

# The understanding of control in patients with advanced cancer. An interpretative phenomenological study

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## Research Article

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# Abstract

## Background

In the context of life-threatening illness, loss of control is argued as a source of suffering and loss of perceived dignity, whereas having control over the dying process has been seen as a way of maintaining personal independence. Little is known about meaning of control since the patients' perspective. Thus, the aim of this study was to explore the meaning of control from the perspective of patients with advanced cancer.

## Methods

We conducted semi-structured qualitative interviews using an interpretive phenomenological analysis approach. Eight patients with advanced cancer from an oncology unit and a palliative care unit from Barcelona (Spain) were interviewed.

## Results

Two themes emerged: 1) factors that influence the perception of control, with subthemes: uncertainty about future suffering, personality traits underlying a need for control; patient-medical interactions; and 2) perceiving control over an uncontrollable illness, explained by perceived control over subjective wellbeing and relinquishing control through coping strategies.

## Conclusions

This study allowed us to understand what control means to advanced cancer patients. The data allowed us to identify strategies that promote a sense of control in these patients. The illness, according to the participants, was experienced as series of losses. However, attention was often focused on areas where they continued to have control. Future research should address how both family members and healthcare professionals can help to empower patients.

## Introduction

For patients with advanced illness, concepts of personal control – related to their involvement in care (i.e., autonomy; dependency) and beliefs about their influence over situations (i.e., self-efficacy; locus of control) – are important to multiple outcomes. Some studies have shown patients with advanced illnesses voice a desire for control as essential to personal identity and wellbeing (1), feeling needs are met (2), preferences for care and sense of dignity (3, 4). This may explain why a perceived loss of control has been associated with negative outcomes including distress related to self-perceived burden (5) and the wish to hasten death (6). Alternatively, maintaining a sense of control has been associated with

positive outcomes including psychological adjustment (7), better mental health (8), patient empowerment (9), and treatment decision-making consistent with personal values and goals (10). Thus, control appears as a multidimensional construct in the literature, relevant to multiple experiences and facets of care for patients with advanced illness.

Although broader understandings of control (11) and autonomy (12) in advanced illness have been reviewed, no empirical research has directly explored patient understandings of control in its multidimensionality. The main objective of the present study was to explore how patients with advanced cancer conceptualized and experienced control in different dimensions of their life, their illness, and their healthcare.

## Methods

### Participants

We recruited advanced cancer patients from the palliative care outpatient clinic of a cancer center and from a general hospital with specialty in oncology and palliative care, both in the Barcelona area. Purposive sampling was used to ensure good informants. Inclusion criteria were: a)  $\geq 18$  years old; b) fluency in Spanish or Catalan; c) diagnosed with advanced cancer (as defined by the American Society of Clinical Oncology (13)); d) ECOG between 0-3; e) emotionally stable; f) considered to be controlling over their illness and circumstances according to their responsible physician; g) signed informed consent. Exclusion criteria were: a) an ongoing severe psychiatric disorder, and b) cognitive impairment with score  $>5$  on the SPMSQ (14). The project was explained to the palliative care physicians and nurses to select the most suitable informants. Physicians informed the principal investigator of potential participants. Eleven patients were approached. One patient died before the interview and two patients declined due to poor clinical status. Eight agreed to participate, six female. Ages ranged from 29-70 years ( $M = 53.3$ ;  $Mdn = 55$ ). All patients were white, over half were married or living with a partner. Two patients had lung cancer, four metastatic breast cancer, one colon cancer with liver metastasis, and one ovarian cancer.

### Data collection

An interview guide around the key themes was designed. Semi-structured interviews were carried out (January 2016 to March 2018) until data saturation was reached, indicating data, themes and content became repetitive. The semi-structured interview examined thoughts of *what* contributed to a maintenance or loss of control, *why* a sense of control was needed in their lives, and *how* a sense of control promoted or interfered with adjustment to illness and dying.

We sought the participants' preferred moment and location for the interview. The interviews were audio-recorded, transcribed and analyzed. All interviews were performed by the same researcher with no involvement in these patients' care to minimize potential bias.

### Data analysis

Data was analyzed using Atlas.ti 8.0 and interpretative phenomenological analysis (IPA), a qualitative approach to understand individual feelings and thoughts pertaining the phenomenon of study (15), ideal to explore individual experiences and understandings of control for those with advanced cancer. Audio-recordings were listened to and read multiple times by the principal investigator (AR) and two other investigators (CM, IC).

In accordance with IPA, statements were analyzed from a descriptive and linguistic level to a conceptual and interpretative outlook (See Figure 1).

All transcriptions were read and re-read with the objective of identifying significant statements and the meanings arising from those statements. Codes were assigned to each of the meanings that emerged. These codes were classified into categories as a function of conceptual similarity. Finally, they were grouped into subthemes and themes. The analysis was first carried out in an independent manner by the main researcher. Afterwards, two researchers reanalyzed the data, obtaining similar categories. The preliminary results were shared with all members of the team for discussion until final results were obtained. Triangulation of data within the research team corroborated the interpretation of the data, and no new or further themes were suggested. The methodological quality of the study was verified using the CASP guidelines (Additional material Table 1) (16). This study was approved by the ethics committees of the two hospitals (Hospital de Bellvitge [PR216/15] and Consorci Sanitari de Terrassa [FR\_20171127]). All participants gave written and verbal informed consent. All interviews were anonymized and three researchers had access to transcriptions.

## Results

The analysis identified 240 codes that were grouped into categories (see Table 1), classified into 5 subthemes. Finally, two themes were identified: 1) factors that influence the perception of control, and 2) perceiving control over an uncontrollable illness. Representative quotations of each theme are in Table 1.

### 1. Factors that influence the perception of control

This theme can be understood as a framework through which participants experienced greater or less control. Three subthemes emerged: 1) uncertainty about future suffering, 2) personality traits underlying the need for control, 3) patient-medical interactions.

#### 1.1 Uncertainty about future suffering

Some participants expressed that although the illness had not currently limited them excessively; one of the biggest concerns was uncertainty related to a future loss of independence.

An unpredictable future loss of physical function, no longer being able to do things, and the anticipation of pain or suffering all threatened their sense of control. Even death was considered the lesser evil compared with the uncertainty of functional deterioration, causing loss of bodily control and independence:

“What really [bis] scares me, is not death, death itself, no, because we all have to die, you die and you don't realize. What scares me is ending up in a wheelchair, having to depend on someone, that, wah - Panic!” (P2)

## **1.2 Personality traits underlying the need for control**

We observed personality traits that helped to better understand those patients in need of control. Some individuals explained how personality influenced the way they live and die. Staying resilient led participants to overcome difficult situations at different times in their lives and to achieve any objective they had set. They identified themselves as proactive, planners, independent, and self-sufficient. A common characteristic was how they sought control of their surroundings through organizational strategies. The participants explained their precise planning of schedules, diets, medical visits and monitoring of treatment, the use of clinical devices, etc.

“I spent several days sorting things out and I made my list of meals [...] the day I stop planning, I'll no longer be me. I am too much of a planner, yes... I usually get things done; I don't set a goal...unattainable goals, right? [...] Now with this I've had a very hard time, we'll see how far we can go if not, but I'm doing my bit” (P4).

## **1.3 Patient-medical interactions**

Bad experiences with treatments, interventions, different medical devices, perceiving a lack of care tenor from healthcare professionals, and experiencing vulnerability due to hospitalization all conveyed a sense of losing control.

A missed diagnosis at an earlier stage of their illness after visiting different specialists, the perception that they received inadequate treatment from their healthcare providers (insufficient information, giving false expectations of the illness, lack of empathy) contributed to the greater perception of a loss of control.

“Everyone said they couldn't see anything... some of them gave me a bit of medication or some said “that, it's an inflammation [...] but everyone told me that I was senselessly worrying about this” (P4).

Another source of a sense of loss of control was the reality of depending on medical devices (e.g. catheterization, colostomy bags, etc.). Those patients described this dependency in terms of “limiting my life” and suffering:

“Everything that wasn't the treatment, has been the bloody port-a-cath. Pissed off with that... that device here. That was what I felt was limiting my life” (P5).

## **2. Perceiving control over an uncontrollable illness**

The second theme encompassed all those elements that explained areas in life patients' felt were under their control, beyond their control or either, depending on the circumstances (Figure 2), which emerged

along with two subthemes: 1) perceived control over subjective wellbeing, and 2) relinquishing control through coping strategies.

## **2.1 Perceived control over subjective wellbeing**

The relationship between maintaining dominion over the situation, being the one who makes decisions and personal wellbeing highlighted to what extent participants felt that they were in control of the situation and the areas in which they exerted this control.

Taking care of themselves through diet and physical exercise, receiving a response from professionals that adapted to their needs, receiving adequate information about medical treatments or having “tied up loose ends with advanced directives”, as commented one participant, contributed to personal wellbeing and maintenance of their sense of control:

“Taking care of your food is a kind of control [...] because it gives you a feeling that you’re taking care of yourself and that you’re helping to improve your health when you get treatment. Not only through medications, but also that you’re also taking care of your body. Another thing that’s important for me, not just because I have a good time and I enjoy sports. It’s another way to say... feel healthy, all things considered!” (P7)

As long as patients exerted dominance over significant areas of their lives, they felt that “my life continues to be in my hands”, as expressed by 7 participants. The awareness of controlling highlighted that realities that were uncontrollable could be distinguished (the fact of having an illness) from those around which they could have a margin of control.

## **2.2 Relinquishing control through coping strategies**

Participants referenced strategies they had developed to manage the illness. These were seen as strategies through which patients could relinquish control over the course of the illness. Deploying these strategies to recognize where they could and could not control their current lives occurred both at a personal and interpersonal level.

### **Personal level**

a) Living in the present. The inability to make plans for the future resulted in many attesting that the illness had helped them focus on the present. For some, living one day at a time was viewed as a form of control over the only thing really in their hands:

“I plan small things that I’m interested in doing but I don’t plan the future... because then I’d worry now and later and [...] it’s not in my power to change the course of events” (P4).

Related to living in the present was understanding life as a gift. Having gone through difficult situations throughout the illness led some participants to value the present and enjoy even temporary wellbeing in contrast with painful situations either from the past or anticipated for the future.

b) Adaptation to the distinct phases of the illness. The experience of having overcome insurmountable situations revealed a capacity for adaptation in each moment. One of the patients explained how it seemed they could not stand wearing a colostomy bag, however, when there was no longer an alternative she was not only able to accept it, but to live as though it was not there. Some patients referred to this reality using the metaphor of “having surpassed the limits that I didn’t believe I had”:

“You overcome lots of things; if they’d told me everything I’ve been through, and that now I’d be here [...] I’d have said that I wouldn’t overcome all of this, I wouldn’t be able to” (P8).

Three participants expressed this idea by highlighting some inconsistency between thought and action: “When the moment comes, you act in a totally different way than what you said previously” (P5).

Another form of channeling the need for control was through the creation of comfort zones, where that person felt most safe and secure. One patient mentioned that away from this comfort zone she felt afraid and insecure so that there was a greater need to remain among surroundings she could control to avoid suffering and distress.

c) Acceptance of what cannot be changed. Living through the illness process meant learning to put life events into perspective and accept circumstances that cannot be controlled:

“You really relativize everything, and when you hear something that makes you say: oh, that’s problematic; you say: well, it’ll get sorted, if it doesn’t sort itself out one way it’ll get sorted another way, and if it doesn’t get sorted then it’s not sorted” (P8).

We observed how some individuals were aware they could choose their attitude to coping; whether negative responses, wondering why they became ill, or focusing on everything they could still do.

All participants indicated there were aspects over which they lost control, but was not necessarily experienced as negative, as long as they were able to generate coping strategies without affecting their core values. The patients referenced the progressive deterioration from the illness and activities they could no longer engage in. For those who considered autonomy as a defining value of their identity, the thought of not making their own decisions or depending on others was very difficult to cope with and, for one participant, even unacceptable.

## **Interpersonal level**

a) Relational Autonomy. Some losses were not experienced negatively, such as the inclusion of loved ones in the care process, which was assumed to be something natural. Leaving care to others was experienced as a mutual agreement where patients continued to have control. They allowed themselves to be cared for and experienced that help as an extension of their will and control:

“Maybe a time will come when maybe it won’t bother me so much that someone close to me helps me to control things. That won’t bother me” (P4).

Some recognized that others helped them exercise greater control over the situation:

“I believe that my life is still in my hands. The thing is... I depend more on the people around me to achieve my goals [...]. But hey, it's always up to me if I want to accept people's control over me [...] Obviously I need people to help me, [...] but I'm the one who decides to do one thing or another, and they cannot make me do what others want” (P6).

b) Desire not to make others suffer. All participants expressed concern over making others suffer, perceiving themselves unable to control their impact on or burden to others. Three interviewees experienced caring for a sick relative. This prior experience convinced them they had to protect loved ones from suffering. One patient said she could deal with the illness, but it seemed unfair that her son had to bear any burden also. Another common issue was the inability to control what would happen to their family and loved ones after their death, as participant 1 stated:

“It's not that I'm worried about dying, as it were. I am more worried about [bis] her [his wife], how she'll be. Her, my relatives, my friends who care about me, who love me; well... I'm more worried about that than me” (P1).

Another participant mentioned she asked her relatives not to accompany her to the doctor because she knew that without them she was freer to express her emotions.

## Discussion

This study provides patient understandings of control as a multidimensional construct in the context of advanced cancer. Our analysis deepened the levels of understanding of control: physical (loss of functionality and independence), psychological (coping strategies), social (relational autonomy) and existential (autonomy, self-determination).

The first theme, factors that influence the perception of control, showed the concept of control is context-dependent (17). The contextual framework marked by the state of the illness, the disposition of the patient and their previous experiences can be considered antecedents that influence the experience of control when living with advanced illness (18).

The uncertainty about future suffering, consistent with previous research (19), was feared and viewed as a threat to control for the majority of patients, marked by anticipating the future impact on physical functioning and further deterioration. These same participants expressed that under certain circumstances they would not want to continue living but acknowledged the difference between a hypothetical versus reality. Thoughts and fears about the consequences of their illness combined with managing their behavioral response is consistent with illness perceptions underlying self-regulation in response to appraisal of health threats (20) that also underlies theoretical response styles to uncertainty (21). Limited research has investigated illness perceptions in the context of patients at the end of life, but this shows they may have an important influence on patients' perceptions of personal control.

Patients' interactions with medical staff and treatments contributed to a perceived loss of control. Some authors (22, 23) have stressed that the social and material environment can threaten the autonomy of patients. The concept of self-efficacy (often equated to a sense of personal control) reflects perceived control over the self and social environment (24), revealing interactions influence personal control. Although research on control and autonomy is often focused on the personal perception of patients, our results underscore the importance of the context of care. Encouraging a comfortable environment can not only protect from the perception of loss of control but also from loss of dignity (25). Caring not only relates to personal treatment of the patient but also highlights the importance of effective communication and shared decision making as one of the aspects most valued by patients at the end of their life (26).

Patients also explained the perception of normality despite physical changes that may be explained by the subjectivity of health-related quality of life (27). When a person evaluates their overall quality of life they are assessing their physical, functional, emotional and social state taking into account their expectations, goals, feelings and personal values. Thus, as long as your quality of life remains positive, a normalized view of the disease could also occur.

The second theme that emerged, perceiving control over an uncontrollable illness, pertained to areas in which patients perceived greater control. Lavoie et al. (1) suggested that exercising autonomy through the accomplishment of smaller daily tasks can generate wellbeing. Participants in the current study relatedly expressed that they could express control by managing their smaller day-to-day meals or medications.

Coping strategies are defined as the set of mechanisms that regulate emotions towards problem-solving (28). This category was most prominent with a total of 118 quotations grouped into 41 codes. Active and passive acceptance, a positive attitude, focusing on the present were strategies used by participants (29). Living in the present was among the most used strategies. Just as most of the participants referred to fear of the future, it was also common to pay attention to the present as the only reality they could control (1).

The analysis of coping strategies from an interpersonal perspective helped to provide a more realistic view of control for patients in this context. Advanced illness conveys a vulnerability inconsistent with the model of self-sufficiency, capable of decision-making (17). Our results suggest including others in decision-making can help avoid the stigma of illness by supporting personal choices in life. However, the desire to not to make others suffer was also reported. Feeling that one is a burden is a source of suffering at the end of their life (30). Promoting a culture of relational autonomy, which highlights the essential and positive link from living interdependently, is key to generating narratives that avoid seeing dependence from the standpoint of guilt and burden (1).

The desire for control plays a relevant role in perceived quality of life (31). Therefore, promoting self-care, strengthening control over treatment decisions, training both patients and family in informed decision making, managing time and living in the now, and favoring conversations about end-of-life concerns can facilitate the perception of control (3).

The study is limited to patients with advanced cancer from public hospitals, limiting generalizability to populations with other illnesses or socio-economic status.

## Conclusions

This study identifies key strategies to promote control in patients with advanced cancer. Although the illness was experienced as a set of losses, many focused on areas where control could still be maintained. These results emphasize that family and healthcare professionals can contribute to empower patients.

## Declarations

**Declaration of conflicting interests.** The authors declare that there is no conflict of interest.

**Authorship.** AR, AB, CM designed the study. AR, IC, CM were involved in analysis and interpretation of findings. AR, IC, DP, AB, JP, CM made substantial contributions to the identification of relevant literature, were involved in drafting the manuscript and revising it critically. All authors gave final approval to this manuscript.

### Ethics approval and consent to participate

This study was approved by the ethics committees of the two hospitals (Hospital de Bellvitge [PR216/15] and Consorci Sanitari de Terrassa [FR\_20171127]). Prior to enrollment, we explained the objectives and procedures of this study. All participants gave written and verbal informed consent. All interviews were anonymized and three researchers had access to transcriptions.

### Consent for publication

Not applicable

### Competing interests

The authors declare that they have no competing interests.

### Availability of data and materials

Due to privacy and ethical concerns, neither the data nor the source of the data can be made available. Those interested can contact the corresponding author for more information.

### Contributions

AR, AB, CM designed the study. AR, IC, CM were involved in analysis and interpretation of findings. AR prepared figure 1 and DP prepared figure 2. AR, IC, DP, AB, JP, CM made substantial contributions to the

identification of relevant literature, were involved in drafting the manuscript and revising it critically. All authors gave final approval to this manuscript.

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## Tables

**Table 1.** Main themes, subthemes and representative quotations.

Themes	Subthemes	Category	Quotations
1. Factors that influence the perception of control	1.1 Uncertainty about future suffering		<p>What worries me most is suffering physically. The psychological I can handle better but the physical... [...] I deal with a lot because now I have a pain but there will come a moment for me when something makes me nauseous or so I think ... and if I fell asleep I would stop suffering like this. But it is what can happen me if it wants to come on like an attack somewhere is this... my physical suffering from the nausea and vomiting, if not for anything, is really strong, really, really a lot. And at that moment I am not in control of myself ... if I have to continue forever with that suffering, I'm that person already. Nor do I let anyone live. Then, yes, if they could do me the favor of turning out the lights. It's done (Participant 2).</p>
	1.2 Personality traits underlying a need for control		<p>Yes, this life has taught me a lot. And I have managed to get out of everything, from any complicated situation, and I have managed things with common sense, as I have always believed. And, okay. And my children are proud of me (Participant 3).</p> <p>The nature of illnesses is very influential. Because I see people that I know, maybe they don't have what I have. What do they have, what do I know... renal colic and they are super... depressed at the same time "ah! why and me?!" (Participant 2)</p> <p>Another very important thing to me, not only because I have fun and I enjoy sports. It's also another way of saying... to feel that I am healthy. (Participant 6)</p>
	1.3 Patient-medical interactions		<p>[The nurse] put me in an armchair, this is all very painful for me, when I was in that armchair, which was old, my arm hurt, it hurt because I was in a bad position and she left me waiting there for an hour because she made a mistake and put another women in my chair [...] And I was waiting and waiting... "Look, you know what? I have a lot of pain and there is something wrong with this chair". [Their response was] "So, now when you leave, ask for a form and make a complaint to the [local Government]" (Participant 4).</p> <p>Because it's just, I was like this, that is, like I did not have malignant cells... well tell her [his wife] this... My goodness. And then, on top of that, they told her how they had taken so long. She says: it's been a long time that they've been over there; they haven't said anything ... She says: and what did they say he had? And my wife: they didn't tell us anything at all. Okay. The doctor said to her: will</p>

you tell him? Because I don't dare tell him (Participant 1).

2. Perceiving control over an uncontrollable illness

2.1 Perceived control over subjective wellbeing

2.2 Relinquishing control through coping strategies

2.2.1 Personal level

a) Living in the present.

b) Adaptation to the distinct phases of the illness.

c) Acceptance of what cannot be changed.

a) What are you going to be worrying about? It's just that, it's absurd. If you are here today, and tomorrow, you don't know where you are (Participant 5)

Friday they will have the results..., and that's that. But still at the moment I don't put myself in this situation, I more have to stay in the now so I don't lose it if I go. I see it that way (Participant 5).

b) Yes, yes, that's it... like a movie. And well, I was seeing myself, my life, I was seeing it as one of those movies. And I said, yikes, but what is happening to me? You know, my hair is falling out! But there comes a time for everything, it's true eh, one sees that you never get used to it, but you adapt. (Participant 2)

c) Of course. As much as you want to control things, there are things you can't control. Well then, could be that you were continually worrying a lot before about things that now you say: Grandma, I can plan to do this, and everything has to go that way, and tomorrow I can be hospitalized and I can't do anything anymore. I mean, it changes everything, it's very ... it's all very relative. You take it all in a different way, you stop worrying about things we used to worry about a lot and now you say, well, we don't have to worry about it either (laughs). What has to happen will happen, and that's it (Participant 8).

2.2.2 Interpersonal level

a) Relational Autonomy

b) Desire not to make others suffer

a) But it's really, really difficult. This is what is most difficult for me, the physical. Mentally, well, I'm very optimistic, and I look forward to things... and I have my moments, obviously, really bad things have happened, but well, I have family where everyone comes together, and they help and...lucky to have them. The family does a lot; my husband, children, I still have parents, siblings. Everyone... I want to say everyone...I want to say... they've always been there for me. And that's been okay. But everything physical is what's hard now, above all. Now I can't do what I used to, and that's hard. But well, you also get used that, eh? You do that, and you don't take notice. And you say, well I won't do it, I'll do something else, I'll do it when I

can. And if I can't, now someone else can do it, and that's it. (Participant 8)

b) And to me, what worries me most is her, in that sense. The thing that makes me worse, I don't know how I'm going to bear it, I don't know. But come on, I think I'll have to put up with it, otherwise they'll give me something to keep going. (Participant 1)

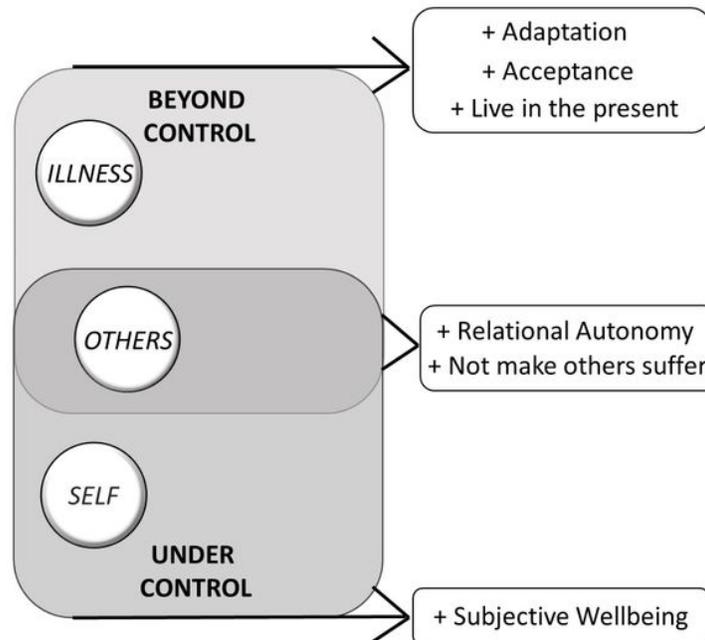
And it pisses me off that my family, my husband, my kids, or whatever, have to be watching after me, and they have to stop their lives because of me. Let's face it - if it's a week, it's worth a fortnight. But if not... no, I don't want to be a burden to anyone, and I think everyone around me sees that pretty clearly; minus the parents, which is pretty normal. But the rest do. (Participant 8)

## Figures



**Figure 1**

IPA analysis process.



**Figure 2**

Perceiving control over an uncontrollable illness. Patients recognized domains under their control, beyond their control, and a gray area where sometimes they could achieve control, as it related to interactions with others. Circumstances that they took under their control contributed to their subjective wellbeing whereas recognizing circumstances beyond their control contributed to coping strategies. Depending on their perceived control over others, patients could achieve relational autonomy or expressed a desire to not make others suffer.

## Supplementary Files

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- [SupplementaryfileCASPguidelines.doc](#)