zimmerman's component 1: Efficacy, perceived control and motivation	1	Knowing that one has the possibility of saying 'no' to treatment	Patient: 'I think that if I had just been told to take anti-hormone treatment without having the possibility of saying "no" then I would have had more questions (...). Because I become unsure about whether it is the right decision if I am just told without having anything to say' (Female, 42–59 years)
	2	Always being able to ask the health care professionals	Interviewee: 'Would you have liked to have more influence?' Patient: 'But I feel that I have had influence. I can always call and ask questions' (Female, 60–88 years)
	3	That the health care providers talk to you about treatment and care	Patient: 'I have a need to be involved in everything ... but the doctor also gives me this opportunity because he talks with me about everything. That is nice' (Female, 42–59 years)
	4	Wish to be motivated	Patient: 'Individualizing the information and consultation – I actually think there could be some possibilities (...).' Interviewee: 'I get curious, what would this individualized information do for you?' Patient: 'It would be motivating of course ...' (Male, 60–88 years)
Zimmerman's component 2: Knowledge and skills	5	Knowing the plan of follow-up, one's disease trajectory, typical side effects and late effects, and pros and cons of treatment	Patient: 'It is something I could not anticipate (...) but if they [the health care staff] said: Listen it will be wise of you to start seeing a psychologist – because then you have already begun to see the psychologist if something bad happens and you need it' (Male, 42–59 years)
	6	Knowing when and how to contact the health care system	Husband to a patient: 'I think it is strange that one is moved from one hospital to another (...)' Interviewer: 'Why did you go to that hospital?' Patient: 'I do not know (...). The doctor also said: What were you doing at that hospital?' (Female, 60–88 years)
	7	Having relevant skills for self-care	Patient: 'I had so much pain and I called the nurse (...) Do you know what she said to me? She said, "Why did you not empty the bag [catheter bag]?" I was speechless (...) How should I know? If they had told me I would have emptied it' (Female, 60–88 years)
Zimmerman's component 3: Empowered behaviors	8	Influence the timing of information and the contacts with the health care system	Patient: 'Fortunately I was so clever that I told the doctor, "I need you to come back and tell it once again when my husband arrives" because I could not take in all the information' (Female, 42–59 years)
	9	Ask questions and contact the hospital system when in need	See Results section
	10	Seeking additional information	Patient: 'I have tried to learn as much as possible about the disease in order to be able to ask relevant questions' (Male, 60–88 years)
	11	Monitoring one's treatment	Patient: 'It was not until later that I realized that (...) sometimes you have to take responsibility because sometimes they have forgotten something' (Male, 42–59 years)
	12	Influencing levels of self-care	Patient: 'They were talking about sending me home on Tuesday. I still had a catheter (...). I was not ready for it. Then she said, "What about Thursday instead?" That was an immense relief' (Male, 42–59 years)
	13	Do what one can at home to remain as strong and healthy as possible	'When I got the disease I decided immediately that I wanted to do as much physical activity as possible. I was also aware of what I could do with my diet' (Male, 60–88 years)

health care staff made sure that they were involved (Table 4, Row 8). Thus, motivation alone did not explain the level of achieved mastery.

Finally, some patients had very little empowerment related to health, care and treatment, but were content that way. Thus, there was not always a direct link between empowerment and satisfaction.

Zimmerman's component 2: knowledge and skills necessary for empowerment

According to Zimmerman's model, one needs to have knowledge and skills to be empowered because this is required in order to navigate the system and exert one's influence. They need to be aware of their options and have skills to acquire and use different resources.

Table 4. Challenges of the empowerment model in cancer follow-up.

Row #	Challenges	Quotes from interviews
1	Patients may feel very much in control of their lives without perceived control of follow-up	See Results section
2	Patients may be completely happy without having knowledge and influence	See Results section
3	Knowledge may not always be seen as positive	Patient: 'And while he was sitting here alone (...) he [her husband] read all the information material and it was not only about my disease (...) so he was completely devastated when I got home (...). He should not have read that material' (Female, 42–59 years)
4	Having influence on health care may be seen as a burden	Patient: 'After that experience, when I saw my oncologist again, I told him (...), "Good, will you be kind and write that in bold letters on the cover of my medical chart, that I need it, <i>because I use a lot of energy on this</i> "' (Female, 42–59 years)
5	Patients often do not see possibilities of empowered behaviors	Patient: 'In my situation there has only been one way to go' (Male, 60–88 years)
6	Patients often do not feel competent of having influence/mastery	Interviewer: 'Are you happy that the doctor takes the decision about when to see you next time?' Patient: 'Yes, because she is the one who knows something about this. I am just a mechanic' (Male, 60–88 years)
7	It may not be possible for the health care staff to enable 'empowerment'	Interviewer: 'What would make you less likely to accept authority?' Husband to patient: '(...). I do not think there is anything to do about people who are old like us' (Female, 60–88 years)
8	Some patients do not need motivation to be empowered	Patient: 'They have been good at giving me information and telling me what to expect and things like that. This is important, it makes you feel safe' (Male, 60–88 years)

Knowledge was mentioned repeatedly by the patients as being necessary to achieve control. Especially crucial was knowledge about one's plan for treatment and care and what to expect regarding complications and/or late effects. Not having an idea about this made it very difficult for patients to navigate in the health care system (Table 3, Row 5). It was also important for the patients to know where they were being treated or cared for and why (Table 3, Row 6). However, many patients talked about not being aware of any options regarding treatment and care – and this did not seem to disempower them (see next section about Zimmerman's component 3).

Having adequate knowledge was again mostly facilitated by the health care staff. Several patients talked about being happy about a booklet containing information, including information about how to navigate in the system.

Not all patients wanted to have as much knowledge as possible. Some patients were happy without it, because they trusted their health care providers to take care of them (Table 4, Row 2). Some found it too difficult to obtain relevant knowledge. And some did not want (too much) information because it made them worry (Table 4, Row 3). A questionnaire thus needs to take these varying levels of desired knowledge into account.

Several patients also talked about the importance of having the skills required for self-care. For example, they needed skills related to having a catheter or injecting themselves. For these patients, not having these skills led to a great loss of control (Table 3, Row 7). Others, however, did not want to have the skills needed for self-care, because they did not actually wish to carry out those elements of self-care.

Another skill mentioned in the interviews as being important in order to influence one's health was to trust and listen to one's body and to do things that one believed would be positive for one's body. (Table 3, Row 13).

Zimmerman's component 3: empowered behaviors

Empowered behaviors are actions taken to influence outcomes. To have empowerment, the interviewees considered it important to be able to make the health care providers attentive to their needs and concerns. For example, it was important to be able to influence the timing of information (Table 2, Row 8) and the level of self-care one had to do (Table 3, Row 12). It was also important for empowerment that patients were capable of asking questions and were allowed to do so. The opposite led to a lack of possibilities, as stated by this woman: 'When I have left the consultation I have sometimes thought, "Well, this did not make me any wiser" ... But one had the feeling that the consultation was over. And I am not good at asking questions' (Female, 60–88 years).

It was also important to several patients to seek information at home, in order to be prepared and able to ask questions (Table 3, Row 10). For some patients it was important to engage in behaviors at home with the aim of staying healthy, such as physical exercise (Table 3, Row 13). A few patients also talked about monitoring their treatment as something they needed to do. This was most often because they had experienced something bad happening (Table 3, Row 11).

However, several patients said it was difficult to engage in empowered behaviors, because they were not capable of doing so. For example a woman said: 'I think it is really difficult (...). For example with this prosthesis that broke. I came in [to the doctor] and she said: There are three options (...the doctor gives an explanation...). Hmmm ... Fish. I have no idea. This is a decision I cannot take' (Female, 42–59 years). The question is thus whether it would have been possible for this woman to have enough information to participate in this decision, or if she would prefer not to have all

this information. Our impression was that she did not want the information that was needed.

For others, it was difficult to engage in empowered behaviors, because they could not see that there were any decisions for them to take (Table 4, Row 5). And for still others, they did not want to act empowered, because they did not consider it their task – at least not in relation to that specific area: Interviewer: ‘We are especially interested to hear about how interested you, as a patient, are in being involved (...) Does it make sense to you?’ Patient: ‘No, I don’t think so. Well ... Before you just asked if I knew what kind of medicine I was getting. I’m almost indifferent to that. I assume that they have the expertise’ (Male, 60–88 years). For this group to act empowered it would require change in the system and with their expectations. This was also the case for an older couple, who did not think they could ever learn to question authority (Table 4, Row 7).

Finally, some patients wanted to have influence. However, gaining influence was burdensome because of different barriers (Table 4, Row 4) and required a lot of energy: ‘The doctor had made his decision. Done (...). At that time I was not so much on top of things that I could protest wildly’ (Female, 60–88 years).

Discussion

In this study, we have conceptualized PE in cancer follow-up based on Zimmerman’s theory and interviews with patients. To our knowledge this is one of the first studies to explore cancer patients’ experiences of empowerment and how these experiences could be related to a model of empowerment that may be translated into a questionnaire.

What were found to be important manifestations of empowerment were that patients had been given the possibility to decide over their treatment and care, the possibility of knowledge, that their wishes and concerns were taken seriously and that they were listened to when needed. Thus, for patients to have PE, it was important that the health care providers were enabling this possibility.

The study also showed some challenges when conceptualizing PE for a PROM in cancer follow-up. It was difficult to find manifestations of empowered behaviors and in accordance with other studies of patients with cancer, the patients did not perceive that there were many potential decisions to engage in about treatment or care [25]. The patients highlighted the importance of having the possibility of acting empowered, but not the wish for actually doing it and giving only few examples of empowered behaviors. This may have to do with the method applied in the study and this should be further addressed in future studies (further elaborated under limitations). However, it is also possible that being empowered was not a value to them. Zimmerman [3] is aware of this challenge to the model and writes that in some contexts people may be empowered without having actual power, when power is not the desired goal. Fumagalli et al. argue [1] that patients may be empowered and then may actively choose not to engage in making decisions, if this is an informed decision itself.

In this study there was not a clear link between empowerment and exerting self-care, a phenomenon also identified in diabetes [12]. Many patients in this sample specifically talked about self-care as something they did not want. It is important to acknowledge that what contributes to empowerment may be different for different patients and that not all aspects of PE may be equally important to all patients, a finding supported by other studies [26].

Limitations and future studies

This study did not present the full story of the informants in the study. For the present paper, we had a specific theoretical focus and asked specific questions of the data, which meant that only parts of the data were used. At a later stage, it is our plan to reanalyze the data in accordance with the content of the data and not the content of a theory. However, we did look critically at the conceptualization made and described examples that did not fit the model.

The study had a strong focus on the patients’ experiences with the health care system, even though we are aware that PE could also have been studied from the perspective of the patients at home. If so, the health care system might have had a smaller role in the patients’ perception of PE [27]. This may also be the reason why none of the manifestations of PE in the current study had to do with meeting other patients or using support groups [28,29].

This was an interview study. An interview study has the advantage that the researchers get the possibility to learn how the respondents understand and experience the world. However, the method has the limitation of being primarily verbal and so primarily reflecting the respondents’ conscious understanding. We would recommend future studies to also include observations of this field because this could possibly reveal empowerment manifestations not acknowledged by the respondents.

Conclusion

In this study we conceptualized PE for patients with cancer who are in follow-up, in order to be able to develop a relevant and sensitive questionnaire for this group of patients. The study showed that it was meaningful to conceptualize PE based on Zimmerman’s theory. Important manifestations of empowerment were that the patients had been given the possibility to have mastery of treatment and care and to obtain knowledge, that their wishes and concerns were taken seriously, and they would be listened to when it was needed. However, the study showed challenges to the model and making a PROM that measure PE in this population, for example patients were not very motivated for empowered behaviors and what was considered appropriate knowledge varied widely.

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