

An exploration of anticipatory grief in advanced cancer patients

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Abstract

Background and objectives: Research on anticipatory grief (AG) has been more focused on the experience of relatives than the terminally ill patients. This study will present qualitative 'thick descriptions' of advanced cancer patient's experience of AG and explore how it is experienced in the family context.

Method: Seven advanced incurable cancer patients (median 58 years) were recruited from the day hospice and five patients comprised the final sample. Participants were invited to attend focus groups and individual interviews to discuss their experience of terminal illness, thoughts and feelings related to AG and how they cope with losses and grief in the family. Qualitative transcripts were analyzed using interpretative phenomenological analysis.

Result: Two inter-related themes of AG were identified. The first main theme 'subjective experience of AG' comprises confrontations with death and multiple losses; and resistance against death and loss. The second main theme 'experience of AG in the family' explored the patient's role in the family interaction patterns and interpersonal processes.

Conclusion: An understanding in the subjective experience of AG in terminally ill patients and their experience of AG in the family may contribute to the development of psychotherapeutic interventions. The generative role of the patient in the family grief process is also highlighted.

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Introduction

People who face death do not only grieve for the loss of life, but also for the accumulating losses of functioning and autonomy, hopes and dreams, and a future with their loved ones [1]. These losses may evoke complex grief reactions such as denial, anger, bargaining and depression [2]. Anticipatory grief (AG) is the total set of cognitive, affective, social and cultural reactions to expected death, over past, present and anticipated losses [3,4].

AG has been studied mostly from the perspective of relatives. Only a handful of qualitative studies explored the subjective experience of patients. In one study of terminally ill home care patients, those with unresolved issues, anxiety, pain and fatigue were distressed by thoughts about death. Fear of dying in pain, severe and frequent pain, and separation anxiety with family were associated with death anxiety [5]. Another study reported that women with breast cancer made death preparations by acknowledging their own grief, being psychologically prepared, seeking information and

support, preparing the family and making end of life arrangements. Psychological preparation also brought about peaceful feelings and self-growth to the patients and their family [6].

The experience of AG and its coping may depend on the developmental stage, age-specific tasks of dying [7], the timeliness of death and the psychosocial and spiritual resources [8] of the patient. Yet, it is not sufficient to ground the understanding of AG from an individualistic perspective, as grief is interpersonal and social by nature [9]. The impact of AG on family relationships had been much debated in the literature. Some argued that AG is a paradoxical process of simultaneously letting-go and holding-on to the dying [1,3]. Others argued that although couples may detach prematurely, terminal illness often strengthen their bonding [10]. Other systemic factors, e.g. family functioning and attachment [9] may affect how family members experience AG. In the present state of science that lack a well-validated measurement tool and rigorous empirical studies, it is difficult to determine

whether AG leads to closer bonding or detachment between family members. However, even if AG in relatives were found to result in gradual detachment, terminal patients seldom detach themselves from loved ones [8] except in cases of high self-perceived burden, or major depression and suicidality [11].

For the grieving family to facilitate an appropriate death, the essential tasks include shared acknowledgement of the reality of death, shared experience of the pain of grief, reorganization of the family system and redirection of family goals [12]. It is important that the family includes the patient in the grieving process to help the patient complete unfinished business, resolve interpersonal conflicts and reach closure.

The present study will present qualitative 'thick descriptions' of advanced incurable cancer patients' experience of AG, and explore how AG is experienced in the family. Qualitative results will be analyzed by means of interpretative phenomenological analysis (IPA) [13,14]. IPA recognizes the role of social processes and cultural-linguistic practices in shaping the psychological world of individuals. It takes into account the interpretative role of the researcher. With different levels of interpretation, a more abstract and critical understanding of the phenomenon of AG will be achieved.

Method

Participant recruitment

Advanced incurable cancer patients ($N = 7$) attending the Shatin Hospital day hospice who participated in a course of anticipatory grief therapy (AGT) were invited to take part in the study. Patients with communication difficulties and unstable medical conditions were excluded. Written informed consent to participate in research and verbal consent for video/voice-recording were obtained. This study was approved by NTEC/ CUHK ethical committee.

The AGT consisted of four weekly sessions led by a trained counselor. A range of experiential (e.g. relaxation with audio-visual imagery and massage) and expressive activities (e.g. art) were used to encourage discussion around the session themes 'Living in the moment', 'Good old days', 'Living and dying' and 'Looking forward'. AGT aimed to help patients prepare for death, reduce depressive symptoms and improve quality of life, and affirm the meaning and purpose in life.

Data collection and analysis

Qualitative data were derived from three focus groups (average $N = 3$) and one individual in-depth interview, conducted by a research assistant in a consultation room. Questions were semi-

structured. Examples include: What are your thoughts and feelings of living with a serious illness? How has the illness influenced your life? Can you describe your relationship with your family members? How do they cope with your illness? How do you communicate with your spouse? Were you afraid of the possibility of dying? How do you feel about separating with your family? Initial discussions found that one participant had family issues in facing advanced illness. This participant was then purposively selected for an individual in-depth interview to further explore the experience of AG in the family.

Participation in AGT could bias the focus group and interview results. More intense emotions may be expressed as a result of pre-existing group cohesion. In order to monitor the validity of findings, participants were asked to review how they have been affected by the course of AGT: What are the most significant benefits from the AGT? What are the changes in the way you perceive death? How has your ability to face losses and grief changed? Response to these questions was analyzed separately from the rest of the data.

Verbatim transcripts from all recordings were analyzed as a single data set using IPA. Despite being an idiographic approach, IPA has been used with focus groups in recent studies [15,16]. Each transcript was read a few times to generate interpretative codes [17]. Only extracts that allow sufficient understanding of a moment of phenomenal experience were selected for analysis [18]. To avoid losing the individual in the analytic process, clusters of codes generated for each individual were compared. Similar codes were clustered across individuals to form themes that illustrate a common experience. Codes that represent an individual's unique experience were also clustered to form exemplar themes. A second reader read through transcripts and codes to validate and confirm themes identified by the researcher. Ecological validity was guaranteed by collecting data in the day hospice setting.

Result

The socio-demographic background information of patients was illustrated in Table 1. The final sample had five participants, excluding one who refused to consent for voice-recording and another one who dropped out prior to commencement. Participants' names were substituted by their initials in the following sections for anonymity.

Figure 1 illustrates the emergent themes in pictorial format. Two higher-order themes were derived from the analysis. First, we presented an account of the patient's subjective experience of

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AG through exploring the patients' acute reactions to an incurable diagnosis, their confrontation with losses in the past, present and future, and their resistance against death and losses. Second, we explored the family experience of AG through examining the patient's active role in the interpersonal processes of the family.

Patient's subjective experience of AG

Confronting death: acute reactions to incurable diagnosis

As the signs of deterioration became apparent, a multitude of emotions were experienced. For CKK, the build up of fear was unbearable: 'In my fifth hospital stay... I couldn't feel my legs at all. I was really afraid, I was afraid that I might, I thought I had a stroke, why was this happening, I couldn't take it any longer.' CKK's mobility had deteriorated and her pain intensified despite five previous hospitalizations. Lack of explanations was the main source of her fear and distress throughout the period of getting diagnosed: 'the worse thing was not knowing the cause'. She first interpreted the worsening signs as work-related injury then later as possible stroke. As the pain became more excruciating and uncontrollable, all explanations lost credibility and her fear only intensified. The fear induced by unexplained symptoms prior to diagnosis was more distressing than the actual diagnosis itself.

In contrast, KLF was shocked by the actual diagnosis of incurable cancer. The reality of 'bone metastasis' was so discrepant with her existing frame of mind 'malignancy' that the shock had left her 'blank'. She was in a state of disorientation and apathy 'I had no idea what I should do, didn't feel sad or cry, didn't know what I wanted to do.'

Being diagnosed with advanced incurable cancer was not experienced as a clear-cut event. Instead, it was experienced as a continuous process of discovery. In a state of shock and disorientation, the doctor's reassurance of possible treatments provided the only hope for both CKK and KLF to

Table 1. Socio-demographic background (Total N = 7)

	N
Total	7
Ethnicity	
Hong Kong Chinese	7
Sex	
Female	4
Diagnosis	
CA Lung	3
CA Breast	2
CA Cervix	1
CA Nasal-pharynx	1
Marital status	
Married	4
Widowed	2
Single	1
Education	
Above secondary	5
Occupation	
Not working due to illness	4
Retired	3
Residence	
Own home	6
Old age home	1
Welfare assistance	
Comprehensive social security assistance	5
Full-waiver of medical expenses	2
Partial-waiver of medical expenses	0
None	0

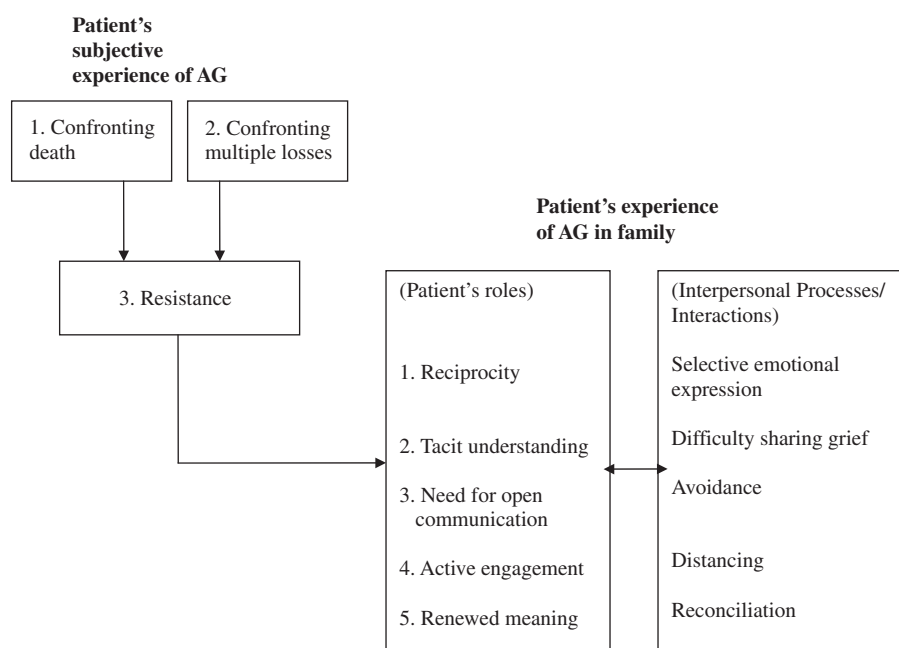


Figure 1. Emergent constructs and themes about anticipatory grief

cling on to. Anxiety was quickly relieved for CKK after being formally diagnosed, but KLF had to embark on a further search for treatments that would work. Her process of discovery was filled with apprehension and anxiety. She described the experience as 'opening one door after another' as she anticipated with apprehension. When the doctor announced that her heart condition might not withstand chemotherapy, she was filled with dread and felt a 'hurtful' panic. It was not just about the mortal threat. With all the previously accumulated efforts and hope, KLF feared she had too much to lose.

Confronting multiple losses in the past, present and future

As the events gradually unfolded subsequent to diagnosis, unresolved grief over losses in the past were evoked. CKF was diagnosed with advanced lung cancer within days of his wife's sudden death from tuberculosis. He was forced to confront death twice in a role, but the grief for her death felt exceedingly painful than the grief for his own end. He wrestled with inner spiritual conflict: 'I thought I'd die for her. Basically it is more painful to be alive than be dead. If there were ghosts... but do they exist? All I know is I do not believe in ghosts or spirits or Gods.' Torn between longing for his wife and his inability to believe in the afterlife, the nothingness that remains was hard to bear as he faced his own death alone.

Upon leaving the familiar caring environment of the hospital, CKK was forced to confront her loss of independence and autonomy, as she was bed-bound at home. When her husband left the flat for a brief moment, she felt profoundly vulnerable in her total disablement: 'it was a terrible feeling... the feeling of being left alone in the flat... I needed the bathroom but I couldn't move myself... I thought I was like a complete cripple. I was completely crippled, I felt so very terrible'.

A sense of failure was evident with the use of the word 'cripple' by both CKK and LW. For LW, total dependence is humiliating and degrading.

Here I am being such a cripple, I needed... I had to be transported to the shower. He said 'you've been sentenced to death, you're useless if you're not dead.' What that means is, struggling to get up... finding the wife to lift (me) and feed (me) spoonful by spoonful, then she'd clean me and pack her own stuff to go home. I feel sorry... I feel sorry for the patients' family.

'Useless if not dead' is a demeaning expression commonly used in Hong Kong slang that describes someone as a worthless burden to society, stripped of dignity. LW expressed the humiliation of being a burden and the guilt toward his wife, by evoking

the socially constructed, undignified image of a disabled dying person that he felt identified with.

For CKF, the future prospect of becoming paralyzed as the disease deteriorates so threatens his dignity that he would rather his life ends immediately, so as not to 'burden himself and others'. The doctor's suggestion of old age home placement was to him a 'second death sentence', which he found very distressing 'The doctor already said I can't be cured, so I've been sentenced to die anyhow. If I move into an elderly home that means waiting to die, right, it just means everything turns meaningless.'

Resistance in the face of death and losses

KYH was confronted with the impending loss of a meaningful aspect of living. Her resistance came in the form of avoidance and bargaining to delay the insertion of a percutaneous endoscopic gastrostomy (PEG) tube, which would eliminate her joy in eating.

'I am a quiet one but I really enjoy eating, I really love and enjoy eating.' KYH faced the loss of not only a physical but also an existential part of her integral self. There is a sense of finality in 'the doctor has ruled... that I must not eat anymore', which shows her painful acknowledgement of the inevitable, despite her desperate avoidance. She raised a contrast between 'being fed milk' as opposed to 'eating food', highlighting her difficulty in accepting PEG insertion. It has caused her much more distress than any other painful side effects of cancer therapy. As her dysphagia began to worsen, KYH endured progressively greater limitations to her ingesting ability and range of food choices. She was desperately trying to avoid the outcome of such decline.

'Indeed I swallow things into my trachea and yes it'd cause pneumonia and stuff... I'm not doing it yet, I told him I don't want to have it just yet, could I have a chance to delay the procedure until my condition gets even worse... he told me how risky that is, but I've delayed it still... that's the way I'm putting it off for now. But then, I know basically I'm just getting worse and worse... I've been refusing the operation, but actually I know how much risk there is.'

Despite her awareness of the potential risks, she bargained with the doctor for further postponement and endured the discomfort. She took the risk and avoided any careful consideration of the adverse consequences, which she only mentioned in passing 'yes it'd cause pneumonia and stuff'. Yet, she was too aware that the delay was only temporary.

For KLF, resistance against death was manifest as a strong will to live, as she anticipated the loss of

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a future with her daughter. She fought for her core meaning of existence—a chance to raise her teenage daughter well. ‘I must not die, I told myself I must stand firm. I must not allow myself such a short life.’ She grieved in anticipation of missing her daughter’s future and lamented for what she ‘won’t see’: ‘if I didn’t persevere to maintain my present mood...I’d have a very short life, I won’t see my daughter, I won’t see her and I won’t know if she learns to misbehave’. Her unfinished business was to fulfill her ‘responsibility’ and to do all she can to raise her daughter well. She believed that staying positive is key to survival: ‘I told myself I must not have such (a negative) attitude, I must stay positive. If I didn’t stay optimistic, I’m bound to lose the battle with those cancer cells keep on attacking me.’

Her optimism was evident as she considered the remaining time ‘The doctor said it would be more than a year, but I think perhaps it’s more than that, perhaps I have five to six years.’ For her daughter’s sake, she set an even higher target for herself: ‘At least to have ten more years for myself. She is fourteen now... ten years later she would be twenty four, things should be stable by then. I would be fifty by that time, and I wouldn’t be young anymore, so it would be normal (to die) right?’ Her high self-expectation reflected her strong motivation. On the other hand, it also reflected wishful thinking, as she grieved for the prospect of premature death.

KLF’s positive fighting spirit completely excluded thoughts about dying in the early stage of cancer. ‘I’ve always had this will to survive... the word ‘death’ never occurred to me until I was admitted to the hospice ward...I had to be reminded if I ever thought about death.’ However, even without conscious thinking, death anxiety continued to loom over KLF. Her resistance against the gradually unfolding, anxiety-provoking uncertainty in the subsequent stages of treatment was manifest as denial and avoidance

‘I don’t dare to take things for certain. I’m like an ostrich. I’m not there yet so don’t ask me...I’d just pretend I don’t know anything and I’m not concerned to find out about things. Like, I won’t make any guesses... at this stage, I just take whatever the doctor tells me.’ The ‘ostrich’ metaphor revealed that KLF was desperately escaping from a cul-de-sac situation of ‘no hope, no cure’. This was reasonable given her late disease stage. Letting-go of control and placing complete trust in the doctor took away the burden of worry to some extent.

The experience of AG in the family

A phenomenological account of AG in the family emerged from close examination of KLF’s narrative of the interpersonal processes and interaction

patterns between her family members. Her role in these processes emerged as the main organizing construct for the subthemes below.

Reciprocity and selective emotional expression

‘When we left the consultation room, I said to my husband, oh I was really, really scared back there. Then he said, I was so scared too, when the doctor said you might not stand the chemo. But when we were in the room... We didn’t show any panic like, oh no, what do we do now? We were privately scared in ourselves. It was only because we were both thinking, we don’t want one another to get hurt... then the doctor told us there is still another option. As soon as we left the consultation room we started talking non-stop. We were both really glad because there really is still a chance...at least we are motivated to go on. Yea we were hopeful.’

In this extract, KLF and her husband experienced the same anxiety and fear of despair. Both KLF and her husband needed emotional support in such a moment of crisis. However, instead of seeking reassurance from one another, they had simultaneously chosen to contain all negative emotions within themselves. The couple restrained their own emotional expression in order to protect the other. It was only after the doctor suggested a hopeful prospect that the couple began to share their sense of relief. The key statement ‘it was only because we were both thinking... we don’t want one another to get hurt’ shows that KLF was clearly aware of their mutual concern for one another. The last statement ‘yea we were hopeful’ showed that the closely bonded pair shared a common vision and direction in fighting cancer. This was only possible with their reciprocal care and concern.

Tacit understanding and difficulty sharing grief

‘In fact, my daughter never said a thing to me about my illness, nothing. I’ve tried, and I thought I’d talk to my daughter about it. But still... we couldn’t. We only need to look one another in the eye, that’s enough to keep our mouths shut. I feel we could read each other’s minds. It’s as if she was saying: Mommy please don’t say it. Don’t say anything... ‘cause deep down we both know what’s happening. It’s alright as long as you exist right now. I won’t make you upset and I’ll be good.’

The above extract shows that KLF found it difficult to initiate the talk about dying, just as her daughter seemed to have difficulty expressing her AG. Talking was expected to be emotionally painful, as open discussion may symbolically confirm the reality of impending separation. KLF understood her daughter’s difficulty, because they both shared the wish to preserve the existing

harmony in the remaining time 'as long as you exist. I'll be good'.

Need for open communication versus avoidance

'I need her to know, to have a common understanding with me. I really think we need to talk, because I feel that she, may be she doesn't know what I want ...but she is being avoidant. We are both avoidant. Sometimes I thought, well never mind, I'll write (words for my daughter) down in my diary...but I was afraid I couldn't help crying. I told myself, don't cry. I'm actually giving time to myself, and I feel that I'm avoiding it as well.'

KLF felt that open communication was necessary in order for her daughter to understand her wishes and legacy for her. This ran parallel to her earlier attempt to communicate openly with her husband so that they could share a 'common ground' of understanding in her preferences in funeral arrangements. However, even though KLF believed open communication and a shared understanding were the only ways to settle unfinished businesses with her family, all three of them were avoidant to a certain degree, due to fear of emotional pain.

Active engagement and distancing

'She (patient's daughter) was so avoidant that she even wanted to quit visiting me. I think she really is avoiding me. She doesn't want to see me... so I insist that she comes and help me shower... even though my sister had already helped me with it (laugh). I'd talk to her during bath time... she stood behind me and I was in front of her... She couldn't see how I was feeling and whether I was crying. From where I sat, I couldn't see if she was crying either. So I told her, mommy is going to have radiation therapy soon, you've got to support me... I'd tell her how it went, when it's done, I'd tell her that my back and my chest were burnt and it was painful.'

KLF's daughter began to distance herself from the anxiety-provoking reality to escape the pain. KLF understood her avoidance, and she created chances to maintain bonding with her daughter and help her cope, by actively engaging her in intimate care tasks. However, they concealed their own sadness from one another even in such closeness. KLF chose to reveal only her physical suffering and pain to her daughter and updates in treatment progress, explicitly asking for her daughter's moral support. In doing so, KLF admitted she was modeling courage to teach her daughter a lesson in life. KLF continued her active role as a caring mother while she was being cared for as a patient.

Renewed meaning and reconciliation

'Before then, my siblings hated each other. We had been estranged for almost four years, but because of my illness, we're together once again. We were in conflict but they would come to visit me despite any hardship... That's why my life force comes from these people, they lift me up. I want to be more active, more positive when I'm with them, I want to stay even closer with them. I mean I could even say I live for them.'

Advanced cancer became a chance for KLF and her estranged family members to be reconciled with each other again. The uplifting effect of reconciliation and continued support from her siblings became an important source of motivation for her. She explicitly stated that she wished to remain closely connected with her family as it gave her renewed meaning in life 'I live for them.'

Discussion

Patients' subjective experience of AG and their experience of AG in the family emerged as two major themes. A range of AG reactions were found in different stages of terminal illness. As patients confronted the possibility of death around the time of advanced diagnosis, intense emotions such as panic, fear and anxiety were evoked by severe unexplained symptoms and uncertainties regarding treatment. These corresponded to the acute responses to advanced diagnosis reported in the literature [19,20]. Multiple losses encountered during the illness affected the self in psychosocial and spiritual domains. Our results confirmed the findings from existing studies on the suffering of terminally ill patients [21,22]. Unresolved AG toward past, existing and anticipated losses may contribute to 'total pain' [23], thus AG should be a target of investigation and intervention in patients with unrelieved pain.

The theme of resistance represented various value-oriented coping responses to loss. Patients in this study showed a spontaneous tendency to preserve a personally meaningful entity. For example, the ability to eat; responsibilities of a mother to her daughter; autonomy or life itself. Both active and passive coping strategies were used when patients resisted against multiple losses in advanced illness. The concept of resistance could be explained by cognitive-appraisal coping theories [24,25], which emphasized that coping strategies were selected based on meaning and personal agenda. The personally meaningful entities that our participants fought to preserve were mainly existential or spiritual in nature. This supported the previous finding that existential well-being was the most important predictor of overall quality of life

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in advanced cancer patients in the last 2 weeks of life [26].

Conducted within a Hong Kong Chinese context, this qualitative study offered a culturally relevant account of AG. Consistent with the relational conception of death in Chinese culture [27], the concerns of our patient were focused on the needs to preserve harmony in the family, to stay connected with family members, and to have family members support each other before and after death. Our results also illustrated the traditional practice of avoiding and inhibiting grief, despite a desire to share grief with family members. Such avoidance could be due to fear of burden, as it was found that the Chinese were more likely to share their grief with best friends, but less likely to share it with other bereaved family members [28].

The relational role of terminally ill patients had previously been discussed in the literature [29], yet the generative nature [30] of such a 'dying role' to family functioning has not been sufficiently explored. Our findings affirmed the idea that some patients in advanced illness needed to share their grief with their family, just as they needed opportunities to voice their concerns and complete unfinished business. These patients could be empowered to initiate open communication, re-establish cohesion and bonding, catalyze the resolution of conflicts; and enhance resilience in the family [9]. Meaning-based therapeutic approaches [31] could strengthen the patient's spiritual resources and help them overcome the fear of experiencing and expressing grief; psycho-education could enhance coping and equip the patient with skills to communicate with avoidant family members. For the dying patient, helping loved ones through AG could be a generative task in itself, and a legacy to leave behind. Health-care professionals would be better able to support patients in the future by incorporating the above intervention strategies early in the course of advanced illnesses.

A delicate balance between holding-on and letting-go needs to be maintained for an optimal grieving process toward an 'appropriate death' [4,32]. Our findings revealed that difficulty in resolving AG could arise from differential responses of family members to terminal illness. Further research should explore how interpersonal processes evolved throughout the course of advanced illnesses, which shall inform the practice of grief therapy. Validity of our study results was limited by the patients' participation in a course of AGT. When asked about the effects of AGT, participants reported that it had helped them re-appraise important relationships and motivated them to deal with unfinished business. AGT may have contributed to heightened awareness of grief and motivation to maintain family relationships. These limitations should be taken into consideration when applying the findings to

other populations. Nevertheless, our results still reflected valid concerns faced by advanced cancer patients [11].

Conclusion

The patients' subjective experience of AG and the experience of AG in the family have been explored in depth. The present study enriched current knowledge on family grief by illustrating how the patient could actively contribute to the family grief process. A better understanding of AG could help inform the design of psychosocial interventions for individuals and families at the end of life.

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