

5-13-2014

Anticipatory Grief and Compassion Fatigue: Definitions and Guidelines for Caregivers

Mary Kay Haupt
Winona State University

Follow this and additional works at: <https://openriver.winona.edu/counseloreducationcapstones>

Recommended Citation

Haupt, Mary Kay, "Anticipatory Grief and Compassion Fatigue: Definitions and Guidelines for Caregivers" (2014). *Counselor Education Capstones*. 3.
<https://openriver.winona.edu/counseloreducationcapstones/3>

This Capstone Paper is brought to you for free and open access by the Counselor Education at OpenRiver. It has been accepted for inclusion in Counselor Education Capstones by an authorized administrator of OpenRiver. For more information, please contact klarson@winona.edu.

ANTICIPATORY GRIEF AND COMPASSION FATIGUE:
DEFINITIONS AND GUIDELINES FOR CAREGIVERS

Mary Kay Haupt

A Capstone Project submitted in partial fulfillment of the
requirements for the Master of Science Degree in
Counselor Education at
Winona State University

Spring 2014

Winona State University
College of Education
Counselor Education Department

CERTIFICATE OF APPROVAL

CAPSTONE PROJECT

Anticipatory Grief and Compassion Fatigue:
Definitions and Guidelines for Caregivers

This is to certify that the Capstone Project of

Mary Kay Haupt

Has been approved by the faculty advisor and the CE 695 – Capstone Project

Course Instructor in partial fulfillment of the requirements for the

Master of Science Degree in

Counselor Education

Capstone Project Supervisor: _____



Name

Approval Date: May 13, 2014

Abstract

Anticipatory grief is characterized as grief that an individual experiences prior to an expected loss of a terminally ill loved one. Anticipatory grief can occur in advance of losses other than death, and is considered a normal grief reaction. Anticipatory grief follows a distinct pattern, though no two individuals process grief the same way. The beneficial effects of anticipatory mourning have prompted caregivers to help individuals and families cope with future losses so that when such losses occur they will be more prepared for them. Professionals who serve as caregivers to those who will experience grief and loss have the potential to be affected in similar ways, experiencing many of the symptoms as those they serve, which are compounded over time. This phenomenon is called compassion fatigue. This paper provides definitions of anticipatory grief and its dimensions, contrasting that process to compassion fatigue which affects those who assist individuals who are coping with loss. Conclusions will be offered as to whether the self-care strategies offered to those experiencing anticipatory grief can be used for those experiencing compassion relief.

Contents

Introduction	1
Review of Literature	2
Definitions of compassion fatigue	2
Causes of compassion fatigue	3
Anticipatory grief as a reaction in the face of expected losses	5
Functionally related aspects of anticipatory grief	6
Dimensions of anticipatory grief	7
Contrast of anticipatory grieving and compassion fatigue	8
Identification of compassion fatigue	10
Self-identification and assessments	11
Anticipatory mourning and its effects on the actual loss	13
The role of supportive care in anticipatory mourning	14
Costs of compassion fatigue	15
Importance of support for survivors and for professional caregivers	16
Conclusion	18
Author's Note	19
References	20
Tables.....	23
Table 1 Comparison of Anticipatory Grief to Compassion Fatigue	23
Table 2 Guidelines for Care Providers	24
Table 3 Are you at risk? Preceptors to compassion fatigue	25

Introduction

Grief is an intense emotional suffering caused by loss, disaster and misfortune, which is accompanied by acute sorrow and deep sadness (Fitzgerald, 1994). If we are human, we have the capacity to grieve and be affected by loss. Caregivers are categorized in two ways for this discussion: as survivors; and as professionals who care for those who experience emotional suffering. It would be a rare person who has not felt grief at the loss of someone or something which has been special or important to them. Loss is a natural part of our human existence, a universal experience which is found in all cultures, and grief is a normal reaction to loss (Fitzgerald). In turn, mourning can be described as a process, and refers to what one does with one's grief (Corr, 2007). Mourning could be considered the actions of someone who is grieving, or specifically, expressions or efforts one takes to manage one's grief (Corr). As inevitable as dying is, grief and mourning are the processes that not only follow, but in most cases begin before the actual event. Anticipatory grief has been defined as the phenomenon encompassing the process of mourning, coping, interaction, planning and psychological reorganization that are stimulated and begun in part in response to the impending loss of a loved one and the recognition of associated losses in the past, present and future (Rando, 2000).

Grief and mourning take their toll on both the individuals who grieve, and professionals who help them cope with their grief, particularly those who interact daily with those experiencing suffering and trauma. Approximately 50% of nurses, 50% of physicians and over one-third of other cancer care professionals have reported high levels of emotional exhaustion, and ultimately suffer themselves (Mathieu, 2011). Compassion Fatigue has been described as the "cost of caring" for others in emotional and physical pain (Figley, 1995). It has also been called "Running on Empty" and STS (secondary traumatic stress), and is a residual effect for those

caring for others on a long term basis. Many of the symptoms found in those who experience anticipatory grief are mimicked in those who experience compassion fatigue. This paper will define anticipatory mourning and compassion fatigue, identify ways in which caregivers can assist individuals who are experiencing anticipatory grief, and explore ways which those working in professional settings can recognize compassion fatigue in themselves or colleagues. Proper care should be given to those not only facing end of life issues, but those caregivers who are experiencing anticipatory mourning prior to the loss of their loved ones. Proper self-care should be practiced by those who work in professional settings and encounter survivors and clients who suffer on a daily basis, before their suffering becomes internalized by their professional helpers. Anticipatory mourning and compassion fatigue are bedfellows, reactions to short-term and chronic loss. It is important that health care professionals, from employee to administrators that work with loss, are aware of the symptoms and challenges these conditions bring to those who care for the dying.

Review of the Literature

Definitions of Compassion Fatigue

Compassion fatigue is a contemporary term in the health care field. The concept of compassion fatigue was identified nearly two decades ago, used in the context of burnout in nurses (Boyle, 2011). Compassion fatigue, also labeled as vicarious trauma or secondary traumatic stress (STS), is more complex than burnout, as burnout can happen at any job, and does not have as many dimensions as compassion fatigue. Figley (1995) subsequently identified compassion fatigue as a more user friendly term to describe secondary traumatic stress disorder (STSD), an outcome of counter-transference whereby empathic caregivers indirectly experience the trauma of their patients (Boyle, 2011). The etiology of characteristics differentiating burnout from compassion fatigue are that burnout is a reactional response to work or environmental stressors (i.e. staffing, workload, managerial decision making, inadequate supplies or resources) which is gradual, over time, whereas those experiencing compassion fatigue can have a sudden, acute onset and is a functional consequence of caring for those who are suffering, i.e. the inability to change the course of a painful scenario or trajectory (Boyle, 2011). The end result for both burnout and compassion fatigue is that the individual may leave the position, and ultimately leave the profession. Anyone who is in the position to help and is subject to traumatic events such as legal systems employees working with abused populations, policemen, firemen, animal control workers, social workers, emergency room personnel, counselors, etc. is at risk for compassion fatigue. Compassion fatigue has a particularly huge effect on those working within the hospice and health care fields who deal with death and dying on a regular basis.

Compassion fatigue sounds very weary, and includes borrowed stress, compulsive sensitivity, disabled resiliency, empathetic stress, indirect trauma, secondary victimization, soul pain and wounded healer (Boyle, 2011). Exposure to considerable pain, trauma, and suffering on a routine basis can cause compassion fatigue. Causes, cures and even symptoms are much debated in health science research because there is such a broad range of symptoms, and it is labeled in a variety of ways. If those who work in professions that require a lot of empathy and compassion were asked what general feelings of burnout or exhaustion might be for them, they might mention many conflicting emotional and physical symptoms such as However, Gentry et al (1999) caution that the presence of even a single symptom could be indicative of compassion fatigue.

Causes of compassion fatigue

The root causes of compassion fatigue are usually deep-seated and are as varied as the organic composition as each one of us. For those who suffer from the symptoms, there is usually one “core” that resonates and surfaces routinely (Smith, 2009). The difference between unhealthy caregiving that leads to compassion fatigue and healthy caregiving that leads to fulfillment and satisfaction is knowing what it is that renew our emotional, mental, physical and spiritual resources – and fills us up (Smith, 2009).

Smith (2009) identifies preceptors which may lead to compassion fatigue: 1) placing the needs of others before your own, 2) unresolved past trauma and pain, 3) lack of healthy professional and personal life coping skills, 4) lack of self-awareness that limits potential growth and change, 5) giving care to others under stress or burnout, 6) lack of personal boundaries, 7)

inability to communicate needs, and 7) overdeveloped sense of responsibility. Table 3 describes these in more detail.

Compassion fatigue is the negative effect of working with traumatized individuals, which includes symptoms of secondary traumatic stress, such as intrusive thoughts, avoidant behavior, and hyper-vigilance (Figley, 2002b). However, there are many positive results of working with traumatized individuals which include satisfaction of being able to provide care and empathy to other individuals in order to alleviate their suffering. This work is noble work and individuals who choose the field are usually those who have a strong identification with those who suffer. Compassion fatigue has many names, and many different types of symptoms, which are identified on *Table 1: Comparison of Anticipatory Grief to Compassion Fatigue*. Compassion fatigue symptoms are displays of chronic stress resulting from the caregiving work. Leading traumatologist Eric Gentry suggests that people who are attracted to caregiving often enter the field already compassion fatigued. A strong identification with helpless, suffering, or traumatized people or animals is possibly the motive. It is common for such people to hail from a tradition of what Gentry labels: other-directed caregiving. Simply put, these are people who were taught at an early age to care for the needs of others before caring for their own needs. Authentic, ongoing self-care practices are absent from their lives.

Anticipatory Grief as a Reaction in the Face of Expected Losses

Many people in our society die from degenerative, chronic, or terminal illnesses which involve a life expectancy which can be determined through a medical diagnosis, sometimes well before symptoms are present and before the patient and family have the capacity to believe it. This can trigger the action of mourning before the actual death of the loved one. As we age, we also experience our parents' aging process and witness the decline in their physical and mental

health come on quickly. In many ways, we begin to feel a sense of loss for the activities that they can no longer engage in such as driving a car, or being physically active. In some cases, our parents or other loved ones may no longer be able to live in their own homes or attend to their most basic needs such as preparing meals, bathing, or feeding themselves on their own. There is an unmentionable nagging worry, a sadness that surrounds us that we identify with and feel this sense of loss, and these are feelings of anticipatory grief. Imagine now, that a sibling has cancer, or a beloved pet is in pain due to tumors which were found in a recent check-up, or undergoing a mastectomy as a necessary operation due to breast cancer. These are other situations in which anticipatory grief may emerge. Other life events in which anticipatory mourning surfaces are when a child has been diagnosed with cancer, or a pregnancy has taken a turn for the worse, and the unborn child has multiple problems affecting their his or her lifespan. Decisions must be made on so many levels that concern the loved one, and this evokes extreme anxiety and worry for the caregiver. These too, are symptoms of anticipatory grief. Anticipatory grief includes many of the symptoms and processes of normal grief which follow a loss (Rando, 1984.) In nearly all of these scenarios, there are professional caregivers on hand to experience the reactions with the individuals or families.

The immediate feelings of anticipatory grief may not feel like grief at all including anger, mood swings, denial, forgetfulness, depression, weight loss or gain, sleep problems and confused behavior, instead of what one would expect as sadness or depression. Though dying patients do experience anticipatory grief, the term most often is used when discussing families of the terminally ill. This mourning particularly affects parents who have a child who is or will be born with an abnormality or diagnosis which has been determined to result in a short lifespan. These scenarios are some of the life events in which mourning begins prior to the actual loss, and the

process of this normal grieving is termed anticipatory grief. Grief before death often involves more anger, more loss of emotional control, and atypical grief responses (Eldridge, 2014). It is important to realize that not everyone experiences anticipatory grief, and it is not right or wrong to do so. Some people experience very little grief while a loved one is dying, and in fact, find they don't allow themselves to grieve because it might be construed as giving up hope (Eldridge).

Functionally Related Aspects of Anticipatory Grief

Futterman, Hoffman, and Sabshin (1972) identified anticipatory grief as a series of five functionally related aspects. The emotions that parallel these aspects seem to flow and ebb like the tide, and at the actual death of the loved one, there will be an upsurge of acute grief once again, followed by mourning. It is noted that this study was intended to identify parental anticipatory grief, but is applicable to all who experience anticipatory grief in general. Fullerman et al. reported that these aspects become more focused with time, and the acute pain characterized in the beginning of the grief becomes a more tempered melancholy. The loss of a child is particularly devastating to a parent, and parental anticipatory grief, no matter the age of the child, is as intense to a parent when a child has died prematurely. Aspects of anticipatory grief are: 1) Acknowledgement: being progressively convinced that the death is inevitable; 2) Grieving: expressing and experiencing all aspects of the loss, including emotional, physical and psychological turmoil associated with it; 3) Reconciliation: developing a perspective on the child's death and a sense of confidence in the worth of the child's life and worth of life in general; 4) Detachment: withdrawing emotional investment from the child as a being with a future; and 5) Memorialization: developing a fixed conscious representation of the dying child which will endure beyond death. This description provides an emotional meter in which all aspects can be experienced at the same time. It shows the struggle and internal turmoil that

outsiders may not see that the griever may experience as they move from aspect to aspect. This feels like the “inner work” that the griever could be doing.

Dimensions of Anticipatory Grief

Fulton and Fulton (1971) identified four dimensions of anticipatory grief which are used today. These dimensions are often referred to in phases or stages. In Phase I, death is seen as inevitable and there is no cure for the loved one. Sadness and depression are most often associated with this stage. Parents of children who are experiencing a terminal illness could be considered experiencing thoughts and feelings in Phase I. They feel helpless, worthless and unable to fix the illness or diagnosis, and this manifests itself in depression. Phase II demonstrates heightened concern for the terminally ill person which may include regret for past arguments or disagreements, and concern regarding how the griever views or fears death for themselves or the loved one. Many physical ailments come at this time such as sleeplessness, weight gain or loss, and anxiety. This could also be considered the “Make a Wish” stage, where parents hope to make their “last vacation” or celebration a great one, or provide whatever experience or comforts they can while the family member is able to accept them. Phase III includes the physical process of preparing for the death, such as making arrangements and saying goodbye, as well as attempting to adjust to the consequences of the death. This stage is the shift to adjusting to the finality of death, similar to the acceptance stage identified by Elisabeth Kubler-Ross (1969). Phase IV is the inner work that the survivor(s) are doing in imagining what their lives are going to be like without the person that is dying. Survivors can include anyone: parents, sibling, relatives, friends or teachers. Additionally, anticipatory grief also allows for absorbing the reality of the loss gradually over time, completing unfinished business with the person such as expressing feelings and resolving past conflicts, beginning to change assumptions

about life and identity, and making plans for the future so that they will not be felt as betrayals of the deceased after death (Fulton & Fulton, 1971). These statements may all seem like a painful process which would be easier to keep in check through denial, but in reality, it is easier to begin these processes before the loved one's death rather than coping with at all at the time of death (Rando, 1984). In contrast to Fullerton's aspects, these dimensions are not as internal, but feel more "public" as they can be viewed by others witnessing the actions and observing the behaviors of the griever. Health care workers would be able to notice these phases through the behavior of the individuals facing the loss. In many cases, health care personnel would be assisting them in coping with the impending loss.

Contrast of Anticipatory Grieving and Compassion Fatigue

Receiving the devastating news of a terminal diagnosis regarding a loved one changes the very structure of our existence, and it is beneficial to understand that the anticipatory mourning process follows the same pattern for many. Though the finality and reality of the death is eminent, the alternative of a loved one being abruptly killed, without warning and offering no chance to say goodbye or make peace and offer words of comfort is much more difficult and the grief harder to overcome. In fact, the more sudden and violent the death, the longer someone is likely to struggle with the shock and anger that accompanies an untimely death (Fitzgerald, 1994). Fulton (2003, p. 19) wrote that anticipatory grief "is not simply grief begun in advance: it is different from post-mortem grief both in duration and form." Grief that is experienced though an expected loss does not mean there will necessarily be any less grief at the time of death; the grievers find themselves encountering a new reality with a new form of grief and a new need to mourn (Corr, 2007). Physical manifestations of anticipatory grief are many, and include sleep

and memory problems, and the emotional and mental symptoms can vary, including anger, guilt, loneliness and anger, depending on the griever.

If anticipated losses take a huge physical and mental toll on the family member, imagine the physical and mental exhaustion that it can take on a professional caregiver who works day-in and day-out with death and trauma, year after year. There is no perceived definite ending for trauma workers, no finished business where they can begin the work of recovery. Interestingly enough, upon review of the dimensions of anticipatory grief and with slight adaptation, they could be used to describe the dimensions of compassion fatigue as well, following the same order. Two of the aspects have been taken away and the result “feels like” the description of compassion fatigue: 1) Acknowledgement: being progressively convinced that the death is inevitable, *resulting in feelings of hopelessness*; 2) Grieving: expressing and experiencing all aspects of the loss, including emotional, physical and psychological turmoil associated with it; 3) Detachment: withdrawing emotional investment from clients (instead of the child) as beings with a future, along with the deep physical and emotional exhaustion and a pronounced change in the helper’s ability to feel empathy. For many in the workplace, compassion fatigue is brought about by the inability to create meaningful change for the client, which can develop into a hatred of the workplace and a loss of sympathy for the plight of their colleagues (Austin et al, 2013).

As the workplace setting has changed, so has the help and support provided by administration. Structural changes that are designed to increase efficiency have the unexpected results of undermining collegial support because face-to-face contact is now limited (Austin et al, 2013). Removal of common meeting areas and spaces, as well as requiring employees work from home, or on the road has diminished and detached them from people and places that generated

deep meaning and significance in regards to their profession. These changes not only increase the difficulty of the work, but create conditions under which compassion fatigue may develop.

Identification of Compassion Fatigue

If compassion fatigue is not addressed in its earliest phases, it can permanently alter the ability of the caregiver to provide compassionate care (Boyle, 2011). It is important for individual health care workers to be aware of warning signs for compassion fatigue so that they may assess their own level. This serves as an important “check-in” process for the individual who has been unhappy and dissatisfied, but does not have the words to explain what is happening to them, and secondly, it can allow them to develop a warning system for themselves (Mathieu, 2007). It is also important for health care institutions to be familiar with the symptoms of compassion fatigue to identify the overall general mental health of staff. In its simplest form, compassion fatigue implies a state of psychic exhaustion, and is the cost of caring. Many workplaces encounter critical incidents such as violence and natural disasters in which these same medical and mental staff members must respond in a meaningful way, yet doing so compounds the feelings of anxiety, dread and hopelessness. In fact, clinicians often report that their graduate programs failed to prepare them to work with trauma survivors, which can increase their risk of compassion fatigue and burnout (Monroe, 1999; Salston & Figley, 2003).

Self-identification and Assessments

As in any high risk job, it is essential to educate professionals about the inherent occupational hazards of their jobs. An individual should not wait until they reach their breaking point in order to seek help concerning compassion fatigue. It is important to provide information on compassion fatigue early on in training so that individuals immediately begin self-care

programs at the onset of their careers. While professionals tend to be in tune with the needs of their clients, they often ignore their own stress symptoms and fail to use healthy social supports (Jacobson, 2012). Potential negative effects of compassion fatigue should be taught to professionals as an ethical responsibility to take proactive steps to recognize and mitigate the symptoms (Jacobson). These issues must be elevated to a greater sense of urgency and awareness before more compassionate medical and mental health professionals are lost.

Fortunately, one assessment that is offered is a simple self-assessment, called the Professional Quality of Life Scale (Pro-QOL R IV), provides insight to the taker where they fall in three areas: predicting potential for compassion satisfaction, predicting risk for burnout, and predicting risk for compassion fatigue. The Pro-QOL was developed by Dr. Beth Hudnall-Stamm, a professor at the Institute of Rural Health at Idaho State University and is the most widely used instrument to determine levels of compassion fatigue, if it does indeed exist for the helper. The assessment is designed to assess these areas within the last thirty days and consists of 30 questions of belief, scored by a Likert scale ranging from *Never* to *Very Often*. There are no right or wrong answers to these questions, and the debriefing of the subscale scoring at the end of the test will provide some insight as to possible next steps for self-care. The assessment also measures a positive outcome called compassion satisfaction, which refers to the positive effects of feeling satisfied with one's ability to provide care and connect with another person using empathy. Compassion satisfaction incorporates personal, professional, and spiritual growth as professionals gain an increased respect for human resiliency following traumatic events (Jacobson, 2012).

Another measurement used to identify personal trauma for major life events is the Stressful Life Experiences Screening Short Form (SLES-S), which screens for major life events

considered stressful or traumatic in a person's life using a 20-item scale. Created by Beth Stamm (1996) this assessment measures 1) the presence of a stressful life experience, and 2) the degree of stressfulness of that life experience. The short form takes just a few minutes to do, but offers good insights to the taker on how they view life experiences. In addition, another test that assesses work related stress is the COPE Inventory which is a multidimensional coping inventory to assess the different ways in which people respond to stress. Five scales of four items each, measure conceptually distinct aspects of problem-focused coping (active coping, planning, suppression of competing activities, restraint coping, seeking of instrumental social support); five scales measure aspects of what might be viewed as emotion-focused coping (seeking of emotional social support, positive reinterpretation, acceptance, denial, turning to religion); and three scales measuring coping responses that arguably are less useful and focus on and venting of emotions, behavioral disengagement, mental disengagement (Carver, 1997). These assessments could assist health care workers by bringing aspects of compassion to the forefront, thus putting helpers on notice that compassion fatigue is a very possible effect of working in fields that endure trauma, stress and death.

Anticipatory Mourning and its Effects on the Actual Loss

A common myth of grief and mourning is that it follows a timeline. First and foremost people need to understand that grief will take as long as it needs (Fitzgerald, 1994). However, grief and mourning are different for every individual and each person expresses his/her grief and bereavement in his or her way. The process of anticipatory mourning does not necessarily lessen the effects of grief at the time of death. Anticipatory grief and mourning are responses to the expectation of death or loss; and postmortem grief and mourning are responses to the reality of that death or loss (Corr, 2007). Knowing that grief has no timeline or volume, then, means that

postmortem grief could last from the moment of the death through the rest of the bereaved person's life (Corr). However, in some ways, the preparation work of anticipatory grief allows for less of an assault on the mourner's adaptive capacities (Clayton et al.(1973); Glick, Weiss, & Parkes, (1974); Parkes & Weiss, (1983). This would naturally vary with individual cases, just as grieving varies with individuals. However, grief is no less painful even when anticipated, and can be as devastating as that occurring with an unexpected loss.

There is a delicate line between anticipating when someone is going to die, and not giving up on them. It is important to remember that the patient may choose to not accept the prognosis and that the caregiver recognize and support their loved one's desire to live in hope. Hope may even contribute to their survival, even while the caregiver is grieving. As Rando (1984, p.12) notes, "some degree of hope persists throughout all the phases of dying, through the emotional reactions, grief and defenses. Frequently, it is hope that sustains the patient through suffering." By understanding that hope is important for the terminally ill to maintain, individuals providing palliative care to those experiencing anticipatory grief can be of great importance and help them keep a sense of boundaries, empathy and instincts so that they can listen for cues to find meaningful interactions with their loved one. As important as it is for the terminally ill to hold onto hope, it is as important for professional caregivers to project it. Where patient hope is now considered an important component of patient well-being, the field has begun to turn its attention to hope for the health care professional (Austin, Brintnell, Goble, Kagan, Larsen & Leier, 2013). Loss of caregiver hope must concern us all, with caregiving hopelessness affecting clients. It is now known that the single best predictor for satisfaction with treatment was "the counselor encouraged me to believe that I could improve my situation." The spirit with which the care is offered has its own potency, spurring momentum towards health and well-being for the

patient (Austin et al., p. 39). Compassion fatigue takes this critical asset away from the professional, crippling the ability for them to do their job.

The Role of Supportive Care in Anticipatory Mourning

Supportive care, or palliative care, is aimed at comfort versus care and treatment, and should be offered to the family members as well as the patient. It is a special type of psychosocial care and those who are experiencing anticipatory grief deserve as much care and attention as possible so that they can “be there” for their loved one. Anticipatory grieving among parents living with a child with cancer is very high. According to Ekhas and Long (2010), fewer than half of the parents in groups that were identified as those which had a child receiving a ‘newly diagnosed’ cancer and a group that had a diagnosis of longer than six months reported being at peace with themselves and their situation in life. They experienced the most common expressions of anticipatory grief which were feelings of hopelessness, despair and worthlessness (Ekhas & Long, 2010). It is understandable that a diagnosis of childhood cancer evokes an emotional crisis for the whole family, but also that the cancer diagnosis can be a longer-term emotional stressor. The way in which the family reacts and deals with the diagnosis will affect the child’s well-being (Hillman, 1997), and it is apparent that the need for palliative care in anticipatory mourning is needed on several familial levels. The symptoms of anticipatory grief are not invisible and professionals who work with family members often absorb common symptoms that the family caregivers are experiencing such as exhaustion, anger, discouragement, sleeplessness, irritability, anxiety and dread with certain clients, in addition to feelings of being overwhelmed.

Costs of Compassion Fatigue

Studies confirm that caregivers play host to a high level of compassion fatigue, often without knowledge and awareness of its devastating effects on their lives (Smith, 2009). Residual effects of compassion fatigue within organizations include chronic absenteeism, worker's compensation claims, high turnover, conflicts between employees and general friction between administration and staff, and most importantly, the potential to lose caring and compassionate people who were initially drawn to their professions by a drawing, pull and "calling," in which their great compassion and empathy is greatly needed (Smith, 2009). Physical costs of compassion fatigue take their toll on individuals, which include headaches, insomnia, and gastrointestinal distress (Boyle, 2011). Compassion fatigue is chronic, can manifest suddenly without warning, and whose symptoms in the long term will never seem to go away, whereas symptoms of anticipatory grief gradually turn to postmortem grief and can be managed over time.

Importance of Support for Survivors and for Professional Caregivers

In a concept review of anticipatory grief, Fulton (2003) concluded that the most practical value of the concept is to alert physicians and other caregivers to the emotional status of the prospective survivor. Individuals can work through their anticipatory grief in a systematic manner and this will help their emotional status. Healthcare personnel and behavioral health providers are in the front line to recognize and aid in the interventions and strategies to provide care to those experiencing anticipatory grief. Table 2, adapted from Corr's (2007), *Guidelines for Care Providers* offers suggestions to those assisting in providing care to those experiencing anticipatory grief. For those serving in the hospice and palliative care professions, one way to reduce compassion fatigue is to develop education and training programs on self-care at the basic entry-to-practice education level (Slocum-Gori et al, 2011). It is important to provide prevention

programs to those professions early on and increase awareness of the possibility that compassion fatigue may manifest during their career so that hospice care (HPC) workers are not blindsided by it and recognize that it is an occupational hazard and that almost everyone who cares about their clients will eventually develop a certain amount of it, with varying degrees of severity (Mathieu 2007). A significant difference between anticipatory grief and compassion fatigue is that anticipatory grief has an ending, albeit a sad one, and compassion fatigue is chronic, with no end in sight, and can be compounded the longer the employee remains in the job. Anticipatory grief will end once the actual event takes place and the normal grief will replace it, allowing clients to come to the end of their emotional rollercoaster. However, compassion fatigue is not short-lived and is compounded over time. It is long the term exposure to trauma that takes its toll on the health care worker, affecting their ability to not only do their job, but live normally at home.

Conclusions

In conclusion, all health care personnel should become familiar with the symptoms of anticipatory grief and of compassion fatigue in order to recognize it in themselves and others. Without awareness and knowledge of these conditions, prevention and self-care strategies will not be initiated early enough to lessen symptoms, which can be lifelong, and of a chronic nature. Caregivers in particular, can encourage individuals in an empathetic and systematic manner to engage in self-care in order to cope with anticipatory grief, which prepares them for the final ending and resulting postmortem grief, whose form and duration cannot be determined prior to death. By understanding the concept of anticipatory grief and its purpose, the survivor and the loved one will have a better understanding that there are additional opportunities to complete unfinished business, move toward a more meaningful relationship, and establish a deeper bond of love that will remain beyond death. Even though the terminally ill may be an incapacitated person that cannot speak, or a baby or child that cannot communicate through words, the final acts of reconciliation and caring are universal.

No one should have regrets for actions they could have taken but did not realize during a time of trauma and emotional strife in either the anticipatory grieving process or the process of caring for those experiencing trauma or impending death. People can only act upon what they have knowledge of at the time, and education in anticipatory grief and compassion fatigue will benefit patients, survivors and professional caregivers and administrators. In particular, caregivers who are employed in the important and noble work of assisting those in pain and suffering need more self-care strategies and training opportunities as compassion fatigue is a well-documented hazard of their employment.

The dying and those who walk along beside them as they suffer can learn much from each other. The unique process of anticipatory grief counseling care provides direction that will allow both the wounded and the healer to live more fully and compassionately as they mourn in unique ways at the same time. Though the final ending for those in the process of anticipatory mourning is death, the individual who survives can arrive at that event in a healthier state of mind based on the intra-psychoic work that started during the process of saying goodbye. The same holds true for those professionals who are involved in the care and suffering of their patients. By self-care strategies combatting compassion fatigue through self-awareness assessments for all, and not just those that are at-risk, as well as implementation of mandatory and professional opportunities to discuss and dissipate symptoms, caregivers will continue to not only provide work at their optimal levels, but grow as loving, caring human beings with kindness to themselves and others.

Author's Note

After reading the literature on compassion fatigue, I feel that it is essential that education must be provided on compassion fatigue as caregivers enter the field, either while in training or upon employment. It is critical that individuals in the helping professions do not reach the point where compassion fatigue manifests. Organizations, particularly hospitals, hospice care centers and other places where helpers work with trauma and death, must invest in training to learn about compassion fatigue and the detrimental effects it may have on their employees, and to implement measures where employees are required to learn about self-care. Compassionate people are driven to enter professions where they can be helpful to others. In many cases, the passion they feel towards others is now their occupation and individuals enter the field with many of the same issues of those they serve. There are many benefits of trauma work, including a heightened sensitivity and enhanced empathy for the suffering of victims, resulting in a deeper sense of connection with others; increased feelings of self-esteem from helping trauma victims regain a sense of wholeness and meaning in their lives; a deep sense of hopefulness about the capacity of human beings to endure, overcome, and even transform their traumatic experiences; and a more realistic view of the world, through the integration of the dark sides of humanity with healing images (McCann & Pearlman, 1990, p. 146-147). Other benefits of working in the helping field include opportunities for human interaction, personal growth and the creation of meaning in our lives, including the ability to grow spiritually. For me, the opportunity to become a more enlightened human being, through a chosen career is a humbling and honoring achievement. Losing comrades and partners on the journey of assisting others is the greatest loss. Not recognizing anticipatory grief in our clients is another loss of an opportunity to assist others.

A great part of my profession will be in recognizing anticipatory grief in others and creating awareness and avenues for self-care in the field of counseling.

References

- Austin, W., Brintell, E., Goble, E., Kagan, L., Kreitzer, L., Larsen, D., Leier, B. (2013). *Lying down in the ever-falling snow*. Waterloo, Ontario, CA: Wilfrid Laurier University Press.
- Boyle, D., (2011). Countering compassion fatigue: a requisite nursing agenda. Online *Journal of Issues in Nursing*, 16(1).
- Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine*, 4, 92-100.
- Clayton, P.J., Halikas, J.A., Maurice, W. H., & Robbins, E. (1973) Anticipatory grief and widowhood. *British Journal of Psychiatry*, 125, 64-74.
- Doka, K. (Ed.). (2007) *Living with grief, before and after the death*. Washington, DC: Hospice Foundation of America.
- Ekhas, A. & Long, T. (2010) Anticipatory grieving among parents living with a child with cancer. *Journal of Advanced Nursing* 66(9), 1980 – 1990.
- Figley, C. R. (Ed.). (2002b). *Treating compassion fatigue*. New York, NY: Brunner-Routledge.
- Fitzgerald, H. (1994). *The mourning handbook: A complete guide for the bereaved*. New York, NY: Simon & Schuster.
- Fulton, R. & Fulton, J. (1971) A psychosocial aspect of terminal care: anticipatory grief. *Omega*, 2, 91-99.
- Eldridge, L. (2014). Why am I already grieving? Understanding Anticipatory Grief, retrieved from <http://lungcancer.about.com/od/Grief-Bereavement-Mourning/a/Anticipatory-grief.htm>
- Futterman, E. H., & Hoffman, I., & Sabsin, M. (1972). *Parental anticipatory mourning: Psychosocial aspects of terminal care*. New York: Columbia University Press.

Hillman, K.A. (1997) Comparing child rearing practices in parent of children with cancer and parents of healthy children. *Journal of Pediatric Oncology Nursing* 14(2), 53-67.

Hudnall Stamm, B. (2005). *Professional quality of life: compassion satisfaction and fatigue subscales*. Retrieved from [http: www.isu.edu/~bhstamm](http://www.isu.edu/~bhstamm).

Jacobsen, J., (2012). Risk of compassion fatigue and burnout and potential for compassion satisfaction among employee assistance professionals: protecting the workforce. *Traumatology*, 18(3). 64-72.

.Kubler-Ross, E. (1969). *On death and dying*. New York, NY: Macmillan.

McCann, I. L. & Pearlman, L. A. (1990). Vicarious traumatization: a framework for understanding the psychological effects of working with victims. *Journal of Traumatic Stress* (3). 131-149.

Munroe, J. F. (1999). *Ethical issues associated with secondary trauma in therapists. Secondary traumatic distress: Self-care issues for clinicians, researchers and educators*. Lutherville, MN: Sidran Press

Rando, T. A., (1984). *Grief, dying, and death*. Champaign, IL: Research Press Company.

Rando, T. (1991). *How to go on living when someone you love dies*. New York, NY: Bantam Books.

Rando, T.A. (2000). *Clinical dimensions of anticipatory mourning: Theory and practice in working with the dying, their loved ones, and their caregivers*. Research Press Company, Champaign, IL.

Slocum-Gori, S., Hemsoworth, G., Carson, A., & Kazanjian, A., (2011). Understanding

compassion satisfaction, compassion fatigue and burnout: a survey of the hospice palliative care workforce; *Palliative Medicine*, 27(2).172-178.

<http://www.compassionfatigue.org/pages/compassionfatigue.html>

Smith, P. (2009). *To weep for a stranger: compassion fatigue in caregiving*. Healthy Caregiving LLC.

Table 1

Comparison of Anticipatory Grief to Compassion Fatigue

<p>Anticipatory Grief “Preparatory Grief” “Loss before the Loss”</p>	<p>Compassion Fatigue Running on Empty, Wounded Healer, Vicarious Trauma, Secondary Traumatic Stress (STS)</p>
<p>Definition: The feeling of loss before a death or dreaded event occurs -- described as a "normal process"</p>	<p>Definition: Deep physical and emotional exhaustion and a pronounced change in the helper’s ability to feel empathy for their patients, their loved ones and their co-workers</p>
<p>Duration: short term, moving to grief</p>	<p>Duration: long-term, chronic</p>
<p style="text-align: center;">Symptoms</p> <p>Denial Exhaustion and general fatigue Mood swings Forgetfulness Disorganized and confused behavior, Anger Depression Anxiety and dread Feeling disconnected and alone Weight loss or gain Sleep problems Nervous behavior, and general fatigue</p>	<p style="text-align: center;">Symptoms</p> <p>Exhaustion Reduced ability to feel sympathy and empathy Anger and irritability Increased use of alcohol and drugs Dread of working with certain clients/patients Diminished sense of enjoyment of career Disruption to world view Heightened anxiety or irrational fears Intrusive imagery or dissociation Hypersensitivity or insensitivity to emotional material Denial Difficulty separating work from personal life Absenteeism: missing work, taking many sick days Impaired ability to make decisions Problems with intimacy and in personal relationships</p>
<p style="text-align: center;">Common Symptoms Exhaustion Anger and irritability Anxiety and dread Sleeplessness</p>	<p style="text-align: center;">Common Symptoms Exhaustion Anger and irritability Anxiety and dread Sleeplessness</p>
<p style="text-align: center;">Affects Individuals, typically those dealing with a loved one Short term, moving to the process of post-mortem grief</p>	<p style="text-align: center;">Affects Professional Caregivers: Nurses, hospice workers, disaster relief workers, journalists, emergency medical personnel, policemen, counselors dealing with trauma</p>

Adapted from “Running on Empty: Compassion Fatigue in Health professionals,” by Mathieu, F. (2007), Journal of Rehab and Community Care Medicine.

www.americanhospice.org/articles-mainmenu-8/working-through-grief-mainmenu-13/80-anticipatory-grief-symptoms-whats-the-big-deal

Table 2
Guidelines for Care Providers

Be Available and Present; Listen		
A person may or may not share their reactions and responses to their anticipated loss. They will never do so if you are not available.	Ask questions and make observations that encourage them to share their concerns.	Listen to what the person says – and does not say. Pay attention to verbal and nonverbal communications, to literal and symbolic disclosures.
Accept and Allow		
It is acceptable for people to grieve and mourn when anticipating major losses. These losses are important and may be life-changing for them and their families.	Acknowledge and validate for the person that loss is a normal part of the human experience.	Persons engaged in anticipatory mourning to do so in whatever ways they need. Only tasks and processes that are directly harmful to the person or others are inappropriate.
Expect and Anticipate		
People have different perspectives on mourning. No one grieves the same. There is no “right” way to grieve. Though the feelings of grief are universal, keep in mind cultural differences in mourning.	The passage of time and changes to the situation can affect anticipatory grief and mourning. Ask the person what their concern is at the PRESENT moment. Assess and reassess what is going on as time passes.	Grief reactions come in various forms: Physical, psychological, behavioral, social and spiritual. Do not limit or fail to appreciate a person’s grief reactions.
Encourage and Adapt		
Pressures associated with impending death may make available time precious. Anniversaries and holidays may be celebrated, reconciliations achieved, and “unfinished business” and last wishes may be pursued. It is okay to do this.	Being cared for by family members who are experiencing anticipatory grief are important roles. Respect this, yet offer and encourage the support from trained volunteers and professionals to keep the person healthy as well.	The more we learn about anticipatory grief and mourning, the better we will be as helpers and fellow human beings. Enabling people to grieve as they should and cope as they must is the noble work of palliative care.

Note: Guidelines are adapted from “Living with Grief: Before and After the Death” by K Doka.(2007). Retrieved from Hospice Foundation of America.

Table 3

Are you at risk? Preceptors to compassion fatigue

<p>Personality traits of the giver <i>Ask yourself: I have...</i></p>		
<p>Placed the needs of others before my own on a regular basis.</p> <p>The majority of patterns and habits begin very early in our lives, and those messages in our head can often do damage.</p>	<p>Given care to others under stress or burnout.</p> <p>How do we effectively take care of ourselves?</p>	<p>Lived in an environment where I was put in the position to take care of others at a young age.</p> <p>Overdeveloped sense of responsibility: who were my role models?</p>
<p>Life skills Viewing yourself in an honest, kind, and merciful way <i>Do any of these resonate with you? I have a...</i></p>		
<p>Lack of healthy professional and personal life coping skills</p> <p>What has happened in our own family unit? How has my family handled stress? Breaking dysfunctional patterns can occur.</p>	<p>Lack of personal boundaries</p> <p>How and when do we say “no” or “enough?”</p> <p>Is the only way to validate and support ourselves by giving care to others?</p>	<p>Lack of self-awareness that limits potential growth and change.</p> <p>We cannot change that which we are not aware. Hope takes root in awareness.</p>
<p>Communication <i>Who is listening to me? Who should be?</i> <i>I need assistance in expressing/resolving...</i></p>		
<p>Inability to communicate needs</p> <p>We need to effectively express our needs. Who is listening to validate us and our worth?</p>	<p>Unresolved past trauma and pain.</p> <p>Professional caregivers come to the table with the same experiences as victims, and at times the same dysfunctions within their family unit.</p>	<p>Recognition of the symptoms.</p> <p>Awareness is the first step that leads to recovery and healing.</p>

Note: The guidelines are adapted from “To Weep for a Stranger” by P. Smith, (2009).