

Taking Away Taboos and Assist the People Who Grief: Towards a Long, Lovely and Meaningful Life

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1. Summary

(Serious) grief may encompass various symptoms and can be regarded as a specific, severe form of sorrow. People being circumvented by the right people and atmosphere, generally experience less difficulties while going through the different phases that embrace bereavement compared to people who are not. It suggests that besides approaching the symptoms associated with grief, the social elements to combat grief are rather important too. Although social support is acknowledged to be helpful during (traumatic) grief, little information is available about the type of support and behavior that is considered helpful.

In this paper we touch upon the taboo that exists surrounding grief, especially if we compare grief with other taboos such as sexuality and peoples' approaching death. We subsequently explore how the taboo surrounding grief can be lessened to facilitate and quicken the process people are going through. A process of grief (which can sometimes endure more than a year) can be perceived as long for people not having experienced a situation as this before, and accordingly be neglected to a certain extent.

We also provide suggestions. Suggestions for the people who grief, the persons supporting the people who grief and the people taking care for the griever in their professional environment. We finally provide suggestions for more attention towards grief from a societal perspective.

2. Introduction

A lack of energy, a lack of motivation and self-esteem, extreme loneliness, powerlessness, existential suffering, increased or decreased feelings for intimacy/sexuality as well as depressive symptoms and the avoidance of situations [1]. This is what (serious) grief may encompass, among other things, and in which the seriousness to a certain extent is dependent on how the griever wants to be cared for by their close environment [2].

Grief may endure more than a year. For one person who died, usually more than one person is grieving and this thus affects a large group in our society, worldwide. It not only affects the close environment, but also the other layers that surround people who are grieving, such as friends [3] as well as their professional environment [4].

Serious grief can have a tremendous impact on peoples' mental and physical well-being and is sometimes labeled as a psychiatric disorder too [5]. Yet, increasing (anecdotal) evidence [6] is showing us that (serious) grief, which to a great extent seems in line with deep sorrow, in a certain way demands a different care approach than the medically oriented approach that is nowadays primarily used to understand and treat grief. Stating the words of Cacciatore et al 'Pathologizing grief is an insult to the dignity of loving relationships and proclaims griever as mentally ill, without consideration of the context' [6,7].

In our paper we touch upon the taboo that still exists surrounding grief, especially if we compare grief with other taboos such as sexuality and peoples' approaching death. We subsequently explore how we can assist in breaking this taboo and facilitate the process of grief, since going through a process of grief (which can sometimes endure more than a year) can be perceived as long for people not having experienced a situation as this before, and accordingly, may result in an uncomfortable atmosphere.

3. Review

3.1. Bereavement

Universal, largely unavoidable and painful with its origin in the loss of meaningful relationships. This is how grief is often seen and experienced [5,8]. Everybody to a certain extent will be confronted with grief during their life. In the vast majority of cases, grief is most intense immediately after the loss and thereafter; It however can subside over a period of months to years. For some people, it may endure longer and may go hand-in-hand with serious symptoms sometimes referred to as a Prolonged Grief Disorder (PGD) [5]. Although the number of people diagnosed with PGD is much lower than the whole group of people who mourn and grief, it may well be possible that the group of people who experience serious pain is in fact much larger than we nowadays expect. Because of the taboo surrounding grief [9], talking about the death of people who recently passed by or talking with people who grief is perceived as difficult [10]. This also holds for the bereaved relatives themselves who often experience problems in expressing their feelings [1].

3.2. The Taboo Surrounding Grief

Interestingly, whereas sexuality [11,12] and discussions about peoples' approaching death [13,14] are also seen as taboos in our society and accordingly extensively studied and discussed where possible, this seems less often the case in the context of grief and patients living longer with incurable cancer. Many people find it difficult to stay in touch when their friends are diagnosed with cancer. The same holds for grief. People find it difficult to stay in touch with people who grief. Femke van der Laan was one of the first who extensively spoke and wrote about her mourning process she was going through as a Dutch columnist after her husband had died from lung cancer. Right now, much more attention is paid towards grief and bereavement, at least in the media [15]. Since cancer patients to a certain extent have to deal with anticipatory grief [1], the problems healthy persons experience with their ill friend to a certain extent maybe similar as is the case for friends who grief. In both situations, they are a human being who work (if possible) and have a life. They at the same time however experience symptoms related to their disease [3]. Although attention towards the taboos surrounding people with cancer increases in attention, grief remains still under lighted.

The taboo surrounding grief to a certain extent can be explained

by the fact that people who mourn are often labeled as healthy persons and – unconsciously – they are expected to be the happy, light and joyful person as soon as possible (preferably after a couple of weeks). Yet, everyone who has experienced grief, will know that this is hardly possible. However, with such high (societal) expectations, the people who mourn may feel obliged to behave differently and hide their true feelings/sorrow, which will only provide additional barriers in the process to combat grief. Moreover, if such behavior will prolong the process of bereavement, the chance can be that your social-environment can have such a negative impact on resilience that even your stress response will rise. Moreover, experiencing stress for a long time may even influence your gene activity. 'Genes answer to their environment, without environmental signs, they cannot function' [16].

3.3. The Right Atmosphere

It thus seems of utmost importance to create the right environment and atmosphere to be able to enlighten the process of grief. The fact that a serious grief process (which can also be labeled as trauma [17], a psychiatric disorder, [5] or deep sorrow [2] may go hand-in-hand with depressive symptoms may limit flexibility. So, in situations where society and/or your close environment demands you to be as strong and resilient as possible, your mind may suggest exactly the opposite.

Serious grief, which has a tremendous impact on your mental state, automatically brings along less (mental) flexibility and accordingly less ability in choosing how to address life's inevitable ups and downs, disappointments and challenges [18]. People who arrive at a situation like this, thus would be helped if there would be close relatives or care professionals with experience in treating grief.

In our previous paper [9] we argue that being optimistic and energetic towards people who grief - where appropriate - seems the right way to go forward. However, being optimistic as a caregiver is something different than expecting them to be energetic and joyful themselves. In fact, healing from grief is a natural process, often divided in different stages, and this can be - just like giving labor – a painful experience. Transforming people who experience pain (physically/mentally) into patients, and approach them as such, is therefore prone to the instigation of complications in either a grief or labor process [17]. That being said, whether it is bereavement, grief or another painful situation, it nevertheless demands a transformation of yourself, which is often referred to as a healing process. This may transform you into a new version of yourself.

3.4. Healing

When someone dies who meant a lot to you, a feeling that at least part of yourself died along with the deceased person can be experienced. Although some describe this as one of the symptoms associated with PGD, many philosophers have described this as the pure result of losing someone you deeply loved; e.g., not a psychiatric disease, but a natural process resulting in emptiness and loneli-

ness [19]. This is also how Keirse describes this in his books about grief [2]. He explains that it is normal to experience some form of meaninglessness and purposelessness without the deceased, and/or some form of identity disturbance. For some, medicalizing grief to a certain extent can assist for the short-time, e.g., to be able to climb out of the dark. However, just like people who are having a severe form of cancer and who already to a certain extent prepare their approaching death as some form of anticipatory grief [1], the same holds for the persons who grief: They need to experience this process. In psychology and psychiatry theories exist in which the mourner is stimulated to emotionally detach from the deceased to reengage life and other relationships. Again, Keirse [2] suggests the opposite in that detachment is not really needed, but finding a new way and place for the deceased in your heart, for instance by making memories.

3.5. Compassion

The current attention towards compassion in healthcare [20] also seems appropriate for people who grief as well as people desiring to talk to these people but feeling hesitant or experiencing obstacles to do so. Compassion, using the words of Gilbert, ‘facilitates cooperation and protection of the vulnerable in a world that requires social connection for survival; Compassion is about coming together to alleviate suffering and nurture human flourishing’ [20]. Compassion therefore demands action arising from ‘being with’ [21,22]. Instead of medicalization of death and grief, which is what to a certain extent happens when the last phase of life is nearing, primarily protocolled with advance care planning [23-25] and end-of-life practices such as (palliative) sedation/euthanasia, another approach seem to be desired too [26-28]. The same holds for grief, when this is easily transformed into a psychiatric disorder [5] such as a depression or PGD, the real needs may be overlooked.

By seeing death, dying and grief also as a relational process, there is more space for informal networks, care and space. There is less chance for the development of stigmas or a prolongation of the dying and grief process [9,29]. Moreover, which is what we also explicated in our previous paper about grief, such an approach provides new opportunities to approach grief in an optimistic way by which the person who grieves, but many other people also, can learn from their experiences [9].

3.6. The Interrelation Between Body Mind and Soul

It should be noted that we need to be aware that even compassion can become medicalized, since there already exist ‘compassion-based therapies’ [30] for people suffering from for instance, trauma [20]. Although the trials testing these therapies reveal positive results, implementing a trial is something different than a compassionate care approach [31]. In our paper about laughing we also referred to this important difference, e.g., we shortly touched upon the differences between a smile as part of being human [32] (which at the same time appears to facilitate communication) versus the implementation of laugh therapy [33] Both strategies can

be effective if approached in the right context. However, this very basis, in which compassionate care is an important starting point, should ideally be present in every (care) situation.

In his recent book, Dr. G. Maté introduces healing with the following quote [34] ‘The mind cries out, explains, demonstrates and protests; but inside me a voice rises and shouts at it, “Be quiet, mind, let us hear the heart”.’ This is exactly what Maté seems to exemplify: The interrelation between body mind and soul during traumatic situations. By writing that the world into which we were born was partly the product of other peoples’ minds, he stipulates that we can do nothing about the world that created our mind, but that we can learn to be responsible for the mind with which we create our world by moving forward, also in the case of grief.

4. Conclusion

Grief can be experienced as a situation of extreme loneliness and powerlessness. Apart from treating the symptoms related to grief, strong social support, of which compassion, seems rather important. This will help to control the mind, which can be regarded as an important basis to go through the different steps in a process of grief and to let go of the darkness and stress as far as possible. This will not only positively effect your psychological state of being, but also your hormone levels (epinephrine, norepinephrine, cortisol) due to better functioning of your cardiovascular, endocrine and immune system.

However, to be able to provide such support, first of all the taboo and hesitations to talk with people who grief need to be broken. Today, grief support (if desired and needed) to a large extent is dependent on family and friends, although the people who grief sometimes report that this is not in accordance with their needs. Moreover, it is very much dependent on the relationship they are having with the person who is grieving as well as the person who has died [35]. Just like people being diagnosed with cancer, their support often fades away while the desire for (mental) support among patients/grievors often continues. In our paper about friendships [3], we noticed that friends to a certain extent ‘took advantage’ of situations like this, which is a remarkable finding and does not seem to reflect a real compassionate approach. Yet, the notion that taking care for people who grief, just like friends taking care for people with cancer, broadened their life and world view too [3]. This finding could possibly be assistant to stimulate people to talk with people who grief as well.

More attention towards grief as well as the added value to broach discussions about grief is thus warranted. Moreover, a general awareness that people who grief are not the same person as before for a certain amount of time due to the emotional work that often needs to be done is needed. People in a bereavement process do not need to apologize for this. They however need to be stimulated positively to combat their grief. Apart from friends and family, perhaps (other) care professionals in the field of chaplaincy [36,37] as well as social work [38] could be helpful in this. They

are familiar to provide mental space and can be assistant in the practicalities that need to be done. Various papers further reported about the positive, meaningful effect of (domestic) animals during trauma/grief, which is an interesting and relevant finding [39]. All is meant to let go the darkness as much as possible, in which positive psychology could possibly also play a role [40,41]. In breaking the taboo, we will not only assist the people who grief, but also society since people in grief are normally not as efficient as usual. Educating friends, family and professional caregivers [9] in guiding people who grief and try to quicken the process will therefore be beneficial for everyone.

5. Funding

Pfizer and Vaillant.

6. Songs

Thom Rosenthal, Hugging you.

References

- Keirse M, Kuyper M. Grief: National guideline 2.0. IKNL, 2010.
- Keirse M. Fingerprint of sorrow. Lannoo, 2016.
- van Eijk M, de Vries DH, Sonke GS, Buiting HM. Friendship during patients' stable and unstable phases of incurable cancer: a qualitative interview study. *BMJ Open*. 2022; 12(11): e058801.
- Wilson DM, Punjani S, Song Q, Low G. A Study to Understand the Impact of Bereavement Grief on the Workplace. *Omega (Westport)*. 2021; 83(2): 187-97.
- Prigerson HG, Kakarala S, Gang J, Maciejewski PK. History and Status of Prolonged Grief Disorder as a Psychiatric Diagnosis. *Annu Rev Clin Psychol*. 2021; 17: 109-26.
- Cacciatore J, Francis A. DSM-5-TR turns normal grief into a mental disorder. *Lancet Psychiatry*. 2022; 9(7): e32.
- Batstra L, Frances A. Diagnostic inflation: causes and a suggested cure. *J Nerv Ment Dis*. 2012; 200(6): 474-9.
- Maciejewski PK, Falzarano FB, She WJ, Lichtenthal WG, Prigerson HG. A micro-sociological theory of adjustment to loss. *Curr Opin Psychol*. 2022; 43: 96-101.
- Buiting HM, Sonke GS. Incorporate experiences as a medical oncologist to enlighten severe loss of a loved one: An optimistic perspective. *Clinics of Oncology*. 2023; 6(17): 1-2.
- Krigger KW, McNeely JD, Lippmann SB. Dying, death, and grief. Helping patients and their families through the process. *Postgrad Med*. 1997; 101(3): 263-70.
- Malta S, Wallach I. Sexuality and ageing in palliative care environments? Breaking the (triple) taboo. *Australas J Ageing*. 2020; 39 Suppl 1: 71-73.
- Allen D. Sexuality and patients: breaking the last taboo. *Nurs Stand*. 2000; 14(32): 23.
- The L. Why talking about dying matters. *Lancet*. 2018; 392(10157): 1488.
- Weissman DE. Talking about dying: a clash of cultures. *J Palliat Med*. Summer. 2000; 3(2): 145-7. clincisofoncology.com
- van der Laan F. *Aan de randen van de dag*. Nieuw Amsterdam, 2022.
- Mate G, Maté D. Chapter 4: Everything I am surrounded by: Dispatches from the new science. In: *The myth of normal. Trauma, illness and healing in a toxic culture*. Penguin Random House, New York, 2022.
- Mate G, Maté D. *The myth of normal. Trauma, illness and healing in a toxic culture*. Penguin Random House, New York, 2022.
- Shackle S. The way universities are run is making us ill: Inside the student mental health crisis. *Guardian*.
- van Tongeren P. *Doodgewone vrienden. Nadenken over vriendschap*. Boom Uitgevers. 2021.
- Gilbert P. Compassion: From Its Evolution to a Psychotherapy. *Front Psychol*. 2020; 11: 586161.
- Grant L, Reid C, Buesseler H, Addiss D. A compassion narrative for the sustainable development goals: conscious and connected action. *Lancet*. 2022; 400(10345): 7-8.
- Grant L, Khan F. The precariousness of balancing life and death. *Lancet*. 2022; 399(10327): 775-7.
- Moody SY. "Advance" Care Planning Reenvisioned. *J Am Geriatr Soc*. 2021; 69(2): 330-2.
- Owen L, Steel A. Advance care planning: what do patients want? *Br J Hosp Med (Lond)*. 2019; 80(5): 263-7.
- Rigby MJ, Wetterneck TB, Lange GM, Maté D. Controversies about advance care planning. *JAMA*. 2022; 327(7): 683-4.
- Arantzamendi M, Belar A, Payne S, Rijpstra M, Preston N, Menten J, et al. Clinical Aspects of Palliative Sedation in Prospective Studies. A Systematic Review. *J Pain Symptom Manage*. 2021; 61(4): 831-844.e10.
- Miccinesi G, Caraceni A, Maltoni M. Palliative sedation: ethical aspects. *Minerva Anesthesiol*. 2017; 83(12): 1317-23.
- van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, Buiting HM, van Delden JJM, Hanssen-de Wolf JE, et al. End-of-life practices in the Netherlands under the Euthanasia Act. *N Engl J Med*. 2007; 356(19): 1957-65.
- IPSO. Retrieved from the internet: www.ipsa.nl.
- Johannsen M, Schlander C, Farver-Vestergaard I, Lundorff M, Wellnitz KB, Komischke-Konnerup KB, et al. Group-based compassion-focused therapy for prolonged grief symptoms in adults - Results from a randomized controlled trial. *Psychiatry Res*. 2022; 314: 114683.
- Leget C, Olthuis G. Compassion as a basis for ethics in medical education. *J Med Ethics*. 2007; 33(10): 617-20.
- Beach WA, Prickett E. Laughter, Humor, and Cancer: Delicate Moments and Poignant Interactional Circumstances. *Health Commun*. 2017; 32(7): 791-802.
- Tse MM, Lo AP, Cheng TL, Chan EK, Chan AH, Chung HS. Humor therapy: relieving chronic pain and enhancing happiness for older adults. *J Aging Res*. 2010; 2010: 343574.
- Mate G, Mate D. Chapter 25: Mind in the lead. The possibility of healing. In: *The myth of normal. Trauma, illness and healing in a*

- toxic culture. Penguin Random House, New York, 2022.
35. Hartig J, Viola J. Online grief support communities: Therapeutic benefits of membership. *Omega journal of death and dying*. 2016; 73(1): 29-41.
 36. Chow R, Tenenbaum L, Balboni TA, Prsic EH. Medical Outcomes of Oncology Inpatients With and Without Chaplain Spiritual Care Visit: The Yale New Haven Hospital Experience. *JCO Oncol Pract*. 2022; 18(3): e334-e338.
 37. Sergi CM, Mullur T. Life and Death Sometimes Coincide, and Pastoral Response is Crucial to the Brokenhearted. *J Pastoral Care Counsel*. 2022; 76(4): 281-4.
 38. Gordon TA. Good grief: exploring the dimensionality of grief experiences and social work support. *J Soc Work End Life Palliat Care*. 2013; 9(1): 27-42.
 39. Cacciatore J, Thieleman K, Fretts R, Jackson LB. What is good grief support? Exploring the actors and actions in social support after traumatic grief. *PLoS One*. 2021; 16(5): e0252324.
 40. Rockwell SL, Woods CL, Lemmon ME, Baker JN, Mack JW, Andes KL, et al. Silence in Conversations About Advancing Pediatric Cancer. *Front Oncol*. 2022; 12: 894586.
 41. Sisk BA, Friedrich AB, DuBois J, Mack JW. Emotional Communication in Advanced Pediatric Cancer Conversations. *J Pain Symptom Manage*. 2020; 59(4): 808-817.e2.