



# When experiences of presence go awry: A survey on psychotherapy practice with the ambivalent-to-distressing ‘hallucination’ of the deceased

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**Objectives.** Experiences of presence, involving the sensory perception or felt presence of the deceased, are common amongst the bereaved (30–60%). Despite them being predominantly comforting and reassuring, a minority (approximately 25%) report ambivalent or distressing experiences. The study’s aim was to explore how psychotherapy is practised with this subset.

**Method.** A mixed-method approach, involving both quantitative analysis and thematic analysis, was used to analyse data from an online survey, conducted in English and Spanish, amongst mental health therapists (i.e., psychologists, psychotherapists, and counsellors). Seventy responded to the survey and four of them were further interviewed.

**Results.** The participants primarily framed interventions for ambivalent-to-distressing experiences of presence as grief therapy, with the severity of the presentation as the main factor influencing their clinical decision-making, but several perspectives co-existed regarding how to intervene. These discourses were categorized into two themes: ‘A normalising and exploratory psychotherapy’ and ‘A grief stages psychotherapy’. The main sources of patient’s distress, as understood by the sample, were located in the bereaved–departed relationship, in pre-existing mental health issues, and in a societal taboo or stigma.

**Conclusion.** After comparing and contrasting the participants’ working hypotheses with existing knowledge on experiences of presence, and contemporary theories in the research area, guidelines are presented on how to intervene with people disturbed by their experiences of presence.

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## Practitioner points

- Perceiving the deceased person, or feeling their presence, is common and normal amongst bereaved people.
- When these experiences are distressing or ambivalent, therapists' share that psychological suffering may originate from the departed–bereaved relationship, pre-existing mental health issues, or the effect of societal taboo or stigma.
- Psychotherapy is frequently aimed at normalizing, accepting, supporting, and exploring patient's experience

Between 30% and 60% of bereaved people experience the continued presence of the person who died (Castelnovo, Cavalloti, Gambini, & D'Agostino, 2015) via a voice (13–30%), a vision (14–26%), a felt presence (39–52%), or a multi-sensory experience (Grimby, 1993; Rees, 1971). Despite the universality of bereavement in human lives, and the pre-eminence of grief in psychotherapy as a whole, these experiences have received little attention from the mental health sciences, and are often kept private by the bereaved. The clinician, as a result of this, is frequently unaware of their prevalence and properties, if not of their existence altogether.

Experiences of presence are here defined as when the bereaved perceive (via hearing, seeing, touching, smelling) or feel (the presence of) the deceased person. This phenomenon is also known as post-bereavement 'hallucination' (Rees, 1971) or as a continuing bond (Field & Filanosky, 2010), but we refer to 'experiences of presence' in this report to focus on their phenomenological properties. These experiences are mainly comforting or reassuring for the experiencer (Hayes & Steffen, 2017), with consequences ranging from helping the bereaved to say goodbye when this had not been possible (Klass & Steffen, 2017) to helping with a practical problem in daily life (Hayes & Leudar, 2016), to name a few.

However, a minority of the bereaved, approximately 25%, disclose unwelcome experiences of presence. This subset could be broken down into distressing (or frightening) experiences, estimated from 5% to 21% (Jahn & Spencer-Thomas, 2014; Lindström, 1995; Rees, 1971), and ambivalent (or mixed) experiences, estimated from 20% to 71% (Carlsson & Nilsson, 2007; Jahn & Spencer-Thomas, 2014; Rees, 1971). These prevalences, nevertheless, should be approached with caution considering the heterogeneity of the studies involved: the definition of the phenomenon, the type of loss, and the conceptualization of valence varies in each paper. Jahn and Spencer-Thomas (2014), for example, reported a 5% of harmful experiences and a 20% of mixed experiences ('neither helpful nor harmful', p. 317) amongst people bereaved by suicide, whereas Lindström (1995) found 21% of 'extremely negative experiences' (p. 15) in a widowed sample. The severity of ambivalent-to-distressing experiences of presence (ADEP) of the deceased, based on available qualitative and clinical literature, can range from a mild intrusiveness, on one end, to suicide-commanding auditory (Shimizu *et al.*, 2017) and visual (Baethge, 2002) experiences, on the other.

Not all experiences of presence, nevertheless, are conceptualized in such a way by the bereaved. As Hayes and Leudar (2016) documented in their investigation on sources of meaning, the practical and emotional consequences of these experiences can be highly varied, and context-dependent, for the experiencer. Besides the helpful consequences reported in their analysis, they highlighted two routes in particular that could lead to distress or ambivalence in experiences of presence: that (1) the experience continued a hostile or rejecting element of a bereaved–departed relationship after the loss or that (2) the experience acted as painful reminder of the bereavement (a 'feeling of absence'). They

concluded that 'given that the consequences of experiences of continued presence depend on their meaning for the bereaved, and that this meaning can change, there is a strong remit for talking therapies to aid those with distressing experiences of continued presence' (p. 206). Hypothesizing a connection between relational difficulties with the departed and some ADEP, they recommended a focus on the meaning of the relationship to the deceased in therapeutic work.

Another potential source of psychological suffering, with respect to ADEP, is stigma. This finding was originally reported by Rees (1971), in the Welsh countryside, who found that 72% ( $N = 137$ ) declared they had never disclosed these experiences to anyone for fear of being ridiculed, judged, or ignored ('I am frightened to tell anyone', 'It is not to be mentioned', 'I do not want to upset them', Rees, 2001, p. 271). A similar situation was later found by Grimby (1993) in Sweden. This idea was further discussed by Steffen and Coyle (2012) and Hayes and Steffen (2017) in their guidelines on working with welcome and unwelcome presences, in which they recommended acceptance of a patient's ways of meaning-making of their experiences.

Evidence from clinical case studies has suggested that psychotherapy can be effective for ADEP across the lifespan, from childhood (Bender & Lipkowitz, 1940; Shimabukuro, Daniels & D'Andrea, 1999; Yates & Bannard, 1988) and adolescence (Aguilar & Wood, 1974; MacDonald & Oden, 1977) to adulthood (Hoyt, 1980; Sluzki, 2008). In these cases, the intervention was usually focused (1) on the interpersonal issues in the relationship with the deceased and (2) on normalizing their experience, by reassuring the patient that they were not becoming psychotic.

Besides these case studies, the only available data on psychotherapy practice with ADEP were published by Taylor (2005) and Sanger (2009). Taylor (2005), interviewing people in the United Kingdom who underwent counselling for these experiences ( $N = 10$ ), found that 80% reported dissatisfaction because of the deflective responses and non-accepting attitudes of their counsellor. One participant reported being pushed 'to come to terms with reality and pull myself together' (p. 3), while another claimed feeling 'abnormal as her experience did not fit with the stages of grief described' (p. 6). Helpful counsellors, on the other hand, were described as empathic and accepting clinicians that normalized and explored their lived experience. Sanger (2009), interviewing social workers ( $N = 21$ ) in the United States on their practice with this phenomenon, described an agreement amongst them around an intervention focused on (1) normalizing and (2) exploring spiritual or religious issues, while (3) understanding the scientific literature on the phenomenon and (4) ensuring that no mental health problem (such as a dementia, psychosis, or stroke-induced hallucination) is present. A limitation of this latter study is that, despite mentioning that some of their work included individual or group psychotherapy, which part of the sample (or of their practise) involved psychotherapy is unknown.

In conclusion, almost nothing is currently known about what is routinely done in clinical practice with ADEP, what resources are generally used in the therapy room, and how these experiences are conceptualized in routine care. This deficit of evidence motivated this pathfinder study on psychotherapy for ADEP, an online survey complemented by qualitative interviewing, which was designed as an exploratory bridge across the gap between what is known on the phenomenon, what is done in private and public health care, and what the existing empirical and theoretical literatures recommend.

This is, to the best of our knowledge, the first data on psychotherapy practice with this phenomenon. We focused on the following research questions:

RQ1. How are mental health therapists practising with ADEP? What are the resources they are drawing from to inform their clinical work?

RQ2. What are their working theories about the sources of ambivalence and distress?

## Method

This pathfinder study followed a mixed-method design, integrating both quantitative and qualitative analysis, aimed at theory generation on psychotherapy practice with ADEP: This was conducted following the tradition of Henwood and Pidgeon (1992). Data were collected in the United Kingdom and Spain through an exploratory survey complemented by qualitative interviewing. The survey data were subject to a mixed-method analysis: The closed responses were analysed quantitatively while the open-ended responses were analysed using discursively informed thematic analysis. The qualitative analysis of the subsequent interview data will be presented in a future report.

## Recruitment

No claims to representativeness or generalizability were sought for the survey: A maximum variance sampling strategy was chosen for recruitment instead, hoping to maximize the chances of obtaining the greatest diversity of practice and theories within the time resources that were available. Maximal coverage was sought regarding profession (psychologist, psychotherapist, medical psychotherapist, counsellor) and approach (psychoanalytic–psychodynamic, humanistic–existential, cognitive–behavioural, family–systemic, integrative–eclectic). Variance was also sought regarding culture: Responses were collected in both the United Kingdom and Spain in order to obtain cross-cultural data in an area of research that, so far, has mostly relied on North American and British data.

Although recruitment was exclusively conducted through British and Spanish networks, some responses may have been submitted from different countries (e.g., a clinician registered in Spain or the United Kingdom but practising in a third country). The link to the survey was sent via (1) professional associations or organizations, (2) the network of our research centre, in the United Kingdom, and of the research team involved in the study, and (3) open professional databases. The professional associations and organizations (or sub-sections within them) included the Spanish Psychological Association (*Colegio Oficial de Psicólogos*, COP), in Spain, and the Medical Psychotherapy Faculty of the Royal College of Psychiatrists (RCPsych), the Society for Interpersonal Theory and Research (SITAR), the Society for Exploration of Psychotherapy Integration (SEPI), the Critical Psychiatry Network (CPN) and the Association for Family Therapy and Systemic Practice (AFT), in the United Kingdom. All other major psychology and therapy associations and organizations (e.g., UKCP, BACP) were contacted, in both countries, but declined to participate.

## Sample

The survey opened on the 22nd of October of 2018 and closed the 17th of March of 2019. Exactly 100 clinicians entered the online survey by the closure date, of whom 70 completed their response and 4 were further interviewed. 49% answered the survey in English and 51% did so in Spanish. The inclusion criteria were to be a qualified mental health therapist, practising or retired, independently of whether they had seen a patient

with ADEP in therapy or not. The reason for this latter criterion was our interest in the various perspectives within our profession, rather than exclusively the view of those with significant expertise with ADEP. The clinicians' post-qualification experience ranged from 1 to 49 years, with a mean of 14.70 ( $SD = 10.94$ ). The sample's demographic information, professional background and route of recruitment is summarized in Table 1.

Only the participants recruited through English language networks were asked about their ethnicity, of whom 16 identified as White British, 6 as White European, 1 as White American, and 9 preferred not to say. This is the case because in opposition to the United Kingdom, where ethnicity categorization is ubiquitous in obtaining demographic information, ethnicity is not included in the Spanish state census (Estevez-Fernandez, 2015). Thus, in connection with that, no consensus is present on what ethnic categories should be.

### **Ethical approval**

The research protocol was approved by the Ethics Committee of the University of Roehampton. The information obtained was anonymized by deleting all personal information. All respondents joined the project voluntarily by giving their written informed consent.

### **Survey design**

The online survey consisted of 16 closed and open-ended questions. The first section included five drop-down menus focused on: (1) How many clients or patients with ADEP the clinicians had seen in their career, (2) the frequency of such type of case in their clinical work, (3) how they intervened in those cases, (4) their level of confidence when doing so, and (5) the factors influencing their clinical decision-making, together with three open-answer boxes focused on (6) their professional opinion (based on their clinical experience), (7) whether they had seen clients or patients worried about other people's response to their ADEP, and (8) a prompt for further information about how ADEP are addressed in therapy. The second section included eight items on professional training, theoretical approach, sector of practice, clinical experience, age, gender, ethnicity, and religion. A full listing of the survey's text is available upon request from the corresponding author.

### **Qualitative analysis**

A thematic analysis, following the six-stage procedure of Braun and Clarke (2006), was used to analyse the open responses in the survey ( $n = 54$ ). An inductive coding at the latent level was applied following the key research foci, RQ1 and RQ2 (see above). The thematic analysis was discursively informed (see Singer & Hunter, 1999) in order to capture the linguistic choices of our sample, the resources these related to and the complexities they reveal. Responses were analysed in their original language, whether English or Spanish, and relevant quotes were translated into English for the purpose of this report.

### **Quantitative analysis**

Data from the survey were cleaned using Microsoft Excel and analysed using SPSS-25. As the sampling was purposive, and designed to maximize likely diversity of experiences, no

**Table 1.** Demographic and professional information

	Percentage (N = 70)
Professional training	
Psychologist	40%
Clinical psychologist	6%
Counselling psychologist	1%
Psychotherapist or psychoanalyst	31%
Medical psychotherapist	6%
Counsellor	7%
Other	4%
Undeclared	18%
Theoretical approach	
Integrative or eclectic	29%
Humanistic or existential	19%
Cognitive or behavioural	17%
Psychoanalytic or psychodynamic	10%
Systemic	6%
Other	1%
Undeclared	19%
Sector of practice	
Private practice	49%
Charity	9%
Public health care	6%
Private clinic or centre	3%
Other	16%
Undeclared	19%
Route of recruitment	
Association or organization	60%
Research network	23%
Open professional database	17%
Age group	
25–34	10%
35–44	30%
45–54	11%
55–64	24%
65–74	6%
Undeclared	19%
Gender	
Female	53%
Male	27%
Undeclared	20%
Religion	
Religious	33%
Christian	27%
Buddhist	3%
Other religion	3%
Non-religious	40%
Agnostic	23%
Atheist	17%
Undeclared	27%

claim to generalizability is made. A descriptive statistical analysis was calculated for each item, focusing on the diversity of practice with patients with ADEP and the theories behind those.

### **Reflexivity**

The epistemological stance of the inquiry is philosophical pragmatism and contextualism (James, 2000). An a-ontological stance (i.e., an agnostic stance regarding ontology, see Szabo & Tarbox, 2015) derives from this positioning in social sciences: Knowledge is seen as context-dependent and not representing a sociohistorically independent reality. The triangulation (Mathison, 1988) implemented between the qualitative and quantitative analyses, therefore, was aimed at obtaining an understanding that can be relevant for clinical practice (Madill, Jordan, & Shirley, 2000) rather than an objective theory. Our pragmatic aim, moreover, was to generate guidelines that can be of use in the alleviation of distress in clinical practice. This focus on the consequences of ADEP, however, does not attempt to diminish the value of other perspectives on these experiences, whether spiritual–religious or not.

Regarding our perspective as a research team, all of us belong to the profession of psychotherapy, with each of us coming from a different theoretical approach, disciplinary training, and cultural background. Our varied background (Spanish, British, and Greek) inspired not only the choice of a cross-cultural study, but also the way that cultural and linguistic differences were considered during the data analysis. Our research expertises and specialties (clinical psychology, psychotherapy, and psychiatry) influenced the decision to use a mixed-method design. We share a view of the self as relationally constituted, so every reference in this report to the relationship between the experiencer, the other and their culture should be read in the context of their mutual intertwinement.

## **Results**

### **Quantitative analysis of the survey's responses**

Twenty-four of the clinicians stated that they had never seen a patient with ADEP, with five therapists having seen twenty or more, and a maximum seen of 200. The median number seen was 1.5. For those who stated having clinical experience of ADEP, most reported that they would encounter a patient with ADEP in their work once a year (15) or every few years (21).

Asked about their intervention with ADEP, those with clinical experience with ADEP marked each option offered in the following way: 32 did psychotherapy for bereavement, 19 reassured the patient (i.e., that there was no reason for concern), 7 did psychotherapy for trauma, 4 referred to psychiatry (i.e., considering the case too severe for psychological intervention), and 2 did psychotherapy for psychosis. Four therapists also marked 'other', and the interventions added included EDMR, palliative care, and therapy as usual. Several clinicians marked more than one option, especially those with a higher number of people with ADEP seen, indicating that the latter group might use different interventions with different patients. The participants' confidence when practising with ADEP was medium-to-high, a mean of 7.2 in a 10-point scale ( $SD = 1.94$ ), though there was a markedly spread distribution of confidence with 13 declaring a low level of confidence (5 or lower) and 16 rating their confidence at 9 or 10.

Prompted in the survey about factors they considered relevant when working with patients with ADEP, the main factor for the participants was the severity of the

presentation (43), followed by the ethnicity or religion of the patient (28), what the clinician felt comfortable treating (27), the similarity of the experience with a psychotic breakdown (20), whether the condition ‘belonged to psychotherapy’ (14) or no option available (6).

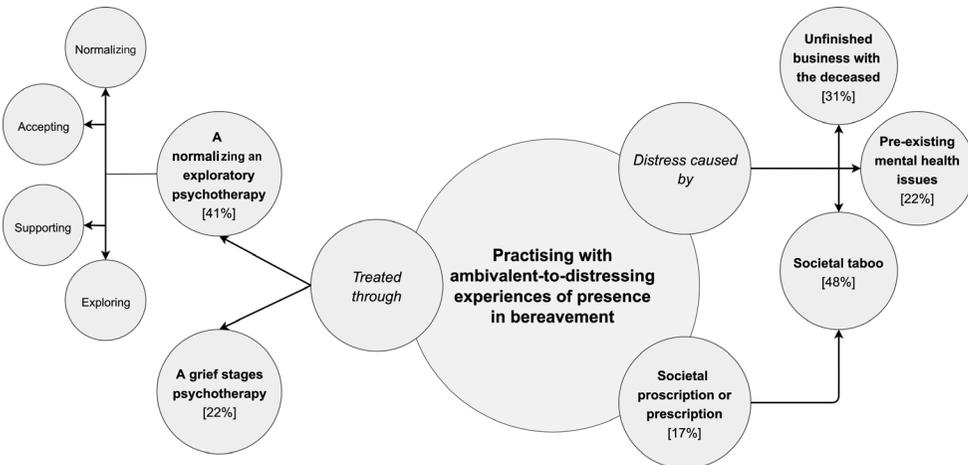
**Qualitative analysis of the survey’s responses**

Six themes were identified in the thematic analysis of data from the 54 participants who gave free text responses to the survey. Forty-three of them had experience with ADEP and 11 did not, although the latter mainly drew from cases of welcome experiences of presence they had seen. Two themes described how psychotherapy was, or should be, conducted with ADEP: ‘A normalising and exploratory psychotherapy’ or ‘A grief stages psychotherapy’. Another three described the causality of ADEP according to them ‘Distress caused by unfinished business with the deceased’, ‘Distress caused by underlying mental health issues’, and ‘Distress caused by a societal taboo or stigma’. A sixth theme, ‘Socio-cultural proscription or prescription’, described the presence or absence of this taboo or stigma around experiences of presence across cultures. These six themes and their respective frequencies are depicted in Figure 1. Five themes have been grouped into two categories for the sake of clarity (‘Treated through’ and ‘Distress caused by’). Each of the six themes, exemplified with illustrative quotes, is described below.

**Sources of distress in ADEP**

*Distress caused by unfinished business with the deceased*

Some clinicians stated that distressing experiences can be due to unfinished business, or unresolved issues (guilt, resentment, regret, fear, anger), in the relationship with the deceased. This theme was present in 17 responses (31%).



**Figure 1.** A depiction of the six themes and sub-themes, and their respective frequency in the dataset, identified through the thematic analysis of the survey data. The frequency indicates the percentage of open-ended responses (n = 54) with a code included in that theme.

"Unwelcome experiences may be connected to unresolved issues in the relationship or the death itself"

"The possible unfinished business (maybe resentment for something, or the need to apologise or express something)"

Experiences of presence can be seen, following this hypothesis, as a relational phenomenon, with their valence depending on the relationship with the deceased and the circumstances before, during, and after their death. Two respondents considered them a sign of ambivalence in the relationship with the departed, while another two connected the suffering with a psychological dependence on the person who died. An unsatisfied need to say goodbye to the deceased person was noted in two responses. One clinician referred to frightening experiences in children 'who fear that the person has come back to haunt them, or hurt them, because they have done something wrong'.

#### *Distress caused by pre-existing (mainly psychotic) mental health issues*

Distressing experiences were also presented as connected to underlying mental health issues, where psychological suffering pre-dating the loss is carried over in the experience of presence. This theme appeared in 12 responses (22%). These difficulties are mainly attributed by the respondents to psychosis, whether they are seen as a risk of progressing towards psychosis or as resulting from a pre-existing psychotic disorder. They were, however, also attributed to non-psychotic difficulties, such as psychological trauma, substance abuse, or attachment style. Some presented them as psychotic or quasi-psychotic: suggesting, for example, the need for a differential diagnosis with delusion and psychosis when very distressing, or that a psychiatric referral may be needed in some cases. The rationale supporting this classification was varied, from a socio-relational perspective to a neurological approach.

"Have seen one or two cases where the patient has moved from distressed bereaved to comfortable psychosis, and the distress is then in relatives/carers"

"[These experiences are] mainly seen in traumatic losses: in order to integrate the trauma the brain generates stimuli of denial and deceit. Sometimes dissociation can take place alongside hallucinatory symptoms."

Two responses, however, decried seeing ADEP assessed and medicated as psychotic breakdown.

#### ***Distress caused by a societal taboo or stigma***

Some experiences of the deceased are not unwelcome *per se*, but become so when being perceived as such by somebody else. The distress is thus mediated by another person's reaction, usually somebody within the social circle of the bereaved person, and by the impact that this has on their relationship.

In my experience the unwelcome component is often related to the sense others make of the patient's difficulties and the impact of this on their relationships rather than the "symptoms"

This theme was present in 26 responses (48%), although a further 14 respondents (26%) reported, when prompted in an open-response box (see above for question 7), not

having seen such socially mediated ADEP. Clinicians frequently saw patients with ADEP as worried about being 'mad' or about being seen as 'mad' by somebody else. They can be reluctant, as a result of that, to tell anybody about their experiences of presence, whether in their daily life or to their therapist.

In a couple of cases, the experience was disturbing for the associations of being "mad"

If telling somebody else about their ADEP, therapists stated that their patients faced (or feared to face) ridicule or shame, being told they should forget these experiences, have their distress minimized, or even being told not to have them at all. This can result in alienation.

They have had experienced marginalisation. For example, "you should be over it by now", "people think I'm crazy", "people say I should move on"

### ***Socio-cultural prescription or proscription***

Experiences of presence are seen as varying across, or being dependent on, the patient's worldview: their social, cultural, and religious environment. This was mentioned in 9 responses (17%). Some stated that they are seen as normal or positive in 'other' cultures, especially in the presence of a religious or spiritual worldview.

"It is dependent, as well, of the patient's worldview, if they believe in an afterlife or not"

"I believe they are natural in bereavement, especially in some cultures and ideologies"

Some mentioned a proscription in the surveyed cultures around experiences of presence, in the form of an internalized socio-cultural discourse driven by fear, concern, and uneasiness. Two respondents mentioned them as countercultural, and under-researched, in psychotherapy as a field.

Many British people who have these experiences are conscious that they may seem to be mad, either to family and friends or to professionals

### ***Psychotherapies for ADEP***

These themes relate to the resources respondents drew upon in their work. The two main perspectives describing a psychotherapy for ADEP were not mutually exclusive in the survey's responses, as some clinicians moved from one to the other from answer to answer. Nevertheless, a reference to a sole perspective, sometimes with a critique to other approach or system, was present in some responses as well.

#### ***A normalizing and exploratory psychotherapy***

This theme, present in 22 responses (41%), describes a way to practise with ADEP by normalizing and accepting them, while exploring meaning, from the ground of a supportive relationship. The first sub-theme, 'Normalising', describes how when the

clinician approaches experiences of presence as a natural part of bereavement, reassuring the patient that they are not 'mad' or 'insane', fear is alleviated:

Most of my patients' experiences are positive and comforting once you have reassured them it is common and normal and they're not going mad.

The second sub-theme, 'Accepting', describes how when the clinician listens with respect, accepting the patient's experience from their own framework, they 'open up':

The person hides it, out of fear of being considered mad, and 'opens up' only to somebody (therapist or not) who they think won't judge them like that

The third sub-theme, 'Supporting', describes how acceptance and normalization are only possible from a protective and supportive relationship between therapist and patient.

When the therapeutic relationship is good enough, the patient feels supported and protected, and with the confidence needed to be able to live the experiences that they need to live

The fourth sub-theme, 'Exploring', describes a focus of the intervention on the meaning of the ADEP. This exploration included (1) the relationship with the deceased, (2) unfinished business with the person who died, (3) religious or existential belief, and (4) the experience in the here-and-now. As part of this exploration, some experiential and emotional-processing techniques (such as the empty-chair technique or EMDR) were mentioned by some participants.

#### *A grief stages psychotherapy*

This theme, present in 12 responses (22%), describes a way to practise with ADEP which would fit the Kübler-Ross (1990) model of stages of grief. ADEP, from this perspective, can indicate a denial of the reality of the loss, and the underlying emotion (rage, fear, sadness) must be expressed so the 'hallucination' will disappear and the person can let go of the deceased and move on. Two responses, moreover, connected them with complicated or 'frozen' grief.

It must be treated with psychotherapy to elaborate all the grief stages to be able to say goodbye to their loved one

We should orient the patient toward understanding and accepting these experiences, so they can "let go" their loved one emotionally"

#### **Other perspectives**

Besides these two approaches, prevalent across the data, other perspectives were present in the text responses to a much lesser extent. Some (9%) highlighted the importance of the 'unknown' in the therapeutic encounter, embracing uncertainty and accepting that 'there are some things that we cannot explain' or that 'there is more to this world that we can know'. Some (9%) approached the ADEP from a functional analytic perspective, asking for the purpose or function of the behaviour, and outlining a behavioural or cognitive

intervention for it ('the habituation that would allow the extinction of the defensive responses'). Other minority perspectives in the data were as follows: ADEP as ego-fragmentation; as a coping mechanism to confront the pain of the loss; as a neuro-vegetative reaction; and as something to be approached from an anti-dualistic or ecological stance.

## Discussion

This discussion first analyses the sample's working theories on sources of distress, when experiences of presence cause psychological suffering, before examining their perspectives on how psychotherapy should be conducted with them. In each case, this practice-based theory is contrasted with the existing literature. The report concludes addressing the weaknesses and advantages of the research design.

### Sources of distress

#### *Unfinished business with the deceased*

Thirty-two therapists framed their intervention as grief therapy or counselling, a framework probably connected with a perceived connection (noted in 31% of the open-ended responses) between unfinished business with the deceased, on one hand, and experiences of presence causing distress, on the other. This assumption is in concordance with literature (Hayes & Leudar, 2016; Hayes & Steffen, 2017), in which anger (Matchett, 1972), abandonment (Aguilar & Wood, 1974), and guilt (Baethge, 2002) were frequently connected to ADEP. The clinician should be aware of this possibility: focusing of the departed-bereaved relationship, along existing guidelines on working with relational meaning (Hayes & Steffen, 2017), and referring to the literature on a continuing bond with the deceased (Klass & Steffen, 2017).

#### *Pre-existing mental health issues*

The intervention was framed by 7 clinicians as psychotherapy for trauma, and several open-ended responses described cases where a trauma pre-dating the loss, or a traumatic bereavement, seemed to underlie the ADEP. Considering the correlation between traumatic death and experiences of presence reported by Field and Filanosky (2010), and the relationship between psychological trauma and voice-hearing (Luhmann *et al.*, 2019; Read, Agar, Argyle, & Aderhold, 2003; Read, van Os, Morrison, & Ross, 2005), the exploration of traumatic difficulties is clearly warranted when working with ADEP. Theories on self-fragmentation as a defence mechanism against psychotrauma (Perona-Garcelán, Pérez-Álvarez, García-Montes, & Cangas, 2015) are a relevant resource here. The clinician, however, should not automatically interpret the ADEP as a post-traumatic flashback, or mere replay, of the traumatic event. Some of the responses described ADEP responding and changing according to the circumstances surrounding the bereaved person, a finding also reported by Hayes and Leudar (2016).

The severity of the presentation or of the manifestation was the main factor when deciding how to intervene for our sample, and 4 therapists referred a patient to psychiatry (on at least one occasion) considering the distress or impairment to be too severe for therapy. The case of a bereaved person moving from ADEP to a psychotic breakdown has so far been documented only anecdotally in the literature by Baethge (2002) and Shimizu

*et al.* (2017). Some of the survey responses, however, described cases where, due to distressing and impairing experiences leading to delusional thinking or risk of harm, the patient was not responsive to psychotherapy. Despite this being a possibility with extreme experiences, the risk of misdiagnosis or pathologization should not be minimized. The confusion of experiences of presence (whether comforting or distressing) with psychotic symptomatology is a distinct and dangerous possibility for the clinician unaware of the literature on the phenomenon, especially for those experiences happening in the auditory modality.

#### *Societal taboo or stigma*

The most frequent source of distress underneath ADEP, as noted by the clinicians, was a societal taboo or stigma. This fear surrounding experiences of presence, whether an uneasiness towards oneself, towards one's social circle, or towards the therapist's response, replicates what Rees (1971) reported in his foundational report five decades ago. The importance of reassurance and normalization has been paramount in literature on the phenomenon since his finding (Hayes & Steffen, 2017; Steffen & Coyle, 2012), and 19 therapists reported to having done so in clinical practice in at least one occasion. ADEP occurring once (or a few times) after a bereavement are not rare, moreover, and the clinician's acceptance can be instrumental in addressing any remaining fear or concern (see Sluzki, 2008, for a clinical example).

These data indicate that, in addition to the content of experiences of presence influencing their valence, the importance of the interpersonal environment surrounding the bereaved person (community, society and culture) should not be sidelined. This influence of context is further supported by the anthropological evidence on how ADEP vary across cultures (see Sabucedo, Evans, & Hayes, 2020) as well as by psychological research focused on the family and community level (Doran & Downing-Hansen, 2006; Hayes & Leudar, 2016; Steffen & Coyle, 2017). This is not to say that ADEP is solely due to social proscription, but rather that how they are evaluated by the bereaved person's social circle, and cultural environment, must be taken into account in order to capture their complexity. This is in concordance with what has been proposed by dialogical self theory, as formulated by Hermans (2001), which has been previously applied to experiences of presence by Austad (2014) and to voice-hearing by Perona-Garcelán *et al.* (2015).

#### **Co-existing clinical discourses**

The sample made use of several discourses when making sense of experiences of presence. Most belonged to psychotherapeutic approaches, to psychological or neuropsychological theories, or to psychiatric nosology, using the specialized language that Peräkylä and Vehvilinen (2003) have termed 'a professional stock of institutional knowledge'. Some also made use of non-specialized discourses belonging to general society, usually in the form of a spiritual-religious perspective.

The majority of the responses, however, referred to two discourses situated within the area of bereavement studies. Klass and Steffen (2017) have described how the field, during the last two decades, has undergone a shift from a 'breaking bonds hypothesis' to a 'continuing bonds hypothesis'. Relinquishing the assumption that the bereaved must 'let go' the deceased and 'move on', based on psychoanalytic notion of grief work, and acknowledging that a continuing bond with the deceased can be healthy and beneficial. The perspectives corresponding to these theories, nevertheless, co-exist in our data on

clinical practice with ADEP. The fact that both themes were frequently coded in the same respondent, and even response, can be seen in theory as an inconsistency with that professional stock, but could also indicate that both are being used in a complementary way by the clinician practising *in situ*. This latter interpretation of our finding would resonate with the ideas of Russac, Steighner and Canto (2002) and Stroebe and Schut (2005), who argued for the need to integrate these two hypotheses.

Existing theories on grief stages or phases, however, have been widely and increasingly criticized during the last decade, based on the empirical evidence contradicting the idea that grief does fit these sequences (Stroebe, Schut & Boerner, 2017). Interestingly, 83% of the responses noting the grief stages perspective came from the Spanish-speaking sample. This may reflect that the continuing bonds literature has not yet been translated into Spanish, while the work of Kübler-Ross (1990) is widely cited in Spanish-speaking psychology.

### **Limitations of the study**

Two disadvantages of the research design must be highlighted. The first disadvantage is that this survey is an exploration of therapists' accounts on their clinical practice and, although this allowed us to analyse the resources they are drawing from, such data do not grant us a direct access to the patient's experience, nor to therapeutic practice *in situ*. Considering how limited the existing evidence is, more clinical research is needed regarding how to identify and alleviate any psychological suffering connected with ADEP. The second disadvantage is that, due to the exploratory nature of the survey and the limited sample size, these data should not be seen as representative of the practitioner population of the United Kingdom and Spain.

### **Conclusion**

Epistemologically grounded in pragmatism and contextualism, this study sought to add empirical information that can be useful for the clinician seeing a patient with ADEP. We hoped that new data would shed light on existing theories, capture the working practices that are usual in the area, and have utility for the therapist working with bereaved people. The survey, based on opportunistic sampling, was designed to maximize the likelihood of revealing a diversity of theories and practices. The combination of quantitative and qualitative data sought to allow individual perspectives to appear, and to increase the reliability of our analysis through analytic triangulation, while defining key variables that could be measured. A feature of the design is that the cross-cultural sampling frames (in the United Kingdom and Spain) provided coverage of clinical practices in both English and Spanish. We hope to see future studies addressing the way that ADEP, as located in different cultures and societies, are worked with and made sense of in clinical practice.

### **Acknowledgements**

We would like to thank Karina Stengaard Kamp for her feedback on an earlier version of the manuscript.

### **Conflicts of interest**

All authors declare no conflict of interest.

## Author contribution

The first author, PS, contributed to every aspect of the research and led in writing the manuscript. The second author, CE, supervised the project, contributed to the research design, the survey design, the quantitative analysis, and the write-up of the report. The third author, AG, contributed to the write-up of the report and held a supervisory role. The last author, JH, designed and supervised the project, contributed to the research design, the qualitative analysis, and the write-up of the report.

## Data availability statement

The data that support the outcomes of this survey are available from the corresponding author upon reasonable request.

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Received 20 December 2019; revised version received 4 May 2020