



## Strathprints Institutional Repository

Campbell, Ann and Carrick, Lorna and Elliott, Robert (2013) *A hierarchy of personal agency for people with life-limiting illness*. *American Journal of Hospice & Palliative Medicine*. pp. 2-9. ISSN 1049-9091

Strathprints is designed to allow users to access the research output of the University of Strathclyde. Copyright © and Moral Rights for the papers on this site are retained by the individual authors and/or other copyright owners. You may not engage in further distribution of the material for any profitmaking activities or any commercial gain. You may freely distribute both the url (<http://strathprints.strath.ac.uk/>) and the content of this paper for research or study, educational, or not-for-profit purposes without prior permission or charge.

Any correspondence concerning this service should be sent to Strathprints administrator: <mailto:strathprints@strath.ac.uk>

Final version in press, *American Journal of Hospice & Palliative Medicine*. ©Ann Campbell, Lorna Carrick & Robert Elliott. This is an author final version and may not exactly replicate the final version. It is not the copy of record. Version: 10 August 2013

## **A Hierarchy of Personal Agency for People with Life-Limiting Illness**

Ann Campbell, Lorna Carrick & Robert Elliott<sup>1</sup>

<sup>1</sup> St. Andrew's Hospice, Airdrie, Scotland (Campbell), and Counselling Unit, School of Psychological Sciences & Health, University of Strathclyde, Glasgow, Scotland (Carrick & Elliott).

*Correspondence to:* Professor Robert Elliott, Counselling Unit, School of Psychological Sciences & Health, 40 George Street, Glasgow G1 1QE UK, [robert.elliott@strath.ac.uk](mailto:robert.elliott@strath.ac.uk), telephone: 0044 141 548 3703.

Other author's contact details:

Ann Campbell: [ann\\_b\\_campbell@yahoo.co.uk](mailto:ann_b_campbell@yahoo.co.uk)

Lorna Carrick: [lorna.carrick@strath.ac.uk](mailto:lorna.carrick@strath.ac.uk)

### **Author Notes**

*Acknowledgements.* The authors thank the people who took part in the interviews, and St. Andrew's Hospice, Airdrie, Scotland, for its support for this research. They also thank Seonaidh MacAonghais for help with the audit and feedback on earlier versions.

### **ABSTRACT**

The purpose of the study was to discover how individuals diagnosed with a life-limiting illness experienced themselves as agents, even in the face of death. In this qualitative, multiple case study design four female outpatient hospice patients with terminal illnesses received humanistic counselling to explore their experiences of themselves and their illness. A graded set of 8 levels of personal agency emerged from analyses of the texts of their sessions, ranging from a passive, objectified Non-agentic mode to an active, autonomous Fully Agentic mode, with multiple subcategories representing further gradations within levels. Our results are consistent with guidelines for supportive and palliative care with advanced cancer, which specify that dying patients' needs be assessed and that they be involved in decisions about their care.

*Keywords:* Hospice care; Quality of life; Psychological care; Life-limiting illness; Palliative care, personal agency.

## A Hierarchy of Personal Agency for People with Life-Limiting Illness

### INTRODUCTION

The need to make sense or meaning is never more acute than when one is faced with one's own death<sup>1,2</sup>. The process of dying can bring a person into close contact with their deepest feelings, thoughts and needs, as they experience the shattering of expectations and beliefs long held about self, others and the world<sup>3</sup>. Avoidance or mismanagement of end-of-life discussions can damage psychological well-being in the dying phase of a person's life<sup>4</sup>, and meaning-making interventions have recently emerged as important elements of palliative and end-of-life care<sup>5</sup>.

End-of-life discussions include several key topics, such as prognosis, fears of dying, and goals and plans for the person's remaining time<sup>6</sup>, including resuscitation and place of death<sup>7</sup>. A key implicit dimension of such discussions is the person's sense of self as author in their own life story, referred to as *sense of agency*. Sense of agency is the feeling a person has of themselves as the source and controller of their own actions or thoughts<sup>8</sup>. Sense of agency is not just a philosophical concept<sup>9</sup> but is also represented in the right inferior parietal cortex and temporoparietal junction of the human brain<sup>10</sup>. Humanistic psychologists and psychiatrists conceptualise sense of agency as a key expression of the *actualising tendency*, defined as a drive by the organism to develop and broaden its own individual capacity towards growth and self-enhancement<sup>11-13</sup>.

Conditions such as psychosis or acute life-threatening illness challenge the person's sense of agency, and can recast them in the role of victim in their personal narrative. Sense of agency can also determine the degree to which a person is motivated and able to enter into end-of-life discussions; it is therefore a key dimension in such discussions and indeed in end-of-life care more generally, as evidenced by the recent emergence of palliative psychosocial approaches such as meaning-making interventions<sup>5</sup>.

However, a growing literature on post-traumatic growth indicates that highly distressing, traumatic experiences, such as major losses or life-threatening events, can foster growth within the individual<sup>12,14</sup>. The ultimate trauma is facing the imminent prospect of one's own death in the form of an incurable illness, which thus provokes an unavoidable crisis<sup>15</sup>. In these situations, a key question becomes whether the individual can rediscover or further develop their own agency, in the form of self-definition and self-direction, and move towards a sense of completion and improved quality of remaining life. At the same time, although the capacity to respond to a life concern lies within the particular person, the fragility and uncertainty that accompany adversity present a challenge to the individual and may require a supportive environment to further the search for meaning<sup>12</sup>.

This study focused on personal agency as perceived and communicated by individuals who were diagnosed with life-limiting illness. As we could find no existing empirical research on the expression of human agency as it occurs in the experiences and communications of people in a hospice setting, we set out to investigate how people facing death experience their own personal capacity for agency. That is, we wanted to learn about the range of experiences about themselves as initiators<sup>16</sup> (or not) of meaningful action and self-definition, including re-assessing their new found circumstances, developing better understandings of themselves, and integrating those altered self-understandings.

## METHOD

The data collection method needed to be sensitive to psychologically distressed participants with life-threatening medical illnesses while also bringing out informants' explicit and implied experiences of themselves as agents. Naturalistic counselling, within the person-centred approach<sup>17</sup>, seemed best suited, due to its theoretical stance<sup>18</sup> which is *phenomenological*, focusing on the lived experience of each individual, and *humanistic*, subscribing to the assumption that humans are active agents in their own lives and construction of reality. Person-centred counselling involves the therapist listening and reflecting back -- with as much precision and accuracy as possible -- to what the client is experiencing and communicating, including both surface and deeper meanings. In this study, the counsellor provided an empathic, caring and genuine therapeutic relationship, aimed at providing the psychological freedom and safety needed to support the person in a process of self-exploration, helping them to realise and put into words what was important to them in the context of their illness and life<sup>19</sup>. Sessions were provided by the first author, an experienced person-centred therapist.

Furthermore, to preserve the uniqueness of each participant's perspective, while still identifying possible commonalities, we employed a multiple case study design<sup>20</sup>. From a pragmatic perspective, a series of case studies allows a build up of knowledge that may lead to the emergence of patterns that can indicate a logical chain of evidence, contributing to conditional generalisation<sup>20</sup>. The analysis, while drawing on grounded theory and phenomenological approaches to qualitative research<sup>21</sup>, focused on the ways in which participants made meaning through their language; thus, an interpretive approach<sup>22</sup> was the adopted approach for analysing therapy transcripts, with the aim of identifying the explicit and implicit ways in which the participants experienced themselves as agents.

### Participants

*Patients.* Following general announcements in the hospice setting, 10 prospective participants volunteered and were initially screened. The study screening consisted of a face-to-face discussion of the information and consent materials and lasted 30 to 45 minutes. This face-to-face intake was used to establish the mental state of prospective participants, allowing both the researcher and participant to decide whether they felt comfortable with the offer to participate. Participants were selected if they (a) had a medical diagnosis of a life-limiting illness; (b) were eligible to attend the day hospice where the data were to be collected; (c) were interested, willing and mentally and physically able to undergo a series of counselling interviews; (d) were willing to take part in the research procedures (counselling/audio recording); and (e) were able to give voluntary, informed consent. All 10 volunteers met criteria and agreed to take part; 6 began counselling but only 4 completed enough recorded sessions to provide at least 3 hours of individual therapy transcripts. With intensive data collection and analysis, four participants can provide both the quality and quantity to reach saturation<sup>23,24</sup>. All four participants were white females from the British Isles; their ages ranged from 51 to 61 (see Table 1).

Prior to commencement of study, ethical approval was obtained from the University Ethics Committee, University of Strathclyde. Whilst a Participant Information Sheet ensured that participants understood aims and participation in research, a Participant Informed Consent Sheet confirmed that consent was based on the criteria of physical and mental competence and voluntariness. Signed participant forms were kept in a safe, with audio recordings securely stored in encrypted files on a password-protected computer. To protect confidentiality only limited information

about the participants is reported here, with pseudonyms used and all examples anonymized.

**Table 1**  
**Demographics of the Four Participants**

Participant	Gender	Age at Study	Ethnicity	Previous Occupation	Married Status	Disease
Amanda	Female	57	White Scottish	Homemaker	Married	Progressive Multiple Sclerosis
Barbara	Female	61	White English	Professional	Married	Multiple Myeloma, Chronic renal Disease due to treatment
Dorothy	Female	51	White Scottish	Non-manual	Divorced	Breast Primary Progressive Advanced Terminal: Liver, Lungs, Cerebral
Elizabeth	Female	56	White Irish	Non-manual	Married	Carcinoid Syndrome Metastatic Carcinoma Tumour

*Researchers.* The first author (AC) acted as counsellor and data analyst. She had a degree in psychology, and a post-graduate diploma in person-centred counselling (the qualification for practice in the UK); She is a member of the British Association for Counselling and Psychotherapy and practices with a humanistic theoretical orientation. She is based at the hospice where the data were collected. The second author (LC) trained both in clinical psychology and person-centred counselling, is a senior accredited counsellor, and teaches counselling. The third author (RE) has a PhD in clinical psychology, practices with a humanistic theoretical orientation and has a long-standing interest in the psychology of death and dying.

### **Procedure**

*Data collection.* Each participant reviewed the information and consent forms for the study prior to beginning individual counselling, which lasted four or five sessions. Although the counselling was open-ended and lasted 5 or 6 sessions, only the first 4-5 sessions of counselling were transcribed and used as data for this study, thus providing a picture of patients' initial experiences of personal agency, prior to more extensive counselling. This number of sessions provided an abundance of data for each patient. All sessions took place in a counselling room within the hospice, as chosen by the participants. They determined the length of each session, which lasted from twenty to thirty minutes. Whilst there were no prepared questions, participants were aware of the focus of the study, which was explained to them as an exploration of their

experience of themselves and their personal beliefs, values and goals in relation to their illness; beyond that, focus, pace and agenda were determined by each participant. Although all participants did experience some distress during sessions and were given the opportunity to discontinue the session and recording, each made the decision to continue. At the end of each session there was time for debriefing when the participants were given the opportunity to reflect upon their experience of the counselling.

As noted previously, sessions were undertaken within a respectful, open and empathic person-centred counselling relationship<sup>25,26</sup>, allowing them to address potential psychological problems and spiritual pain, including a realistic and immediate threat to their continued existence. Here, the counsellor (AC) adopted a focused approach in order to follow each participant's experience as it unfolded moment by moment and to encourage them to explore and make sense of their illness, life, and circumstances<sup>27</sup>.

*Data Analysis.* Participants were given the opportunity to check the transcripts of their audio-recorded sessions; they indicated no inaccuracies. Then, under the guidance of the third author, the main analyst (AC) used a combination of standard qualitative data analysis techniques<sup>28,29</sup>: First, she immersed herself in the data, repeatedly reading it. Then she systematically deconstructed the text into meaning units<sup>28</sup> (usually consisting of a sentence or two expressing a specific experience). Next, she determined whether or not a given meaning unit contained information relevant to personal agency (e.g., telling a story about themselves or reflecting on their experience, as opposed to telling about something that happened to someone else). Categories were then formed by describing the kind of agency present in the meaning unit, using one or two words to describe what kind of agent the informant experienced themselves as being (e.g., despairing, fighting). As the categories emerged, the analyst compared them to each other to locate larger grouping of categories. At this point it became apparent that more than anything else the categories varied in the degree of personal agency they evidenced, and point to the existence of a single underlying dimension organized the categories. The primary analyst searched for other ways of organizing the categories (e.g., self-evaluation) but none fit the data well. Saturation<sup>23,24</sup> was achieved: After analysing the first 140 meaning units the full set of 8 main categories and 20 subcategories (representing gradations within levels) had been identified; after this, a further 311 meaning units were analysed and assigned to these categories.

Analysis of each of the four participants was carried out separately, and each participant was shown their own particular results. Each agreed that the naming of categories represented how they individually experienced themselves as agents. Then the results were cross-analysed for consistencies across cases. During this process, the categories, the subcategories, and the overall structure of main categories and subcategories was repeatedly reviewed renamed, and fine-tuned. The result was a graded hierarchy consisting of eight main categories representing a range of self-representations, expressed in degrees of agency, with graded subcategories within most of the main categories. The number of levels of personal agency in terminal illness was determined by the data: We started with "0" for "no agency" and added as many main categories as there appeared to be meaningful distinctions in what participants were telling us.

Four research auditors carefully reviewed the analysis to make sure it accurately represented the data: Initially, the first and third authors (AC and RE), plus a professional quality systems auditor carefully reviewed the categories and subcategories, together with the meaning units under each; discrepancies were

discussed to consensus. Then, as a final check, the second author (LC) thoroughly reviewed the analysis yet again, with further discussion to consensus.

## RESULTS

Results indicated the extent to which individuals in palliative care are not just products of their life givens but actively assess their constraints, make judgements about their capabilities and bring about desired effects through their own initiation. The main categories emerging from the analysis formed a hierarchy of personal agency in terminal illness and were each given a numerical value, ranging from zero to seven, indicating levels of agency: 0. *Non-agentic*, 1. *Limited*, 2. *Reflexive*, 3. *Collective*, 4. *Reacting*, 5. *Willing/Wanting*, 6. *Enriched*, and 7. *Fully agentic*. Subcategories emerged within the majority of main categories and contributed additional, useful information; they were ranked accordingly, as shown in Table 2, which also displays examples of each.

**Table 2**  
**Hierarchy of Experiences of Personal Agency in Relation to Life-Limiting Illness**

Agency Level	Categories: Main and Subcategories	Participant Quotes
<b>0</b>	<b><i>Non-Agentic Self</i></b>	
	0a Objectified (A, B, D, E)	“I was this quivering wreck” (D)
	0b Despairing (A, B, D, E)	“... it was the blackest moment” (D)
	0c Disappearing (B, D, E)	“It’s ... life-limiting ...” (E)
<b>1</b>	<b><i>Limited Self</i></b>	
	1a Bodily-Limited (A, B, D, E)	“Muscles had gone ... there was nothing” (A)
	1b Non-Functional (A, B, D, E)	“Your inability to do nothing” (B)
	1c Strongly Puzzled (A, B, D, E)	“[Trying to] get my head round that” (D)
	1d Detached (A, B, D, E)	“Like up on the ceiling looking down” (D)
<b>2</b>	<b><i>Reflexive Self</i></b>	
	2a Changed (A, B, D, E)	“Because that was definitely not me” (D)
	2b Defiant (A, B, D, E)	“But I am not a defeatist” (B)
<b>3</b>	<b><i>Collective Self</i></b>	
	3a Relinquishing (B, D, E)	“They are making the right decisions” (D)
	3b Actively Collaborating (A, B, D, E)	“Thank-you for listening to me” (B)
<b>4</b>	<b><i>Reacting Self</i></b>	
	4a Avoiding (B, D, E)	“Pushing them away ... subconsciously” (D)
	4b Coping (A, B, D, E)	“To live with the things I cannot change” (B)
	4c Morally Evaluating (A, B, D, E)	“More grateful for what you’ve got today” (E)
<b>5</b>	<b><i>Willing/Wanting Self</i></b>	
	5a Motivated (A, B, D, E)	“Needed to be in ... the land of the

		living” (D)
	5b Imagining (A, B, D, E)	“I may be able to walk without my sticks” (B)
	5c Fighting (B, D, E)	“I’m not going down without a fight”(D)
<b>6</b>	<b><i>Enriched Self</i></b>	
	6a Historic (A, B, D, E)	“I wanted people to treat me normal”(D)
	6b Accepting/ Transcending (A, B, D, E)	“We live through our sons.... daughters” (A)
	6c Joyfully Engaged (B, D, E)	“The world is a beautiful place” (B)
<b>7</b>	<b><i>Fully Agentic Self</i></b> (A, B, D, E)	“I live my life to the fullest” (E)

Note. A, B, D, E refer respectively to participants Amanda, Barbara, Dorothy and Elizabeth.

*Level 0.* The *non-agentic self* represented the lowest level of agency. Results show how participants expressed themselves, within that category, as agentless, with no perceived capacity to engage in a process of self-evaluation in order to cope with their impending end of life. Thus, Barbara, who presented symptoms of multiple myeloma, experienced herself as “emotionally bare” and thus *objectified* in the face of powerful, external forces (Level 0a). Experiencing intense existential *despair*, Amanda, who presented symptoms of progressive multiple sclerosis, wanted to give in and die: “I’ve had enough. I can’t take any more.” (Level 0b). Threatened by the inevitable, approaching *disappearance* of her existence, Dorothy, whose prognosis was described as “terminal”, expressed her experience of being consumed by disease and death: “...that was it...my life was over.” (Level 0c).

*Level 1.* As *limited selves*, participants assessed the boundaries of their capacity for personal agency within their world and while aware of their terminal illness, their internal organising processes were unable to react to incoming information to allow themselves to adapt or cope. This could take different forms: First, aware that her physicality had been rendered vulnerable by disease and pain, Barbara saw herself as *bodily-limited*, describing herself as “...not being able to move” (Level 1a). Second, they perceived themselves as inept and *non-functional*; for example, Dorothy, reported a state of helplessness: “I had no control...over what I was saying...over my thoughts...over my body...” (Level 1b). Third, at a loss to understand their dilemma, the informants expressed feeling troubled and *strongly puzzled*, in a now uncertain world, as communicated by Amanda: “I couldn’t believe her [nurse from her place of work]... What am I going to do now?...” (Level 1c). Fourth, participants found, however, that by adopting the disengaged stance of observers, they could *detach* themselves from the what was happening to them: “...like an out-of-body experience..” (Level 1d; Elizabeth, diagnosed with carcinoid syndrome and metastatic carcinoma tumour).

*Level 2.* With *self as reflexive*, participants were more self-aware and, even in the face of death, they experienced an internal agency, manifested in their striving for self-preservation. Their focus turned back on their lived experience and themselves as experiencing people: (a) Participants experienced themselves as *changed*, with their identity prior to their illness replaced by another identity that brought with it feelings of loss and lack of personal control. For example, Elizabeth was aware of the threat to her continuity: “I lost my whole identity. I became another person.” (Level 2a). (b)



However, participants also communicated their *defiance* of the limitations, the self-defeating attitudes, and the negative stereotypical images of people who have a life-limiting illness (Level 2b). Thus, whilst Elizabeth acknowledged a change of identity, she also experienced herself as standing up to illness and death: “Right up to the end I will fight...this cancer.”

*Level 3. The collective self:* The experience of a life-limiting illness prevented participants from living their lives with individual autonomy and thus they sought what they needed through collaboration with others. On the one hand, participants chose to *relinquish* their autonomy to appropriate professionals who they expected would respond prudently to their needs (Level 3a). For example, Dorothy chose to relinquish her autonomy because: “...You ...put faith in your doctors....Whatever they are putting into me is keeping me alive.” On the other hand, Elizabeth chose to *actively collaborate* through exercising collective agency/efficacy with helpful professionals: “The...Doctor...I’m going to see if I can see him sooner and explain...” (Level 3b).

*Level 4. As reacting selves,* participants sensed and internally responded to their specific circumstances, expressing recognition, identification and appreciation of their incurable disease. This included first of all *avoidance*, which enabled them to contain their anxiety by staying away from truths about their reality in order to not become overwhelmed (Level 4a). This experience of reacting to circumstances without full awareness was expressed, for example, by Elizabeth: “...the Doctor....no, he couldn’t possibly have been talking to me....” Alternatively, participants *coped*, by consciously assessing their physical, psychological and social resources, in relation to their particular circumstances; they thus selectively affirmed those aspects of their illness they perceived as positive and complained and protested about those they identified as negative (Level 4b). For example, Dorothy reported: “...It doesn’t matter ...what treatment they give you...if you give up hope that just pulls you down.” Finally, as *morally evaluating selves*, participants mentally engaged in a process of self-regulation that helped them to keep track of what they felt was appropriate in their circumstances (Level 4c). Moreover, they showed concern for others who shared similar circumstances and aligned themselves to causes they saw as honourable or worthy, such as participating in drug trials. For example, Elizabeth stated: “...If I test the drug and it is good then I can think of all the people in the future that it is going to help.”

*Level 5. As willing/wanting selves* participants, even within the dying phase, were pro-active and purposeful, allowing themselves to experience their desire or need to initiate action, even if the action was not necessarily implemented. This took three forms: (a) Participants were *motivated* to reinforce their own effectiveness from the perspective of wanting to continue their identity and activities, communicating this through personal wishes, desires and hopes (Level 5a). For example, Barbara experienced self as goal-oriented, wanting to continue to take part in activities: “...I still have the ...desire to go and do things....all the time...” (b) Another form of willing/wanting was *imagining*, which went beyond exploring options to project self mentally into the future, musing on what could happen or what could be (Level 5b). For example, Amanda vividly wished for: “...just an hour to walk in high-heeled shoes.” (c) Participants also at times began to believe in their self-efficacy, which helped them to remain resilient in the face of adversity, expressing a *fighting self* (Level 5c). Dorothy, for example, reported: “....I’ll fight it as long as I possibly can, and so far so good.”

*Level 6. As enriched selves,* participants continued to be aware of their impending finality but developed their capacity for autonomy, even if through their

thoughts and attitudes. They engaged in a dialectic between the partial restoration of their historic or normal self and an accepting/transcending future self, thus giving rise to an enriched, joyful, present self. First, they wanted to restore themselves to the self they had been before the life-limiting illness, and so they tried to connect to their *historic selves* through memories of the self they had previously known (Level 6a). For example, Barbara said: “I am grateful for the little glimpse I’ve got of what I had.” Second, participants *accepted* themselves as finite beings: rather than deny or ignore the threat to their existence, they chose to transcend it by imagining some form of after-life, mostly through children and grandchildren (Level 6b). Thus, for Amanda death was not the end: “...when our bodies [are] used up we’ve served our purpose here... You live through grandchildren... Traits ...and genes get passed on...” Third, with full awareness of their finiteness, participants expressed *joyful engagement*, with an intensified delight in the time they had left, turning their attention towards internal satisfaction and the intrinsic rewards of understanding, contentment and harmony (Level 6c). That experience of joy as a result of purposefully engaging in life was experienced by Barbara: “I am so enjoying this remission....It’s just amazing.”

*Level 7. As fully agentic selves*, participants, even although in palliative care, were not content to live as individuals moulded by their limit-situations. Participants were aware of the limits of their agency; however, determined not to remain as disabled selves, they chose to live authentically, as best they could, reporting that they did not perceive themselves as either blindly driven by their circumstances or devoid of plans and goals. For example, the choice to progress forward, by actively engaging in life, was stated by Amanda: “So I looked [at] the paper and I found the (...) Group. I phoned first. I spoke to the woman....I went.” Dorothy, with optimism and awareness of her situation, experienced herself as an active autonomous being and reported: “So I live my life to the best of my ability....under the circumstances...”

Figure 1 depicts these categories and subcategories as a hierarchy of levels of personal agency, representing how participants, diagnosed with a life-limiting illness, communicated the experiences of themselves as agents, to varying degrees. Each participant experienced all of the main types of agency, although particular participants experienced some types more often, with participants advancing and regressing between categories and subcategories. The hierarchy provides a framework for understanding a key dimension of the dying process, the gradations of personal agency in individuals in palliative care.

## DISCUSSION

In the UK, the NICE Guidelines for supportive and palliative care for adults with cancer<sup>30</sup> specify that dying patients’ needs be assessed and that they be involved in decisions about their care: “Patients want to be treated as individuals, with dignity and respect, and to have their voices heard in decisions about treatment and care”<sup>30(p. 3)</sup>. Policies like this assume and even depend on people faced with a terminal, life-limiting illness retaining a sense of personal agency.

According to psychiatrists, psychologists, linguists and philosophers, personal agency is a fundamental aspect of human experience: For example, K. Goldstein’s<sup>11</sup> early work on self-actualization inspired later humanistic psychologists ranging from Rogers<sup>31</sup> to Maslow<sup>32</sup>, while the linguistic and philosophical distinction between “agent” (the originator of action)<sup>16</sup> and “patient” (the object of action) is recognized as a basic feature of human language and experience<sup>33,34</sup>.

At the same time, the graded set of categories and subcategories that we identified is not a generic view of personal agency, but appears to be very specific to

patients' experiences of personal agency in the face of a terminal illness. The identification of a complete range of experiences of agency in a small sample of people facing the ultimate extinction of their ability to act as agents provides a kind of proof of concept for the argument that agency is all-pervasive in human experience. If people are able to experience themselves fully as agents in their life and death, then it is important always to take seriously and respect people's agency, even to the point of death from a terminal illness.

When we set out to study hospice patients' experiences of personal agency we expected to find a set of categories pointing to different aspects or kinds of agency. We did not expect to find a graded set of categories pointing to an underlying dimension. In retrospect, it seems logical enough, but it was not what we expected, and thus more like a discovery than a construction of the data.

Still, the results that emerged were based on the lived experiences of three hours of counselling in each of four patients. Although small samples can be enough to identify universal aspects of human experience<sup>35</sup>, in our view this is a limitation of our study, which thus needs to be replicated with a larger number of participants. Moreover, patients were involved in a form of counselling that emphasizes client agency, so it is possible that some of our results may reflect effects of the treatment. Further investigation with a different sort of psychosocial interview, such as psychodynamic or cognitive-behavioural might yield different results. Exploring this topic with dying patients in other psychological treatments or even other aspects of their lives is important for replicating and providing a context for what we have reported here.

Beyond the need to replicate and extend our research, we recommend measure research developing and testing the graded personal agency hierarchy presented here into a clinical rating scale to be used by health care workers in palliative care settings. A further application would be the development and testing of self-report measures of perceived personal agency in terminal or other severe, chronic medical conditions. Such measures could then be used to predict adherence to prescribed treatment regimes or disease prognosis, given that personal agency may be related to psychological hardiness, which has been found to predict coping with chronic illness<sup>36</sup>. In addition, level of personal agency appears to be a promising variable for use in outcome research on the efficacy of agency-focused psychosocial interventions for supporting patients with terminal illnesses, in palliative care and elsewhere.

### **Implications for Practice**

Although in need of replication, the work presented here has several practical implications. To begin with, the personal agency hierarchy (or systematic, validated measures based on it as described above) could be used in palliative care settings to assess the level of patient agency at intake and to monitor changes in personal agency over time and in response to illness phase, medical interventions and psychosocial treatments.

Most centrally, it is important to recognize and support patient agency within hospice settings<sup>30</sup>. We recommend that hospice staff be trained to listen for, recognize, validate, and actively support personal agency in their patients, and to avoid regarding them exclusively in terms of physiological disease processes. Lower levels (levels 0 & 1) of the agency hierarchy probably signal the need for psychological treatment, while the middle levels could be supported by medical staff attuning to and supporting movement up the scale. Moreover, treatment planning by health care professionals can foster personal agency by systematically offering patients choices about their care and

support for decision-making. The graphical representation of the hierarchy, including the numeric categorisation, could also provide a common language for information exchange among healthcare professionals in an interdisciplinary team, promoting the implementation of intervention plans associated with, for example, pain control and psychological treatment. Further, stepwise models like the personal agency hierarchy we have described can be used to guide intervention by defining zones of proximal development<sup>37</sup> at or just above the person's current status; for example, if a patient is currently at stage 2 (Reflexive), then they are likely to be receptive to stage 3 (Collaborative) interventions.

More generally, however, there is a role for treatments that empower patients and support their sense of agency, including humanistic approaches that traditionally have championed human agency. Examples include traditional approaches such as person-centred counselling<sup>17</sup>, which has always promoted client self-directedness and autonomy, and existential psychotherapy<sup>2</sup>, which emphasizes free will and responsibility in the face of human mortality. In addition, more recent developments have focused more on medical populations, including patients with serious or terminal illnesses; two examples of these are supportive-expressive group therapy<sup>38</sup>, and dignity therapy<sup>39</sup>. In all of these approaches, the psychotherapist or counsellor plays an important role in the palliative care team, helping the patient to unfold their internal experience moment-by-moment, continually supporting them in exploring their personal meanings, to make sense of their current circumstances, and to exercise their personal agency for as long as they are able to do so.

## REFERENCES

1. Stolorow RD. *World, Affectivity, Trauma: Heidegger and Post-Cartesian Psychoanalysis*. New York: Routledge; 2011.
2. Yalom ID. *Existential Psychotherapy*. New York: Basic Books; 1980.
3. Janoff-Bulman R. *Shattered assumptions*. New York: Free Press; 1992.
4. Larson DG, Tobin DR. End-of-Life Conversations: Evolving Practice and Theory. *JAMA*. 2000;12: 1573-1578. doi: 10. 1001/jama.284.12.1573
5. Henry C, Wilson J. Personal care at the end of life and after death. *Nursing Times*. 2012; 108: online issue.
6. Balaban RB. A Physician's Guide to Talking About End-of -Life Care. *J Gen Intern Med*. 2000;3:195-200. doi: 10.1046/j. 1525-1497.2000.07228.x
7. Chapple A, Evans J, McPherson A, Payne S. Patients with pancreatic cancer and relatives talk about preferred place of death and what influenced their preferences: a qualitative study. *BMJ Supportive & Palliative Care*. 2011;1:291-295. doi: 10. 1136/bmjspcare- 2001-000091
8. Jeannerod M. The mechanism of self-recognition in human. *Behavioral Brain Research*. 2003;142:1-15.
9. Sartre J-P. *Being and Nothingness*. Tr. Hazel Barnes. New York: Washington Square Press;1992.
10. Farrer C, Franck N, Georgieff N, Frith CD, Decety J, & Jeannerod M. Modulating the experience of agency: a positron emission tomography study. *NeuroImage*. 2003;18:324-333.
11. Goldstein K. *The Organism*. New York:World Book; 1939.
12. Joseph S, Linley PA. Positive adjustment to threatening events: An organismic valuing theory of growth through adversity. *Review of General Psychology*. 2005;9:262-280.

13. Rogers CR. A theory of therapy, personality, and interpersonal relationships, as developed in the client-centred framework. In: Koch S, ed. *Psychology: A Study of a Science 3: Formulations of the Person and the Social Context*. 1959; 184-256.
14. Cordova MJ, Cunningham LLC, Carlson CR, Andrykowski M. Posttraumatic growth following breast cancer. A controlled comparison study. *Health Psychology*. 2001;20:176-185.
15. Weissman DE. Decision making at a time of crisis near the end of life. *JAMA*. 2004;14:1738-1743. doi:10.1001/jama.292.14.1738
16. Bandura A. Toward a psychology of human agency. *Perspectives on Psychological Science*. 2006;1:164-180.
17. Rogers CR. *On becoming a person*. Boston: Houghton Mifflin; 1961.
18. Sanders P. Ed. *The person-centred primer*. Ross-on-Wye: PCCS Books; 2006.
19. Bryant-Jefferies R. *Counselling for death and dying: Person-centred dialogues*. Oxford: Radcliffe Publishing; 2006.
20. Yin RK. *Case Study Research: Design and Methods*. 4<sup>th</sup> ed. London: Sage; 2009.
21. Creswell JW. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. 2<sup>nd</sup> ed. London: Sage Publications; 2007.
22. Packer MJ, Addison RB. Eds. *Entering the circle: Hermeneutic investigation in psychology*. Albany, NY: SUNY Press; 1989.
23. Bowen GA. Naturalistic inquiry and the saturation concept: A research note. *Qualitative Research*. 2008;8:137-152.
24. Morse JM. The significance of saturation. *Qualitative Health Research*. 1995;5:147-149.
25. Rogers CR. The necessary and sufficient conditions of therapeutic personal change. *Journal of Consulting Psychology*. 1957;21:95-103.
26. Schmid PF. "The necessary and sufficient conditions of being person-centred": On identity, integrity, integration and differentiation of the paradigm. In Watson JC, Goldman RN, Warner MS, eds. *Client-Centred and Experiential Psychotherapy in the 21<sup>st</sup> Century: Advances in theory and practice*. Ross-on-Wye: PCCS Books; 2000:36-51.
27. Elliott R, Watson JC, Goldman RN, Greenberg LS. *Learning Emotion-Focused Therapy*. Washington, DC: American Psychological Association; 2004.
28. Wertz FJ. Phenomenological research methods for counselling psychology. *Journal of Counselling Psychology*. 2005;52:167-177.
29. Corbin J, Strauss A. *Basics of qualitative research: Techniques and procedures for developing grounded theory*. 3<sup>rd</sup> ed. Thousand Oaks, CA: Sage; 2008.
30. National Institute for Clinical Excellence. *Improving Supportive and Palliative Care for Adults with Cancer: Full Guidelines*. 2004. Online: <http://guidance.nice.org.uk/CSGSP/Guidance/pdf/English>
31. Rogers CR. *Client-centred therapy*. London: Constable; 1951.
32. Maslow AH. *Toward a Psychology of Being*. New York: D. Van Nostrand Company; 1968.
33. Givón T. *Functionalism and Grammar*. Amsterdam: John Benjamins Publishing; 1995.
34. Taylor R. Agent & patient: Is there a distinction? *Erkenntnis*. 18;2:223-232.
35. Giorgi A. An application of phenomenological method in psychology. In Giorgi A, Fischer C, Murray E. eds. *Duquesne Studies in Phenomenological Psychology 2*. Pittsburgh, PA: Duquesne University Press. 1975.
36. Brooks MV. Health-related hardiness and chronic illness: A synthesis of current research. *Nursing Forum*. 2003;38[3]:11-20.

37. Vygotsky LS. *Mind and society: The development of higher psychological processes*. Cambridge, MA: Harvard University Press; 1978.
38. Spiegel D, Bloom JR, Yalom I. Group support for patients with metastatic cancer. *Archives of General Psychiatry*. 1981; 38: 527-533.
39. Tait GR, Schryer C, McDougall A, Lingard L. Exploring the therapeutic power of narrative at the end of life: A qualitative analysis of narratives emerging in dignity therapy. *BMJ Supportive & Palliative Care* 2011;1:296-300.doi:10.1136/bmjspcare-2011-000051

Figure 1

