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Research paper

Stepping back into life: How Psychedelic Assisted Psychotherapy transforms the way of life of the terminally ill☆

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A B S T R A C T

This qualitative study of how successful Psychedelic Assisted Psychotherapy (PAP) transforms the way of life of terminally ill subjects provides new knowledge for researchers and clinicians contemplating its use. Using an interpretive phenomenological approach (IPA) and interviews with subjects before and after PAP from a recent randomised control trial, we find that participants with extreme death anxiety have become displaced from their own life, afraid and alone in an all-encompassing present. PAP can enable them to fully inhabit their life in a more abundant and joyful present, even in the face of death. The psilocybin component is found to be necessary but not sufficient for this achieving this outcome. These novel findings expand our conceptualisation of death anxiety and of the personal transformation that constitutes successful PAP.

Clinical trial details
Australian New Zealand Clinician Trials Registry.
https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=378101&isReview=true
registration: ACTRN12619001225101.

1. Introduction

Death anxiety, the obsessive dread of death, can rob individuals with terminal illness of the capacity to enjoy what remains of their life [21]. In 1963, Kast and Collins [29] while investigating the analgesic properties of LSD for patients with advanced cancer, noted that it gave them a startling capacity to speak "freely about their impending death with an affect considered inappropriate in our western civilization, but most beneficial to their own psychic states". Building on this chance discovery, Psychedelic Assisted Psychotherapy (PAP) evolved as a structured psychotherapy program that leverages these effects of a psychedelic compound, and in best-case outcomes it can not only provide end of life patients with reduced anxiety and depression [20] but also with a radically revised perspective on death [57]. Despite decades of research on PAP, the profound transformation in subjects' engagement with their fears that so surprised Kast still presents as a mysterious marvel to practitioners and their patients alike. The aim of this paper is to make explicit the nature of the startling transformation in the way of life of patients that constitutes successful relief of death anxiety through PAP.

To this end we use interviews with subjects before and after PAP, collected as part of a recently completed randomised control trial (RCT), and employ an interpretive phenomenological orientation to uncover the transformation to the lives subjects that results when PAP is effective for relief from death anxiety. We find PAP enables them to regain their lost capacity to fully inhabit their life. We explore the significance of this finding for research, and for psychiatrists and psychotherapists working clinically with PAP.

2. Related literature

Left untreated, death anxiety has a psychologically corrosive effect at end of life [8,21,34], underpinning suffering and preventing clear communication about needs at end of life [13,54]. Treatments that focus on symptom reduction have limited efficacy [25]. Benzodiazepines and antidepressants are commonly prescribed but cause side-effects that worsen quality of life including sedation and nausea [5,11]. Psychotherapy alone has a small to medium effect on symptoms of death anxiety, primarily from interventions that incorporate anxiety management strategies of Cognitive Behavioural Therapy [40]. Subjects with a terminal illness want to live without the constant focus on illness,

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to regain meaning in their lives, and to find joy in the present moment [31]. Mainstream treatment strategies that focus on the symptoms of death anxiety do not address these fundamental patient needs and death anxiety remains an intractable condition within mainstream palliative care.

By contrast, PAP has been shown to impact both the personal experience and the symptoms associated with death anxiety [9,50,53,57]. Following PAP, subjects dealing with advanced cancer regain their feeling of vitality and belonging, reclaim personal agency [57] and report lasting changes to their sense of identity [9]. However, to date these subjective assessments have been made only after PAP has ended, in some cases 12 months after their last contact with the trial therapists [57]. The passage of time, and retrospective nature of these reports weaken any conclusions about the actual personal transformation taking place. What is needed is a direct before / after comparison with a common cohort.

Clinically significant improvements in symptoms of anxiety and depression have been reported for PAP that are rapid and durable [4,20,52]. Reductions in suicidal ideation have been shown within 8 h of treatment and is still present 6 months later [51]. Attempts to explain how PAP leads to these symptomatic improvements attempt to relate measures of the acute psychedelic effects, such as mystical experience [28], to measured outcomes [37,38], but one long-term follow-up of subjects with cancer-related distress revealed no correlation between these acute psychedelic experiences and sustained improvement in mood symptoms [3]. In addition, the potential for self-deception regarding the meaning of these acute experiences [39] casts doubt on their causal significance. So, while many researchers attest to the profound personal transformation possible with successful PAP, focus on the content of psychedelic experiences and symptom reduction deflects research from this important phenomenon.

The changes seen in subjects after PAP are so striking that has led some to assert that the psychedelic drug is the primary driver of change [1,19]. And research on how PAP causes these changes tends to focus on how the psychedelic drug component changes molecular, cellular and psychological function [55], to the neglect of the role of the psychotherapy component. This psychotherapy component typically requires two therapists working together for many hours with the subject before, during and after the acute psychedelic effect [23], and factors such as therapeutic alliance and the amount of therapy provided have indeed been shown to mediate subject outcomes [18,44]. Furthermore, psychotherapy is inconsistently described across research settings [35] making it difficult to incorporate into empirical research and mechanistic explanations of the outcomes seen with PAP [55]. Some have recently even suggested that therapists should limit themselves to a supportive role [19], whilst others still contend that skilled therapy is essential to PAP [22,62]. This debate, and the overall focus on the psychedelic drug component of PAP, have arguably taken research attention away from the transformation in subject's lives that constitutes successful PAP.

We have recently reported the results of an RCT examining the impact of PAP at end of life and found clinically meaningful reductions in symptoms of anxiety, depression and death anxiety [50]. Drawing on interviews with subjects before and after PAP conducted in that trial, we now ask "For terminally ill people who describe PAP as successful, in what way are their lives changed?"

3. Research design

3.1. Conceptual design

This sub-section outlines key research choices and how they were operationalised.

Because the aim of the project was to uncover the transformation in subjects lives that represents the best-case outcome from PAP, we chose to use only the success cases from the parent study. 21 participants from the parent study self-reported that the trial was successful in response to two open ended questions in the final interview. These were "In what ways do you feel the study has affected your life since the sessions, if at all?" and "Has this experience specifically impacted your life in any way?" with prompts to further explore the experience. Each researcher independently reviewed the participant responses and categorised them as successful, unsuccessful or unsure. Participants unambiguously declared their experience as either successful or unsuccessful, and there was no disagreement between raters.

Because we aimed to make conclusions about actual changes to subjects' lives, we made use of interviews conducted prior to the first double blind dose to understand how patients lived with death anxiety, and interviews conducted one month after the open label doses to understand how life was transformed by the treatment. In selecting interview material to use, we prioritised statements subjects made about their actual life patterns over insights or revelations. Accordingly, parts describing the psychedelic experience per se were not used. In this way we ameliorated concerns about subjectivity and ineffability of subject's experiences [45] and concerns that insights occurring during or after psilocybin ingestion may not be reliable or veridical [39,63].

3.2. Methodological orientation

Because we sought to capture how participants experienced their own lives, we adopted an interpretive phenomenological approach (IPA) [33,46]. IPA has been extensively used in clinical settings to understand how people make sense of life changing events such as major surgery [60], the impact of psychotherapy [26] and to study the experience of participants undergoing MDMA therapy at end of life [7].

The interpretive aspect of IPA seeks to uncover and present the researcher's (third person) interpretations of the subjects (first person) interpretations of their own lives, others and their world. That is, it uses a so-called double hermeneutic process [46]. The phenomenological aspect of IPA aims at "attaining an understanding and proper description of the experiential structure" ([17], p9). The logical basis of IPA is abductive [15,49]: in the present context, this means that it seeks an answer to the question 'what must the life situation of the subjects be like such that they provide the responses that they do to the questions posed to them'.

Our work as clinicians and psychotherapists in a palliative care service informed our research stance in keeping with other phenomenological research contexts that focus on in-depth lived experience [16]. Each member of the research team had a minimum of 15 years experience working as a clinician in a palliative care unit as part of a multidisciplinary team (except for author RBJ). Disciplines included psychoanalytic psychotherapy, sensorimotor psychotherapy, mindfulness-based interventions, music therapy and spiritual care of the dying.

Our own implementation of IPA had 3 steps. First, a computer-aided thematic coding of data from the interview text was undertaken to produce a coding tree (see below) by accepted methods [46]. Second, from the multitude of text fragments stored during the coding process, a selection was made of a small number that most typified the majority, while being sufficiently acontextual for clear presentation. Third, the text fragments were woven with succinct interpretive sentences into a narrative that faithfully presents the researcher's understanding of the text gleaned through the whole process. As is usual for this type of research, the actual process was far more incremental and iterative than the above linear description.

3.3. Parent study method

In the RCT phase of the parent study, participants with an advanced, life-threatening illness with an expected prognosis of more than 6 months received Niacin 100 mg or psilocybin 25 mg, and 6 weeks later, psilocybin 25 mg in an open label phase. Both doses were nested within

a manualised psychotherapy process that involved 3 sessions of preparatory psychotherapy and education about the psychedelic experience itself, and 3 sessions of integration work. The trial therapists had a minimum 15 years of experience working in palliative care and their own extensive vocational psychotherapy training, as well as specific training and psychotherapy supervision for the trial. Of the 28 participant the fully completed the trial, 21 participants described their treatment as successful. Subject enrolment data are given in appendix 1.

On the psychedelic dose day, participants ingested the drug early in the morning in the presence of the psychotherapy dyad and then donned eyeshades and listened to a curated music selection through noise cancelling earphones. The psychedelic dose day took place in a homely environment, and the participant remained in the dose space with both therapists until judged medically and psychologically ready to leave with their loved one.

Semi-structured interviews (see appendix 2) were conducted with every subject in the parent study before the double-blind dose and one month after the open label dose by a trained qualitative researcher by phone or face-to-face. All interviews were recorded and then transcribed verbatim. Researchers conducting the interviews had no prior relationship to the subject, and did not discuss their motivations for being involved in the study.

3.4. Coding and analysis

All interview data were coded with researcher-created descriptive labels using Atlas/Ti 9 [6]. Two researchers were fully involved in all coding procedures, both independently at the beginning of each step, and then collectively later. First, a small number of broad topics that were *common* to the before and after interviews were identified. Within these major themes, sub-themes that characterised the *differences* between before and after transcripts were identified. These were simplified through regrouping, rereading transcripts, and negotiation until consensus was reached on a small number of final themes as per [46]. Finally, all interview transcripts were re-read to check the extent that these themes captured the sense of responses across all participants.

4. Findings

4.1. Results of the coding process

The themes, sub-themes and their frequency of occurrence across participants are set out in Table 1. Common to the before and after states were descriptions by the subjects of actions and patterns of thought concerning death, mood, temporality and lifeworld. The terms temporality and lifeworld are standard within phenomenological practice [24]. They denote the perspectival interpretation of time and the world by a subject, as opposed to objective clock-time and physical world, respectively. Temporality refers to the way the passage of time and the relations among past, present and future are experienced by the subjects. Lifeworld refers to the way the subject's own life and body, the lives and relations with others, and the world around them are experienced by the subject. The sub-theme codes which capture the differences in the before and after states within the main themes are also shown.

First, it should be noted that all the sub-themes are found to occur in a high proportion of the interviews with the 21 subjects. Second, the sub-themes that distinguish the before and after states are rather consistent across participants. Together these observations provide evidence that a well-defined change results from PAP.

4.2. Narrative interpretation of coding

In this sub-section, we present selected fragments of text that most typify those collected against each sub-theme code during the coding process, and which require least access to the textual context in which they occurred. Our intention here is to allow the subjects to 'speak' their own lives to the reader. In the interest of narrative clarify we weave these among short interpretive statements of our own linking the quotes and conclude each main theme (before or after) with an overall interpretation. Note that these statements are the interpretive outcome of the whole IPA process rather that just these fragments presented.

Table 1
Common topic, distinguishing themes and frequency of occurrence (N) of distinguishing themes across the 21 participants.

Before PAP		After PAP	
Common Topic			
Distinguishing theme	N	Distinguishing theme	N
Death			
Death is physical obliteration	17	Death is also part of life	14
Wholly unprepared for death	19	Death feels familiar and accepted	15
Mood			
Obsessive focus on death	19	Calmer and more joyous thinking	19
A pervasive state of angst	16	Emotions affirm a life to be lived	20
Temporality			
Past provides no ground	11	The past provides an anchor	11
Future is an agonizing wait	15	Future opens up with hope	19
Present is endless marking time	19	Present part of in the flow of life	19
Lifeworld			
Symphonic unity and meaning lost	19	The world is bigger and radiant	19
Body is alien and uninviting	20	At home in their own skin	21
Relationships pervaded with loneliness	19	Relationships are nourishing and affirming	18

4.2.1. Death – before intervention

Death confronts the participant with their complete annihilation from life.

> *I just think once you're dead, you're dead… I don't believe in heaven or an afterlife or reincarnation or anything like that. I think you live on in people's memories. And apart from that… once you're gone, you're gone. PN2*

> *Its gonna kill me that's what its going to do. It's impacted profoundly and has taken me a long time to get to a point of acceptance. But even acceptance is not an embrace [it] is just simply an understanding that this is ocurring and this is going to happen. And I have to live with that. PN5*

Death is imagined as a relentless and disempowering process of suffering.

> *I'm mindful that this illness doesn't end particularly well. It's not like getting hit by a bus. It's a gradual decline and a loss of faculties…. it's unpleasant… It's horrible…. It's brutal. But at the same token, it's what's going to happen. PN22*

> *I'm on my first line of treatment. I've been on it for 18 months. I'm already a miracle. But when I think about the disease progressing, moving on to different treatments, I think about once it gets to the point of quickly burning through them, then you know that that time is ticking. I've thought about what is it called when you ask doctors to help you die? …. I'm thinking about how bad it's going to get. It just hurts. PN19*

Theme Summary: The unavoidable fact of the subjects impending physical demise is profoundly confronting and threatens to obliterate everything in the subject's life. The process of dying is imagined as merciless and unpredictable, and the subject feels completely unprepared for what will come.

4.2.2. Mood – before intervention

The participant broods over inescapable thoughts of their death.

I know it's all over red rover. It's just a question of time. So what I'm trying to do is to align my spirit with the reality of that without it taking me into the depths of despair. But that's a very difficult kind of tightrope. PN5

I have thoughts of my body failing me like my lungs stopping working, having a heart attack. I picture lying on that bed close to death and people talk about how painful it is to die from cancer. Having my daughter, seeing all of that, the upset that she's going to have to live. PN19

A pervasive mood of despair dominates the subject's emotional state.

But it's more that I dwell….. I just can't get this out of my head, you know…. Even if its not dwelling on dying it's just dwelling on the context. PN24

I am actually irritable almost constantly. I'm always much more easily frustrated and my temper is shorter. And so behaviorally it's had an effect on me a lot. I just feel pent up generally. PN6

Theme Summary: The subject ruminates over their impending death, and this casts a pall over their daily life that leaves them feeling anxious and emotionally drained. They are acutely aware of these painful feelings just below the surface. They try to keep at bay this constant emotional turmoil whilst attending to the emotional demands of everyday life.

4.2.3. Temporality - before intervention

The irreversible nature of the diagnosis segregates the participants from their past and accumulated know-how.

I was being offered a big opportunity at work. [It] just unreasonably stressed me out to the point I went to my GP for the first time ever asked for help with a mental issue…. I had a mini breakdown. I responded disproportionately to the situation…. I was like "What am I doing like? Should I take this job, is the cancer going to come back?"…. and I had this massive stress out. PN6

I can't change my past. I can't change the choices I made, that leads me to where I am today". PN12

The imagined future has become a crushing spectre of looming treatment milestones, prognostic timelines, and ultimately death.

The process of dying it's what's going to happen before. And missing out on things that I expected I would to be able to be part of with my family. PN34

The lack of future is one that sticks out a lot these days. … just being 37 and nowhere near where I would like to be in life. PN20

I was really fit, looking forward to a long and productive retirement. So the impact has been really incredible. Both my parents and all my grandparents lived into their mid, late 80s. I thought I'd outlived them at least. PN34

The present is spent marking time, anxiously awaiting the next scan or symptom.

I feel like I'm treading water. Underneath my feet are going 100 miles an hour just to keep my nose above water. But I am keeping my nose just above water most of the time, but it feels like it's really hard work. PN3

Around scan time I drink too much alcohol just to get out of my head. PN19

All I hear is that clock ticking higher and higher. PN12

I feel stuck, trapped and unable to, you know, I won't even book a holiday six months in advance because I'm too scared that I'm going to get a bad scan. So I just feel like everything is on ice. PN6

Theme Summary: No longer grounded by the past or heading toward a future, the participant has become stranded in the present, which is spent endlessly watching the clock. They find themselves stuck and outside the flow of life.

4.2.4. Lifeworld - before intervention

Things that had previously held meaning for the participant have become arid and uninviting.

It has always given me immense joy and pleasure just to be a part of this landscape and to participate in it, and to pursue my own intellectual aspects and I'm finding myself cut off from those now. I just don't have the will or outlook anymore. PN5

Absolutely hate the word cancer. It's changed relationships. It's changed my brain… It's just a part, part of everything. All the good moments are tinged with worry and sadness that I'm not going to be a part of other moments. PN19

Their body is present as a cluster of distressing symptoms and disrupted basic functions.

I'm chemically castrated… I have hot flushes, I have sweats. I have some fatigue, not much. But I have minor incontinence, but other than that, I'm fine… PN34

….all I did was get out of the car and walk across the road, which is just about 25 m. And I'm holding onto something to support me, trying to get my breath back and my son said "are you alright?" He said "I can't believe that you're out of breath just walking across the road!". PN9

The medical system that the participant has entrusted their care to only serves to compound this sense of fragmentation.

I saw this oncologist back in March for the first time, he didn't know me from a bar of soap. He just basically comes out and says"You've got six months". You know, I'm looking at him and saying "What the hell are you talking about?". It was devastating…. He doesn't know my strengths and weaknesses. PN14

In relationships, there is a growing distance from others who appear oblivious to the plight of the participant.

I have people [who] want to come over and support me. You can't make me laugh, I feel shit. You know, people being kind. But they don't get it… you can't make me laugh. I don't want to do that. I want to curl up in the corner and just be quiet… the energy of having someone there just trying to get me happy. It just takes my energy from me. PN12

I try not to harp on it. You know, at the end of the day people get tired of you. They ask you how you're going "Oh, I'm sick, I'm unwell, I hate cancer blah, blah, blah". So I just go on as if I'm OK you know. PN14

Theme Summary: Entities (body, relationships, place, culture) that had collectively constituted the participant's lifeworld have lost their former symphonic unity. The participant is alone, no longer at home in their world, and this is revealed as a loss of meaning.

4.2.5. Death – after intervention

Death no longer stalks the subject and has now become integrated into the natural order of life.

Like I say, it's not something that I want to do, but it's also not going to happen in the next immediate future. So I can see it I want to say in the rearview mirror, but no, the opposite of tha I can see it in the foreground. But it's so tiny and minuscule, its not even kind of in my vision. PN19

When I think about dying, I was upset more for leaving my children or that the grief I would impose upon them. But I've just let that [go]. I'm thinking, no, I'll be fine. We've all gone through it, they'll go through it and they'll be fine. It's not upsetting me like it was. PN1

The uncertainty of what follows death has been resolved on a visceral level.

But now I have a feeling that… people do go on, in essence, in a spiritual way after they've gone, after they've passed. That life essence continues in some way. PN24

Well, nobody actually knows. But I'm confident that through this experience, I've realized my perspective is such that that we live on in some manner or form. [I] don't know what but that somehow we will be held by this universal God. PN29

I feel it even more strongly now, that after we die, it's going [to be] kind of like going home somehow. PN3

Theme Summary: Death is now understood as an essential part of the natural order. The fear of inevitable annihilation no longer pervades the subject's life. This brings comfort and an awareness of possibility. There is a sense that dying is akin to returning home.

4.2.6. Mood – after intervention

The subject's emotional state is marked by calmer and more joyous thinking.

[It] made me feel a bit calmer. Like the sense about everything is as it sould be right now. When I find myself getting a little bit overwhelmed, I sense everything is as it should be right now [and it] is quite calming.PN6

I am able to just enjoy what I'm doing at this minute without having the panic attacks …I haven't had any. And I haven't had of those horrible thoughts where it just sort of passes through. I've haven't had that I [am] feeling happier. PN11

Obsessive thoughts, angst and despair have given way to a range of personally affirming emotions.

There's more to life than just the illness. I'm more open to everything that's going on. But…it hasn't changed my attitude to the illness. I'd still like them to find a cure. PN34

I feel happier and at the moment healthier than I have in years. And that seems incredible to say, but it's the absolute truth…. I'm really excited about life, I've joined a choir. PN3

Theme Summary: The subjects emotions affirm the life that is yet to be lived. There are natural frustrations with, and need to attend to, the illness, but these are fleeting and no longer dominate the emotional landscape.

4.2.7. Temporality - after intervention

The participant feels newly grounded via their past, and this leads to bracing moments of discovery, exultation, and self-expression.

I've always just been given positive rewards for being a quiet little churchmouse kid and being the only kid around a lot of adults a lot of adults … [giving] positive reinforcement to you … when you you're quietly reading in the corner. I was just suppressing everything. In cafes [someone] might push in in front of me in a line. In the past I might have taken that a bit personally and then be like standing in the line holding a grudge … now I don't give a shit … or I'll say something. PN22

I have a photo of myself when I was about three or four … I kind of held her and gave her permission… to be all the things that I hadn't allowed … I feel like I've given myself some freedom to be all those things that I shut down so long ago. And I feel like I'm just beginning to reclaim a lot of who I am and it's really, it's really wonderful. PN3

The future now opens to the participant and is greeted with hope.

We still make plans for traveling and stuff like that … we've made plans right up June next year or this year. if the inevitable happens, before that, it happens. … So we still look forward to what's ahead of us. PN14

I'm just much more relaxed about it and more mindful of living in the moment and doing what I want to do in the moment and not letting whatever might happen in the future stop me from doing that. PN24

In the present moment, the participant is back in the flow of life.

[The] heavy feeling of despair sitting on your shoulder is gone. I'm much more easily enjoying all the moments of life and not always thinking "Is this going to be my last time I have this?". I feel like planning for the future has become a huge part of our lives. PN19

Furthermore past, present and future are now imbued with continuity and potential. For example, PN22 reflected on old anxieties that had held her back from higher education and made the decision to pursue a master's degree, not for the sake of a qualification but because she found intense satisfaction in reading and new knowledge. Others had taken up musical instruments and new hobbies.

Theme Summary: Past is reclaimed, future is now available, and the participant now acts for intrinsic value in the present moment. Time is no longer a ticking clock, and the participant has stepped back into the flow of life.

4.2.8. Lifeworld - after intervention

The world has become a symphonic experience.

It's definitely had an impact on my visual, my sight of the world. I look at the world around me and it's just sparkling and the beautiful. The colors are intense and… I do feel a great sense of connectedness with the world. PN1

… just the feeling of being connected to most things in general, like connected to myself, more connected to other people, my family, my friends, more connected to my job, more connected to nature. More connected to motivations. Wanting to do more stuff…. connected to my future. PN19

I think it's just changed the way that I go about living whilst knowing that I'm dying… Life's much more abundant and free now. PN29

The body, no longer a dominant theme, has receded into moments of embodied health, sensuality, and self-expression.

it gives me fresh perspective… to go out and be sexual and sensual and it's ok. PN10

I've had the belief that if I think about my illness or give it too much attention, it will grow…. If I focus on my body too much, then the cancer will get worse. So I've actively tried to avoid doing that. And what I realized in my session was that what my body wanted was exactly the opposite. It wants me to tend to it, to take more notice, to not be scared to do that, so that was a total reverse. PN3

Participants now engage with the medical system to affirm this newfound sense of wholeness.

It affirmed that I was going in the right direction of decreasing medical intervention and just letting nature take its course PN4

Relationships now affirm the rich individual lifeworld of the participant and others. PN22 had spent her childhood keeping quiet and tending to the needs of the adults around her. This led to moments of simmering resentment and self-reproach throughout her adulthood that are now resolved.

Instead of going to the sniffy, angry, superior response I kind of just sat on the couch and said 'When you nod and say yes to me and don't really hear me it makes me feel really invisible, like an invisible little kid and I really don't like it". And then I cried, which I don't do in front of [the loved one]. She slowed and stopped and she just came sat down on the couch and she just sort of looked at me and she said, "Oh I am so sorry. I was not listening to you at all. I am so sorry. And I have been doing that since you were a little girl. Oh, I've seen it now, I'm so sorry". And it literally has changed both of us, it's like then we had this huge breakthrough. PN22

Theme Summary: The participants have rebuilt their lifeworld on their individual terms, and this rejuvenated lifeworld is more expansive and radiant than the lifeworld inhabited before the diagnosis. Everyday

moments have become astonishing encounters, and the world brims with possibility.

4.3. Overall evaluation of findings

Our phenomenological orientation reveals death anxiety and its relief through PAP more fully as *existential* issues - existential not just because the person's physical existence is at stake but also because how the person sits in relation to their own life and its temporality are disrupted too.

Prior to PAP, life was not fully *lived*. PN29 explained that the terminal diagnosis had "caught her mid-step" and left her unable to step back "into her skin". From this situation, time has become an all-encompassing 'now' wherein the person, alone and fearful awaits the appointed moment of physical demise. The future is unavailable because it is where death lurks: the past no longer serves to provide meaning to live by. The lifeworld, including the physical body, has lost its transparent familiarity and become an uncanny assemblage of meaningless entities. It is as if the person is now taking a point of view outside the flow of their life and its temporality, and this external perspective is accompanied by profound loss and loneliness.

After PAP, these participants are once again able to step back into the flow of life and live more fully, even in the face of death. Death becomes a part of a natural order, and this makes each lived moment more precious and sacred. The person is re-homed in a vibrant lifeworld that affirms their individuality. The temporality of their life is rebalanced so that past now propels them toward a less threatening future into a present moment lived for its own sake. The person is now situated *within* their lifeworld and its temporal flow. This rehoming is often accompanied by exultation and unexpected ease with the prospect of death. Life is not just lived unnoticed as it was before the diagnosis but has become more fully experienced and precious.

How then should we characterise that *nature* of this transformation? First, as we pointed out earlier, participants who rate PAP successful are unequivocal that a change has taken place. Furthermore, it has for them the nature of a binary transition from a before state to an after state. Above we have interpreted what the subjects say as an 'inversion' of where the subject sits in relation to their life - from being an observer to being a participant. The participants themselves reflect on what has happened to varying degrees, but overwhelmingly their own relation to change is action centred - they start *doing* things again that they have not done since before the diagnosis, often with more purpose and vigour. Thus, the change that accompanies successful PAP is a definite, binary transition in the 'way of life' of the subjects.

5. Discussion

5.1. Contributions to literature

Our findings shed new light on the death anxiety condition that the subjects share prior to PAP. Death anxiety has hitherto been characterised as a core psychological fear that transcends diagnostic boundaries [25]. While subjects expressed a range of fears concerning their physical demise, including loss of contact with children's lives, their condition was revealed as more that just a sum of their fears. We find that at its core sufferers live in a state of exile from their own life in an endless 'now'. Hints of this phenomenon are evident in subject accounts across a range of life-limiting diagnoses and in other cultural contexts ([14,56,61]. For instance, Chen et al. [14] reported poignant comments by advanced cancer sufferers, such as "I really want to escape from the present, everything in the present is making me miserable" while Strang et al. [56] reported subjects with COPD saying that the "very foundation of life" was shaken by the disease. However, our interpretation of this phenomenon in terms of the 'outsider' position subjects take on their life and its temporal flow, provides a new way for researchers to make sense of such subject accounts, and for practitioners to reflect such an understanding back to patients. Our observation that loss of meaning is at the heart of death anxiety explains why subjects can feel powerless, isolated, and terrified - factors linked with psychological suffering at end of life [10]. Our findings that existential issues are at the core of death anxiety also explains why strategies focussing on reduction of anxiety and depression symptoms alone are found to have little effect [21,25], while failing to address the core concerns held by the dying [36,42]. Our findings situate these individual symptoms of death anxiety within a larger coherent whole.

Our findings contribute to the literature on PAP in several ways. While the findings for the 'death' and 'mood' themes were expected from the selection criteria, the extent to which PAP allows death to be normalised as part of life is a notable new finding, and consistent Kast's original observation [29]. The extent to which, and the range of ways PAP transforms the participant's encounter with their lifeworld and even its temporality are new findings. While prior studies using only retrospective accounts of PAP have noted some of these changes, such as living more fully in face of death [57] and lasting changes to identity [9], our use of a longitudinal design has allowed the full existential nature of both death anxiety, and its relief, through PAP to be revealed for the first time. The changes we observed are rather consistent across subjects and between before and after states (Table 1), and centre on the way that subjects change how they live, as evidenced through their choices, behaviour and relationships rather than simply how they feel. This contrast also speaks to the different roles that psychotherapists and the psychedelic drug have in achieving the desired therapeutic outcomes. None of these changes were evident following placebo administration, confirming that psilocybin itself is a *necessary* component of the treatment. However, it is not *sufficient* as shown by the 7 cases that self-described their outcome as unsuccessful. There were too few cases of the latter kind in the parent study for an analysis and comparison.

Regarding the emerging debate about the relative contribution of psilocybin and psychotherapy to the therapeutic outcomes of PAP [19], our research design allows us to make a novel contribution based on the *kind* of transformation that we find constitutes successful PAP. As Table 1 shows, the subjects' relation to their lifeworld and temporality undergo a transition that is consistent and coherent on multiple dimensions from before to after PAP. In fact, transitions of this kind are already familiar to psychotherapists and indeed are no different to outcomes described with other modalities of psychotherapy [32], where patients reclaimed a sense of holistic lived experience that had little to do with their presenting symptoms. This kind of transition in a 'way of life' is *qualitative* and *extensive* in nature and quite distinct from the *quantitative* kind of change in symptom *intensity* one might expect from administering drug alone. This suggests that the psychotherapy component that accompanies successful PAP makes a contribution beyond something simply spooned out in an undifferentiated way as when psychotherapy is portrayed as comfort factor [19]. Thus, we argue that casting psychotherapists in a role subordinate to acute psychedelic drug effects would misunderstand the nature of the 'life change' we observe, the personal work of all parties required to bring it about, and deprive subjects of the possibility of a deeper engagement with their own life situation.

5.2. Implications for PAP practice

We have shown that death anxiety strips subjects of the capacity to make sense of their life situation, and that successful PAP brings them into immediate contact with the possibilities of life in a more abundant present moment. We now explore the clinical implications of this transformation for psychiatrists and psychotherapists. Our focus is not on any particular modality of psychotherapy but rather on those factors that have been identified as common to all modalities, namely: the therapeutic alliance, a healing setting, a psychologically derived explanation for distress as an adaptive response, and a set of procedures that lead the subject to enact something that is helpful [43].

5.2.1. Assessment and preparation

The psychotherapy assessment begins with an understanding that the subject will struggle to comprehend and express the totality of change in their life situation. The presenting symptoms are a useful starting point and allow spontaneous comments about broader life changes to emerge. Participant 5 commented that his illness had robbed him of the joy he felt when tending to rugged landscape surrounding his home and this had caused "immense grief". Rather than dissecting his grief for evidence of depressive mood change, exploring how he now feels when he walks around his land can allow him to build the picture of how his life has changed. Making this change explicit is important as it shows subjects that they can make sense of their situation and view their symptoms as a natural consequence of it. This will lay the foundation for the future change following PAP and provide subjects with realistic expectations of possible therapeutic benefits so they can make an informed decision about whether to proceed with PAP.

5.2.2. Psychedelic dose session

Our work shows that change with PAP takes place on the level of the patient's relationship to their life situation, and that this is not related in any simple way to the phenomenology of the acute experience. Vivid accounts of psychedelic experiences in the press, e.g. [47], may mislead participants who have less impactful experiences into feeling cheated or under-treated. Working with subjects to maintain focus on the change to come rather than expecting immediate relief can prevent subjects from prematurely foreclosing on their experience [2]. Where important psychological material does come to light during the acute psychedelic experience, it should be treated in the same way as any other material that surfaces in psychotherapy. Rather than viewing it as a singular event occasioned by the drug itself, it should be incorporated into the ongoing work. In this way, the focus of therapy always remains on the subject's life situation as it becomes clear to them.

5.2.3. Integration

Following successful PAP, the therapist needs to anticipate a shift in their work as the subject makes contact with possibilities in the present moment. Working with the transformation as it emerges requires the therapist to pay attention to moments where this life change becomes apparent. Participant 22 described such a change whilst attending to her garden: "It's taken me months to decide what to put in the garden and everything's been out there sitting in pots…. Now I've just thrown every plant out there in the garden and it was it's all a bit wild and it's exactly how it should be. And if I don't like where the plant is I just dig it back up and stick it in somewhere else…. it's just so much more freeing". Rather than attributing this to the impersonal effects of drug administration, the therapists affimed the importance of this moment, situating it within the subjects life and thus in their control. As the therapeutic relationship draws to a close, the subject needs to be explicitly acknowledged by the therapist as the expert in their own life.

5.3. Implications for research

Our use of interpretive phenomenology reflects our view that participants are experts on their own life and should be allowed to articulate the most salient phenomena. A recent systematic review of the mechanisms of PAP [12] commented that many participants experienced benefits beyond reduction in symptoms, and that participants did not regard symptom reduction as the primary benefit. However, these observations were treated as interesting anomalies rather than central effects. Our research uncovered that both death anxiety and its relief are more complex phenomena than previously recognised in PAP research, and this argues for research approaches that allow participants to speak about their life situation free from researcher preconceptions.

Our findings also set a constraint on any theory of the mechanism at work in PAP since it should be able to explain the changes we observe. Since these changes are existential in nature, it is an interesting open question what kind of explanation might be up to this task.

5.4. Ethical implications

Our findings address some of the complexities of consent for PAP [27] because therapists and participants can now become better informed about possible outcomes.

For therapists to recognise and work effectively with the totality of participant change, we would argue that a personal psychedelic experience should be a foundational training experience, without which the participant will be on their own as they try to make sense of their PAP outcome.

5.5. Limitations and opportunities

The study used a purposive sampling strategy from a population of affluent Westerners willing to undertake psychotherapy. Given the roots of medicinal use of psilocybin in quite distinct indigenous populations, it would be instructive to explore the extent to which our findings generalise to other subject cultures.

Extending our approach to those who do not have a successful experience would clarify important issues concerning subject selection for PAP [41] and help clinicians assessing requests for PAP. In the parent study, there were too few such participants to meaningfully describe this group.

Including a phenomenological study of therapists' perspectives on the unfolding therapy process in addition to participant's would further deepen our understanding of subject selection, the therapy process and therapeutic phenomena in the acute psychedelic state. Whilst therapist perspectives on ethics and professionalism have been well studied [30], the actual process of therapy from perspective of both participant and therapist has not.

We also recommend that participant life situation should be a central consideration in all psychedelic therapy research.

6. Conclusion

This qualitative study of how successful Psychedelic Assisted Psychotherapy (PAP) transforms the way of life of terminally ill subjects provides new knowledge for researchers and clinicians contemplating its use. Using an interpretive phenomenological approach (IPA) and interviews with subjects before and after PAP from a recent randomised control trial, we find that participants with extreme death anxiety have become displaced from their own life, afraid and alone in an all-encompassing present. PAP can enable them to fully inhabit their life in a more abundant and joyful present, even in the face of death. The psilocybin component is found to be necessary but not sufficient for this achieving this outcome. These novel findings expand our conceptualisation of death anxiety and of the personal transformation that constitutes successful PAP.

CRediT authorship contribution statement

Justin Dwyer: Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Robert B. Johnston:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Formal analysis, Data curation, Conceptualization. **Clare O'Callaghan:** Writing – review & editing, Methodology, Formal analysis, Data curation, Conceptualization. **Margaret Ross:** Writing – review & editing, Resources, Project administration, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization.

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Declaration of competing interest

All authors declare that they have no financial interests to declare. Margaret Ross is an unpaid member of the Scientific Advisory Board for MIND Foundation.

Appendix A. Appendix 1: Subject enrolment and characteristics of subjects and interviewers

For the parent study, 106 potential participants were screened, 36 were enrolled and 8 participants subsequently withdrew (combination of covid lockdown, medical illness, family commitments and one recommenced antidepressants). 28 participants completed the 2 doses, including all randomised placebo participants. 21 of these described their treatment as successful.

Inclusion criteria were 18–85 years of age with a with an advanced, life-threatening illness with an advanced, life-threatening illness with an expected prognosis of more than 6 months and associated psychological distress. Exclusion criteria included a personal psychiatric history or first degree relative with psychotic or Bipolar disorder, a personal history of substance dependence (except nicotine or caffeine) in the last 5 years, and other disorders considered incompatible with establishing rapport or safe exposure to psilocybin. Medical exclusions included intracranial pathology and conditions likely to impact metabolism of psilocybin, such as liver failure.

This report draws on interviews prior to dose 1 and at the end of the trial with the 21 who described the treatments as successful. All interviews were conducted by phone except for one face to face interview at the clinical trial site. In one interview, the subjects spouse was present, otherwise only the subjects were present. Mean interview duration was 29.5 min for interview 1, and 38 min for interview 3. At the end of each interview, the content was summarised by the researcher and checked for accuracy by the subject. Study findings were not checked with participants as many had died. Further, there is no evidence that participant feedback on research findings improves their quality [59] and participants' views can evolve over time [58].

The demographic and clinical characteristics of this group are described in Table 2.

Table 2
Subject characteristics.

Demographics	Placebo $n = 12$	Active $n = 9$
Age years mean yrs	50.9y	63.9y
Gender female %	58.3 %	55.6 %
Current partner	7	5
Prior psychotherapy	12	8
Prior psychedelic exposure	4	4
Primary medical illness		
Malignant / non-malignant	11/1	7/2
Primary psychiatric diagnosis by absolute number		
Major Depressive Disorder	4	4
Adjustment Disorder with mixed depressed mood and anxiety	2	3
Adjustment Disorder with depressed mood	2	1
Adjustment Disorder with anxiety	1	0
Generalised Anxiety Disorder	2	0
Persistent Depressive Disorder	1	0
Panic Disorder with Agoraphobia	0	1

Ethnicity – all Australian born except one male in niacin/placebo group.

A.1. Researcher positionality statement

All researchers and inter-viewers (except RBJ) have a clinical role in a Palliative Care Unit, and work to "improve the quality of life of patients, their families and caregivers" in accordance with the consensus-based definition of palliative care set forth by the International Association for Hospice and Palliative Care [48].

The gender, specialisations and highest qualification of the researchers were as follows: JD male, Psychiatrist (FRANZCP); RBJ male, qualitative researcher (PhD); COC female, Music Therapist and Social Worker (PhD). MR female, Psychologist (D Psych). VK female, Social Worker.

As researchers from Western, educated, industrialized, rich and democratic countries, we acknowledge that our findings may not be universally representative, and our identities may have shaped the research question and interpretation of the data.

Appendix B. Appendix 2: Questions used in the semi-structure Interviews

B.1. Before PAP

Questions	Prompts (if necessary)
How did you come to participate in the study?	How did you hear about it? How did you decide to participate, etc
What are your expectations about the study as you're about to commence?	How are you feeling about it? Excited, nervous, open, skeptical, etc.

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Questions	Prompts (if necessary)
Had you had previous experiences with psilocybin? Or other psychedelics?	Or what had you heard about psilocybin? Positive? Negative? (How open are you to the exp.?)
What particular experiences are you hoping for? CONCERNED ABOUT (FEARS?)	Happy, introspective, religious, etc.?
OK, so we're going to shift the focus for a moment to your illness. We'd like to understand how your cancer has impacted you - How do you feel your cancer has impacted your life?	Emotionally, relationships, spiritually,
How have you been dealing with your experience? What insights have you experienced since your cancer diagnosis (positive or negative)? What precipitated this insight? (e.g. therapy, discussion with a friend, solitude, book or reference, etc)	How have you made sense of your experience?
Some people with cancer to find it complicated when they think about the future. And some people experience ideas about HOW their illness could progress and even about how they may die. These ways we envision our own illness and death this can be frightening or negative, or they can be positive or even deeply meaningful- in terms of your experience, how would you describe your thinking in this regard?	What sort of ideas do you have about this? If no real ideas, Is it something that you actively try to avoid thinking about?
Do you have any fears around the illness or dying?	Other concerns; emotions thoughts - regrets
Some people have beliefs about what happens after we die. Do you have any specific ideas or beliefs about this?	
Have you had any psychological therapy for distress since your cancer diagnosis?	If so, what was it? What was that like for you? How has the experience of therapy affected your life since that time? How much of an overall impact has it had for you?
Have you had any medications such as anti-depressants, or anti-anxiety medications to help with managing the cancer diagnosis?	If so, what was it? What was that like for you? How much of an overall impact has it had for you?
And now I'd like to focus on the personal and deeper aspects of your life. What is meaningful, important or sacred for you?	What sort of activities or experiences make you feel more replenished, alive, connected with?
How has the cancer impacted this aspect of your life? Is it easier to connect with sources of meaning, OR do you find it harder to connect or even disconnected from your sources of meaning? (if meaning a concept that you consider)	Here & now, in the moment things that bring you joy, make feel alive;

B.2. After PAP

Questions	Prompts (if neccessary)
How did your experience in the study compare with your expectations from the beginning?	
What experiences were expected? What experiences were unexpected?	
Was it what you'd hoped for? REFLECT CONCERNS?	
Now that you've experienced the two treatment sessions, do you think that you received the psilocybin in the first or second treatment dose?	
For the session that you believe you received the psilocybin: Can you describe you experiences during this treatment session?	
	What perceptual changes did you experience? (see, feel, hear?) What internal changes did you experience?
What insights or new understandings did you gain, IF ANY?	
What emotions arose during your experience, IF ANY?	
How would you describe your experiences after the session ended and later that evening?	
In what ways do you feel the study has affected your life since the sessions, IF AT ALL?	
IN what ways do you feel your participation in the study has altered your anxiety level, IF AT ALL?	
HAS the experience changed your perception of or attitude toward the cancer? CLARIFY	
When we originally spoke to you, we spoke about how some people with cancer find it complicated to think about the future, and how some people experience ideas about HOW their illness could progress and even about how they may pass – this may be distressing or maybe positive or even deeply meaningful. At this moment in time, how would you describe your thinking in this regard?	
Do you have any fears or concerns around the illness or dying?	Other emotions, thoughts around it Selves others
Some people have beliefs about what happens after we die. Do you have any specific ideas or beliefs about this?	
What is meaningful, important and sacred for you?	What sort of activities or experiences make you feel more replenished, alive connected?
How has the psilocybin treatment impacted your connection with sources of meaning in your life, if at all?	Is it easier, harder, has it changed in some way?
We will focus the final part of the interview on questions related to your experience of the music during the session in which you believed you received the psilocybin (for second dose, 'when you were aware that you received the psilocybin') How did you think the music affected your experience, if at all?	
How did the different styles of music affect your experience?	
Please describe the music you preferred and why you think that is so?	Is this music that you would usually like?
Please describe the music you did not prefer and why you think that is so?	Is this music you would usually like?
Were there any times in the sessions which stand out as a point when you saw, felt or considered something from a different perspective?	If yes, ask to clarify, and then: 'what stood out for you about the music at that time, if anything?'
Has this experience specifically impacted your life in any way?	
(FOR THE 3RD INTERVIEW ONLY) How did your experience of the music during the first session compare with your second session?	Did you opt for similar music or different music? What made you choose the music that you chose the second time around?
INTERVIEWER SUMMARISES CONTENT AND SEEKS VERIFICATION/CLARIFICATION OF INTERPRETATION	

Data availability

The authors do not have permission to share data.

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