



# Experiences of Powerlessness in End-of-Life Care

Green Paper (October 2015)

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THE ETHICS OF  
POWERLESSNESS

# Experiences of Powerlessness in End-of-life Care Green Paper

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## 1. Introduction

In this Green Paper we shall review recent studies on experiences of powerlessness in health care with specific interest in end-of-life care. Our aim is to bring into view the central features of experiences of powerlessness in end-of-life care contexts, as these experiences have been described in empirical research. In an appendix we list a number of questions we believe call for future research.

## 2. Empowerment and Control

Authors who discuss power and powerlessness in healthcare contexts often focus not on powerlessness directly but, rather, on empowerment. If powerlessness is discussed at all by these authors, it is typically understood, derivatively, as the condition that is to be overcome by becoming empowered. There is, however, no real consensus on what ‘empowerment’ amounts to. Drew (1990) and Gibson (1991) demonstrated the somewhat bewildering array of conceptions of patient empowerment that were available by the early nineties. Aujoulat et. al. (2007a) and Milberg et. al. (2004) point out that even more than a decade after these reviews, consensus had not been reached. Since there is no consensus on empowerment, and powerlessness is typically understood as the condition that empowerment overcomes, this means that there is no consensus among these authors on the nature of powerlessness.

That said, Aujoulat and her colleagues have identified a dominant tendency.

the underlying philosophy of an empowerment-based approach is recalled in many [...] research articles [...], i.e. a philosophy which views human beings as having the right and ability to chose [sic] by and for themselves. Self-determination therefore appears to be a strong guiding principle of empowerment-based interventions. (Aujoulat et. al. 2007a, 15)

This tendency was already identifiable by the early nineties. Lord and Hutchison (1993), for example, pointed out that most of the extant literature at the time ‘associate[d] empowerment with personal control’ (op. cit. 3). Thus, many authors identify ‘empowerment’ as a goal and they understand empowerment to be a matter of increased personal control. Furthermore, ‘personal control’ is often cashed out in terms of individual choice and self-determination.

But if empowerment is understood as control, then the state that is to be overcome by becoming empowered—powerlessness—must be a lack or loss of control, that is, a lack or loss of choice and self-determination. This implication is made explicit in a number of papers. Dryer (2007), for instance, quotes from a number of sources to define powerlessness in terms of a loss of the power to control oneself and the environment:

Powerlessness, as defined by Wilkinson (2005), is “the perception that one’s own action will not significantly affect an outcome; a perceived lack of control over a current situation or immediate happening” (p.386). [...] The exact opposite phenomenon—power—can be defined to describe what powerlessness is not. Power is “the ability to influence people and events—the sense that one’s opinion counts and will be heard” (Craven & Hirnle, 2003, p.

1255). A similar view is given in Taber's Medical Dictionary (2001), which defines empowerment as "participating actively and autonomously in policies or events that affect one's health and well-being" (Dryer, 30)

Dryer is by no means alone in articulating powerlessness in this way. For example, Boudioni et. al. describe the relationship between powerlessness and empowerment as follows:

[Powerlessness] is defined as occurring when an individual assumes the role of an object acted on by the environment rather than a subject acting in and on the environment. On the other hand, "patient empowerment" refers to the mechanisms enabling patients to gain control and make choices in their health and health interventions. More choice, more information, and more personalized care may be mechanisms that lead to empowerment of patients and carers, being described as the act or process of conferring authority, ability, or control (Boudioni et. al. 530)

Thus, where empowerment is understood as increased choice and self-determination, powerlessness is typically understood as a loss of choice and self-determination.

The understanding of empowerment in terms of increased patient self-determination and choice and the correlate conception of powerlessness as the loss of that is not just prevalent within empirical research articles but has had much more widespread influence. For instance, a focus on patient empowerment-as-control is reflected in the Mandate for NHS England 2014-15. This document is the primary mode of ministerial instruction to NHS England and patient empowerment is mentioned in several places.

NHS England's objective is to ensure the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment [...] Achieving this objective would mean that by 2015 [...] far more people will have developed the knowledge, skills and confidence to manage their own health, so they can live their lives to the full; everyone with long-term conditions, including people with mental health problems, will be offered a personalised care plan that reflects their preferences and agreed decisions; patients who could benefit will have the option to hold their own personal health budget as a way to have even more control over their care (DoH, 11)

The focus should be on what we are achieving for individuals rather than for organisations [...] We want to see improvements in the way that care [...] empowers service users so that they are better equipped to manage their own care, as far as they want and are able to. (ibid. 12)

We want to boost professional and public pride in all the caring professions, and to empower patients to demand improvements where care is not as good as it could be. (ibid. 18)

Thus, the Department of Health (DoH) suggests that choice and self-determination are to be facilitated by increasing the power of service users across two dimensions. Firstly, service users are to be given more powers to achieve certain goals, namely: manage their own healthcare, hold a healthcare budget, and make decisions over their own care and treatment. But service users are also to be given more power over elements of healthcare provision. For instance, the DoH clearly wants patients to be able to 'demand improvements' from caring professions and for those demands to be efficacious. The notions of choice and self-determination are taken to amount to a kind of managerial control, involving the power to make decisions as well as power over healthcare providers.

Despite the prevalence of this conception of empowerment/powerlessness and the reach of its influence, there are critics of the idea that increased patient choice and self-determination should be the sole or primary healthcare goal in response to experiences of powerlessness. Correlatively, there are worries over the conception of powerlessness that is derived from this understanding of empowerment. We now shall review these critical voices.

#### Section Summary:

- Powerlessness is often defined, derivatively, as that which is to be overcome by 'empowerment'.
- 'Empowerment' is often understood to be a matter of 'control', where this is understood as increased power to make choices and power over healthcare provision.
- This model of empowerment/powerlessness has been influential in shaping government policy.

### 3. The Limits of Control

Over a number of articles Peter Salmon and George Hall have argued that patient empowerment-as-control is a bad ideal for healthcare. Their arguments attack the ideal of patient empowerment from three different directions.

Firstly, Salmon and Hall (2004) claim that the scientific basis of the hypothesis that increased patient control is beneficial for patients is 'weaker than it first appears'.

Although controlled studies of empowerment—for example, arranging for patients to choose the nature or timing of treatment, or teaching them 'coping skills'—do often favour intervention groups, effects are variable; sometimes they are transient or favour lack of choice. Moreover, whereas it is normally assumed that such interventions enhance feelings of choice or control, researchers have rarely demonstrated that they do. In a study of treatment choice in breast cancer, even though patients of surgeons who offered choice were happier, choice was not the critical factor. (Salmon and Hall, 2004, 53)<sup>1</sup>

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<sup>1</sup> In this respect, Salmon mirrors a complaint made as early as 1991 by Kubsch et. al., who argued:

Thus, Salmon and Hall argue that the ideal of empowerment-as-control is inadequately evidence-based.

Secondly, Salmon and Hall claim that the ideal of patient empowerment-as-control may serve the practitioners more than it does the patients, insofar as it amounts to a transfer of responsibility for patient care from doctors to patients. For instance, patient controlled analgesia, in which patients are given the tools with which they can administer their own pain relief, may be 'popular with staff because it removes a responsibility for their patients' pain that is practically and emotionally burdensome' (Salmon and Hall, 2004, 55). Thus, the goal of patient empowerment as increased control may reflect the needs and experience of service providers more than it does service users

This argument alone does not imply that patient empowerment should not be a primary healthcare goal. After all, it does not follow from the claim that patient empowerment is beneficial for healthcare providers that it is not beneficial for those who receive healthcare. However, with this second line of argument Salmon and Hall attempt to explain why practitioners would be attracted to the idea that patient empowerment should be a primary healthcare goal despite what they take to be the lack of evidential support for it.

Finally, Salmon and Hall argue that there are clear cases in which increasing patient control over their condition disempowers patients. For instance, one way in which the ideal of empowerment can figure in healthcare is in the encouragement of a 'fighting spirit'. But, according to Salmon and Hall

Such language can refer to attitudes very different from the commitment to defeat the disease (Frank, 1991). Although Byrne et. al. (2002) confirmed that patients with cancer freely used the language of fighting, struggle and effort, this language signified, not resistance to the disease process but, instead, suppression of expressions of emotional distress. Because emotional disclosure is a major way in which individuals assert their own needs to others, 'fighting' should therefore more accurately be regarded as disempowering than as empowering. (Salmon and Hall, 2003, 1975)

In other words, increasing patient control could lead to further repression of emotional distress and be deleterious for those patients it is meant to help, undermining the empowerment it is supposed to encourage.

Thus Salmon and Hall present a three-pronged criticism of the ideal of patient empowerment-as-control in healthcare. They argue that it is unwarranted by the evidence, may be motivated by the self-interest of practitioners, and is in many cases often deleterious to the welfare of the patients it is supposed to help.

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Despite the seriousness of the problem of powerlessness, it tends to be ignored. Nurses have been observed to misdiagnose it as anxiety, ineffective coping, or noncompliance [...] By so doing, nurses have become confused about appropriate interventions and employ the wrong ones. In futile attempts to restore power, nurses use the intervention of decisional control (Snyder, 1992), providing clients with more choices about their environment, food, and schedule. (8)



Aujoulat et. al. (2007b) point to a further reason to be sceptical of the appropriateness of empowerment-as-control as a healthcare goal. They quote Rappaport, who argues as follows.

[Empowerment is] difficult to define positively only because it takes on a different form in different people and different contexts ... Understanding that H<sub>2</sub>O can be in liquid, gas or solid form and still be H<sub>2</sub>O is like the realisation that empowerment for a poor, uneducated black woman can look very different than for a middle class college student or a thirty-nine year old business man, a white urban housewife or a single elderly person resisting placement in a nursing home. (Rappaport, quoted in Aujoulat et. al., 2007b, 773)

Rappaport's point can be reconstructed as follows. For example, it might be that a white, middle-class male who has spent his life as a manager experiences powerlessness distinctly through a loss of control over his environment. Should his experience be taken to be paradigmatic and general methods of empowerment designed accordingly? There are reasons to think not. While those who have understood themselves as managers may experience powerlessness through a loss of capacities associated with management, it might be the case that, for instance, someone who has never sought to exercise managerial control over her environment does not experience powerlessness in just the same way. It might be that the ex-manager is helped by being given certain powers of control, for this may address his specific experience of loss. But such a remedy might be of little or no use at all to someone who has no experience of management. Indeed, the problem could be made much worse. Rather as someone with no experience with numbers might recoil in terror at the prospect of having to file a tax return, in the same way the attempted empowerment of a patient with no managerial experience by the provision of new powers of managerial control might leave the patient feeling more powerless than ever. Thus, if researchers treat the experiences of powerlessness of a certain demographic as paradigmatic, then treating those who do not fall within this demographic in the same way could further disempower those individuals.

Given that there is already inequity in palliative service provision across demographics, this potential problem could be particularly pronounced (cf. Dixon et. al., 2015, pp.7-8). For this and similar reasons, Aujoulat et. al. argue that we need to investigate *how patients actually experience powerlessness* and then tailor our model of empowerment accordingly.

In summary, authors have identified a number of potential dangers that come with relying on abstract definitions of power, powerlessness, and empowerment as a matter of patient control. Firstly, such definitions are often assumed and are unwarranted by the evidence cited in their support. Secondly, the assumed definitions of powerlessness are derived from an ideal of empowerment which is at best questionable in theory and at worse harmful in practice. Together, these various reasons raise the question of the appropriateness of the model of empowerment-as-control as a primary healthcare goal for those who experience powerlessness.

## Section Summary:

- Authors often assume that powerlessness is a loss of control and allow that assumption to guide analysis.
- This assumption has been criticised in the literature as leading to two dangers:
  - such definitions are not adequately supported by evidence
  - the assumed definitions of powerlessness are derived from an ideal of empowerment which is at best questionable in theory and at worse harmful in practice
- Authors have taken these reasons to motivate further research into the nature of experiences of powerlessness, to test the appropriateness of empowerment-as-control as a healthcare goal.

In recent years, several authors have attempted to address directly the question of the appropriateness of empowerment-as-control as a healthcare goal. These authors attempt to avoid assuming what powerlessness is and focus instead on articulating the lived experiences of those who find themselves to be powerless. They then aim to tailor models of empowerment on the basis of the analysis of the experience of powerlessness. In the following section we shall review these analyses.

#### 4. Experiences of Powerlessness in Palliative and End-of-Life Care

##### a) Patient Experiences of Powerlessness

##### i. Powerlessness in light of chronic illness

Aujoulat and her colleagues have approached the phenomenon of patient powerlessness from a different direction to authors such as Dryer and Boudioni et. al.. Rather than beginning with an assumed definition of powerlessness which is then used to guide the interpretation of patient experiences, they begin with descriptions of patient experiences and draw from these an interpretation of powerlessness. While the authors do not focus specifically on experiences of powerlessness in end-of-life care, we shall see that their findings have been replicated to some degree in the more specific context with which we are concerned.<sup>2</sup> We shall thus articulate their findings before narrowing our focus and turning to experiences of powerlessness in end-of-life care, specifically.

In their study, Aujoulat et. al. (2007b) present a number of case studies of patients who have experienced powerlessness as a result of illness. They argue that those who experience powerlessness experience a loss of familiarity across several dimensions. This loss of familiarity explains the presence of two key features of experiences of powerlessness

- a disruption of identity

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<sup>2</sup> We note that these results have only been replicated to some degree because the papers referred to do not directly attempt to confirm the results of Aujoulat et. al.'s study.



- an increased sense of insecurity

We shall now summarise and elaborate Aujoulat et. al.'s identification of the various ways in which one might lose familiarity with oneself before drawing the connection between the loss of familiarity and these two features.

### *Loss of familiarity with bodily responses*

Aujoulat et. al. argue that illness can disrupt our familiarity with our own bodies. For instance, an illness might mean that one experiences new sensations which one does not understand.

I had a crisis ... it was the first time ... and I got so terribly frightened because it would not stop ... and I got so terribly frightened. I lost my sensitivity, my fingers hurt ... it was horrible. And I did not know if was the disease, I did not understand what the problem was. (Aujoulat et. al., 2007b, 777)

Furthermore, the authors indicate that feelings of which one would not have taken much notice before—and with which one would have been familiar—might lose their familiarity in the light of a diagnosis.

When I go home after a day of work and it's hot like today and I feel tired ... how do I know whether my tiredness is normal and everybody would be tired under the same conditions, or whether my tiredness is due to my illness? (ibid.)

As well as triggering unfamiliar sensations or defamiliarising once familiar sensations, Aujoulat et. al. find that illnesses can also introduce an element of unpredictability into bodily responses and capacities. Typically, we can make plans well ahead of time because we take our capabilities to be stable enough to depend on in advance. Because illnesses can not only make one's bodily responses unfamiliar but leave one's capacities unpredictable, they can unsettle the confidence required to plan into the future and undertake activities dependent on one's capacities holding out.

My hobbies mean a lot to me but I'd like you to know that it has become very difficult to plan anything now. It's hard to decide let's do this or that next weekend because who knows if I'm not going to be stuck and unable to move. It has happened before and we had to cancel our plans. Of course, the children complain. (op. cit. 779)

There is no future. There was a time when I did not even know what I would do the following day. It was impossible to make any holiday plan. (ibid.)

Aujoulat et. al. argue that in these ways illnesses can disrupt one's familiarity with one's bodily responses and one's confidence in one's capacities.

### *Loss of familiarity with emotional responses*

As well as a disrupted familiarity with one's bodily responses to the environment, the authors claim that illnesses can also change how one emotionally responds to one's environment. Individuals previously unfamiliar with anxiety, for instance, might find themselves anxious in situations in which they otherwise would have remained calm: 'one patient, who demonstrated a high level of distress and anxiety during the interview, complained about not being the same person as before, as she never "used to be like that before."' (op. cit. 777).

### *Loss of familiarity with social standing*

The study also indicates that illnesses can disrupt one's familiar social standing. There are at least two ways in which this can happen. Firstly, one's illness might mean that one cannot continue in one's employment.

Before, I was in my role ... even when I was a little girl, I always used to ... and everybody used to say to me that I should have a job where I would be supervising others ... Well, I had my job and I was the boss, wasn't I? ... So when you fall and you can't get up again, you wonder "what happens to me?" and you start putting yourself down and you don't know who you are anymore. (op. cit. 780)

Secondly, since those close to those with illnesses can also find it extremely difficult to know their way about the changed and changing circumstances, familial roles may also be disrupted by the onset of an illness. For instance, Aujoulat et. al. present an example of a woman who took up a quasi-parental role with respect to her own mother.

Let's put it that way: whereas we used to have a normal parent-to-child relationship before, the disease changed it all . . . it was as if she had become the parent and me the child. And that, I couldn't accept . . . She always wanted to decide things for me and I kept telling myself, what is going on here? We had many disputes, we broke off many times. (op. cit. 858)

### *Loss of familiarity with one's environment*

As well as a loss of familiarity with *themselves*, Aujoulat et. al. also report that patients experience a loss of familiarity with their *environments*. This may be a result of a being placed within a new environment within which the patient is unable to do things she would like to:

Even in hospital, you know . . . I was in hospital and during two days, I did nothing but cry. I was out of my home . . . I felt like a fish taken out of the water and left on the floor to... you don't know who you are anymore. Even in a hospital . . . don't you think it's different! Even there . . . you're so dependant [sic] on others. (op. cit. 779)

For other patients, environments became unfamiliar if their conditions meant that their environments were no longer supporting and secure. These patients often felt that their worlds had shrunk to the limited spaces in which they were able to act, leaving them uncomfortably dependent on others.

The loss of familiarity with oneself across the three dimensions—bodily responses, emotional responses, and social standing—and the loss of familiarity with one's environment can leave one feeling **profoundly insecure**:

I am terrified that something could happen. I might consider leaving my home for the day. But more than that is impossible for me . . . it's like jumping in the dark . . . I do not control things and do not know what to expect. (op. cit. 778)

#### Mid-Section Summary:

- Aujoulat et. al. emphasise various ways in which illnesses can result in a **loss of familiarity**
- The onset of an illness can mean that one loses a familiar grasp of
  - One's bodily responses
  - One's emotional reactions
  - One's social standing
  - One's environment
- The loss of familiarity across these three dimensions can leave patients feeling **profoundly insecure**.

#### *Disruption of identity*

Aujoulat et. al. also emphasise a deeper consequence of this loss of familiarity with various aspects of oneself and one's environment. Under circumstances of unfamiliarity and accompanying insecurity one can feel that one can **no longer be oneself**. It is for this reason that they take the loss of familiarity to explain a 'disruption of [the patient's] identity'. For having lost familiarity with oneself and one's environment, one can find it difficult to understand oneself as being the same person.

One participant explained that she had not been able to be fully a grandmother because of her fear that she might drop her grandchildren while trying to hold them in her arms when they were babies. [...] One male participant felt particularly distressed, as he felt he could be neither a proper spouse nor a proper father, and maybe not even a proper man (op. cit. 781)

It is not just that one might feel unable to perform certain tasks, one might also feel unable to be oneself. This might also leave one feeling hopeless and depressed.<sup>3</sup>

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<sup>3</sup> Though it is beyond the scope of this Green Paper to address the connection between depression and a loss of familiarity with oneself, recent work on depression may provide promising leads in this direction. Cf. Owen et. al..

Above all, there is an overwhelming feeling of powerlessness . . . the feeling that you are not in control of your own life anymore, of your existence, of your future. Everything in front of you is black. (Participant) (op. cit. 776)

### *The connection between loss of familiarity and insecurity*

We have seen that Aujoulat et. al. argue that there are several ways in which one's familiarity with oneself and one's environment can be disrupted, such that one feels profoundly insecure. What is the connection between a loss of familiarity, on the one hand, and the sense of insecurity, on the other?

Aujoulat et. al. briefly offer a suggestion as to the connection between the loss of familiarity and the sense of insecurity.

A sense of security provides the basis of world exploration and self-growth, and develops very early in childhood, as infants experience constancy in bodily perceptions and responses of their environment (i.e., their caregivers) to their actions. (op. cit. 783)

We can reconstruct the point as follows. Each form of familiarity—bodily, emotional, social, and environmental—plausibly contributes to a person's ability to confidently make decisions for what is best for her. For instance, on the basis of a person's familiarity with her bodily responses, her emotional reactions, her social standing, and her extended environment she can decide that it is best not to eat too much breakfast, to avoid the hospital porter (with whom, perhaps, she has problems on Monday mornings), and go out into the world. If these forms of familiarity are a basis for making decisions for one's best, however, then their disruption would undermine one's ability to navigate the world accordingly, for one would have lost the settled standard against which various options can be measured as better or worse. In other words, these forms of familiarity provide the standards against which one can make decisions securely.

Thus, the loss of familiarity with oneself and one's environment might explain the sense of insecurity that Aujoulat et. al. have pointed to. For a patient's confidence that she is making the right decisions and navigating the world for her best could be undermined by a loss of the stable standard against which various possibilities for action are measured as better or worse. Could the loss of familiarity with oneself also explain the sense of a loss of control? We shall return to this issue below when we focus specifically on the place of control in experiences of powerlessness.

### *The connection between loss of familiarity, insecurity, and disruption of identity*

What is the connection between the loss of familiarity and consequent loss of security, on the one hand, and the disruption of identity on the other? Aujoulat et. al. draw on various theoretical sources to sketch an answer to this question. A sense of identity, they suggest, is a sense of sameness where the sense of sameness is understood as the sense of 'uniqueness, continuity and permanence'. They suggest that through disrupting settled forms of familiarity with oneself, this 'sense of sameness' is disrupted

precisely through undermining one's sense of continuity and permanence. There are, however, two problems with this suggestion.

Firstly, it might be that a disruption of the sense of sameness enables one to be oneself for the first time. For instance, an alcoholic who sobers up surely experiences a profound disruption in his sense of sameness. But this disruption may not be best described as a disruption of his identity: for it may be precisely *through* the disruption in his sense of sameness that he is able to 'come into himself' for the first time. Thus a disruption of the sense of sameness does not necessarily result in a disruption in the sense of identity.

Secondly, it is not clear why a disruption of the sense of self-sameness should necessarily manifest as an experience of *powerlessness*, specifically. After all, it is possible to imagine a person who feels greatly empowered precisely through undergoing a profound change in her life. For example, a person might feel greatly empowered having given up an addiction. In this case, there is a profound break or interruption in the individual's self-understanding. But there need not be an accompanying feeling of powerlessness, far from it. The fact of their having been a profound change in the patient's life cannot, then, by itself explain why these patients would feel specifically powerless as a result of that change.

We shall return to these questions in our conclusion and offer a different interpretation of the difficulties in continued self-understanding occasioned by loss of familiarity with oneself.

### *Summary*

There is strong evidence that those who experience powerlessness in the face of illnesses lose familiarity with themselves in various ways: bodily, emotional, and social. They may also lose familiarity with their environments. This can leave such individuals feeling deeply insecure, uncertain of themselves or what to do. This experience can, further, leave individuals feeling as if they cannot be themselves. In this situation, an individual might feel hopeless and depressed.

The loss of familiarity may explain why one feels insecure insofar as one's confidence that one can make decisions for one's best involves understanding oneself as continuing stably over time. So too, one's understanding of oneself as being the same seems to also rely on being familiar with oneself and one's environment, which is undermined by an encroaching illness. However, it is unclear why these features should together manifest as an experience of a disrupted identity or an experience of powerlessness, specifically.

As we have noted, Aujoulat et. al. describe experiences of powerlessness of patients broadly. They do not focus on the experiences of patients in end-of-life care. We shall now narrow our focus and turn to studies of experiences of powerlessness in end-of-life care. As we shall see, the features described above recur in the more specific studies we shall look at. But we shall also see that these studies reveal further aspects to experiences of powerlessness that seem to be more specific to end-of-life care.

## Section Summary:

- Aujoulat et. al. identify two central features to experiences of powerlessness in light of chronic illness
  - Disrupted identity
  - Increased insecurity
- There are various ways in which patients can lose a sense of familiarity
  - Loss of familiarity with one's bodily responses and capacities;
  - Loss of familiarity with one's emotional responses;
  - Loss of familiarity with one's social standing.
  - Loss of familiarity with one's environment.
- If patients experience themselves to be powerless, they can feel hopeless and depressed.
- The loss of familiarity may explain patient insecurity insofar as familiarity is a basis for confident decisions about what is best for one.
- The loss of familiarity may explain patients' sense of 'disrupted identity' insofar as patients' power to be themselves depends upon a stable sense of continuity of oneself over time.
- It remains unclear, however, why these features should
  - Manifest as a disruption of identity
  - Manifest as an experience of powerlessness.

## ii. Powerlessness in end-of-life care

In a study into the experiences of powerlessness of those dying from cancer, Lisa Sand and her colleagues (2008) confirmed a number of the results of the study by Aujoulat et. al. (for another paper in which similar results were reported, see Pascal and Endecott (2010)). For instance, they confirm that the experiences of powerlessness they describe involve uncertainty, experiencing oneself as newly limited, dependent on others, and in some cases hopeless (Sand, et. al, 2008, 858). Thus there appear to be common features to the experiences of powerlessness of those with life-limiting conditions and the experiences of powerlessness of those with illnesses which are not necessarily terminal.

Sand et. al., however, also emphasise other elements of powerlessness not specifically thematised by Aujoulat et. al. but which do feature prominently in end-of-life care contexts. Most prominent among these is 'existential loneliness' (ibid.), which Sand and Strang investigate in more detail in a separate article (Sand and Strang, 2006).<sup>4</sup>

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<sup>4</sup> Eric Ettema (2010) and his colleagues, however, have surveyed the literature and presented a systematic analysis of the concept as it appears in the literature. As they are at pains to point out, their analysis should be taken only as a further clarification of a difficult concept and not as a definitive elaboration. Ettema et. al. identify three 'dimensions' to existential loneliness: everpresence, experience, and process. Existential loneliness is everpresent because it is part of the human condition. But it may or may not be experienced as part of the human condition. If it is experienced as part of the human condition, this may lead to a process of 'inner growth' through which one is able to become more 'authentic'. As the 'process' dimension of existential loneliness



There has been a great deal of research into existential loneliness, though there is no theoretical consensus on the nature of the phenomenon. Nonetheless, two principle features emerge from Sand's research. We will call these 'individuation' and 'isolation'.

Firstly, Sand and Strang report that for those who experience existential loneliness, the possibility of death appears no longer as something that happens to other people but, rather, as something that will happen to oneself.

The reality of the illness had transmuted death from something abstract concerning others, to something real, concrete, and highly relevant. (Sand and Strang 1379)

A terminal diagnosis can thus rather starkly force one to confront one's own mortality as one's own. One is 'individuated' with respect to death because one realises that one has an individual relationship to that possibility.

This realisation that death will happen to oneself individually can be accompanied by a second feature of existential loneliness, namely, a feeling of isolation.

Both patients and next-of-kin experienced that they now had thoughts and feelings impossible for others to really comprehend. (ibid.)

In other words, one might feel that no one can know what one is going through when confronting one's own mortality.

Sand and Strang demonstrate the distressing number of ways in which this sense of isolation can be further compounded by the patient's relation to others. For instance, others might find it very difficult to broach the topic of death in conversation such that one feels pushed away from others.

But only few people dare (speak about Death). My sister-in-law doesn't dare "You will get well!" she exclaims. Then I say slowly, "I have a fatal, chronic disease." Then she becomes silent and so we talk about things (op. cit. 1381)

Moreover, one might feel a sense of duty not to burden others with having to discuss and consider the difficulty of one's situation, such that one withdraws from others.

A husband described his decision not to talk to his wife about the seriousness of the disease: 'No, that I don't want! ... I think that ... that will burden her even more, eh? ... Well, ... But, but (sobs) I have said (cries, looks helpless and appealing) that we will fix this, haven't I? ... and ... I will not change that (ibid.)

Furthermore, the circumstances of one's illness might make it exceptionally difficult for one to leave the house and socialise, such that one feels compelled to withdraw.

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belongs to overcoming experiences of powerlessness, we shall put it to one side. For now, we are interested in the experience of powerlessness itself.

Symptoms from the body that were experienced as embarrassing could lead to withdrawal from other people. Not being able to eat and drink as before had a great impact on the social togetherness surrounding meals. (op. cit.1380)

One might also feel either ignored by others (op. cit. 1381) or otherwise kept in the dark with regards one's own condition by medical professionals (op. cit. 1382). In these further respects one might feel excluded from the social world.

Sand and Strang list several other ways in which individuals can feel isolated in end-of-life care contexts, but we have enough of the phenomenon in view to summarise the main features of existential loneliness that they identify. Those who are individuated by the confrontation with their own mortality can feel isolated in their individuation with respect to death. This isolation can be compounded in various ways, either by

- withdrawing from social activities
- or being pushed out and excluded by others.

But what is the relationship between existential loneliness and the other features of experiences of powerlessness that we have described above? This is, we submit, an area that would benefit from further research: for it is not clear from the evidence we have reviewed how we should account for this relationship. In particular, future research is needed to investigate the following questions:

- Is existential loneliness connected to the sense of a loss of familiarity with oneself and one's environment and if so how?
- Does the presence of existential loneliness make for a *qualitative* distinction between experiences of powerlessness of patients with life limiting conditions and those with non-terminal illnesses?
- What are the most appropriate ways to respond to experiences of existential loneliness?

In summary, studies have suggested that the experience of powerlessness of patients in end-of-life care has several prominent aspects. Patients experience disrupted identities, an increased sense of security, and existential loneliness. In this condition, they feel as though they cannot be themselves and may feel hopeless and depressed. Despite the clear connection between patient experiences of powerlessness in end-of-life care and patient experiences of powerlessness more broadly, we have not found a sustained comparative analysis upon which we can draw to identify the precise differences between the two settings.

Now that we have seen certain key features of the patient experience of powerlessness in end-of-life care, we shall turn to the experiences of those otherwise connected to the patient who also feel powerless. We shall begin with the experiences of the next-of-kin before moving on to the experiences of carers.

#### Section Summary:

- Sand et. al. show that the features of experiences of powerlessness identified by Aujoulat are also present in palliative care contexts.
- Those who feel powerlessness in these contexts also experience 'existential loneliness'.
- Existential loneliness has two prominent features:
  - Individuation (the realisation that, for instance, death will happen 'to me' as an individual)
  - Isolation (the feeling that one is alone, that no one can reach one). Isolation can be compounded by
    - withdrawing from social activities
    - being pushed out or ignored by others.
- It is not clear, however, whether
  - a) there are substantial differences between experiences of powerlessness in healthcare generally and experiences of powerlessness in palliative care more specifically; and if so
  - b) whether such differences are qualitative or a matter of degree.
- While there is some evidence to suggest that existential loneliness is more prevalent in end-of-life care contexts, it is unclear why this should be the case.
- Moreover, it is unclear what is the precise relationship between existential loneliness and experiences of powerlessness.
- **More generally, from the combination of the empirical studies considered, experiences of powerlessness share three main features, namely:**
  - **a loss of familiarity with oneself and one's environment**
  - **a sense of profound insecurity**
  - **existential loneliness**

## b) Other Experiences of Powerlessness in End-of-Life Care

### i. Next-of-kin experiences of powerlessness

Anna Milberg and her colleagues (2004) have studied next-of-kin experiences of powerlessness in palliative care settings. They identify several features of this experience: perception of patient's suffering, perception of patient's fading away, feelings of insufficiency, and reactions to and deeper meaning of powerlessness and helplessness. The first two features describe that in the face of which the next-of-kin felt powerless, whereas the latter two describe features of the experience of powerlessness itself.

Milberg et. al. state that the perception of physical, psychological, social and existential forms of suffering in patients engendered feelings of powerlessness in the

next-of-kin. There is also a clear sense that the next-of-kin felt powerless in the face of changes in the condition, where those changes were understood to be for the worse.

Every time I saw that there was a change for the worse in mum, from one day to another (I felt powerless). (op. cit. 124)

The next-of-kin do not just feel powerlessness in the face of an increased level of suffering. They also feel powerlessness in the face of the patient's fading away:

The disappearance concerned different dimensions of the patient as a human being, i.e. negative changes as regards the patient's body, strength, functions and individuality. (ibid.)

The next-of-kin experienced these changes in the condition of the patient to be a gradual disappearance of the person in front of them, as if that person were fading or slipping away. That in the face of which the next-of-kin felt powerless, then, was perceived changes for the worse in patient. Such changes for the worse were perceived across two dimensions: an increase in suffering and the gradual loss of the person.

Having perceived changes for the worse in patients, the next-of-kin often felt insufficient. For example, the husband of a dying woman stated.

After the operation I was told that it was incurable (the doctor's words). I, who all my life—I am 75—have been used to organising and deciding everything together with my family about our lives. I was suddenly totally helpless. I was seized with deep powerlessness when I understood that I couldn't do anything to help my wife. I thought I lost my foothold in life [...] When I was deepest down in my depression I considered taking my own life. (ibid.)

As the authors point out, the feelings of insufficiency expressed in this passage depend upon the desire to be 'sufficient, take part and act in relation to the patient's situation' (ibid.). That is, the husband wanted to help his wife to recover and felt insufficient in believing that he could not do so. But we are also in a position to offer another possible interpretation to this sense of insufficiency.

Through our discussion of Aujoulat et. al. (2007b), we saw that illnesses often force individuals to lose a familiar grasp of themselves. If this happens, they can feel that they are no longer able to be themselves. It is possible that we can see a similar experience articulated in the passage quoted above. The husband understands himself as someone who, along with his family, has been in control of things his whole life. Plausibly, his experience of his inability to control the health of his wife is not just a sense of an inability to do something. Rather, it may also be an experience of a disruption of his familiarity with his social standing in such a way that he feels that he can no longer be himself.

Similar experiences are reported by Kars et. al. (2011) in their interpretation of experiences of parents of children with cancer. While they do not discuss experiences of powerlessness explicitly, certain features of the experiences they describe are clearly in line with the key features of experiences of powerlessness that we have already identified. For example, parents express that they experience the child being gradually

lost. Thus, as with the experiences of next-of-kin discussed above, powerlessness is experienced upon a disruption of a familiar grasp of the world, occasioned by a loved one's fading away. Moreover, they experience the death of a child as posing a severe threat to their power to be themselves.

During the curative phase parents and medical staff worked side by side for the survival of the child. The 'treatment failed' message confronts parents with the inescapability of the loss of their child. The dominating feeling is that they cannot let him go; life is meaningless without him/her. (op. cit. 29)

Parents fear their own disintegration (op. cit. 32)

With these examples the authors indicate that the meaning of the parents' lives is intimately wrapped up with the health and security of the child. Thus the loss of the child can be a threat to the very identity of the parents: they might feel that they cannot be themselves, given the loss of the child.

In the face of the decreasing health of the child and the increasing threat to parental identity, parents can strive to maintain the status quo and may even be resistant to unwelcome news that alerts them to the instability of the situation and its tendency toward decline.

As a consequence the outside world, including professionals, can become a threat to their [the parents'] stability. Highly preservative parents showed the greatest tendency to withdraw from their social and health system. (op. cit. 31)

The authors suggest that the desire to preserve the life of the child and the world in which they are able to be the primary carers of the child can blind parents to the changing needs of the child.

For many parents in our study it appeared to be difficult to stay attuned to changes in the child's condition and needs. We identified parents who lagged behind and parents who got ahead of their child's situation. 'Preservative' parents more often lagged behind. Sometimes the difference between parental perception and the real situation resulted in unnecessary suffering for the child or inadequate care. (op. cit. 32)

Thus the authors suggest that the threat of the loss of the child and the accompanying threat of a disintegration of the self can be so strong that parents can 'hold on' to a view of the world in which this threat is not so pronounced. They may desire and seek to exercise control over the situation in order to preserve a sense of stability in the health of the child and their understanding of themselves as parents. This can adversely affect the health of the child.

Sand and Strang (2006) point out that the next-of-kin may also feel existential loneliness, particularly with regards to the responsibility they may feel to care for their loved ones (op. cit., 1383), a result repeated in Milberg et. al (2004).

“It was like being alone in the whole world, you had nobody to talk to although you have children and grandchildren.” [...] (The wife of a 76-year-old patient with prostate cancer that had been cared for by APHC.) (op. cit. 125)

We have noted that a core feature of existential loneliness is the sense of ‘individuation’, that one bears an individual relationship to something of which one had previously had only an abstract grasp. We also noted that one can feel alone in light of the recognition of this relationship. Plausibly, we may find these features present in the next-of-kin’s sense of responsibility for the care of their loved ones. When one feels responsible for someone, one often feels that one cannot simply delegate the duty to someone else. That is to say, one often feels personally called to the task of ‘owning up to’ what one takes to be one’s responsibility, such that one might feel guilty if one passed the task on to someone else. In this sense, being confronted with a sense of responsibility can be individuating, for one feels that one bears a personal, individual relationship to the care of loved one. And rather as one might feel alone in the need to make a decision, so too one might feel alone in responding to the sense of personal responsibility one feels with respect to the care of one’s loved one.

Note, however, that such experiences of existential loneliness in light of a recognition of one’s personal responsibility are not necessarily connected to experiences of powerlessness. After all, it might be precisely because one recognizes the great *extent* of one’s power that one recognizes one’s responsibility and consequently experiences oneself to be alone. We make this point in passing now only to further emphasise the need to work out in more detail the relationship between existential loneliness and powerlessness. For if it is correct that the one can be experienced without the other being present, it is not clear that they are properly considered as two parts of the same phenomenon.

In summary, next-of-kin experiences of powerlessness discussed in the papers presented above appear to reflect key features of patient experiences of powerlessness, inflected by their particular perspective. Rather as patients can feel that they can no longer be themselves and feel profoundly insecure through losing a familiar sense of how to carry on as they had before, so too the next-of-kin can feel as though their identities have been compromised. A husband may be no longer able to act as an organiser; a parent may no longer be able to be the primary source of care. This threat can lead to despair and hopelessness. If and when control is desired, it may be desired in order to maintain the stability of a situation of which the decline cannot be arrested. Moreover, from the evidence we have reviewed it is plausible that the next-of-kin might feel existentially lonely, individuated by the responsibility of caring for the loved one and isolated from others in facing up to that responsibility.



## Section Summary:

- Next-of-kin experiences of powerlessness reflect key features of patient experience of powerlessness:
  - Loss of familiarity with oneself and one's environment
  - Insecurity
  - Disruption of understanding of how to be oneself
  - Existential loneliness
- Next-of-kin can experience the desire to gain control of the situation, often to stabilise inherently unstable situations.
- The desire for control may be linked to a desire to preserve one's understanding of oneself. For instance, the parent may wish to exercise control to maintain his status as the primary care-giver.
- Similar questions remain over the relation of these various features of the experience. For example
  - Is existential loneliness an essential part of the experience of powerlessness?
  - Is it a possible but not necessary feature of such experiences?
  - Or is it a separate phenomenon?

## ii. Carer experiences of powerlessness

In their study of the experiences of powerlessness of burns nurses, Kornhaber and Wilson (2011) show that a number of themes we have already identified are mirrored in different ways in the experience of carers. For example, nurses felt powerless due to feeling inadequate.

It's just this horrible inadequacy that I can't do my job properly, that this patient is showing this emotion and this level of pain that you're angry at them, that you're sad for them. Um, it kind of goes against everything in nursing: you're supposed to help these people and fix these people but you can't. (op. cit. 174)

Similar feelings were also expressed by the psychiatric carers interviewed by Dahlqvist et. al. (2009) as well as the end-of-life care nurses interviewed in a study by Espinosa et. al. (2010):

In addition to feeling abandoned, the nurses reported that they feel powerless and like a failure when their patient does not get well. For example: 'Yeah, it felt like you had failed. I mean, even after a patient codes or doesn't survive, it feels like—like you couldn't do enough. You should have . . . we save lives . . . I mean, that's the way you were taught . . . and then you are withdrawing everything.' (Espinosa et. al. 277)

Once more we see that individuals connected to the dying person feel powerless when they are unable to do something that they understand to be central to a role with which they identify. It is not just that the nurses quoted in these studies felt unable to

complete a particular task, such as healing the patient, it is that their inability to complete this task is perceived as a compromise of their power to be nurses.

While there is clearly a sense of disrupted social status in these experiences, we did not find evidence to suggest that carers experienced disruptions of familiarity across the other dimensions Aujoulat et. al. (2007b) emphasised (i.e. familiarity with one's body, familiarity with one's emotional responses, familiarity with one's environment). This raises questions over the relationship between each individual dimension of the loss of familiarity and the broad experience of powerlessness. For it would seem that a loss of familiarity with a person's social standing brought about by an inability to enact what she understands to be required of her position as a carer may be sufficient for an experience of powerlessness.

Burns unit nurses' experiences of powerlessness also involved a sense of apprehension. Specifically, nurses worried how patients would fare after leaving their care. As well as indicating a concern for the well-being of the patient, we submit that the sense of apprehension could be linked to their sense of inadequacy. If the nurse feels that it is her task to heal the patient, and if she recognises that the health of the patient is at greater risk outside of her care, she may feel apprehensive about the patient leaving her care. Rather as a parent might feel unable to be a parent once his child has left home, so too a nurse might feel her power to be a nurse compromised by a patient stepping out of her care.

Moreover, nurses felt vulnerable in the face of the patient's condition.

Makes you feel a bit vulnerable because ... you know, it can happen to people that are close to me, means it can happen to me. (Kornhaber and Wilson, 174)

The experience of vulnerability expressed here is, arguably, close to those experiences of existential loneliness that we have described above. As we have seen, one of the central features of the experience of existential loneliness is an experience of individuation or, in other words, the feeling that one is singled out as an individual by a unique relation to something in particular. Typically, we understand death as a possibility for human beings without necessarily relating this possibility to ourselves. Experiences of existential loneliness can involve the confrontation of death as something that will happen to oneself, not merely a problem that afflicts members of the species. In the example above, we find that this nurse appears to be expressing an awareness of the possibility that she, personally, could suffer severe burns. Thus at least one of the features of existential loneliness is plausibly also present in the experience of carers.

To summarise, there are several features common to the various experiences of powerlessness we have discussed above, namely: a disruption of familiarity with oneself and one's environment, a loss of security, and a sense of existential loneliness. All of this can leave one feeling that one cannot be oneself. In difficult cases, the sense of powerlessness can be accompanied by depression and hopelessness. There is evidence that some of the central features of the experience of powerlessness are common to the experiences of patients, next-of-kin and carers alike, although they take on different inflections in each case. It is difficult to discern, however, whether there are key differences between experiences of powerlessness in end-of-life care and experiences of powerlessness more broadly in healthcare as we have found no systematic comparison between the two demographics. Moreover, we raised some

particular questions with regards to the relationship between the various features of the experiences of powerlessness that we have described above.

In the following section we shall return to the issue of control. Do the studies that we have examined support the dominant model of powerlessness as a loss of control or do they provide yet further reasons to question it?

#### Section Summary:

- Experiences of powerlessness of both next-of-kin and carers reflect the key features of powerlessness identified by Aujoulat et. al. and Sand et. al.
- Patients, next-of-kin and carers all experience
  - Loss of familiarity (in some respect)
  - Disrupted identities
  - Insecurity
  - Existential Loneliness
  - Hopelessness and depression
- Next-of-kin and carers may also feel insufficient. This may be connected to the sense of disrupted identity.
- Next-of-kin can experience the desire to control the situation.
- While there are similarities between these experiences of powerlessness and those others we have discussed, there is no systematic review of the differences. It is therefore difficult to discern whether there are substantial differences and, if so, whether they are qualitative or quantitative in kind.

#### Questions Raised

- Is existential loneliness connected to the sense of a loss of familiarity and if so how?
- Is existential loneliness an essential feature of experiences of powerlessness in palliative care such that it makes for a *qualitative* distinction between experiences of patients with life limiting conditions and those with non-terminal illnesses?
- Are there other substantial differences between experiences of powerlessness across terminal and non-terminal conditions?
- If so, are such differences qualitative in kind or a matter of degree?
- Does the fact that one can feel powerless through losing familiarity with one's social standing without losing familiarity with one's body, emotional responses, or environment indicate either:
  - that the loss of familiarity with one's social standing is more fundamental; or
  - that one need not lose a familiarity across all dimensions in order to experience oneself as powerless?

## 5. Returning to Control

In section 3 we presented various critical voices to the conception of empowerment-as-control and of powerlessness as a loss of control. In our review of empirical research into patient experiences of powerlessness, however, we have seen that many individuals do become profoundly aware that they do not control their bodies, their environments and other aspects of their lives in light of the experience of

powerlessness. As Aujoulat et. al. (2007b) state, ‘the participants reported that their lives and worlds had become unpredictable, leading them to feel insecure and **out of control**’ (op. cit. 776-7, emphasis added). They also quote a participant who comments ‘Above all, there is an overwhelming feeling of powerlessness . . . the feeling that you are **not in control** of your own life anymore, of your existence, of your future’ (op. cit. 776, emphasis added). Moreover, Kars et. al. (2011) showed that patients’ next-of-kin can become profoundly aware that they do not control the health of those for whom they care and that they may desire to gain control of the situation (op. cit. 31). Beyond these specific examples, research papers are often replete with the language of control. So are those critics of empowerment-as-control we have discussed wrong to oppose that model?

Despite the prevalence of issues connected with control in the literature we have reviewed, there remain at least three reasons for criticising an **exclusive** focus on empowerment-as-control as a response to powerlessness. As we shall also see, however, there are also reasons not to simply jettison this view of empowerment.

Firstly, the key features of experiences of powerlessness—loss of familiarity, increased insecurity, disruption of identity, and existential loneliness—are difficult to explain solely in terms of a loss of control. This is because at least two of these four features can result from an *increase* in control. For example, upon taking up a new position a person might be handed so many new powers and responsibilities that he no longer recognises himself and feels deeply insecure. So too, having attained this powerful position in which he does not feel at home, he might feel existentially lonely through a recognition of his own responsibility. This is roughly what we have in mind when we say that it is ‘lonely at the top’. At least two of the central features of experiences of powerlessness, then, cannot be explained solely in terms of a loss of control, for they may result from an increase of the scope of one’s control. In such cases, increasing control further, rather than helping with experiences of insecurity or existential loneliness, would likely intensify such experiences. If only for this general reason—namely, that powerlessness cannot be explained solely as a loss of control—we should not presume that overcoming powerlessness is simply a matter of increasing patient control.

Secondly, while there is a great deal of evidence to suggest service users do often experience a lack of control, the experience of a lack of control and the consequent desire to gain control are not necessarily indicative of an experience of a loss of control. Indeed, the experience of the desire to gain control may be explained by a loss of familiarity with one’s environment even if one never had control over that environment. Consider the following example. One might recognise that the recession of a cliff-edge is threatening one’s house. As the cliff edge approaches, one might recognise that coastal erosion is out of one’s control and one might desire that one had control. It would, however, be a mistake to conclude that one had lost control of coastal erosion, for one never had control. It might also be a mistake to try bring the erosion under one’s control, for it might simply be uncontrollable. Thus one might perceive erosion as being out of one’s control not because one has lost control of the erosion but because the erosion has started to pose a threat. It makes sense that one might respond to the perception of a lack of control with the desire to gain control. But it does not follow that the correct response would be to try to bring the erosion under control. For it might be that we have only now come to see that we never had control, for such things are uncontrollable.

Similarly, a patient with a chronic illness may feel that his bodily responses, the stability of his capacities, his emotional reactions to the environment, and his environment itself are out of his control. But it would be a mistake to conclude from this impression alone that he has lost control of any of these such that he would be helped if control could be regained. For it may be that he was never in control of his bodily functions to begin with. He may be only now coming to perceive himself as lacking control because his bodily functions have become problematic. In this case, it may well be that the experience of a lack of control is explained by the loss of familiarity with oneself and one's environment. For it is under circumstances of a loss of familiarity with oneself and one's environment that one can become aware that one is not in control and that this lack of control is problematic. But in this case it may also be inappropriate to respond to the patient's sense of a lack of control with an attempt to increase his control, for his sense of a lack is not a sense of a loss.

Thirdly, even if it is the case that an individual feels powerless in the face of a loss of control, it still may be the case that it is inappropriate to try and help that patient regain control. For example, it might be the case that a parent once had some form of control over the health of her child insofar as she was able to administer basic medicines or take her child to the doctor. But circumstances might change such that it is simply impossible for her parent to do anything to arrest the decline of the health of her child. In this scenario, where there is no possibility of a return to control, a focus on empowerment-as-control would quite plausibly be inappropriate. Indeed, expecting individuals to take control of a situation that they cannot control may be not only inefficacious but also cruel.

In summary, while the lack of control is clearly a prominent feature of patient experiences of powerlessness experiences of powerlessness are not all reducible to experiences of a lack of control; experiences of lacking control are not necessarily experiences of a loss of control; even those cases in which the experience of lacking control is an experience of a loss of control, it may still be inappropriate to attempt to help the individual to regain control, for the loss of control may be irreversible. For these reasons, it seems that critics of empowerment as a universal healthcare goal have raised genuine concerns, for increased patient control may not be an appropriate response to all experiences of powerlessness.

#### Mid-Section Summary:

- While the lack of control is clearly a feature of patient experiences of powerlessness
  - Experiences of powerlessness are not all reducible to experiences of a lack of control;
  - Experiences of lacking control are not necessarily experiences of a loss of control;
  - Even in genuine cases of experiences of loss of control, it may still be inappropriate to attempt to help the individual to regain control.
- It may be the case that some experiences of lacking control, which are not experiences of a loss of control, are explained by a loss of familiarity with oneself.

However, these criticisms may be taken too far if, as Salmon and Hall sometimes suggest, they are taken to imply that individuals could never be helped by being given increased control. It is misleading to present empowerment-as-control as

either the *sole* method of intervention into experiences of powerlessness or having no place at all within healthcare. Rather, it is more accurate to present empowerment-as-control as having *limited* value, requiring the specific judgement of practitioners, patients and their families to decide *in which circumstances* increased control would be a worthwhile healthcare goal. We have seen that the central features of experiences of powerlessness include a loss of familiarity with oneself and one's environment, an increased sense of insecurity, and a feeling of existential loneliness. It may be that increasing individuals' control over certain aspects of their own care and environments helps address these features. For example, it may well be that patients experience themselves as powerless because they have lost the power to do certain tasks and the power over certain environments, and that these losses can be addressed by healthcare interventions aimed at increasing patient control. For example, a patient with a chronic condition may be unable to climb down stairs, such that she feels that she can no longer leave the house and as such not in control of her life. An intervention that restored her ability to leave the house by, for instance, installing a ramp in place of the stairs could help.

In light of these considerations, while the exclusive focus on empowerment-as-control seems unwarranted insofar as it may fail to address key aspects of patient experiences of powerlessness, it may be the case that patients are genuinely helped by being given new powers of control, insofar as the increased control addresses the core features of powerlessness we have identified. Thus while empowerment-as-control is no panacea, it may be appropriate to increase individuals' control in some circumstances, if applied in such a way that is tailored to addressing the key experiences of powerlessness we have identified above, namely: a loss of familiarity with oneself and one's environment, a sense of profound insecurity and the coming to the fore of existential loneliness.

#### Section Summary:

- Empowerment-as-control is not necessarily an appropriate healthcare goal in response to experiences of powerlessness.
- Empowerment-as-control may be an appropriate healthcare goal if it is tailored to address the core features of experience of powerlessness: loss of familiarity, increased insecurity, disruption of identity, and existential loneliness.
- Whether empowerment-as-control is an appropriate goal within healthcare is for the judgement of practitioners, dependent on whether they believe it may help address any of the core features of experiences of powerlessness.

## 6. Conclusion

In this paper we have reviewed the state of the art of research into experiences of powerlessness and drawn out some prominent features of those experiences. We have found that the dominant model of empowerment-as-control and the associated conception of powerlessness as the loss of control, while not ungrounded, is not sufficient to capture the full complexity of experiences of powerlessness. Those experiences also centrally involve features that cannot be reduced to a loss of control.



We also found that while the empirical research into experiences of powerlessness is impressively rich and articulate, certain key questions remain, regarding a) the relationship between the various aspects of experiences of powerlessness; and b) the relationship and differences between the experiences of powerlessness of various individuals (the patient, the next-of-kin, and carers) involved in contexts of end-of-life care. These questions are summarised in the appendix to this document.

Before discussing empirical implications of the questions we have raised, we shall return to an issue that we noted towards the end of our discussion of Aujoulat et. al., namely, the question of why the features of the experiences they identify manifest as experiences of *powerlessness*, specifically. As we noted, a disruption of identity may in fact lead a person to feel greatly empowered, as when overcoming an addiction. Moreover, existential loneliness may result from having a great degree of control over a particular situation. For what reason do some experiences of disrupted identity or existential loneliness manifest as an experience of powerlessness, rather than as an example of newfound identity or increased control?

### *Powerlessness and the power-to-be-oneself*

Why do the various features of experiences of powerlessness manifest as experiences of powerlessness, specifically? To begin to answer this question we can ask what we mean by ‘power’. If we have a sense of what power is, we should be able to get a better idea of why those features we have described above manifest as a loss of power. Amy Allen (1998) articulates a distinction between various senses of power, which we can borrow to get a better grasp of the concept.<sup>5</sup> We use the word ‘power’ in different ways. For instance, we can say that a person has it within her power to do something. We can also say that a person has power over another. What is the difference between these senses of power? In sketching out what it means for someone to have power over something, Allen makes use of Robert Dahl’s definition: “A has power over B to the extent that he can get B to do something that B would not otherwise do”. You would not be exercising power over me by telling me to administer your medication if I would have done so anyway. But if I would not have administered the medication without your intervention, then your intervention would be an exercise of power over me. Thus where one person has power over another, the former must be able to make the latter do something he would not otherwise do.<sup>6</sup>

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<sup>5</sup> For a good introduction to the contemporary debate over the nature of ‘power’ see <http://plato.stanford.edu/entries/feminist-power/>

<sup>6</sup> There are further complications. Power-over need not be directly exercised. For instance, you need not march me to the kitchen and plunge my hands into the sink in order to exercise your power over me. You might, instead, present me with a compelling ultimatum. Nor must power-over be intentionally exercised. You might, for instance, self-deceivingly feign illness, thus forcing me to take on a task it was your turn to complete. Nor must power-over be exercised at all. You would still have power over me if, for instance, you had material with which you could blackmail me, even if you never decided to use that material in this way. Nor, finally, must the exercise of power go against the best interests of the person who is made to do something he would not otherwise do. Arguably, a parent might exercise this kind of power over his child. The main point, however, is just that power-over exists between two entities when one is able to make the other do something it would not otherwise do.

In contrast to power-over, Allen defines power-to as ‘the ability of an individual actor to attain an end or series of ends’ (Allen, 34). That is to say, insofar as a person has a goal (an ‘end’, to use Allen’s term) and is able to reach that goal then she has power-to. For example, you might have the power to make a cup of coffee, go for a run, or take your pills. Unlike power-over, in having the power to do something one need not have the power to force anyone to do anything at all. For instance, I have the power to close my eyes. But I need not be exercising power over anyone in acting in this way.<sup>7</sup>

Using Allen’s analysis, we can identify two aspects in which individuals may lack power. Individuals may lack the power to do something within their environments. For instance, a person may lack the power to administer her own medication. She may also lack power over some aspects of her environment. For instance, she may lack sufficient power over her healthcare providers to make them pay attention to her. A person may also lack power in both senses. For instance, she might lack the power to administer her own medication while lacking sufficient power over the service providers to make them administer the medication for her.

Mid-section summary:

- There are various senses of ‘power’. Amy Allen identifies two:
  - Power-over (the ability to make someone do something s/he would not otherwise do)
  - Power-to (the ability to achieve some goal)

The dominant model of empowerment-as-control and the accompanying understanding of powerlessness as a loss of control presupposes the distinction between power-to and power-over. For example, the DoH insists that service users should be given increased powers *to* make choices and to manage their healthcare. Moreover, it insists that service users should be given increased power *over* healthcare institutions, by being ‘empowered’ to ‘demand improvements’ from the NHSE, thereby making the institution do something it would not have otherwise done. For authors who emphasise control as central to experiences of powerlessness, then, it is clear why a loss of control should amount to a feeling of powerlessness. Since *having* control is understood precisely in terms of having certain powers-to and powers-over, to lose that control just would be to lose one’s power.

However, we have seen that it is a mistake to understand experiences of powerlessness exclusively in terms of control. The central features of experiences of powerlessness in end-of-life care are a disruption of familiarity with oneself and one’s environment, a sense of profound insecurity, and the coming to the fore of one’s existential loneliness. Can these features of experiences of powerlessness be just as easily analysed as involving a lack of power-over or a lack of power-to?

While those who experience themselves as powerless do often experience themselves as not having power over certain aspects of their environments (e.g. the parents who desire to control the situation in which their child is dying) and also often

<sup>7</sup> Allen also introduces a third form of power: power-with. Power-with is like power-to insofar as it is an ability to attain an end. But where power-to pertains to individuals, power-with pertains to collectives.

experience themselves as not having the power to do certain things (e.g. the patient who felt unable to socialize as before), it is not clear that it is the lack of power-over or the lack of power-to as such which leads them to feel powerless. This is because not just any lack of power-over or power-to will lead to a feeling of powerlessness. Only the lack of power with respect to some important aspects of individuals' lives and environments will leave them feeling powerless. For example, an illness might rob you of the power to cauterise a wound, but that lack might not by itself leave you feeling powerless if you'd never had call to exercise this power. Furthermore, an illness might rob you of the ability to direct others' actions. But unless this form of power over others is important to you, its absence might not matter at all. What makes the difference between those lacks of power-over and power-to that manifest as experiences of powerlessness and those which do not?

We suggest that there is a third dimension of power, not articulated by Allen, that is lacking in experiences of powerlessness. We will call this dimension 'power-to-be'. As we have seen, patients, next-of-kin and nurses often feel powerless not simply when they lack the ability to do certain things, but when they lack the ability to do certain things through which they feel that they can **be a certain way**. The grandmother felt powerless when she could not hold her grandchild because she felt that this withdrew her **power to be** a grandmother. The husband felt powerless when he could not intervene in his wife's illness because he felt that he no longer had the **power to be** an organiser. Another husband felt powerless when he felt that he lacked the **power to be** a man. A nurse felt powerless when she could not apply bandages without causing pain because she felt that she was **not really being** a nurse. In each case, the inability to do something manifested as a sense of powerlessness when the individuals in question felt that they lacked the power to be a certain way, be it a grandmother, organiser, man, or nurse.

On this proposal, then, individuals experience powerlessness when the lack of power-over and/or power-to results in a lack of power-to-be.<sup>8</sup> This hypothesis requires further elaboration, however. For as it stands it cannot yet explain why patients experience themselves to be powerless. This is because not just any lack of the power to be any particular way will lead one to experience oneself as powerless. Rather as the lack of the power to perform a certain action may well be disastrous for one person but more or less unimportant for another, so too the lack of the power to be a certain way might strike one person as devastating while leaving another person relatively untouched. For example, an illness might deprive two people of the power to drive, such that they no longer have the power to be taxi drivers. But the loss of the power to be a taxi driver might matter a great deal to one person but matter very little (if at all) to another. So the lack of the power to be a taxi driver cannot by itself explain why its lack precipitates a feeling of powerlessness. What we need is an account of why the lack of the power to be something or other might lead to a sense of powerlessness in one person but leave another untouched.

Aujoulat et. al.'s notion of 'disrupted identity' gives us a clue as to how we might proceed. For it is not just any lack of a power to be that leads to a sense of powerlessness, but one that leaves one feeling as though one does not know who one is any more. That is to say, the specific lack of power may not just be a matter of a lack

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<sup>8</sup> For a related suggestion, see Kathy Charmaz (1983) and (1987), in which she argues that chronic illnesses can lead to a crumbling of a 'self-image' that patients can struggle to regain.

of a power to be some way or other, but a lack of a **power-to-be-oneself**. One no longer has the power to be who one took oneself to be. For example, the loss of the power to perform a certain operation might only lead to an experience of powerlessness when the loss of that power compromises one's power to be a surgeon and if one does not know how to be who one is without being a surgeon.

If this hypothesis is correct, then it would explain why the loss of some powers-to-be may not lead to an experience of powerlessness. For, insofar as a person has never taken herself to be a surgeon, the lack of the power-to-be a surgeon, thanks to a loss of the power cauterise wounds, might not manifest as a compromise of her power to be herself. But for one who did identify with that role, the loss of the ability to fulfil it may well be disastrous.

Moreover, our hypothesis can help to answer a problem raised at the end of section 4.a).i. We suggested that a disruption of a sense of self-sameness is not sufficient for explaining why individuals may feel powerless, for one might experience oneself to be greatly **empowered** given a profound change in one's life. Our hypothesis explains why some profound changes in lives may be experienced as engendering powerlessness and others not. Insofar as a profound interruption of self-sameness manifests as a loss of one's **power-to-be-oneself** then this can explain one's feeling of powerlessness. But a profound change might actually enable one to feel as though one has the power to be oneself for the first time. In this case, the profound change may manifest as a sense of real empowerment, insofar as it enables a newfound **power-to-be-oneself**.

Thus we can state our hypothesis briefly:

*The features of experiences of powerlessness that we have identified above manifest as an experience of powerlessness, specifically, insofar as they undermine one's power to be oneself.*

As it stands, this hypothesis may not be sufficient for encompassing all experiences of powerlessness in end-of-life care. The experience of powerlessness as a loss of the power to be oneself may be prominent among those who suffer from an illness. The experiences of powerlessness of those surrounding those with the illness may be different, however. Consider again the example of the husband who felt powerless in the face of his wife's illness. It seems wrong to say that the primary focus of his experience was on his lack of power to be himself. He was concerned primarily with his **wife**, not in the first instance with the loss of himself. Thus there is a danger that exclusive focus on the notion of the power-to-be-oneself may obscure important features of the experiences of powerlessness of carers and next-of-kin, for whom the primary focus of concern is not themselves but, rather, the other who is dying. This issue does not necessarily undermine the importance of the notion of power-to-be-oneself to understand powerlessness, but it does provide a compelling reason to refine the concept and its applications further.

### *Directions for Future Research*

In light of the conclusions of this paper, we can identify several interrelated pathways to further research. Firstly, further work needs to be done to expand and elaborate the fundamental notion of **power-to-be-oneself**. Further conceptual analysis of the power-to-be-oneself that is found to be lacking by those who experience themselves to be powerless will help researchers better understand that which is to be overcome by healthcare interventions aimed at empowerment. Importantly, this research may also lend further weight to the suggestion that the patient should be cared for ‘as a whole’: if the power that is experienced as lacking in experiences of powerlessness is not the loss of any specific power-to or power-over but one’s power-to-be-oneself, then healthcare would have reason to consider the person, broadly conceived, rather than any aspect of the person’s experience.

In concert with this fundamental research, further work is needed in order to

- a) investigate the connections between the various elements of experiences of powerlessness identified above;
- b) further determine the connections and differences between the experiences of powerlessness of patients, next-of-kin, and carers.
- c) develop models of empowerment based on the lessons of the research we have reviewed above. How can the power-to-be-oneself be fostered, or restored, in a health-care setting?

Important work addressing the third point has already been advanced by a number of researchers. Sopcheck (2015), for example, has detailed the recent development of the concept of ‘peaceful letting go’, as it applies in contexts of end-of-life care. Moreover, Aujoulat et. al. (2008) have begun to develop a model of empowerment as a dual process of ‘holding on’ and ‘letting go’. Both studies recognise the limitations of empowerment-as-control and attempt to advance alternatives in light of these limitations. The first study focuses on a response to next-of-kin experiences of powerlessness in light of the loved one’s fading away, while the second study focuses on methods of responding to patient experiences of powerlessness, not specific to contexts of end-of-life care.

While these studies advance our understanding of what alternative approaches to empowerment could involve, similar questions and issues are raised with this research as with that discussed above. For this reason, we submit that this research could benefit from further investigation into the two other questions—a) and b)—we have identified above.

Aujoulat et. al.’s study argues that patients become empowered through ‘holding on’ to their control of some aspects of their lives and environments while ‘letting go’ of their control of other such aspects. In letting go of the desire to control themselves and their environments, patients are able to adjust to changing circumstances, allowing themselves to be ‘a same, yet different’ (op. cit. 1236) person. As we have seen, however, patients are not the only individuals who experience themselves to be powerless in healthcare contexts. Is the process of holding on and letting go a fitting model for intervening in the experiences of powerlessness of next-of-kin and carers alike? Further work on the differences between the different subjects of experiences of powerlessness could help answer these questions.

Moreover, we have seen that there may be substantial differences between the experiences of individuals in contexts of end-of-life care and those in contexts of non-terminal conditions. Is the process of holding on and letting go equally effective in contexts of *end-of-life* care? Sopchek's study suggests that 'letting go' may be the most important concept when it comes to addressing next-of-kin experiences of powerlessness in end-of-life care. This finding is reflected in Kars et. al.'s suggestion that parents of dying children often further harm their children by trying to hold on to the stability of a situation in irreversible decline. Does this point to a substantial difference in the needs of these distinct groups of service users that reflect differences in experiences of powerlessness? Is there any place for 'holding on' in contexts of end-of-life care? Does the process of 'holding on' address the experience of existential loneliness, common in contexts of end-of-life care, and if so how? Further research into the connections between the features of experiences of powerlessness across different contexts could help to advance research in response to these questions.

Furthermore, Aujoulat et. al.'s (2008) emphasis on the importance of patient experience of a coherent self further motivates the need to develop a concept of power suitable to explain why and when coherence could be experienced as specifically **empowering**. This is because there is no relation of entailment between self-coherence, on the one hand, and power-to or power-over on the other. A person (such as a hermit, for example) could have no power over anyone and nonetheless understand herself 'as a whole'. Conversely, a person could plausibly lose self-coherence without losing a power to do something. For example, you might learn a fact about your past which profoundly changes your understanding of yourself, such that you do not seem to be the same person any more. But this need not manifest as a loss of a power: you might be able to get on with just the same tasks that you had undertaken before, and might retain whatever power you had over others. For these reasons, a loss of self-coherence need not coincide with either a loss of power-over or power-to. Thus neither Aujoulat et. al.'s emphasis on self-coherence, nor the usual focus on power as power-over or power-to, are enough to account for experiences of powerlessness. We suggest that the notion of the power-to-be-oneself is a promising lead in this regard.

Finally, it is not clear what exactly is involved in 'letting go' of control and what response this process demands from patients. After all, it does not seem that patients simply have it within their power to let go of the way they have understood themselves. Unlike letting go of a hand, which is a voluntary act, letting go of a way of understanding oneself seems outside of one's control. Rather as one cannot simply decide to no longer be in love, so too one cannot simply decide to no longer understand oneself as a parent, manager, doctor, or husband. This issue raises a further question:

- d) What is involved in letting go of a way of understanding oneself? In which sense(s) can we 'do' something which we cannot voluntarily set out to achieve? What healthcare interventions are appropriate for this specific form of agency?<sup>9</sup>

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<sup>9</sup> All questions explicitly raised in this Green Paper are collated in the attached appendix.



*Green Paper Summary*

We have shown that recent research into experiences of powerlessness has identified four key features of such experiences:

- Loss of familiarity
- Increased insecurity
- Disrupted identity
- Existential loneliness

We suggested that while the dominant model of empowerment-as-control may be appropriate if tailored to address these issues, it should not be taken as a panacea. This is because increased control may not necessarily help address any of these features. Finally, we suggested that the features identified above manifest as a sense of **powerlessness** insofar as they undermine one's **power-to-be-oneself**, though this notion requires further work if it is to be satisfactory. We propose to undertake this work in future research.

## APPENDIX

## Collated Questions in Order of Appearance

1. Is existential loneliness connected to the sense of a loss of familiarity and if so how?
2. Is existential loneliness an essential feature of experiences of powerlessness in palliative care such that it makes for a *qualitative* distinction between experiences of patients with life limiting conditions and those with non-terminal illnesses?
3. Are there other substantial differences between experiences of powerlessness across terminal and non-terminal conditions? If so, are such differences qualitative in kind or a matter of degree?
4. Does the fact that one can feel powerless through losing familiarity with one's social standing without losing familiarity with one's body, emotional responses, or environment indicate either:
  - a. that the loss of familiarity with one's social standing is more fundamental; or
  - b. that one need not lose a familiarity across all dimensions in order to experience oneself as powerless?
5. How should the notion of power-to-be-oneself be further developed?
6. Is the process of holding on and letting go a fitting model for intervening in the experiences of powerlessness of next-of-kin and carers alike?
7. Is the process of holding on and letting go equally effective in contexts of *palliative* care?
8. Does the process of 'holding on' address the experience of existential loneliness, common in contexts of palliative care, and if so how?
9. What is the connection between a loss of coherence of self and a loss of power?
10. What form of agency is involved in letting go of a way of understanding oneself, if not fully active control? What healthcare interventions are appropriate for this specific form of agency?

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