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Applying the phenomenology of grief: An autoethnographic study

Arnout ter Haara and Geert E. Smidb,c

^aPrivate Psychotherapy Practice, Amsterdam, The Netherlands; ^bARQ National Psychotrauma Centre, Diemen, The Netherlands; ^cThe University for Humanistic Studies, Utrecht, The Netherlands

ABSTRACT

In contrast to normative views on grief, phenomenological descriptions of grief aim to provide a comprehensive picture of the lived experience, providing space for both uniqueness and universality. However, it is unclear how application of phenomenological descriptions contributes to bereavement care. The aim of the current study was to evaluate the clinical applicability of phenomenological descriptions of grief through autoethnographic exploration. The lived experience of the first author's grief following the death of his husband illustrates two strands of time that increasingly desynchronize: the alienated reality of everyday life and the lingering presence-in-absence of the deceased. Processing grief involved a fundamental reorganization of his identity through representation of and identification with the deceased. Clinical applications of phenomenological descriptions include diagnosing existential manifestations of Prolonged Grief Disorder, cultural aspects, and psychoeducation for the bereaved and for those close to them.

Grief comprises existential, psychological, and physical reactions to the loss of a loved one and can cause long-standing and severe suffering. Recently, both ICD-11 (WHO, 2018) and DSM-5-TR (APA, 2022) included prolonged grief disorder as a new diagnosis, characterized by intense yearning for the deceased person or preoccupation with thoughts or memories of the deceased, and at least three additional symptoms such as identity disruption since the death, disbelief about the death, avoidance of reminders that the person is dead, intense emotional pain, difficulty reintegrating into personal relationships and activities, emotional numbness, feeling that life is meaningless, or intense loneliness as a consequence of the death that is accompanied by severe suffering or functional impairment for at least 6 to 12 months after death, going beyond cultural norms of grief responses (APA, 2022).

Many descriptions of grief and grieving processes reflect norms for grief, such as stages of grief to be gone through or specific timeframes in which the grief must take place: 'going through' bereavement and 'coming to terms' with loss (Akehurst & Scott, 2023). Normative views on grief are also common in the immediate environment of the mourner: do not dare to be cheerful too soon, and do not dare to continue grieving too long! Van den Bout (1996)

refers to these as 'mourning veils', because normative views on grief conceal the fact that everyone's grief is different. In contrast to normative views, phenomenological descriptions aim to provide a comprehensive picture of the lived reality, providing space for the uniqueness of experience, thus enabling a look beyond mourning veils into the face of grief. Phenomenology starts from the direct and intuitive experience of phenomena (e.g., grief) and tries to deduce from this the essence of those experiences, and is based-among others-on the work of Husserl (e.g., Fuchs, 2018; Ratcliffe, 2019b), Heidegger (e.g., Gunter, 2014) and Merleau-Ponty (e.g., DuBose, 1997; Ratcliffe, 2019b).

The phenomenological literature on grief is relatively limited. An early phenomenological study of grief involves a description of the lived experience after a miscarriage (DuBose, 1997). The study elaborates upon the author's experience of what was lost and how he coped with the loss: "We found ourselves in a different life-world from the one we had inhabited before the miscarriage, and different from the one we inhabited before the pregnancy. In the world of pregnancy, we were parents, if only for eight weeks" (DuBose, 1997, p. 367). DuBose (1997) relates the experience and its meaning to the thinking of the French phenomenological philosopher Merleau-Ponty,

who described the body (rather than consciousness) as the primary site of knowing the world. Merleau-Ponty emphasized that the perceiving body and its perceived world cannot be disentangled from each other; the structure of the flesh is seen as chiastic, an intertwining of mutual relationships (DuBose, 1997). "The chiasms shared between my wife and me, within ourselves, and in relation to the larger society and environment, brought meaning to our own experiences of loss" (DuBose, 1997, p. 374). A later interview study (Spaten et al., 2011) concerns the phenomenology of grief in men after losing their spouse. From this study, the themes of grief and self-reflection, meaning of life and loss and reorientation to one's life emerge. In a study of the phenomenology of grief in children after losing a sibling (Gunter, 2014), recurring themes were expressing of emotions, commemoration of life, and reinvestment in life. These children considered expression of their grief as a key element for their progress.

The British philosopher Ratcliffe (2015, 2019a, 2019b) describes grief as an alternation between experiences of presence and absence, a variable and changeable way of relating to the dead, the living, and the social world. Ratcliffe speaks of indeterminacy in grief. There are two different ways to experience this indeterminacy of loss: a partial or complete understanding of the loss, or the experience of an enduring connection with the deceased. An enduring connection implies that the bereaved person's sense of identity continues to include the relationship with the deceased loved one. For the bereaved, the deceased was not only part of the world, but also a condition for understanding that world. A sense of connection with the deceased can play an important role in navigating the indeterminacy of loss and can persist even when one seems to have adjusted to the loss. Relationships with the dead are thus an important aspect of interpersonal and social experience.

Fuchs (2018) uses the concept of ambiguity, in many ways similar to indeterminacy, to describe a conflict between presence and absence tendencies as a central feature of grief after the death of a loved one. His phenomenology of grief describes the phenomena in the following areas: the body, alienation of the world and self, temporality, ambiguous presence, grief processing and re-integration.

It is unclear to what extent phenomenological descriptions of grief can be applied in clinical practice. Sophisticated formulations using subtle, uncommon language may complicate their application in clinical practice. Nonetheless, phenomenological descriptions may be useful for clinical practice, e.g. to further

elucidate diagnostic formulations and to provide psychoeducation. Therefore, the aim of the current study was to explore the clinical applicability of Fuchs' phenomenology of grief by applying it to a lived experience of grief using autoethnography. Specifically, the first author, dealing with his own grief following the death of his husband, used autoethnographic methods (keeping a diary, writing letters and e-mails to friends) and evaluated his daily entries later on by applying Fuchs' (2018) phenomenological descriptions.

Autoethnographic research is characterized by a spontaneous, unsystematic and disorderly process of moving between lived experience and analytical reflection (Akehurst & Scott, 2023). Although autoethnography has reached an established place within qualitative inquiry, it remains an unusual choice of method: foregoing one's own subjectivity and reflecting upon sensitive and emotional personal experiences demand deep honesty and vulnerability that for many remains unappealing (Akehurst & Scott, 2023). Nevertheless, autoethnography is exactly the method we think is appropriate for our goal.

Our research questions are: To what extent can the lived experience of the first author's grief add to the theoretical assumptions of Fuchs' phenomenology of grief? Can phenomenology help clinicians chart a patient's grief experience to facilitate a proper diagnosis of prolonged grief disorder? And can autoethprovide tools—in nography terms psycho-education-to offer to those who grieve and to bereavement care providers, both professionals and laymen? As in our case the subject of the grieving process is also a trained and qualified clinical psychologist and psychotherapist, whereas the second author is a psychiatrist; the autoethnographic method here used thus enables an integration of personal experience with professional knowledge and experience. After elaborating on the autoethnographic method, a summary of Fuchs' phenomenology is described, followed by the lived experience of the first author's grief. In the discussion we will try to answer the above-mentioned questions.

Method

Autoethnography

Autoethnography is an approach to research and writing that seeks to describe and systematically analyze personal experience in order to understand cultural experience (Ellis et al., 2011). Ethnographic research in the context of grief has been described as "applied phenomenology" (Klass, 2022). In order to write

autoethnography, a researcher uses aspects of autobiography as well as ethnography. As a method, autoethnography is both process and product. Even though researchers often assume that research can be done from a neutral, impersonal, and objective stance, most now recognize that such an assumption is not tenable. Consequently, as Ellis et al. (2011) state: 'autoethnography is one of the approaches that acknowledges and accommodates subjectivity, emotionality, and the researcher's influence on research, rather than hiding from these matters or assuming they don't exist.'(Ellis et al., 2011, p. 274).

Autoethnography can be an appropriate method for researching complex emotional experiences such as grief (Akehurst & Scott, 2023), and although it now has an established place within qualitative inquiry, it remains an unusual choice of method; in order to reflect upon one's own sensitive and emotional personal experiences, deep honesty and vulnerability are required. Autoethnography is procedurally complicated, insofar as it does not follow the stages, guides and practices of conventional research involving other participants (Akehurst & Scott, 2023). We used autoethnography to add to theoretical assumptions of Fuchs' phenomenology of grief and to explore clinical applicability of phenomenological descriptions in terms of PGD diagnostics and psychoeducation.

Breton et al. (2021) proposes the complementarity of two narrative regimes, the description of lived experience or embodied experience as per Merleau-Ponty and the narration of life history based on the theory of hermeneutics and biography of Ricoeur. Central in Ricoeur's theory is the temporal distance between the lived experience and the narrated experience. The latter is based on the principle of succession, that orders the facts experienced in time, and gives meaning to these facts and configures the self-narrative. To bring narratives to a deeper level of understanding, a mix of both narratives is needed: embodied and authentic on the one hand, and meaningful, coherent and continuous on the other hand (Breton et al., 2021).

A narrative is itself an accumulating construction and can be defined as a temporal sequencing of events. As a consequence, narratives are not the objective accounts of events occurring across time that they seem to be. They follow narrative principles of 'emplotment', and describe sequences in a coherent way with a beginning and an ending (Andrews et al., 2000). Narratives can bring solace, a means of keeping on with life. Although sociologists and psychologists working with narratives tend to assume that these bear a strong resemblance to the structure and content

of the lived, social world, individual stories contain elements of cultural meta-narratives, thus being much more significant than the apparent narrative of the individual (Andrews et al., 2000). Narrative practices may play a role in identity construction (Bamberg, 2012) and have a temporal dimension where sameness versus change across time is part of the narrative, such as a change after the death of a loved one. Narrative inquiry (Freeman, 2015) is arguably the most appropriate vehicle for studying and understanding human lives. For Seale (1998) the narrative reconstruction of personal biography is seen as a resurrective practice, enabling bereaved people to maintain the human social bond with the deceased (cf. Klass, 2022).

In line with narrative theory, Walter (1996) presented an alternative for the dominant model in the bereavement literature, where grief is seen as a working through of emotion with the goal of moving on and live without the deceased. Walter (1996) describes bereavement as a starting point of never-ending and reflexive conversations with the self and others who knew the deceased. These conversations enable finding a secure place for the deceased. Together they construct a story, a durable biography that places the dead within their lives, a story capable of enduring through time. The process focuses on talking rather than feeling, with the goal of moving on both with and without the deceased (Walter, 1996).

For the autobiography method the personal experiences described in this paper were assembled using entrances from the first author's diary and from letters or e-mails written to friends who asked how he was doing. Three weeks after the death of his husband, he started this diary and made daily entrances, and does continuously so up to the time of writing this paper. For the ethnography method, being both an observer and a participant of the way western society deals with grief and mourning, common values and beliefs as well as shared experiences with other bereaved who lost a spouse or lover, were integrated in the personal experience of the first author's own grief and mourning process. From there on these personal experiences were compared to the work of Fuchs (2018), whose paper on the complex phenomenology of grief is summarized more extensively below. Fuchs' analysis was based on self-reports, descriptions in the psychological literature and his own clinical practice, and was focused on the loss of a loved one (a spouse, parent or child), since the phenomenon of grief becomes most visible there. Fuchs gives a methodological caveat in his paper: 'Grief is a complex and heterogeneous process, which proceeds and manifests itself in manifold ways, and

which is subject to considerable cultural variation and modification. [...] A phenomenological account of grief attempts to grasp its typical basic structures, yet cannot completely exclude that it also arrives at ideal types that correspond primarily to the European cultural tradition and do not capture forms of grief in other cultures with equal concision. [.] Notwithstanding these reservations, a phenomenological investigation still assumes that there is a core structure to the experience of grief which despite all variations may be addressed and carved out to a certain extent. This could also be valuable for further comparative anthropological research or even for a transcultural phenomenology' (Fuchs, 2018, p. 45). In order to organize all the daily - and therefore quite random - reflections of the first author's grieving process, we will follow Fuchs' classification of the basic components of grief, starting with grief and the body. Then successively alienation of world and self, temporality, ambiguous presence, grief processing and re-integration will be described.

A summary of Fuchs' phenomenology of grief

Central features of grief according to Fuchs are ambiguous presence and absence tendencies. The grieving person experiences a fundamental ambiguity between living in the present and the past, between the absence and presence of the deceased. This ambiguity in grief manifests primarily as a bodily experience: it is as losing the ground under one's feet, accompanied by a general physical weakness, numbness, and often derealization. Once the immediate shock and numbness subsides, symptoms develop that to some extent resemble those of depression: a feeling of heaviness, head and shoulders hunched over, walking accompanied by a bowed gait. Pressure on the chest, shortness of breath, sighing, crying and 'choking with grief', fatigue, passivity, lack of motivation, loss of appetite and sleep disorders. Unlike depression, there is no general bodily rigidity or loss of affective resonance. The psychological pain is felt physically and is therefore indistinguishable from physical pain. As attachment to a loved one is not only a mental state, but also a shared intercorporeality, the death of a loved one will disrupt this intercorporeality, and is felt as a wound, pain, or amputation (Fuchs, 2018).

Furthermore, a sense of *alienation* can occur because common or shared habits and routines become meaningless after the death of the loved one, and the familiar environment becomes a place where the absence of the other is painfully present, feels empty, or can even lead to alienation from that

environment. Ordinary life feels empty, hollow, and unreal, the reality is no longer one's own. Because the loved one was present to oneself *as other*, but also as *the other-in-oneself*, thus as part of one's own experiences, the loss of that other is a double loss: not only do you lose the other, but also half of your own self (Fuchs, 2018).

Loss and grief can also cause a sharp crack in the dyadic sense of time: the unquestioned continuum of living together is suddenly cut off from the present and transformed into an irrevocable past, while real time just keeps on ticking away, distancing the bereaved person from the moment when the loved one was still there. In other words, the loved one is dead and the world moves on, but in the memory the loved one is still alive, and even remains unchanged despite the passage of time. The mourner thus lives in two conflicting worlds: the ongoing reality of everyday life on the one hand, and the lingering presence of the deceased loved one on the other hand. The one time flows, the other time is arrested, solidified, and these two forms of time increasingly desynchronize. Being trapped in congealed time means that tangible memories of the deceased loved one are often cherished and preserved, such as clothing and other linking objects to keep the deceased present as much as possible (Fuchs, 2018).

From these conflicting notions of time, Fuchs arrives at the core conflict of grief, namely the ambiguity between presence and absence, which immediately begins after death itself. The dead body is still there, but the person no longer is. The bereaved one continues to feel, perceive, or behave as if the other is still alive, even though he knows that his loved one is dead. This 'as if presence' becomes visible in the aforementioned linking objects that belonged to the other person or were used by the other person: the sight of these objects evokes the loved one's presence, and is at the same time a painful realization of his absence. Shared daily routines, familiar sounds, and the anticipation of contact with the deceased are still part of the intercorporeal memory. This felt persistence of the loved one may also be understood as mitigating the pain of the loss by retaining contact. And while the above is an understandable response to the loss of the loved one, it can also generate an cognitive-affective conflict, where the deceased is experienced as gone rather than dead. In the same way, the image of the deceased person is still intact even though his body is no longer there, and the conflict between what was and what is no longer there cannot simply be resolved (Fuchs, 2018).

In order not to get stuck in grieving, the bereaved must undergo a complex process of transformation, a gradual adjustment to the loss, and so finally enabling a re-integration of the conflicting realities. This involves the question: who am I, now that my loved one is no longer here? It offers the possibility of resolving the ambiguity in two complementary ways: on the one hand, by incorporating and identifying the lost loved one in yourself, as it were, and on the other hand, by representation, through memory, narrative, or symbolization. With identification, the other person is gradually incorporated into oneself rather than continuing to search in vain for that person in one's surroundings. This creates a new inner presence of the deceased that is no longer in conflict with the external reality. In representation the loss is acknowledged, the loved one is retrieved from your memory with full awareness of the absence of the loved one. These memories represent what was, the shared past. Together, the inner identification and the outer representation form a new balance: through the identification, a new form of continuity is created, while in the as if character of the representations, the irreversible is confirmed. Through this double book-keeping, the internally felt reality and the external, objective reality can exist side by side without coming into conflict with each other (Fuchs, 2018).

Results

Grief and the body

In the first few months, besides an omnipresent sadness, loss and longing, I felt a strong physical disturbance as an expression of my grief: a heavy and oppressive feeling in my chest, which felt painful without being able to pinpoint it precisely, and the feeling that somewhere in my body a hole had appeared. My motor skills faltered, which resulted in stumbling, dropping things out of my hands, illegible handwriting, and once I even fell off my bike, as if my body didn't know how to ride a bike anymore. Apart from that, I was dizzy at times, both during the day and at night when lying in bed, and I woke up every day with muscle strain, as if I had been exercising too intensively. Almost every night I was wide awake between 03.00 and 05.00 AM. I suspect that the silence and emptiness next to me in our bed, where I was used to movement, body heat, breathing and snoring for years, woke me up and kept me awake. Both from lack of sleep and from grieving itself, my energy level was low. Cognitive functions such as concentration and memory were also

disturbed, resulting in double or forgotten appointments and not being able to reproduce properly what had been discussed the previous day (for clarity's sake: I do not use drugs, medication, or alcohol). Also, my general physical resistance seemed to be reduced, resulting in frequent colds, fatigue, and also injury proneness. But the strangest sensation of all was the feeling that my body had shrunk somehow. It was as if the mental map of my body image no longer fitted the new experience of my body-in-grief. As if with the death of my husband, not only his body but also a part of my own body that was connected to him, had disappeared.

Alienation of world and self

Being at home, the place where more than thirty years of shared history took place, has proven to be very comforting. I began to attribute an almost childlike sentimentality to objects and customs: his comb or a bottle of shampoo, but also his ring, watch, handkerchiefs, and key ring all became objects of inestimable value. They became linking objects (Volkan, 1972), in which the object becomes a symbol for the other person, offers comfort and reduces fear in the absence of that other person. Certain rituals or preferences were also given this function: going shopping and buying food he liked, making sure there were always flowers in the house because that was how it used to be, visiting places that he used to enjoy. I was always aware of the fact that I was looking for him in these objects and actions, and sometimes found him more in them than in looking at pictures of him. Going out and leaving the house was very difficult in the beginning; it was as if leaving the house also meant leaving him behind. Alienation from the social environment did and still does occur. It's not that I isolated myself or had no need for social contact, but anything involving more than three people soon felt like an insurmountable obstacle. I thrived best in a one-on-one situation, but not with everyone. It was as if I had developed a new sense that enabled me to tell within seconds whether there was room to talk about my sadness and distress, or whether the other person was going to come up with well-meant advice, clichés, or encouragement to go out and do fun things. It was not so much that I wanted to talk about myself and my sadness all the time, but I did want to have the feeling that it would be possible when necessary; whenever this was completely ignored, I felt even more alienated from others, and a fathomless feeling of loneliness would arise. Some friends proved unable to empathize with my situation or simply ignored it, while unexpected people (the guy who cleaned our windows, local shopkeepers) would sometimes come up with a heart-warming conversation that would help me through the rest of the day. On birthday parties I felt like a deer caught in the headlights; I wasn't able to chat along about superficialities, but repeatedly expressing my situation was not possible either, because the social context of a party is not suitable for that. In every conversation - which usually starts with the question: How are you?—there was always doubt what to answer. Am I going to say that I am doing well, because that is what is expected—even though it is not true - or am I going to say that it is difficult because my husband is dead, which is true, but which can also frighten others. One time at a birthday party, the conversation abruptly stopped after I mentioned my recent loss, and the other person walked away without saying anything. At times like that, I was able to see that it was the other person's inability to deal with my loss, but that didn't make the situation any less painful. Managing other people's inability is not something you can attend to in a grieving period, but you nonetheless end up with it. Several times I was fortunate enough to meet a stranger who had been through the same kind of loss, either recently or longer ago, and then a conversation arose with depth and meaning as if we had known each other for years. It is as if you speak a new language after a drastic loss, a language you did not master before, but which now comes out fluently with the right audience. Recognition and acknowledgement by others of my situation and my new status as a widower are key words for me to counteract social alienation. I was tended to wear a funeral band, not so much to draw attention to myself, but mainly to show the world: beware, here comes a vulnerable person, a wounded animal, skinless (to quote the Israeli author David Grossman on how he felt after the death of his son). It also made me look at the world around me with a certain distance, and very often my view seemed to be out of focus, almost foggy, even though there was nothing wrong with my eyes. In an interview Dutch novelist Connie Palmen said about the death of her husband: 'as soon as the we is gone, the I collapses' (Van Gelderen, 2019). Alienation often manifested itself more strongly when I was going out, walking, cycling, taking the train or car between my home and another destination. Being on the road and not anchored anywhere created a vacuum in which alienation presented itself in all its intensity. I felt like a buoy on the loose, severed from its anchor, and although I had my own buoyancy, I was otherwise rudderless and at the mercy of the wind and the current.

Temporality

I felt a strong urge to go back in time, to relive and preserve all that had happened in our shared past, the good and the lesser moments that characterize any relationship. At the same time, I found the passage of real time a cruel stroke of life: as if it wasn't enough that my beloved was dead, now I had to watch helplessly how the moment when he was still alive, and we were together, became more and more distant with each passing day. It seems as if the gap between the frozen time and the continuous real time is stretched further and further. When I think about him now, it has become a composite image of how I knew him in the nearly forty years we were together, as a young man of 28 until his death at 68. But otherwise, that image will not change, it is a solidified image. In the meantime, I have gone through changes since his death that he doesn't know about: first loss of weight and then weight gain, my hair is shorter now than when he was alive, I have a scar that he never saw. Changes have also been made in our home without his knowing. The purchase of a new sofa made the split in time experience painfully visible. With the disappearance of the old couch, more than twenty years of our shared time on that couch disappeared, so to speak. Of course, I know that those memories are not stored in the couch but in my brain, but seeing our couch being crushed by the garbage truck symbolized for me very clearly the time we once had together, and the time that is ticking by in which a new couch has come that he will never sit on. Furthermore, activities I have undertaken since his death, all take place in the time that is no longer shared, while I try to keep that shared time alive in my memories. Only in my dreams do both experiences of time converge again: when I dream about him, I am surprised and happy to see him again, while at the same time, on a kind of meta-level, I do know very well that he is dead. In such dreams I experience a pleasant excitement: after all, we have so much to catch up on with all the time that has passed since his death. In one of my dreams the convergence and divergence of time experience was very visual: I dreamt that I was cycling and that I suddenly became aware that he was cycling in front of me, at about thirty yards distance. I felt enormous happiness and felt that a heavy burden had been lifted from me, even though I did know that he was dead. This, however, did not prevent me from pedaling harder to get closer to him and to be able to ride next to him. But no matter how hard I tried, the distance between us remained constant, unbridgeable, and too

far away for him to notice my presence. So, I kept on riding behind him, following his course, with an unbridgeable distance in time between us.

Ambiguous presence

I have experienced, in line with what was described earlier, that knowing very well that he was dead, he remained strongly present in his absence. He became a point of reference in everything I did or thought or felt, sometimes very explicit by starting a dialogue with him and imagining what his reaction or response would be, sometimes very implicit by doing things that were in line with our relationship as it used to be. Everyday objects could offer comfort one moment as an extension of the missing body, but at other moments they could generate a deep sorrow and despair as silent witnesses of his absence. This phenomenon also occurs at familiar locations or when doing familiar things. For example, being in the supermarket where we often went to do our shopping, his absence imposes itself on me strongly: it is as if I have to experience again and again that he is not there, even though I can effortlessly project him next to me, or imagine him walking around elsewhere in the supermarket. The cliché of the amputation is often used when talking about grief. This is not surprising, because it expresses so well that a part of the self disappears with the death of the loved one. I often experience a conflict between his absence and the lively image of his physical presence that is still anchored somewhere at a neuronal level in my central nervous system. Phantom pain with intense sadness and phantom feelings with warm memories or desires are very familiar to me. I suspect that despite my conscious knowledge that he is dead, my internal image of him as being alive is still activated in his absence and refuses to, or is unable to go along with the changed reality.

Grief and grief processing

Looking back at the years since the death of my husband, I can say that the grieving process began immediately after his death. Although it was clear that his time was running out (esophageal cancer with metastases in the lung membranes), his death came sooner than was expected. At home, in our own bed, and in my arms, he quietly passed away. After his death I could lie with him for a while, waiting for the medical examiner. In the meantime, a befriended undertaker had been alerted, who sensed exactly what was wanted and suitable, and took charge without being intrusive. An important moment that day was the washing of his body; a very intimate moment, during which I knew this would be one of the last actions I could do for his body, just like dressing him and transferring him into the coffin. He died on a Sunday morning, and cremation would take place the following Friday. Until then, his body would remain at home, in the house he loved so much. That gave me the opportunity to spend five days in the presence of his body, touching him, sitting with him, even in the middle of the night if I wanted to. In those five days I saw his body change, which helped me to close the coffin the day before his cremation. Very painful was the moment I had to take off his ring, which he wore day and night. I took something away from him that was so inextricably connected with him, that it felt like blasphemy. Because his ring does not fit me, I now wear it on his keychain as a linking object with me every day, and that is comforting. In the days between his death and the cremation there were many visitors, which was also comforting. I was very firm in my wish to have nobody in the house in the evenings and at night, so I could be alone with him, which gave ample room to my feelings and thoughts. When the moment had come to put the lid on the coffin, it felt as if I tucked him in for the very last time.

In the weeks after the cremation, I was fully occupied, on the one hand by many visits, phone calls, e-mails, and letters, on the other hand by all kinds of practical things that had to be arranged with the bank, notary, municipality, subscriptions, and memberships. Although these were not pleasant tasks, they did help me to get one step further in the process each time.

Sometimes, a letter addressed to my husband would upset me, seeing his name on the page knowing he would never read his mail again; other times the same situation could comfort me, because his name was still being used and thus not forgotten.

During the thirty days that the ashes, according to Dutch legal regulations, had to remain in the possession of the crematorium, they were placed in a closed display case at the cemetery, so that next of kin would have a place to visit during that first month. This proved to be valuable; in the first days after the cremation, I felt a strong need to be close to his ashes, as if that could bring me close to him.

Because my cognitive functions faltered so much in the early days, and my memory often failed me, I decided to keep a diary. I started three weeks after his death and have written in it every day since. Not only did it prove to be beneficial as a back-up for my memory, the writing itself also turned out to be a good moment of reflection, consciously dwelling on the jumble of feelings and thoughts of that day or that moment, of dreams or encounters, and trying to find the right words for what I felt, thought, or experienced.

Going through, organizing, and partly getting rid of his personal stuff was so painful that I postponed it for a while. Going through his desk drawers, opening folders, seeing which things he had kept because they represented emotional value (the chestnut that was always in his father's coat pocket, his tin soldiers in a box, a silver birth spoon with his name, but also little notes and letters in my handwriting, a self-made marble bag from his childhood...). Afterwards it was also purifying, because now I knew what was in his desk, without having to read or go through everything. In a cabinet I found drawings from his childhood and a beautiful wooden boat, made by him as a child, which I had never seen before. It was as if I received a present from him after his death.

Finding a destination for his clothes was less difficult: what was seldom used I gave to a secondhand shop; the rest could stay until I felt that I wanted to do something else with it. For his jeans and shirts, I had a clear destination: I made a quilt out of them. The craft with needle and thread turned out to be a mindful activity, in which reflection on his life, our life together, and my life without him presented itself. By doing so, I turned the beautiful words of the poem Separation by W.S. Merwin into action: 'Your absence has gone through me like thread through a needle. Everything I do is stitched with its color.'

Re-integration

In the beginning, pictures as external representations were of great value, as was the bringing home of the ashes. It felt like he was coming home, which I found reassuring, as if he could experience being home again himself - but at the same time his ashes were the painful proof of the fact that he was dead. I enjoy looking at his pictures, although there is always ambiguity there as well. On the one hand these images refer to carefree times in which he looks alive and vibrant; on the other hand, they have become images that do not change anymore - his face will not get older than in the last photo taken of him - and the photos are not only solidified snapshots but also witnesses of a solidified (past) life. I like his representation through narrative: I like it when people mention his name, or bring up memories of him in a conversation, and I regularly mention his name in conversations myself and try to weave his perception and experience into what is being discussed in the here and now. I do think I also started at the very beginning with the identification process, such as making dishes that he liked (which did have a connecting effect, but also often evoked acute sadness), playing music that he liked, and sometimes wearing his clothes. But more than that, it was about incorporating customs and habits, and through a dialogue I could create, as it were, to hear what he would answer to my questions, how he would react to certain news, what would make him laugh and what would make him angry. Also visiting places where he had been because of work or because he liked it there, gave me connection through identification: I am now standing here on the same spot where he once stood, he has seen what I am seeing now.

Post scriptum

Looking back at the years that have passed since the death of my husband, I dare to say that I managed to overcome meaninglessness and existential isolation by acting upon my new existence as a widower, and in the state of mindfulness of being (alive). Part of me is the same, and is inseparably connected to my husband and the 39 years we spent together, whereas another part emerged slowly during the grieving process. I started a daily routine of early morning swimming in outdoor water the whole year round to give my days a solid foundation, a self-invested mindfulness start that enables me to confront all the good and bad things that can happen during the day. At the end of the day, before going to bed, I make daily entries in my diary. The early morning swimming and these entries give coherence to my life as a single man. I miss my husband every day, but his absence doesn't prevent me to live my life without him. Looking back on my loss and grief, I can say that I have changed essentially or even existentially; during the acute grieving phase, initially little of myself remained, but gradually I rediscovered myself and by incorporating who my husband was into my own thoughts, feelings and actions, I also grew and became more than the one who I was before.

Discussion

Drawing from lived experience, a reflective, personal, phenomenologically informed exploration of grief highlights aspects of grief that are at once unique and universal. Phenomenology of grief and autoethnography share a focus on personal meaning and empathic connection to provide space for 'embodied struggles' (Ellis, 2013), ambiguity, complexity and differences (Niemeijer & Visse, 2016). Autoethnography can be an appropriate method for researching complex emotional experiences (Akehurst & Scott, 2023) such as grief. Phenomenology helps bereaved individuals and care providers to reflect on grief with understanding and allows the uniqueness of grief resulting from the unique characteristics of the relationship with the deceased person to transpire. Thus, normative, restrictive perspectives on grief become less dominant and 'mourning veils' (Van den Bout, 1996) are lifted.

Adding to the theoretical assumptions of Fuchs' phenomenology of grief

The autoethnographic material confirms Fuchs' assumptions in laymen's words. The everyday language of autoethnographic descriptions is probably more accessible for use in clinical practice than the often complex and abstract concepts of phenomenology. As an addition to Fuchs' descriptions, existential aspects of death and grieving emerged from the autoethnography. Yalom (1980) pointed out that there are universal existential conflicts that flow from the individual's confrontation with the givens of existence, and grouped them into four ultimate concerns: death, freedom, isolation, and meaninglessness. Heidegger believed that the awareness of our personal death acts as a spur to shift us from a state of forgetfulness of being into a state of mindfulness of being (Yalom, 1980), from inauthenticity to authenticity (Heidegger, 1962). The death of a loved one confronts us with the sense of our own mortality and brings us from forgetfulness of being into mindfulness of being. Freedom for Yalom refers to the awareness of authorship or responsibility, to act upon situations or life events, and to the willingness to change. Where the death of a loved one could easily 'invite' you to passively undergo the loss, Yalom emphasizes that we should act and take responsibility for our own life and destiny. Existential isolation refers to an unbridgeable gulf between oneself and any other being, and a separation between the individual and the world. Dying is the loneliest human experience. The death of a loved one casts a person into a fundamental state of being completely alone, despite the presence of close friends or relatives. Meaninglessness refers to the loss of coherence, the loss of what was intended to be. How do we find new meaning in our life when our loved one has gone?

The death of a loved one disrupts identity, relationships, and social roles. Death shakes the foundations on which the self of the survivor is constructed and known. The self is constructed and defined in social interaction with significant others. When the loved one dies, the social nature of the self becomes painfully obvious and makes grief a social phenomenon. It is not only the loss of the loved one but also the loss of self that was constructed through interactions with the deceased (Jakoby, 2012). From this perspective, grief is defined as a painful reconstruction or rebuilding of the self and everyday life. This concept is supported by the frequently heard expressions of falling apart or falling to pieces during bereavement, along with the fundamental question: what does my life mean without my loved one? Grief can be understood as a process of personal transformation, an important vehicle for understanding the meaning of other events and oneself, or a stimulant for a deeper meaning in life (Jakoby, 2012). It corresponds to a rite of passage, toward a change of being. Rethinking and replanning one's life in the face of bereavement should be regarded as an essential component of grieving, a forward looking dimension (Cholbi, 2022). If grief is seen as a loss of oneself, then grief represents a kind of ignorance of self, no longer recognizing oneself as oneself, than a reconstruction of one's knowledge of self should be part of a successful resolution of the grieving process. Emerging from grief with a rejuvenated practical identity and a more stable sense of self is the result of the fact that grief afforded us a richer knowledge of who we have been and who we seek to be. 'When we attain the self-knowledge grief affords us, our lives have a greater level of autobiographical coherence or integrity' (Cholbi, 2022, p. 99).

Charting a patient's grief experience and diagnosing PGD

The existential aspects of grief that emerge from this autoethnographic exploration draw attention to symptoms of PGD according to DSM-5-TR (A.P.A., 2022) that represent existential manifestations of grief (Smid, 2023). Their phenomenological description enhances clinical recognition. Existential manifestations of PGD include the confrontation with loss and mortality, and the ambiguity and indeterminacy that comes along with bereavement (DSM-5-TR PGD criterion A); identity disruption: who am I without my loved one? (criterion C1); a confusing sense of freedom leading to difficulties in moving on with one's life (criterion C5); a sense of meaninglessness due to the separation of an alienated present from a still ongoing past (criterion C7); and existential isolation or intense loneliness which sometimes can be relieved by an as-if presence of the deceased (criterion C8).

What may be considered a normal grieving process in one culture can be regarded as pathological in another culture, putting diagnostic challenges in cross cultural practice. The indeterminacy or ambiguity of loss and 'as if presence' of the deceased are at the basis of cultural explanations of grief experiences. The indeterminacy of grief is filled in, as it were, with ideas and experiences from culture, faith, spirituality, or worldview, causing individuals, families, and communities to create or maintain explanatory models and cultural norms (Smid, 2020; Smid et al., 2018). Whether grief processing consists of continuing bonds with the deceased or relinquishing these depends on the bereaved person and their cultural context (Stroebe & Schut, 2005). In Western cultures, grief is associated with individual processing and acceptance. 'Putting the grief to rest', as Dutch people often say. In non-Western cultures, this may be completely different. Emotional and physical reactions following the loss of a loved one can be explained as the result of actions by the spirit of the deceased loved one. According to traditional beliefs, circumstances surrounding death may result in the spirit of the deceased being unable to find peace or a reluctance to leave the land of the living. This is why forms of as if presence-dreams or hallucinations or other forms of encounters with the deceased—often have cultural explanations (Smid et al., 2018).

Ambiguity is a central theme in the concept of ambiguous loss (Boss, 2000). This concept involves two kinds of loss: leaving without goodbye and goodbye without leaving. Leaving without goodbye refers to the situation whether it is not clear if the loved one is dead or alive (e.g., soldiers who went missing in action or kidnapped children). There is physical absence and psychological presence. In the case of goodbye without leaving it is the other way round: physically present but psychologically absent, for instance when a loved one has Alzheimer's disease, severe addiction, or mental illness. The uncertainty of ambiguous loss is not only severely stressful, but it also leads to painful symptoms that are often missed or misdiagnosed. By elaborating ambiguity, Fuchs' phenomenology helps clinicians identify ambiguity in grief due to bereavement as well as ambiguous loss.

Psycho-education for those who grieve and care providers

In caring for patients with prolonged grief, therapists may ask phenomenologically informed questions such as: what does grief do to the bodily experience of my patient? Does my patient experience alienation from himself and his environment? Does my patient experience a split between the shared and congealed time with the deceased on the one hand and real time on the other? And how is the ambiguity between absence and presence tendencies experienced by my patient? By exploring these dimensions therapists allow patients to elaborate on and articulate their personal phenomena of grief. Exploring and monitoring how the grief process proceeds, and giving words to all the feelings that arise in the identification and representation processes, will be both supporting and helpful. Furthermore, the therapist being able to contain the intense emotions that can arise during grief counseling will help the patient to express and experience these emotions without restraints. In doing so an implicit but crucial message is given: if the therapist can handle and bear the patient's intense emotions, then surely the patient gradually can learn to handle and bear them. By focusing on the phenomena of grief, the easily made trap of covering up and comforting interventions will be reduced. For example, advising a bereaved patient to go on holiday, to start dating, to get rid of the loved one's clothes, to get a dog or to look at the bright side of things may be understood as increasing a bereaved individual's alienation. In therapy, bereaved patients may forget appointments or arrive late at appointments or might even forget what was discussed in a previous session. From a phenomenological point of view, these phenomena may be understood as related to grief, and not necessarily as resistance. The same applies mutatis mutandis for friends or relatives of someone who is grieving.

In the treatment of PGD, common components of psychological interventions enhance representation through memorization, narration, symbolization and enable reflective evaluation of identification processes and other aspects of meaning attribution. Such interventions have proven effectiveness (Boelen & Smid, 2017; Johannsen et al., 2019).

Grief does not follow a linear course but manifests itself in waves along the different phenomenological dimensions. Although grief has a well-defined starting point—the moment the loved one dies—it does not have an ending at all. The balance between the inner identification with, and the outer representation of the deceased loved one is represented in models of

continuing bonds (Klass, 2022). According to Klass (2022), continuing bonds represent a set of culturally shaped, interpersonal, multidimensional phenomena or narratives, that may include beliefs in a deceased person's continuing active influence on thoughts or events. Through the process of re-integration, the internally felt presence and the external reality of absence co-exist without conflict: 'The blurred border between life and death is both redrawn and bridged at the same time' (Fuchs, 2018, p. 59).

Implications for research

An existential perspective on grief implies the necessity of interdisciplinary research on grief. Integrating philosophical, psychological, psychiatric, anthropological, sociological, religious, and spiritual perspectives using a variety of methodologies will further clarify the nature of human reactions to loss across cultures and stages of development. Interdisciplinary research may further the establishment of a bereavement care network, needed to integrate the efforts of religious and spiritual care providers, volunteers, mental health professionals, social workers, and other healthcare professionals in a globalizing society.

The first author's autoethnographic research on his own grieving process by keeping a journal and monitoring everything that he felt or thought on a daily basis, was extremely helpful for him to achieve re-integration. The phenomena as described by Fuchs proved to be a valuable frame of reference for charting and organizing his thoughts and feelings and served as a form of psychoeducation. Putting overwhelming and confusing experiences into words helped him deal with the ambiguity of absence and presence and shape a continuing bond with his deceased husband.

Ethical approval

The Ethical Review Committee of the University of Humanistic Studies (Utrecht, The Netherlands) has approved this study. Case number: 2023-25.

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