# Persona Professional Diploma in Counselling and Psychotherapy AUDIO/ASSIGNMENT COVER SHEET

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Assignment Title: Research Project: What is the purpose of Person-Centred Counselling at the of end of life?

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# **Declaration of Intellectual Integrity:**

I submit this work as my own, and have read Persona's academic regulations relating to assignments and declare that this work complies with those regulations.

Signed Bill Paterson Date Submitted: 14 March 2023

If I can provide a certain type of relationship, the other will discover within himself the capacity to use that relationship for growth, and change and personal development [...] By this I mean whatever his feelings—fear, despair, insecurity, anger, whatever his mode of expression—silence, gestures, tears, or words; whatever he finds himself being in this moment, he senses that he is psychologically *received*, just as he is, by the therapist.<sup>1</sup>

#### Introduction

This essay has afforded me the opportunity to identify and review some of the current research findings on the emotional/psychological distress experiencing at the end of life, and the interventions developed to *treat* the distress of the dying. I've found there is a dominance of directive/teaching interventions. Validating these interventions is evidence drawn from small studies, including Random Clinical Trials (RCT). With one exception, there is an absence of any Person-Centred Approaches (PCA) in this review of research. This has encouraged me to reflect again on the quality of the space a non-directive PCA offers clients to be psychologically *received*. At its best, I would argue that it provides a 'relationship of equals', such that psychological contact is empathetic, non-judging and deep human connection is possible. I think such a relationship empowers a client to be vulnerable, and to experience and communicate what is uniquely important to her at the end of her unique life. I think this is the purpose of PCA at the of end of life. This is not to deny the utility of these directive approaches as they may enable clients that cannot engage in psychological contact.

To develop this argument, the essay is constructed in the following manner. Firstly, I will explain my rationale for choosing the topic by reflecting on my experience of working on placement with a client that has a fatal diagnosis. This has caused me to reflect on my beliefs, my learning around relations of power and what I am supposed

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<sup>&</sup>lt;sup>1</sup> Carl Rogers (1961) *On Becoming a Person*. Boston, Hougton Mifflin; p. 130.

to be doing in these sessions. With the research question defined I will then explain the process of developing my systematic literature review. From the key words and scope of the search I then critically examine the literature that emerged. I identify the dominance of directive approaches over non-directive approaches to counselling. I then explain how this review has provoked me to reflect on creating 'a relationship of equals', to consider the PCA writing on 'the space between', embodied empathy and congruence, and to apply this to my clinical practice and personal relationships. If I accept a phenomenological approach and the importance of developing 'a relationship of equals', it draws me to conclude that clients ought to have access to both these directive and non-directive approaches to meet the diverse psychological needs of clients. Finally, I explain how I would use the review of this literature to create a small research project to evaluate the impact of PCA for clients at the end of life.

## Rationale for the research question

My rational for this research question comes from my learning about Buddhist teachings and practices for living and dying; practicing an approach to therapeutic change that is embedded in secular mindfulness and compassion training;<sup>6</sup> and my experience as a person-centred counsellor in training. Buddhist philosophy informs my sense of spirituality and gives meaning to my living and dying.<sup>7</sup>. For example,

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<sup>&</sup>lt;sup>2</sup> See Rose Cameron (2002) 'In the Space Between', in Wyatt et al (2001) *Rogers' Therapeutic Conditions: Evolution, Theory and Practice* Volume 4: Contact and Perception; PCCS Books Ltd. Monmouth, p. 259.

<sup>&</sup>lt;sup>3</sup> Mick Cooper (2001). 'Embodied empathy', in S. Haugh & T. Merry (Eds.), *Empathy* (pp. 218-229). Ross-on-Wye: PCCS Books.

<sup>&</sup>lt;sup>4</sup> Jeffrey H. D. Cornelius-White (2007) 'Congruence: An integrative five-dimension model', in *Person-Centered and Experiential Psychotherapies* 6(4), pp.229-239.

<sup>&</sup>lt;sup>5</sup> Mick Cooper and John Mcleod (2011) *Pluralistic Counselling and Psychotherapy*. Los Angeles: Sage.

<sup>&</sup>lt;sup>6</sup> Mindfulness Based Cognitive Therapy, Mindfulness Based Living Course, Compassion Based Living Course. I am registered with the British Association of Mindfulness-Based Approaches (BAMB). Four years of practice with Alistair Appleton's somatic practice.

<sup>&</sup>lt;sup>7</sup> See Yongey Mingyur Rinpoche (2020) *In Love with the World: A Monk's Journey Through the Bardos of Living and Dying.* New York: Random House; Chodron, Pema (2019) *Embracing the Unknown: Life Lessons from the Tibetan Book of the Dead* Audio CD – Unabridged. Sounds True Inc; Unabridged edition, 5 Mar. 2019. Accessed 6 Feb. 2023.

death is described as not only the end of the flesh and blood, but also the end of the personality/ persona/ identity of the individual. All that remains after death is the consciousness".8 Similar to Rogers there is a belief that this "consciousness is but a fragment of a cosmic consciousness, the fragment being absorbed into the whole upon the death of the individual".9 Amongst others, Chodren teaches the key practices to prepare for living that can be practiced when dying so that fear or terror are limited, and the potential for enlightenment or reincarnation are at their optimum.<sup>10</sup> Irvin Yalom points out that "Death anxiety is the mother of all religions [...] attempts to temper the anguish of finitude. [...] it softens the pain of mortality through some vision of everlasting life but also palliates fearful isolation by offering eternal presence".<sup>11</sup> Maybe so, but I think it also raises the question of what does a personcentred approach offer those that are dying?

Studying for my Diploma in PCA to Counselling, I have come to understand that Buddhism, mindfulness and compassion training are very directive teaching methods creating hierarchical power relations.<sup>12</sup> As Gillian Proctor, points out most psychological distress is created by the experience of powerlessness, and so "A key aim in person-centred therapy relationships is for the therapist not to dominate the client and be an expert, but to create a relationship of equals".<sup>13</sup> Penny Natiello reinforces this point stating "Rather than guiding, manipulating, or directing clients, [...] instead they create the conditions where they can claim their personal power and

<sup>&</sup>lt;sup>8</sup> Pema Chodron (2019) Embracing the Unknown: Life Lessons from the Tibetan Book of the Dead Audio CD

<sup>-</sup> Unabridged. Sounds True Inc; Unabridged edition, 5 Mar. 2019. Accessed 6 Feb. 2023.

<sup>&</sup>lt;sup>9</sup> Carl Rogers (1980) 'Speaking Personally', in Howard Kirschenbaum & Valerie L. Henderson (Editor) *The Carl Rogers Reader*; Robinson; Reprint edition (23 April 1990): p. 50.

<sup>&</sup>lt;sup>10</sup> Pema Chodron (2019) *Embracing the Unknown: Life Lessons from the Tibetan Book of the Dead* Audio CD – Unabridged. Sounds True Inc; Unabridged edition, 5 Mar. 2019. Accessed 6 Feb. 2023.

<sup>&</sup>lt;sup>11</sup> Ivan D. Yalom (2009). *Staring at the Sun: Overcoming the Terror of Death*. San Francisco: Jossey-Bass, p.

<sup>&</sup>lt;sup>12</sup> Gillian Proctor (2017). *The Dynamics of Power in Counselling and Psychotherapy: Ethics, Politics and Practice.* 2nd ed. Monmouth: Pccs Books, p. 72-97.

<sup>&</sup>lt;sup>13</sup> Gillian Proctor (2017). *The Dynamics of Power in Counselling and Psychotherapy: Ethics, Politics and Practice.* 2nd ed. Monmouth: Pccs Books, p. 5.

discover their own answers".<sup>14</sup> Therefore, the challenge for me throughout my 140 hrs of clinical placement has been to put down my old habits of directive teaching and inquiry, and to learn and trust the non-directive art of meeting clients with the six necessary and sufficient conditions to create a relationship of equals.<sup>15</sup> This has been at the fore of my mind whilst reading for and writing this essay.

Professionally over the last two years I have worked with two clients that have received a fatal diagnosis. The first approached me in my capacity as a mindfulness teacher. He asked me to teach him how to accept his diminishing health and ultimate death through mindfulness and compassion practices. He has found this transformative and comforting. The second is a client that has been allocated to me at my clinical placement. As a person-centred counsellor in training, I have sat with this client as she is trying to make sense of her life and the terror of death. Given how helpful my last dying client found the practices on acceptance and compassion, it has been a struggle to maintain a non-directive approach. On more than one occasion I have thought to myself "what should I be doing?". Consequently, the question arose "What is the purpose of Person-Centred Counselling at the of end of life?".

#### Details of my systematic literature review

In researching this question, I had to accept some limitation. Firstly, I do not have access to a university library catalogue and search engines. Secondly the absence of access to a university also limits my access to free publications. In this respect I acknowledge that this is less than a systematic literature review. However, what I have done is to explicitly detail the methods I have employed in my search with the

<sup>&</sup>lt;sup>14</sup> Penny Natiello (2002). *The Person-Centred Approach: A Passionate Presence*. Ross-On-Wye: Pccs Book, p. 11.

<sup>&</sup>lt;sup>15</sup> Carl Rogers (1957) 'The Necessary and Sufficient Conditions for Therapeutic Change', in Howard Kirschenbaum & Valerie L. Henderson (Editor) *The Carl Rogers Reader*; Robinson; Reprint edition (23 April 1990): p.219-235.

aim of producing reliable and replicable results.<sup>16</sup> Given these caveats, I have relied on two search engines Google and Google Scholar using specific terms. The terms 'counselling', 'psychotherapy', and 'psychology' were included as key words in the search because they all provide interventions for psychological distress at the end of life.<sup>17</sup> The term 'meta-analysis' was also included to identify any publications that had already conducted a literature review of these terms. In all the key terms that emerged from the research question were 'person-centred', 'counselling', 'psychotherapy', 'psychology', 'end-of-life care', 'death' and 'meta-analysis'.

Given the word count limitations of the essay, I have only considered the top ten results since 2019. Then I read through the abstracts, and removed those articles that did not contain the key terms. I have only accessed the publications that were free. Of note was Richard Bryant-Jefferies (2006) book, which specifically deals with personcentred approach to death and dying<sup>18</sup>. Whilst it was outside the 2019 cut off point, I have included this book because it is specific to the research question. To support the analysis of the research articles, I have also consulted a number of secondary sources.

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<sup>&</sup>lt;sup>16</sup> Arlene Fink. (2014) describes a systematic literature review as a "systematic, explicit and reproducible method for identifying, evaluating and synthesizing the existing body of completed and recorded work produced by researchers, scholars and practitioners". See Arlene Fink (2014) *Conducting Research Literature Reviews*, SAGE Publications, p. 3.

<sup>&</sup>lt;sup>17</sup> I will use these three labels to mean a person trained to work with emotional or mind state distress. The BACP states "Counselling and psychotherapy are umbrella terms that cover a range of talking therapies. [...] Clinical Psychologists are trained in behavioural sciences. [...] They usually work in hospitals or NHS clinics and clients are referred to them by a psychiatrist or GP. Counsellors and psychotherapists [...] mostly work outside hospitals in a wide variety of settings". See BACP (2021) 'Introduction to counselling and psychotherapy', https://www.bacp.co.uk/media/11060/bacp-introduction-counselling-and-psychotherapy-client-information-sheet-march-21.pdf <sup>18</sup> Richard Bryant-Jefferies (2006) *Counselling for Death and Dying: Person-Centred Dialogues*, Radcliffe Publishing Ltd, Abingdon.

Table of the six publications that emerged from my limited systematic literature review.

William S. Breitbart, Wendy G. Lichtenthal, and Allison J. Applebaum (2022). 'Meaning-Centered Psychotherapy', in: Steel, J.L., Carr, B.I. (eds) *Psychological Aspects of Cancer*. Springer, Cham.

Salamanca-Balen N, Merluzzi TV, Chen M. (2021) 'The effectiveness of hope-fostering interventions in palliative care: A systematic review and meta-analysis', in *Palliative Medicine*, 35 (4): 710-728.

Maia S Kredentser and Max Harvey Chochinov (2020) 'Psychotherapeutic considerations for patients with terminal illness', in *American Journal of Psychotherapy*, Vol. 73, no. 4 137.

Russell C, Fountain A. (2020) 'Role of Clinical Psychology in UK Hospices', in *BMJ Supportive & Palliative Care* Vol. 10: 196–200.

Rebecca M. Saracino, Barry Rosenfeld, William Breitbart & Harvey Max Chochinov (2019) 'Psychotherapy at the End of Life', *The American Journal of Bioethics*, 19:12, 19-28.

Richard Bryant-Jefferies (2006) Counselling for Death and Dying: Person-Centred Dialogues, Radcliffe Publishing Ltd, Abingdon.

# Critically evaluating the existing literature

I will start my review with Rebecca Saracino, Barry Rosenfeld, William Breitbart & Harvey Chochinov (2019) because they detail the psychological needs of the dying.<sup>19</sup> They begin by setting their research within the context of the work of Elizabeth Kubler-Ross.<sup>20</sup> A key figure in the Death Awareness Movement that emerged in the 1950s.<sup>21</sup> It sought to challenge the medicalization of dying and death. It was argued that the effect of developments in high-tech medicine and hospitalisation was to make death invisible or portray death as a failure of medicine: such that power was turned over entirely to doctors, and death "deprived of its human, existential meanings".<sup>22</sup> In contrast, Kubler-Ross sought to place the patients experience of dying at the centre of end-of-life care. Seeking to continue this legacy of focusing on the patient, the authors

<sup>&</sup>lt;sup>19</sup> Rebecca M. Saracino, Barry Rosenfeld, William Breitbart & Harvey Max Chochinov (2019) Psychotherapy at the End of Life, *The American Journal of Bioethics*, 19:12, p. 20.

<sup>&</sup>lt;sup>20</sup> Elizabeth Kübler-Ross (1997). *Questions and answers on death and dying: A companion volume to On death and dying,* New York: Touchstone Book/Simon & Schuster.

<sup>&</sup>lt;sup>21</sup> Lucy Bregman (2017) 'The Death Awareness Movement', in Moreman, C. (Ed.). (2017). *The Routledge Companion to Death and Dying* (1st ed.). Routledge. P. 412

<sup>&</sup>lt;sup>22</sup> Lucy Bregman (2017) 'The Death Awareness Movement', in Moreman, C. (Ed.). (2017). *The Routledge Companion to Death and Dying* (1st ed.). Routledge. P. 412

highlight the psychological needs of patients at the end of life identified by researcher, such as anxiety, anticipatory grief, demoralization, depression, and fear of death, loss of dignity, loss of meaning and purpose and low self-esteem. Maia Kredentser and Harvey Chochinov (2020) also draw attention to the experience of spiritual distress. They explain this as

"Distress related to life's meaning and purpose and lack of control in the face of loss and imminent death often result in spiritual distress [...] In health care, spirituality is defined as "the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred." <sup>23</sup>

They point out that spiritual well-being can mitigate depression, hopelessness, and desire for hastened death in terminal illness. On the other hand, a patient with a strong sense of religion and spirituality can also "feel they are being punished or abandoned" causing increased psychological and emotional distress.<sup>24</sup> The concept of "total pain" is used to encompass spiritual distress, psychological, social and physical distress. This biopsychosocial-spiritual model emphasizes the totality of a patient's experience in the context of their illness and/or dying.<sup>25</sup>

It strikes me that this focus on connectedness and deep human connection is essential for being with the clients experiencing total pain. As Brene Brown's research shows, the type of relationship where intimacy occurs is when individuals let down their

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Palliative Medicine and Supportive Care. Oxford; New York, Oxford University Press.

<sup>&</sup>lt;sup>23</sup> Maia S Kredentser and Max Harvey Chochinov (2020) "Psychotherapeutic considerations for patients with terminal illness." *American Journal of Psychotherapy*, Vol. 73, no. 4 138.

<sup>&</sup>lt;sup>24</sup> Kredentser Maia S Kredentser and Max Harvey Chochinov (2020) "Psychotherapeutic considerations for patients with terminal illness." *American Journal of Psychotherapy*, Vol. 73, no. 4 138. <sup>25</sup> Sriram Yennurajalingam, and Eduardo Bruera (2006). *Oxford American Handbook of Hospice and* 

guard or lay down their armour to really experience themselves. To be emotionally aware requires one to be emotionally open and curious about what one is feeling and to find a language to articulate what is found.<sup>26</sup> In my experience, not everyone is able or knows how to do these thing.

Having identified the psychological distress, Kredentser and Chochinov (2020) state that they will "review several evidence-based treatments for enhancing end-of-life experience and mitigating suffering", such as dignity therapy, meaning-centered psychotherapy, acceptance and commitment therapy, and cognitive behavioral therapy.<sup>27</sup> However, with the exception of dignity and meaning-centred psychotherapy, this is much more of an overview of the rationale and content of each of these psychological interventions (see below). There is little focus on the 'evidence base' that justifies these directive interventions. Including a number of small studies, they state it provides an "empirical bases" for dignity and meaning-centred psychotherapy. For example, there is no description of how or when this data was collected. Finally, they argue that psychotherapy at the end of life must be based on a "strong therapeutic relationship that is based on trust, therapist empathy, presence, and unconditional positive regard'.28 This relationship maybe to open the client to the directive interventions cited above and perhaps to help the client find a means to express what they are feeling. It can also sound like a description of what the expert therapist can do to the client.

What the clients need is stated in explanations of the rationale for interventions and research findings. For example, Saracino, Rosenfeld, Breitbart & Chochinov draw

<sup>&</sup>lt;sup>26</sup> Brene Brown (2021) *Atlas of the Heart: Mapping Meaningful Connection and the Language of Human Experience*: Vermilion; London p. xxi

<sup>&</sup>lt;sup>27</sup> Maia S. Kredentser and Harvey Max Chochinov (2020) "Psychotherapeutic considerations for patients with terminal illness." *American Journal of Psychotherapy*, Vol. 73, no. 4 137.

<sup>&</sup>lt;sup>28</sup> Maia S. Kredentser and Harvey Max Chochinov (2020) "Psychotherapeutic considerations for patients with terminal illness." *American Journal of Psychotherapy*, Vol. 73, no. 4 138.

attention to the rationale and findings of small studies on the effects of Dignity Model and Dignity Therapy (DT). First, they explain that the psychotherapist provides questions that the patient develops into "a legacy or generative document that they can share with loved ones".<sup>29</sup> They also draw attention to Meaning Centered Psychotherapy (MCP) where patients are educated through and eight-week Supportive Group Psychotherapy (SGP) or a shorter seven week or three session 1-2-1 Individual Meaning Centered Psychotherapy (IMCP). The purpose is to identify and develop individual sources of meaning and purpose at the end of life. They highlight that twenty-eight articles evaluating the impact of Dignity Therapy demonstrated statistically significant decreases in patients' anxiety and depression scores over time.<sup>30</sup> A number of small studies of less than 120 participants found that IMCP "improving spiritual wellbeing, sense or meaning, and overall quality of life, while also reducing hopelessness, DHD, depression, and physical symptom distress".<sup>31</sup>

Finally the authors highlight Managing Cancer and Living Meaningfully (CALM) as a brief, structured intervention that focuses on the importance of spiritual well-being and a sense of meaning.<sup>32</sup> They cite a 2018 large-scale Radom Control Trial of CALM involving 305 participants. It found that "CALM demonstrated significantly greater improvements in depressive symptoms and overall quality of life but no difference in changes in anxiety, spiritual well-being, or death anxiety".<sup>33</sup> In closing the authors point out that it is important that *evidence-based* psychotherapies "provide a non-judgmental space for open discussion of fears and concerns around death and dying

<sup>&</sup>lt;sup>29</sup> Rebecca M. Saracino, Barry Rosenfeld, William Breitbart & Harvey Max Chochinov (2019) Psychotherapy at the End of Life, *The American Journal of Bioethics*, 19:12, p. 22.

<sup>&</sup>lt;sup>30</sup> Rebecca M. Saracino, Barry Rosenfeld, William Breitbart & Harvey Max Chochinov (2019) Psychotherapy at the End of Life, *The American Journal of Bioethics*, 19:12, p. 22.

<sup>&</sup>lt;sup>31</sup> Rebecca M. Saracino, Barry Rosenfeld, William Breitbart & Harvey Max Chochinov (2019) Psychotherapy at the End of Life, *The American Journal of Bioethics*, 19:12, p. 24

<sup>&</sup>lt;sup>32</sup> Rebecca M. Saracino, Barry Rosenfeld, William Breitbart & Harvey Max Chochinov (2019) Psychotherapy at the End of Life, *The American Journal of Bioethics*, 19:12, p. 25.

<sup>&</sup>lt;sup>33</sup> Rebecca M. Saracino, Barry Rosenfeld, William Breitbart & Harvey Max Chochinov (2019) Psychotherapy at the End of Life, *The American Journal of Bioethics*, 19:12, p. 25

remains a cornerstone of these interventions".<sup>34</sup> It would appear that this is advocating that a non-directive therapeutic space is still open to the client after the directive teaching intervention is completed.

Breitbart, Lichtenthal, and Applebaum (2022) give greater detail to Meaning-Centered Psychotherapy. They site a study that found that physicians believed "loss of meaning in life" accounted for 47% of patient requests for assisted suicide". Similarly, they highlight that "In a study of the psychosocial needs of 248 patients with cancer, 51% reported that they needed help overcoming fears, 41% needed help finding hope, 40% needed help finding meaning in life, 43% needed help finding peace of mind, and 39% needed help finding spiritual resources". They highlight a small number of studies, and one with 253 patients in a RCT between 2010 – 2015. These studies found that Meaning-Centered Psychotherapy improvement depression, hopelessness, desire for hastened death, spiritual well-being, and quality of life. Whilst this feels like a comprehensive evaluation of the needs of individuals at the end of life, I could not find a copy of the survey used with clients to determine whether it was directing the clients towards these psychological needs and then evaluated them.

Breitbart, Lichtenthal, and Applebaum (2022) continue by describing Meaning-Centred Psychotherapy as a "brief manualized intervention".<sup>36</sup> A seven-week programme where the therapist teaches the patient about the importance of finding meaning and introduces didactic and experiential exercises to inspire clients to see meaning in life and death. For best results, they state the therapist ought to be educated in existential philosophy and psychotherapy so that they can guide the patient towards "additional existential concepts" and to provide an "existential nudge

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<sup>&</sup>lt;sup>34</sup> Rebecca M. Saracino, Barry Rosenfeld, William Breitbart & Harvey Max Chochinov (2019) Psychotherapy at the End of Life, *The American Journal of Bioethics*, 19:12, p. 26.

<sup>&</sup>lt;sup>35</sup> Alyson Moadel et. al (1999) 'Seeking meaning and hope: self-reported spiritual and existential needs among an ethnically-diverse cancer patient population' in *Psychooncology*. 8(5):378–85.

<sup>&</sup>lt;sup>36</sup> Breitbart, W.S., Lichtenthal, W.G., Applebaum, A.J. (2022). 'Meaning-Centered Psychotherapy', in: Steel, J.L., Carr, B.I. (eds) *Psychological Aspects of Cancer*. Springer, Cham, p. 399.

to gently challenge the resistance of patients to explore difficult existential realities, such as the ultimate limitation of death or existential guilt" <sup>37</sup>. The therapists ought 'detoxify death' by talking openly about death as the "ultimate limitation that causes suffering and for which meaning can be derived through the attitude that one takes toward suffering". This all sounds very directive, a teaching of philosophy with the expert therapist seeking to cultivate emotionally awareness, curious about what one is feeling and a language of communication. Given that powerlessness is often a cause of emotional distress I wonder if this teaching inhibits the client from exploring what is most urgent for them?

Natalia Salamanca-Balen , Thomas V Merluzzi and Man Chen (2021) <sup>38</sup> offer a systematic meta-analysis of hope-enhancing interventions delivered by psychotherapists. They point out that "hope theory has developed in a context that includes a focus on goals and outcomes", but includes the existential issues of meaning, spiritual and philosophical issues. However, they draw their evidence from 19 studies from mainly Dignity therapy and Meaning Centered psychotherapy where 'hope' is part of the criteria for evaluating the outcome of these intervention. It feels like a real effort to find a place for hope in the existing research.

Given the above celebrations of these psychological interventions it is important to also consider the question of resources, and the potential of patients to have contact with a counsellor, psychotherapist or clinical psychologist of any modality. Charlotte Russell and Averil Fountain (2020) draw attention to the fact that only 41% of UK hospices had access to a clinical psychologist, with only one day per week allocated

<sup>&</sup>lt;sup>37</sup> Moadel A, Morgan C, Fatone A, Grennan J, Carter J, Laruffa G, et al. (1999) 'Seeking meaning and hope: self-reported spiritual and existential needs among an ethnically-diverse cancer patient population' in *Psychooncology*. 8(5):378–85.

<sup>&</sup>lt;sup>38</sup> Salamanca-Balen N, Merluzzi TV, Chen M. The effectiveness of hope-fostering interventions in palliative care: A systematic review and meta-analysis. *Palliative Medicine*. 2021;35(4):710-728.

to hospice work. <sup>39</sup> The percentage of time carrying out clinical activities ranged from 10% to 85%, with a mean of 57% across the sample. The range of therapeutic approaches including Cognitive Behavioural Therapy (CBT), Acceptance and Commitment Therapy, Compassion Focused Therapy and Mindfulness. <sup>40</sup> I think this article illustrates that lack of resources to provide any psychological intervention and those that are employed are directive in nature.

### Person-Centred Approach to Dying

My search found only one publication on person-centred counselling at the end of life, but I was disappointed to find that there is no evidencing the impact.<sup>41</sup> Rather after explaining the significance of PCA, Bryant-Jefferies offers dialogues that he has experienced to help other PCA therapist working with clients at the end of life. There is a focus on theory and practice but no evidence. I appreciated that Bryant-Jefferies immediately acknowledges the importance of a phenomenological approach in PCA,<sup>42</sup> such that the diversity of the beliefs each person has about death and dying are because of the uniqueness of each human being's life experience. He states that 'from a person-centred perspective there is a need to honour the uniqueness of each person in finding their own way to come to terms with what can be one of the most profound, challenging and painful aspects of being alive".<sup>43</sup> The way to honour the client is to "avoid using particular descriptive theories in a prescriptive manner". There is a danger that such therapists

<sup>&</sup>lt;sup>39</sup> Russell C, Fountain A. (2020) 'Role of Clinical Psychology in UK Hospices', in *BMJ Supportive & Palliative Care* Vol. 10: 197.

<sup>&</sup>lt;sup>40</sup> Russell C, Fountain A. (2020) 'Role of Clinical Psychology in UK Hospices', in *BMJ Supportive & Palliative Care* Vol. 10: 197.

<sup>&</sup>lt;sup>41</sup> Richard Bryant-Jefferies (2006) *Counselling for Death and Dying: Person-Centred Dialogues,* Radcliffe Publishing Ltd, Abingdon.

<sup>&</sup>lt;sup>42</sup> Mick Cooper (2007) 'Experiential and Phenomenological Foundations', in Cooper, M. O'Hara, M. Schmid, P. Wyatt, J. (Editors) *The Handbook of Person Centred Psychotherapy and Counselling*; Palgrave Macmillan, p. 102-117.

<sup>&</sup>lt;sup>43</sup> Richard Bryant-Jefferies (2006) *Counselling for Death and Dying: Person-Centred Dialogues*, Radcliffe Publishing Ltd, Abingdon, p.1.

"[...] come to feel that unless people experience certain feelings or deal with those feelings in certain ways, they will suffer psychological or even physical harm. Trying to force what happens to real people into rigid prescriptive theoretical models is at best unhelpful, at worst it prevents counsellors seeing what is really happening and make them see only what they expect to see"44

Drawing on previous studies<sup>45</sup>, Bryant-Jefferies asserts the primacy of the therapeutic relationship rather than modality. Specifically, he describes the importance of the six necessary and sufficient conditions for working at the end of life.<sup>46</sup> It is this PCA therapeutic relationship, Bryant-Jefferies argues, that enables the client to experience the therapist "to be their companion as they try to come to terms with what they perceive, what they experience, and what they feel themselves to instinctively shrinking back from [...] The person-centred counsellor stives to offer a healing relationship, not to take the pain away. [...] Perhaps heartfelt listening and understanding are as precious as life itself."<sup>47</sup> Whilst this book is theoretically eloquent, it feels like a statement of faith without evidence.

#### What does the review mean for my clinical and professional experience?

It has been inspiring to read about the many different interventions that have been developed to address psychological distress at the end of life. However, these are all

<sup>&</sup>lt;sup>44</sup> Green J and Sherr L (1989) 'Dying, Bereavement and Loss', in Green J and McCreamer M (eds) *Counselling in HIV Infection and AIDS*, Blackwell Scientific Publishing, Oxford, p. 207-23.

<sup>&</sup>lt;sup>45</sup> Mick Cooper (2004). 'Towards a Relationally-Orientated Approach to Therapy: Empirical Support and Analysis', in *British Journal of Guidance & Counselling*, 32(4), p.453.

<sup>&</sup>lt;sup>46</sup> 1. Psychological contact, 2. Client incongruence, 3. Therapist congruence, 4. Therapist attitude of Unconditional positive regard towards the client, 5. Therapist attitude of empathetic understanding towards the client, 6. The client to some degree experiences the therapists empathetic understanding and unconditional positive regard.

<sup>&</sup>lt;sup>47</sup> Richard Bryant-Jefferies (2006) *Counselling for Death and Dying: Person-Centred Dialogues*, Radcliffe Publishing Ltd, Abingdon, p. 70.

directive interventions which create specific power relations between the client and therapist. I have to wonder how much the client has scope to explore what they need to explore. In contrast there is a glaring absence of a non-directive approach, such as that found in PCA. In PCA the therapeutic relationship is everything and creates a space for a specific form of psychological contact to develop where the client feels safe enough to explore and work with what is meaningful for that individual.

In writing this I can reflect on the power of that special space that can be created by a non-directive approach between two human beings with the necessary and sufficient conditions.<sup>48</sup> For example, I am aware that normally when I come away from the counselling sessions with my dying client, I feel very emotional and sometimes tearful. When I have sat curiously with these emotions, I have realised that I am not sad because of the client's fate. Rather, I am aware that the strong emotions and sensations that I feel in my body are linked to the moments when we have experienced deep connection and vulnerability – often when not much is said. In these moments there is a relationship of vulnerable equals.

This realisation has brought me to reflect and revisit the work of Rose Cameron, Mick Cooper and Margaret Warner. As Mick Cooper points out experience is not located 'inside' people, but rather via communication on an 'inter-subjective' plane". Similarly, Margaret Warner defined psychological contact between human beings in terms of feeling meaningfully "present both verbally and non-verbally, to themselves and each other". Developing this, Rose Cameron identifies different levels of

<sup>&</sup>lt;sup>48</sup> Carl Rogers (1957) 'The Necessary and Sufficient Conditions of Therapeutic Personality Change', in Howard Kirschenbaum & Valerie L. Henderson (Editor) *The Carl Rogers Reader*; Robinson; Reprint edition (1990): p.219-220.

<sup>&</sup>lt;sup>49</sup> Mick Cooper (2007) 'Experiential and Phenomenological Foundations', in The Handbook of Person Centred Psychotherapy and Counselling. Cooper, M. O'Hara, M. Schmid, P. Wyatt, J. ed. Pub: Palgrave Macmillan 2007

<sup>&</sup>lt;sup>50</sup> Margaret S Warner (2001) 'Psychological Contact, Meaningful Contact and Human Nature', in Wyatt et al (2001) *Rogers' Therapeutic Conditions: Evolution, Theory and Practice* Volume 4: Contact and Perception; PCCS Books Ltd. Monmouth, p. 80.

psychological contact "basic (meeting), cognitive (understanding), emotional closeness and intimacy or 'subtle' contact'.<sup>51</sup> It is the latter that is really interesting, not least because there is not really a language or vocabulary to explain 'subtle' contact that happens 'in the space between' the client and the therapist. It invites the therapist to tune into, 'sensing' or trusting the felt sense of the experience of the client that occurs in the space between them.<sup>52</sup> I think this demands the therapist actively cultivates a deep congruence as Jeffrey H. D. Cornelius-White describes.<sup>53</sup> Under these conditions when the client feels safe, experiences acceptance and non-judgemental presence/energy of the therapists she might coherently articulate thoughts, emotions, physical sensations, memories, images, attitudes and values that are drawn across domains of the mind in a way that she might create a new narrative.<sup>54</sup> When the flow of this narrative is also comprehended and meaningfully experienced by the therapist there can be a deep psychological contact. I have had moments of this whilst working with this client.

### How does the review relate to my personal and professional experience?

The review of the literature on counselling at the end of life, has been beneficial both personally and professionally. Not all clients are comfortable or able to engage with the type of psychological contact or relational depth I have described above. For example, Brown's research asking seven thousand participants to list all the emotions that they recognise and can name found that the average was three: happy, sad and

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<sup>&</sup>lt;sup>51</sup> Rose Cameron (2002) 'In the Space Between', in Wyatt et al (2001) *Rogers' Therapeutic Conditions: Evolution, Theory and Practice* Volume 4: Contact and Perception; PCCS Books Ltd. Monmouth, p. 259.

<sup>&</sup>lt;sup>52</sup> Mick Cooper (2001). 'Embodied empathy', in S. Haugh & T. Merry (Eds.), *Empathy* (pp. 218-229). Ross-on-Wye: PCCS Books.

<sup>&</sup>lt;sup>53</sup> See Jeffrey H. D. Cornelius-White (2007) 'Congruence: An integrative five-dimension model', in *Person-Centered and Experiential Psychotherapies 6*(4), pp.229-239.

<sup>&</sup>lt;sup>54</sup> Margaret S Warner (2001) 'Psychological Contact, Meaningful Contact and Human Nature', in Wyatt et al (2001) *Rogers' Therapeutic Conditions: Evolution, Theory and Practice* Volume 4: Contact and Perception; PCCS Books Ltd. Monmouth, p. 80.

angry.<sup>55</sup> She describes the existence of 150 emotions and experiences from her research, and this is important because "the ability to name this emotion or experience is essential to be able to process it in a productive and healing manner".<sup>56</sup> Not having the emotional awareness and language can be anxiety inducing. Therefore, it is inspiring to know that it is possible to offer clients an opportunity to develop discussions on dignity, hope, meaning etc, that could help the client to identify what they need to explore. Developing this form of dialogue within a therapeutic relationship with the six conditions might also provide the opening to finding deep psychological contact. They could be offered to the client in a person-centred manner in a 'relationship of equals'. There might also be 'fragile processing' or even 'dissociated processing', due to past experiences of traumatic events, which would perhaps require pre-therapy.<sup>57</sup>

This has been my experience with my current client. After using the first twelve session to review her life, at the start of last six sessions she asked me, "do you remember our first session?" She reminded me that at her first meeting she had told me she was terrified of dying. I had replied that this was completely understandable. Not least because Buddhist monks had practiced their whole life for meeting death, and they too were often frightened at the point of death. She then asked me to teach her how Buddhists learn to accept death. After practicing meditation together for a few sessions and inviting her to practice at home, she now shares deeply what she is experiencing. We often just sit together 'in the space in between'. After writing this review I am more aware and more present in the space, if not more curious and receptive to what she is feeling in our shared vulnerability. I think meditating together

<sup>&</sup>lt;sup>55</sup> Brene Brown (2021) *Atlas of the Heart: Mapping Meaningful Connection and the Language of Human Experience*: Vermilion; London p. xxi

<sup>&</sup>lt;sup>56</sup> Brene Brown (2021) *Atlas of the Heart: Mapping Meaningful Connection and the Language of Human Experience*: Vermilion; London p. xxv.

<sup>&</sup>lt;sup>57</sup> Margaret S Warner (2001) 'Psychological Contact, Meaningful Contact and Human Nature', in Wyatt et al (2001) *Rogers' Therapeutic Conditions: Evolution, Theory and Practice* Volume 4: Contact and Perception; PCCS Books Ltd. Monmouth, p. 80.

enabled her to feel comfortable with silence, to be comfortable with just being with, seeking to allow, and exploring letting go of difficulty and joy. On using the breathing exercises, we have talked about how it feels to let go of the breath, and even letting go of the last breath. However, I understand that all of this is unique to this client, and the development of our relationship may not be replicated again. I have felt as Bryant-Jefferies confessed: "I am left wondering how much of my own beliefs have become entangled in the therapeutic process [...] I guess that is inevitable". <sup>58</sup> Regardless, I feel blessed to have had this understanding of psychological contact to enable me to be present for this experience of being with a courageous human being at the end of her life. I think it has encouraged me to say less, and to feel more empathetic understanding for others including me wife and children.

### Consider how a small research project could examine this area of interest

A key question that has emerged from this review is, why is there not more research conducted on the effect of PCA at the end of life? What gets in the way – perhaps there is a reluctance to fund and resource PCA because it does not fit the medical model? This was certainly Rachael Freeth's point.<sup>59</sup> Reflecting today, Lucy Bregman argues that whilst the Death Awareness Movement changed the rhetoric around death, it leads her to question whether there has been an acceptance of death in our culture.<sup>60</sup> Similarly, Clark argues that because we dread the process of dying "it is more appropriate to view medicalisation as the expected rather than unintended outcome of the growth of palliative care".<sup>61</sup> Perhaps the dominance of directive psychological interventions illustrates the continued dominance of the medical model of illness-

<sup>&</sup>lt;sup>58</sup> Richard Bryant-Jefferies (2006) *Counselling for Death and Dying: Person-Centred Dialogues*, Radcliffe Publishing Ltd, Abingdon, p.169.

<sup>&</sup>lt;sup>59</sup> Rachael Freeth (2007) *Humanizing Psychiatry and Mental Health Care: The Challenge of the Person-Centred Approach*, CRC Press: Boca Raton, p. 61.

<sup>&</sup>lt;sup>60</sup> Lucy Bregman (2017) 'The Death Awareness Movement', in Moreman, C. (Ed.). (2017). *The Routledge Companion to Death and Dying* (1st ed.). Routledge. P. 412

<sup>&</sup>lt;sup>61</sup> Clark, D. (2002). Between hope and acceptance: The medicalisation of dying. British Medical Journal, 13(324), 905–907. https://doi.org/10.1136/bmj.324.7342.905

diagnosis-treatment-cure, rather than being with the suffering of the dying. Perhaps it is cultivating emotionally awareness, curious about what one is feeling and a language of communication for the client.

A small research project could involve evaluating clients experience of a PCA at the end of life. This might involve firstly a literature review of the term 'psychological contact' to really understand how this concept has been articulate throughout the PCA community. It would also be possible to do a review of the different research tools that have been used by other approaches to measure the impact of their interventions at the end of life. Given the absence of resources or funding for such projects, one could then spend two or three years volunteering at an end of life organisation like Maggies<sup>62</sup> to offer free PCA counselling to clients. In return for the free access to a counsellor the organisation might allow the counsellor to respectfully collect data on the impact of the PCA to counselling at the end of life.

#### Conclusion

I began this essay by asking "What is the purpose of Person-Centred Counselling at the of end of life?" Researching and writing this essay has enabled me to understand the psychological issues facing clients with terminal illness, and it has also opened my eyes to the development of new interventions seeking to alleviate human suffering, such as dignity therapy, meaning-centred psychotherapy, CALM etc. A key finding was the absence of research on the application of person-centred approaches at the end of life. What did exist felt like a declaration of theory and PCA faith. Rather the research literature is dominated by directive interventions to 'treat' psychological distress consistent with the medical model. Given that powerlessness is often a cause of emotional distress I wonder just how much space and permission there is for the

<sup>&</sup>lt;sup>62</sup> Maggie's Centres. (n.d.). *Maggie's Fife*. [online] Available at: https://www.maggies.org/ourcentres/maggies-fife/ [Accessed 14 Mar. 2023].

client to explore what is most urgent for them? Questions of relationship power dynamics, and the role of intimacy and vulnerability has encouraged me to reflect again on the quality of the space a non-directive PCA offers clients to be psychologically *received – not treated*. I would argue that to be received requires a relationship based on 'being with' vulnerability 'in the space in between'. The rational for this is that it can create a relationship of equals so the client can be vulnerable, make her own unique sense of the end of her unique life, rather than perhaps being distracted by the teachings of a directive approach. I think this is the purpose of Person-Centred Counselling at the of end of life. This is not to deny the utility of these directive approaches as they may enable clients to cultivate emotionally awareness, curious about what one is feeling and to learn a language of communication that opens the way to psychological contact.<sup>63</sup>

<sup>63</sup> Mick Cooper and John Mcleod (2011) Pluralistic Counselling and Psychotherapy. Los Angeles: Sage.