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Even in Fateful Situations a Vital Optimism Remains: Social Work “Accompaniment” with Persons with Cancer

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Abstract

To advance a social work model for working with patients with diagnoses of cancer in diverse global contexts, this paper draws from qualitative research with clients diagnosed with cancer, and their social workers, in Lithuania. As in many countries, Lithuanian social work is a new profession, finding its way to helping people through many life stressors in a unique cultural context. The threat cancer presents – of dying from a protracted and painful illness – requires social work strategies, especially because many countries lack Hospice supports. Key aspects of the findings are the life crisis that a diagnosis of cancer presents, with great fear, anguish, and shifts in personal identity. Clients and social workers describe physical and emotional suffering and alienation from others. While some aspects of clients’ suffering cannot be alleviated by social workers, alienation can be, so here we focus on that possibility. The data from clients and social workers are used to revise crisis intervention theories to suit this unique type of crisis, and an alternative concept of “accompaniment” is offered to capture how social workers can reduce alienation. Drawing from the work of Farmer, Watkins, and O’Donoghue, accompaniment is compatible with strengths-based and wholistic approaches to practice and is adaptable for those with any belief system.

Keywords

social work with persons with cancer, accompaniment with persons with cancer, spiritual caring with persons with cancer

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Introduction

Social workers need to have a practice standpoint for working with patients with diagnoses of cancer for many reasons. Approaches based on crisis intervention are helpful but tend to be inadequate for addressing the existential concerns raised, especially when the diagnosis is terminal. Moreover, in many countries Hospice services are not available, spirituality and religious beliefs are pervasive, and social workers are expected to be sensitive to existential and spiritual concerns that arise when facing a potentially fatal disease. Drawing from Lithuania, where the great majority of the population are practicing Catholics and social

work is a relatively new profession, this article reports on a study that examined the lived experiences of persons with cancer and the reflections of social workers serving them.

The situation in Lithuania parallels that of many countries of the world, where Hospice care expertise may not be present or is limited, the social work profession is relatively new, and expertise in care for the dying is rare if not nonexistent (Blumberg, 2015). In addition, even in developed countries where Hospice care is prevalent, persons may refuse Hospice care because it signifies a state of dying which they do not want to accept (Saunders, 1995), but they will welcome a social worker. A social work perspective on how to be of help in such momentous circumstances is essential.

In order to gain a social work perspective, this paper draws from the findings presented here and focuses on remedying one of the causes of increased anguish for those suffering from terminal cancer: Alienation resulting from (1) the strain others feel in relating to someone who is suffering and dying, which can cause them to pull away or even reject the suffering person, and (2) the dying person's struggle to stay connected while "saying goodbye."

Traditional approaches to social work intervention with persons with cancer draw heavily from crisis intervention theory, which focuses on recovery from a crisis in the context of addressing psychopathology. However, the suffering and imminent death faced by the person with cancer has aspects that require a different approach. Strengths-based, holistic, and individualized approaches that attend to clients' social and spiritual needs are promising, so this paper describes them using a metaphor coined by physician-researcher Paul Farmer (2015), psychologist Mary Watkins (2017), and social worker Siobahn O'Donoghue (n.d.) as "accompaniment." Accompaniment enhances the important formulations by Cicely Saunders of the United Kingdom, a nurse, social worker, and founder of the Hospice Movement (1995). The authors' personal experiences with cancer and professional experiences caring for patients with cancer ground this paper as well.

Background

A Global Perspective

Cancer, according to the World Health Organization (WHO), is one of the leading causes of morbidity and mortality worldwide. In 2015, 8.8 million people worldwide died from cancer, nearly 1 in 6 of all global deaths. According to the data provided by National Institute of Cancer of Lithuania (Nacionalinis Vėžio Institutas, 2015), about 3% of Lithuanians are affected by cancer. WHO calls on countries to reduce disability, suffering, and deaths caused by cancer worldwide, via effective and affordable programs in early diagnosis, screening, treatment, and palliative care.¹ The U.N.'s 2030 Agenda for Sustainable Development, Goal Number 3, "Good Health and Well-Being," calls on countries to ensure healthy lives and promote well-being for all ages, including to reduce by one-third premature mortality from noncommunicable diseases through prevention and treatment (Target 3.4).

The social work profession is well-suited to respond to the WHO and UN's priorities. Social workers can provide personalized support to persons fighting cancer and coming to the end of their lives. Watts (2013) describes how social workers offer a positive relationship for clients in palliative care, centred on helping people to deal with core existential questions associated with suffering and facing one's mortality, and she draws from several sources in professional practice literature to detail skills involved in competent social work, such as preventing intra-family conflicts, preserving connections with persons outside the family, and

¹ <http://www.who.int/cancer/en/>

clarifying multidisciplinary team members' roles. At the same time, the findings we describe below suggest another dimension is needed in addition to specific skills.

Social Work in Lithuania

Lithuanians initiated the profession of social work in the early 1990s, after winning their freedom from the Soviet Union via the "Singing Revolution" (Vardys & Sedaitis, 1996). The Soviet ideology was that social problems did not exist. Social and behavioural sciences existed only to support the maintenance of the Soviet system. The Soviet occupation was systematically, traumatically oppressive of the Lithuanian population: citizens were deported without resources to Siberia and the Ural Mountains. Lithuanian citizens were systematically murdered and tortured in ways that terrorized surviving citizens (such as their corpses being hung at the entrances to villages). The Soviet Union strove to bring about mind control through limiting available information, informing on and severely punishing dissenters, aggressive propagandizing, and persecuting those practicing their religion. Soviet spies infiltrated Lithuanian civil society organizations (e.g., trying to addict members with alcohol and drugs) and invaded individual and family privacy through spying and recording with impunity.

After the Singing Revolution, both democracy and the social work profession have developed rapidly in Lithuania, sparked in part by the inspiration of the country's indigenous non-violent movement for freedom, *Sajudis*, and by the citizens' commitment to international dialogue and education to surmount the deprivations endured under the Iron Curtain (Vardys & Sedaitis, 1996).

Medical social work in Lithuania has only existed for a decade. While limited systematic research has been carried out in Lithuania about caring for persons with cancer, it is well-known that due to inadequate professional supports, the burden of care for persons with cancer falls significantly on family members. For instance, a teenager whose parent had cancer assumed responsibilities of supporter, nurse, and head of family (Jurkuvienė et al., 2014). Parents of a child with cancer felt alone, confused, and hopeless, relying on cultural as opposed to professional bases (Butkevičienė & Pudžemienė, 2012). Social workers helping persons with cancer experience great uncertainty due to the lack of culturally relevant, research-based practice principles (Skubiejūtė & Petružytė, 2016). Non-governmental civil organizations strive to meet the needs of families with cancer, but their staff have limited capacities and uncertain preparation. Accordingly, there is a great need in Lithuania for social work expertise in caring for dying persons and their families.

Social Work Theory About Helping Persons with Cancer

Examining general social work theory about serving persons with cancer, crucial tasks have been identified for social workers working with persons with cancer and their families: helping clients (1) explore their feelings and behavioural options, (2) communicate as openly as possible with their significant others, and (3) become aware of resources outside themselves (Pilssecker, 1979). Persons with cancer can feel extremely vulnerable and sensitive, complicating communication with health care professionals. Social workers can use their empathic training facilitate helpful conversations between patients, physicians, and other health care staff (King et al., 2008). Because the availability of supportive relationships is essential for persons with cancer, a systems approach identifies complex flows of information and actions within and across the systems' boundaries (Payne, 2014).

Persons with cancer respond differently to their diagnoses (Taplin, 2016), depending in part on whether the illness is imminently life-threatening or a condition with which the person will live to some degree for a sustained period of time. Those diagnosed with cancer who

survive report significant changes in their identity. They experience disruption in their sense of identity, liminality, a different sense of time and individual purpose, post-traumatic reactions and concerns about recurrence or aggravation of illness, and intense mixed feelings about survivorship (Taplin, 2016).

Since a diagnosis of cancer represents a life crisis, crisis intervention theory has some relevance. First, a diagnosis of cancer fits the definition of a life crisis, which is when a hazardous event disturbs an existing, steady state, overwhelming the person's customary coping strategies. Second, crisis intervention theory holds crisis events offer both stress and opportunity (Kast, 2006), as persons coping with a crisis can rebuild their existing strengths by identifying new support systems and learning new coping skills (Payne, 2014). Other relevant elements of crisis intervention theory are comprehensive psychosocial assessment, listening and reflecting skills that aid the client in processing the event and its meaning, supporting successful coping efforts, offering a calm and supportive relationship, being explicit about time limits of care, and considering the client in a holistic context (Thompson, 2011).

Cancer presents another dimension to conceptualizations of life crisis, in that persons with cancer commonly experience questioning both the meaning of their lives and their being itself. Social workers need to be familiar with spiritual assessment, spiritual language, and various forms of religion and/or spiritual practices that improve their clinical work with patients who have cancer. They can provide insight to guide social work interventions designed to enhance spiritual well-being (Stewart, 2014). Health and quality of life are enhanced by working towards the following experiences:

- “Transformation,” by enabling people to change their identity to become self-affirming and able to deal with and prevent the difficulties in their lives.
- “Transcendence,” a sense of purpose, hope, meaning, and affirmation in life, even in the face of oppression or difficulty.
- “Wholeness,” by shaping persons' identities as a whole, integrating a focus on social structures as well as personal well-being.
- “Hope,” by helping people think about the opportunities available to them for improving the quality of their life in the future.
- “Resilience” in the face of negative events by developing skills in bouncing back from things that go wrong (Payne, 2014).

An essential part of a social work perspective for caring for persons with cancer is care for the social worker. Social workers serving patients with cancer and their families experience the intense and unique stress of the suffering and loss of those for whom they care (Davidson, 1985; Oktay et al., 2012). This stress requires a uniquely tailored clinical supervision to prevent vicarious trauma (Joubert et al., 2013). Kahn (2005) describes a supervisory and administrative perspective that recognizes the stress that practitioners experience, and that responds with consistent caring for the practitioner. He emphasizes this caring for the social worker is an essential agency context for effective practice – in essence, the supervisory and administrative care for the social worker is the necessary fuel for the care the social worker provides for clients.

Still, with all this support, the social worker may need a state of mind that is not adequately conveyed by different skills. One way to understand this is to consider compassion has two dimensions: one is competence, and the other is presence (Nouwen, McNeill & Morrison, 1982). Presence is particularly important when one is basically helpless in the face of the event besetting the person for whom one cares (Ibid), which in the context of medical social work occurs as medical conditions evolve outside the control of the client or caregivers. To capture this dimension, we use the concept of accompaniment.

Accompaniment

Paul Farmer, an anthropologist and physician working on developing systems of care in severely deprived circumstances, developed the concept of accompaniment to describe the care needed for someone going through great, and potentially incurable, duress (2015) in conditions in which expertise and rationality are inadequate. Compassion, imagination, and “being with” are needed in order to develop solutions. In the framework of accompaniment, the duration and forms of care are defined by the person being accompanied and the challenges being endured. As Farmer (2015) said:

To accompany someone is to go somewhere with him or her, to break bread together, to be present on a journey with a beginning and an end...There’s an element of mystery and openness...I’ll share your fate for awhile, and by “awhile” I don’t mean “a little while.” Accompaniment is much more often about sticking with a task until it’s deemed completed by the person or person being accompanied, rather than by the *accompagneur*. (para. 5)

Methodology

Phenomenological Inquiry

The approach to inquiry used here is phenomenological, which affords a focus on a specific kind of event and the experience surrounding it (Kahn, 2005). Phenomenological methods were used previously to identify existential changes in the accounts of persons with cancer (Halldorsdottir & Hamrin, 1996) and to describe how young adults with cancer experience their bodies (Snöbohm et al., 2010). Phenomenology was used to understand the meaning of creating art for four women with a diagnosis of breast cancer (Stark, 2010). It was also used to illuminate the experience of cancer survival (Pascal, 2010).

Phenomenological inquiry aims to illuminate specific phenomena as they are perceived by the actors in a situation. The phenomenological interview method proposed by Bevan (2014) was used in this research. The structure for phenomenological interviewing consisted of three main domains:

- Contextualization (natural attitude and life-world)
- Apprehending the phenomenon (modes of appearing, natural attitude)
- Clarifying the phenomenon (imaginative variation and meaning)

Each of these three structural interview domains are undertaken by the researcher while gathering data and carrying out thematic data analysis.

Sampling

Interviews were carried out at the Oncological Centre of St. Francis in Klaipėda city. This centre was established in 2005 by the civil initiative of the Association of Women with Cancer Zunda, the Association of the Support for Persons with Cancer POLA, and The Little Brothers of St Francis of the Province St Kazimir. The centre offers psychological, social, health, spiritual, and shelter support for persons with cancer. It is staffed by social workers and volunteers.

Four women with cancer (see Table 1) and three social workers participated in the research (see Table 2). Their personal and professional identities are disguised to preserve confidentiality.

Table 1

Research Participants: Persons with Cancer

Identification Code	Age	Status	Type and Stage of Cancer
r1	38	Working	Stomach cancer, IV stage
r2	45	Working	Ovarian cancer, I stage
r3	49	Working	Breast cancer, III stage
r4	23	Student	Ovarian cancer, III stage

Table 2

Research Participants: Social Workers

Identification Code	Age	Status	Relation with Oncological Disease
r5	46	Social worker	Professional
r6	54	Social worker	Having ovarian and breast cancer
r7	47	Social worker	Having a family member with cancer

Findings

Shock and the Terror of Not Being as One Knows It

The diagnosis of oncological disease is apprehended as a supreme crisis, which shakes the person to the core and causes great internal turmoil. Initially, persons experience shock, denial, and isolation (Kast, 2006; Kübler-Ross, 2008). Only later do persons have alternative responses of negotiation, mobilization, coping, and resignation, with concomitant opportunities for reconciliation and hope. One person who felt healthy described her shock, “you realize one day that you are sick” (r3). Another research participant retraced her shock and grief when she learned about her cancer diagnosis: “At first I was shocked...when I found out that there already is metastasis...For half a day I was in shock and cried” (r1). Then, she expressed denial and fear: “I immediately denied it, because it is very complicated, when a person who has never been sick, worked all his life” (r1).

The social workers described shock combined with great fear and resistance:

At first there is a very big denial. Well, maybe nothing wrong will happen...and there is an endless fear. (r5)

Non-acceptance, fight against that message. (r6)

She talks about everything but not about the disease ... but this denial also helps to survive in this situation, so maybe one wants to protect oneself. (r7)

In addition to fear, people can feel guilty because they cannot work or perform their regular roles and need others to care for them. According to Kast (2006), fear of death or of

dying without support is not the first thing patients experience. Instead, they tend to focus on fears about very specific life events they expect will come in the near future, such as loss of hair, injection of medicine, the possibility of cure, or, sometimes, symbolically redirecting fears to relatives. Some were afraid of losing their mental health along with their physical health:

I was very afraid of psychological break down. That was the only thing that I was afraid of. (r3)

However, I was suffering from fear that I will not improve. I was very afraid of the consequences of the operation. I had thoughts about hormones, how they affect my well-being, behavior, etc. I was very afraid that after the operation I would wake up as a different person. (r4)

Social workers commented,

These few years as a cancer patient is very scary... the emotion that grows into fear, the fear of the future...This fear of the future is the fear of ignorance. You are afraid of something you do not know yourself. I'm afraid, but I do not know why. (r5)

Cancer patients fear to die alone, afraid of physical pain, that they will no longer see their relatives, or that they will no longer carry out works they have planned, that the meaning of life will disappear...They are scared while thinking what is waiting for them after death. (r7)

And, with that fear, a person can fall into complete despair, depression and no longer recover. (r6)

These courageous people describe a level of fear that is not comparable to any experience other than the threat of extreme pain and imminent mortality. While some cancers are curable, for many persons whose cancer is not, there is a sense that neither patient nor physician can have significant control over the course of the suffering and the outcome. Suicide can feel comforting, because at least then one has some control over what is happening:

It seems that winds are roused in your head, that you do not want to live, do not want anything or anyone to see or hear. (r1)

I have tried to overdose medications. I wanted to disappear. (r3)

I can be lightened with the idea in my head that I can get out of my life. At these moments I'm coming with the idea that I'm no longer needed for anyone. All of you live, and I will go away. (r2)

These persons express one of the major problems they face: How can one remain connected to others while knowing death is imminent and others will have to go on with life? The existential import can feel impossible to grasp. As one client (not in this sample) said, "I guess I will just disappear from here and others will just go on and there will be nothing of me left."

A Changed Perspective on Time and the Future

Oncological disease produces a very different perspective on one's future. Rather than seeming relatively enduring, the time one must live becomes a precious object of negotiation. Research participants recalled their efforts to dream of time to prolong a life. They found themselves searching for ways to prolong their lives, including prayer and self-castigation. The loss of a sense of future brought about deep emotional suffering (Martins & Boscoe, 2011). They suddenly experienced the value of being alive and prayed desperately for more life:

It seems that those five more years would be very much ... And then you think, Jesus, just five more years. (r1)

I have only one dream, so that God will allow me to live as much so that I could see my husband leading our daughter on her wedding day in church. This is what I really want (smiles). (r3)

As a mantra, I kept saying in my head the phrase "At least another five years ..." (r4)

Some thought the disease robbing them of time was a retribution or punishment for misbehaviour:

I started to weep in the middle of the corridor, and in my mind I kept repeating "This time it's serious." To be true, I don't really understand why I got that phrase in my mind, I felt like I was getting what I deserved. (r4)

Telling Family and Friends

Persons who learn they have cancer are shocked and do not want to face their diagnosis, yet they have to inform their family members about their disease. Some want to keep the illness secret for personal reasons, trying to spare their children and others worry. Others are in careers that are highly sensitive to public images of strength, such as executives and politicians, and they try to conceal it as long as possible to avoid the public claiming they cannot do their jobs. Some patients have marginal resources and face destitution if they lose their jobs (depending on the country's safety net).

Experiences of research participants informing others of their diagnosis varied. Some of them, in shock, announced the diagnosis to others without reflection. Others, especially those with children, announced the diagnosis with great pain. Parents with cancer underwent the pain of not only their own emotions, but also their children's painful emotions:

Daughter's first reaction - she began to cry ... And it's hard for children (crying). (r3)

For those you are afraid for, that will be very painful. I told my children about my situation very slowly, a little bit about what is cancer everyday. I told them that it is serious, that I am really sick... I let them to receive the information really slowly and take their time to cope with the information that I gave. I want to protect them from it for as long as I can. (r1)

Disclosing a cancer diagnosis is an extremely uneasy process, but can also give persons with cancer a sense of solidarity and reciprocity that allows them a deeper connection with others:

I told everyone immediately that I have been diagnosed with cancer. (r3)

It was weird to say these news to friends. They did not believe at once, they thought I was joking. (r4)

It was very difficult to announce ... because you are afraid to scare them. Because you are scared yourself and fear for them. (r6)

Grieving and Social Alienation

Thoughts about oncological disease and a probably interrupted future life depress and hurt the research participants. Helping people express their thoughts and feelings enables them to process and master the multiple, complex, and painful feelings about their situation. In this process, expressing waves of grief through crying becomes very important. The research participants remember emotional outbursts everywhere and whenever:

When I was informed about another operation, I cried all day...When I worked at school, I stood next to the wall and cried - who will work instead of me? (r2)

I cry especially when I'm on my way to home, when I'm in a car all alone. I try not to cry in front of my husband. Sometimes he asks: "what is wrong, everything is just alright, what are you crying for?" Sometimes you just cry. (she starts to cry in the interview; r3)

Somehow it happened, the worst part about it, that it's the fourth stage [of cancer]. (r1)

Part of the grieving process is anger (Kübler-Ross, 1969/2008). Unlike forms of trauma inflicted by other human beings, the person afflicted with cancer and related illnesses cannot blame a torturer for their suffering. Who rightfully deserves their anger at all the loss and fear they experience? A husband afflicted with cancer threw his food at the nurses. When the social worker sat with him, he gradually disclosed the real cause of his anger: because he was so ill, he was terrified about who would take his wife, who was ill with a cardiac condition, to her doctor. Because the man was unable to share the source of his fear, his anger at his situation was taken out on nursing staff. Once the source was identified, he and the social worker found a solution to care for his beloved, and he no longer needed to throw food at medical staff. Anger unreasonably directed outward on undeserving others can tear relationships asunder, but anger directed inward can greatly magnify self-blame and fear.

The profound grief and anger, unlike emotions felt by those not afflicted with terminal illness, can result in social isolation:

Some people do not dare to go out even to the street, they are afraid of their neighbors. (r6)

For another, it's a shame, almost as if it were "contagious." He is a loser because he lost his life. (r7)

Another social worker commented:

Indeed, one may like to be interested in it, asked about his illness, somehow taking care of it, helping out. Another person can completely reject, say, do not cling to me, leave me alone ... And sometimes people who are sick do not want to disappoint their loved ones, they try hard to be positive, and if they did not succeed of doing that, they can be a little disappointed with themselves. Or a person can think, that nobody will understand him. It's most likely to hurt that other people doesn't understand my situation, then you start to feel alone. (r6)

Loss of Physical Wholeness and Psychosocial Identity

Oncological disease can be considered a risk event when the emotional, psychological, and physical and social integrity of a person is violated. One's customary personal identity is overwhelmed. Research participants talk about how cancer changes their bodies; with the physical changes comes an emotional pain and a great need for support:

The hardest thing was when the hair started falling out. I cried for almost two weeks. I was worried about it because women are mostly recognized by their hair. I had never encountered and did not imagine what that feeling was. My children did not want to cut those hairs; I pulled out what was left of my hair by my own hands. (r2)

The loss of hair is loss of style, a loss of one's being; ...you may one day digest the same food, do not digest it the next day. (r7)

Well, now the main effect of my illness is weakness, it is hard climbing stairs and numbness of hands, feet. (r1)

Due to the physical ravages of cancer treatment and the disease itself, a person may rapidly go from behaving youthfully every sense, to the hesitation and fragility associated with old age. The sudden transfer from one life stage to another constrains a person to experience a double crisis of age's stages in addition to the situational crisis resulting from the disease. This impedes the adaptation to the challenging situation of having cancer:

I feel like an old woman in a menopause, with crumpled bones, with a heart-burning heart, blown with my sexual life ... what else should I do in my life? ... Am I still a woman if I do not have an ovary, uterus, etc.? How do I meet my new life goals? (r4)

Some clients experience loss of physical functions that tend to be associated with human dignity: they cannot control urination or defecation, find their body emits disgusting odours, or that they are disfigured. These losses of dignity can be compounded by certain aspects of medical care that focus on parts of their body rather than on their person. It can feel like one's personhood has been stripped. Hearing staff unintentionally describe one as body parts can compound it, "there's a liver in Bed 3." Persons can feel horrified at the eventual loss of their body, even while recognizing their loved ones may need to plan things like cemetery plots or cremation.

Persons with cancer confront new roles to which they have to accommodate and adapt. The shift in roles from being strong to being weak, from caretaker to cared-for, is challenging.

Some find it intolerable and have to be repeatedly persuaded that it is okay at this time to be the receiver of care. A loss of one's former sense of self is felt, as these mothers said:

My whole life I've taken care of them, I don't know how to be: For God's sake, I'm asking to live as much that my children would reach the age of majority . . . you brought them to world, your duty is to raise them up, to prepare them for life. (r1)

These elder children are still big enough, they don't need me that much. (r2)

Men with an oncologic disease are very hard to come to terms with the fact that their social status changes while they are ill . . . Men feel as if they were losing the role of their lives. (r6)

In countries without adequate safety nets for those suffering from illness, fear of destitution aggravates the fear associated with cancer: "Not only are the prospects of life collapsing, but you are now losing your financial life" (r6). A key aspect of a country's support of its citizens is ensuring an adequate standard of living for those who are struggling with terminal cancer (Blumberg, 2015).

Suffering

Profound physical suffering happens all too often with cancer. Part of the process of living with cancer and trying to fight it is enduring great pain that was unthinkable before:

That week after chemotherapy was a real torment, I calculated hours until I got better. I knew that on the fifth day I will be able to get up a bit and watch a movie, read something, and finally, eat a regular meal. (r4)

You want to eat, but you can't . . . you drink these medicines, enzymes, but you do not even need to vomit as you just bend a little and everything runs out from your mouth. (r1)

Pain walks all the way your body. (r2)

I was very weak . . . I was inflamed during surgery very seriously. There were great pains and now there are bumps. (r3)

I received sixteen chemotherapy, survived two different cancer ... the abdomen was cut out, I am sick of pain. (r6)

Facing Death, Considering Life's Meaning: Oncological Disease and "Opportunity"

According to Kast (2006), every life crisis is a new life opportunity. However, for a person with cancer, regarding this condition as an opportunity is questionable as an orientation if it means untimely and unwanted death. But under some circumstances, the crisis of oncological disease can lead to internal transformations that cause a person to become more open and to experience new forms of faith, hope, and intimacy. Social worker Professor Howard Goldstein, who died from cancer, told his wife to please tell everyone at his funeral

that he was so surprised that when he relinquished needs for control and independence, he was much more open to give and receive love.

Research participants talked about new existential experiences such as religious faith, human relationships, and internal strengths that they discovered when looking for signs of hope: "Now I started walking to church and praying" (r2); "While listening to those good, positive experiences it gives you a lot of hope . . . that there are people even living with the fourth stage of cancer" (r1). A social worker commented, "You can notice big changes in human life if he starts to have hope, faith in God. Person starts to trust in doctors, he finds strength inside to fight with the illness" (r5).

The first association of cancer by patients is relating to death, as the illness presents an obvious approach to it. The process of awareness of the end of life occurs. This also opens another life perspective: "The first question that I asked my doctor, is this a sign of my death?" (r3); "You always identify the disease with a quick, immediate death, not with life" (r6); "That fear of death intensifies" (r7).

At the same time, contemporary medical advances mean that many people stricken with cancer live for a long time and need to learn a new way of living with cancer: "The sick person is not dying ... His present is life, not death" (r5); "Cancer is not a death sentence" (r4).

People report feeling a deep solitude, because others cannot comprehend the depth of their physical suffering or take it away. This severe pain can deepen social exclusion. Frankl (2011) describes another kind of response:

When a person finds that it is [her]his destiny is to suffer, [s]he will have to accept his suffering as his task; [her]his single and unique task. [S]He will have to acknowledge the fact that even in suffering [s]he is unique and alone in the universe. No one can relieve [her]him of his suffering or suffer in [her]his place. (p. 78)

But then there is awareness that everyone suffers, so there is the possibility for a person to understand something new, what may have been unknown in her/his life.

A cancer diagnosis bursts the internal balance of a person, disturbs a daily life rhythm. Research participants emphasized the deeply felt shifts in meanings of their life. They re-prioritized, viewing old goals as less important, discovering new values, including the joys of life. Every day one lives is a treasure:

People only want to work, to earn as much money as possible to buy better items or to get on a vacation. You get sick one day, who needs that money then? (r1)

Like a squirrel in a rush, you can no longer jump off. And when I was thrown out of that wheel, there was a shock at first, and then I sat down and thought, that finally I can rest. (r6)

Maybe you need to more self-assess, love yourself, and not just work. (r2)

After I become cancer patient I slow down and changed my attitude about life ... In the past I was very nervous, I pressed myself up, instructed, I did not allow myself to rest. I just demanded too much from myself. (r3)

I feel that I grow up psychologically, I used to be very categorical in the past, now I am more "soft." (r4)

In the past I did not spare myself. And I wanted to greatly justify others' expectations. I could do a lot, ... and I forgot my hopes. (r6)

Now you wake up in the morning and you are just happy that you are alive, healthy. (r3)

Sources of Strength

What resources come which would help a person to restore his/her balance, to find internal peace, to rebuild a new identity, to reconstruct relations with others? Some people close themselves off, and as a result they can lose strength when undergoing oncologic disease. Others share their experience, and in this way, they have the opportunity to get support from relatives, but also from unexpected sources. Research participants revealed new experiences of religious faith as sources of strength and hope:

Even those who don't believe in God, asks to tell them about God, maybe there is a slight chance that He really is. Those who were not close to religion or did not practice it, they have questions about how to meet with God, how to get acquainted with. (r6)

As they say, God is everywhere. Will we call it a good energy, some kind of positive vibe. (r1)

Now I have my faith from the heart. And now I like that very much, that way of faith. (? Informant)

I do not know, it seems difficult to believe that you will get better without faith. (r3)

When suffering through cancer, a hope can be found in other people who have the same cancer experiences and life histories, leading to a strong sense of community. When a person has this sense of community, the connection becomes a very important source of hope:

Communion with other people connects us with each other ... helps us to strengthen, to overcome the time of treatment, to endure everything. (r7)

You find people that really care about you. (r3)

Yes, I was looking for people who live with cancer. Not those who died from cancer, but those who lived with it ... I had to hear them testify. I needed the testimony of those other people, those who are in the same shoes that, are in the same situation as you ... when you see, that you are not so alone in your trouble, then you start to think that maybe I can somehow learn how to live with it. (r6)

Relatives and friends undergo crisis when they learn about cancer of their relative or friend as well. According to Payne (2014, p. 192), "reciprocity is the idea that if one part of a system changes, that change affects all the other parts." Although relatives and friends are affected in different ways, cancer as a risk event can influence the functioning of all systems of relatives and friends. However, sharing knowledge about the disease gives an opportunity for all involved to understand each other better, to empathize together in the time that is given

to them. In another way, if a person stays apart from relatives and friends, those systems cannot understand and recognize the underlying process. Research participants described meaningful relationships and support from others when sharing experiences with them:

Someone needs to protect me (r1)

A man began to look at life in some other way. Understands more. It has not been evaluated in the past, and now it is otherwise. (r2)

After my chemotherapy my husband would go home after his work really fast just to stay with me if something would happen to me. (r3)

My friends took care of me. I was taken to a doctor and registered with their help ... If not for them, I would not know how to get over it. (r2)

My friends lived the same rhythm as I did at that time, from one chemotherapy to another. They carefully wrote messages to skype, my phone ... (r3)

We should all thank our fellow man who is with us on this cancerous journey (r6).

Even unknown persons could be very supportive for the participants in this study:

Even Benedict Vanagas [famous Lithuanian racer] wrote to me and he sent me a book . . . At the beginning I told my friends, maybe he has a secretary who writes me letters, but then he gave his phone number to call in order to pass the book . . . He was in Canada and got acquainted with a person who got out of the fourth stage of cancer, and that person published a book. And he wants to give me that book . . . But see what kind of message I got "Hello, today you will get a call from Alex Monaco, do not ask anything, just listen. Every day can not be good, but there's something good in every day." That's it, you get such messages, it does not cost anything and you get a lot of positive, good energy. (r1)

A Social Work Practice of Accompaniment

Essential Elements of Crisis Intervention Theory

When coping with crisis in crisis intervention, Thompson (2011) highlights some principles: begin assessment early, focus on both emotional reactions and external factors, look for social resources, focus on positives, avoid medical labels, identify problem focus, formulate clear plans, and balance potential gains against risk. Social workers in the Oncological Centre emphasized empathic listening with clients who undergo cancer as a life crisis. According to Payne (2014, p. 141), Listening is key ... because failure to pick up important emotional and practical issues in the client's life may mean that you develop an unhelpful strategy." It is important to concentrate the attention to events that will help the client to survive crisis.

A person in crisis is more open to seeking help and being helped. Research participants emphasized the gift of saying and listening: "First of all, I came to this center to share my story" (r3); "Even if the person freshly heard of his diagnosis, or just started his treatment it's a big success that should be noticed by the others" (r5).

According to the social workers in this study, it is important to help individuals with cancer express their emotions. When intense emotions are retained, they have a tendency to fixate, whereas the expression of emotions helps clients to change:

Maybe there's no space where the person can slop over, maybe this centre is the place where he can do that without fearing that somebody would see him and do not understand him. Here we let people cry, encourage them to do that ... There comes a huge relief after person cries out, talks about his fears. (r7)

The research participants described the changes in their attitudes toward cancer. First, when learning about the disease, cancer is related with death; then, the awareness of the remaining lifetime as a meaningful experience comes. Social workers in the Oncological Centre help individuals accept cancer as a risk event, a life challenge. When perceiving oncological disease as a life challenge, the new emotional response emerges from loss of life towards new life expectations and hope:

Well, then, when the nervous system, the psychological, emotional state is already exacerbated, you can be a normal person again, not to identify with the disease that you have. (r6)

He faltering, blushing, that is not necessarily the way he is thinking about his cancer, it could be different. He does not die on this day after he has heard the diagnosis. A sick person is a living person. He lives further, can rejoice, rethink his values. (r7)

Research shows an explicit need for social work throughout health care systems. Not only is medical intervention necessary, but social work intervention through consultation, information, and interinstitutional mediation is also necessary. The time from announcement of their disease to patients' involvement in a process of treatment can be challenging. Shock, negation, fears, and feelings of helplessness can make it hard for patients' to adequately seek out resources and supports for treatment. Social workers are essential sources of these connections and resources,

I am talking to one such woman, who said to me via telephone what kind of sports I can take, gave me psychologists phone number ... And this is important, because you dont have strength to do that by yourself, maybe you are in some sort of depression, you do not want anything. (r1)

People are sometimes unaware that they need to go to cope with a certificate of incapacity for work, that they are less able to work, to receive sick pay allowance, to reduce their workload a bit, to ask about sanatoriums and about some other medical institutions. We provide information on social benefits where a person can receive them. (r6)

In crisis intervention, according to Thompson (2011), the social worker mobilizes appropriate support systems, through advocacy, family, and community engagement. Research participants disclosed the lack of financial resources and the importance of material support from friends and family:

They drive me to procedures and take it from there. (r2)

My neighbor was taking me to chemo, drove me, carried me. She always had a key from my house if something would have happened to me. (r3)

It's a big money, you're working a public job, you are not some kind of businessman. And it is even strange, because people sacrifice in large amounts. It's hard to accept, but it's a pleasure that they offer you. (r1)

Research participants shared the importance for their coping of having more knowledge about the disease and treatment:

I think, at the same time, it is necessary to tell a person that when the treatment begins, that he will understand the consequences of the treatment, that it may be bad, that it may change the color of the skin, bother with weakness. (r5)

It can feel like that during treatment ... information about what to eat, what extra can you use, what tea to drink ...When it comes to talking with a person, it comes with a clarity. (r7)

In the existential perspective of social work, according to Payne (2014), “helping people develop spiritual narratives enables them to see how the meaning of events has changed over time for them, and to reinforce\ beneficial changes” (p. 291). “Spiritual assessment explores whether people can transcend suffering and despair, building self-esteem and hope. It seeks to identify the beliefs that help individuals deal with problems in their lives, sometimes in particular focusing on religious beliefs” (Payne, 2014, p. 290). The Oncological Centre of Klaipėda draws from Christian spirituality to help persons with cancer survive existential transformations of life. Within the experiences of research participants, transformation to a new identity of integrity is observed when affirming life in the face of cancer:

Then you see that I can somehow learn how to live with it. (r6)

These people are encouraging me and I tell them so I will try to live. They give me so much strength. And they say, you do not have to try to live now, you have to live (weeping). (r1)

Bugental (2014) emphasizes the effort by patients to have, internally, as much life as possible and as less death as possible. Research participants, when experiencing cancer as a life crisis, are open to the new life being with freedom of choices and responsibility as well as with meaning of life and hope:

You always try to have it positive, to believe. (r1)

When a person perceives what he can do, he no longer feels so helpless. He takes on the responsibility of what he can do, he can take control of the situation, which is very important to the person. He already knows he is no longer in a desperate situation. (r7)

For oncological patients it is typical to have hope . . . a paradoxical thing . . . even in unrealistic situations, there is still that lively optimism . . . Take that illness, understand how to live with it. What do I have to change now, what I have to do. I have to choose priorities. (r6)

This aspect of social work support is existential. Colombero (2008) extends Carl Rogers' concept about "making friendship with facts" (pp. 234-236). A fact such as cancer diagnosis can be an enemy, because it can destroy us, as well as be unjust, unreasonable, and cruel. Yet Colombero suggests it is wise to make friendship with facts, to learn get along with them, to give them a meaning, and be oriented towards the future. If the facts of cancer can be accepted, then anger can be surpassed and persons come to terms with cancer as a meaningful part of one's life trajectory. These existential tasks require a unique dimension of supportive social work.

Accompaniment: A Bridge of Connection

A diagnosis of cancer and terminal illness constitutes a unique form of crisis that necessitates some unique orientations on the part of the social worker. In part, this amendment is necessary for the social worker who faces, by caring for the client facing death, their own existential questions. Moreover, with the loss of the client to cancer, the social worker struggles to live fully in each moment with the client, to care deeply, and say goodbye at the same time. From the standpoint of accompaniment, the chief task of the social worker is to be the support person, wherever the person is in the stages of the illness and psychological adaptation to it, reducing the suffering caused by the person's extreme loneliness and exclusion.

A study carried out in Portugal about how nurses alleviate the suffering of their end-of-life patients described a social process of providing a relationship of "accompaniment" (Martins & Basco, 2011) that offers a framework for social workers. Accompaniment eases the aspect of the client's suffering that is caused by the existential crisis elicited by a diagnosis of cancer, and the loneliness triggered by experiencing pain and disconnection from others:

"Suffering is not so much a consequence of pain and discomfort but can be a consequence of the awareness of the terminal situation, the absence of future, the undermining of dreams, the uncertainty of what is to come, and the fear of death." (Martins & Basco, 2011, p. 164)

Accompaniment is especially important as an orientation when the conditions the client is experiencing are outside the social worker's ability to change. Farmer developed the concept in the context of providing medical care to Haitian citizens suffering from the 2010 devastating earthquake. The U.S. professionals found themselves caring for persons suffering devastating loss and pain, faced with conditions for which no preparation could be adequate, without any ready solutions. Farmer emphasized that the more the professional could be flexible, compassionate, and responsive to individually specific conditions, the more s/he could be helpful. It required a focus on "being with" rather than specific knowledge, skills, and accomplishing goals.

To accompany means that the client is self-determining about what happens in the relationship: "To accompany someone is to join someone in her/his way of life, adapting to her/his pace, sharing the moments of her/his life, and taking a secondary role" (Martins & Basco, 2011, p. 169). It is an especially tender form of mutuality, characterized by genuine sharing and even love: "all aspects of caring are developed to help the person deal with this last stage of life with greater physical well-being and even die with serenity and peace" (p. 169). The deep bond allows both the accompanied and the companion to deal with suffering and even death (Martins & Basco).

Accompaniment is a different orientation to many forms of contemporary social work practice in that it does not impose any agenda or set of goals to indicate effectiveness. The goal is to be with the suffering person, wherever s/he is, and as far on the journey as s/he desires,

even up to the moment of dying. There is accompaniment in all social work practice, to some extent, but in caring for persons with cancer, this becomes the central part of social work activity.

Several actions that reflected nurses' accompaniment are also part of social workers' traditional activities, such as using a gentle tone of voice, ensuring the patients experience dignity and personal value, and fostering connections between the patient, friends, and family members. The person who accompanies another through a diagnosis and treatment for cancer, and towards what is beyond, acts as a kind of bridge between the world of the person struggling with issues that can create social alienation and the world of others' everyday lives, in which such deep existential questions necessarily take a back seat. Listening and empathy are key, as was emphasized by the social workers at the Oncological Centre of Klaipeda: "Primarily all you need to do is listen to a person that came to you. ... listen completely, carefully, responsibly, and then try to speak" (r7).

Interpersonal relationships cure many forms of suffering, including aspects of the suffering experienced by those with cancer. For healthy relationships, a trust is needed which arises from an empathic understanding of another person. According to Buber (1998), transformative empathy occurs not only from moments of being understood, but also from a distinctive form of relating, I-Thou, in which persons know each other not through identifying characteristics, contexts, or needs, but rather through completely being in relationship. This means the accompanied person recognizes that the accompanier will remain faithful and accompany the suffering one throughout the depth of their suffering, eliminating the accompanied person's fear of abandonment. Research participants disclosed both the difficulty and the significance of this deeply committed caring:

During the conversations person starts to heal inside; that others notice that you are ill, taking care of you. (r2)

It's most likely to hurt that others does not understand . . . Still, that empathy should be, the understanding of how the person feels. (r6)

Trying to understand what that person is going through at that moment, asking questions sensible. (r7)

An example of the power of accompaniment comes from Mr. F, an elderly man in a large public hospital, who was skeletal with the impact of the last stages of colon cancer. He greeted every person who came to his bedside by turning his face away from them and not speaking. The nurses called the social work intern to help. When the intern first greeted him, he turned his head away. Perplexed, she sought the help of her supervisor. The next time she went to see him, she said:

I know that when you go through this you feel terribly alone, and that it feels like no one can understand. I understand it feels that I could not comprehend the pain and suffering you are going through. But if it is okay, I will just come and sit with you and if you like I will read or pray with you (she knew he was devout).

The man turned and looked deep into her eyes, and took the hand she offered, and held it. They never shared any words as he was too weak to speak and did not indicate a wish for her to talk. She went every day for about two weeks, and every day he looked at her and held her hand. One day, she went to see him, and he was gone.

Accompanying a patient with cancer can lead one to discover a profound existential reality: that compassionate human connection can make even the most difficult suffering more bearable and that given compassion, cancer patients can discover strengths, connections, and understanding they could not have previously considered.

Self-Reflection

Accompaniment entails personal self-reflection about one's own vulnerability and mortality (Martins & Basco, 2011), a gentle, reflective attention to one's own inner state. It may be helpful to the person if the social worker shares her/his own grief, resonates with the client's anger, and affirms the client's existential reflections. But unlike traditional crisis intervention, where the social worker actively advises, interprets, counsels, and sets limits, accompaniment is necessarily extremely gentle and non-intrusive. The client already is intruded upon by a life-threatening illness and affording the client the ability to regulate the relationship with the social worker is of paramount importance if the client is to be able to experience a self that is empowered despite a massively disempowering physical illness.

Similarly, when dealing with a research object related to death, the researcher faces his/her own existential angst and ontological fear. For the researcher to approach death together with a research participant, or "to stand on the same stair," means personal spiritual reflection. A researcher meets through the research process with his/her own fears. As researchers we were prepared for such a challenge, although the research process has surpassed expectations. It was more challenging and rewarding than we expected, and at the same time we have gained a wisdom, peace, and optimism.

Conclusions

This analysis of experiences of persons with cancer and social workers caring for them demonstrates cancer as a life risk event that evokes existential reflections. Consistent with this, cancer patients, after the announcement of their disease, undergo shock and negation that is accompanied by profound fear, and struggle to confront the painful information. Persons with cancer must face fear of suffering, the limited time in front of them, and experience a psychological crisis accompanied by the loss of emotional stability and mourning. Critical points of crisis manifest through awareness of the finality of life, the sense of powerlessness, meaninglessness, and even suicidal thoughts as a wish to have some control over these uncontrollable events. The crisis is followed by loss of emotional, psychological, physical, and social integrity, including a past identity. Research participants raised existential questions about death, suffering, and striving to survive with these profound changes.

Research reveals social workers need to help persons with cancer understand their existence, to find their own personal meaning of life, ways to experience support and compassion, and to build hope. Social workers can build from traditional crisis principles, including a systemic approach to ensure clients are supported at micro, mezzo, and macro levels.

An additional approach to social work is needed, which we have termed accompaniment, drawing from approaches to care for those at end-of-life and others facing profound life crises for which there are no ready solutions. Social workers as accompaniers focus on being with the person with cancer in his/her fear, shock, and helplessness facing death. Accompaniers create a bridge over the existential divide prompted by the threat of death, to help clients' friends and family mobilize emotionally supportive resources. Such long-lasting "being with" clients inevitably causes the social worker to ask personal existential questions, and this is a relevant topic for further understanding.

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