

Relationality as the basis of hope: embodied experiences during life-threatening illness

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In this chapter we will give examples of embodied experiences during life-threatening illness from various empirical studies conducted through the years. Through our research, we add more theoretical knowledge on hope and despair of those suffering from cancer and AIDS. We have seen a great need to formulate a relational theology in the context of embodied experiences during the process of life-threatening illness. Relational theology will consider both the positive and negative aspects of human relations between themselves and God.

Introduction

Pastoral care has always involved an encounter between persons. The mode of operation is often verbal and the focus of the encounter intellectual. The problem in this type of encounter is that in many cases it does not approach people holistically and it does not recognize the different ways people express themselves during their illnesses (Demmons 2008, 365). The focus of counseling is on the relationship existing between persons. Through the relational turn, the encounter between persons and also between humans and God himself has become even more important in pastoral practice and in practical theological research (see for example Cooper-White 2004; Lartey 2006, 63–66). Relational theory stresses that a person's identity is constructed through relationships and that we are all embedded in a web of social relationships and that all our decisions are affected by responsibilities towards those who are significant to us (Nedelsky 2011, 19–20; Harding 2014).

A relational theology is a key in understanding the embodied experiences during life-threatening illness. Pamela Cooper-White writes: "A relational theology both models and makes room for difference, for a multiplicity of ways of knowing, and a flux among sensation, hunger, emotion and rational

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thought. It is a theology that is not set abstractly apart from bodies but locates itself in and between them" (Cooper-White 2004, 184). Relational theology begins with a personal relationship to God or a higher power and to other people. Both of these relations are important for one's wellbeing (McClure 2010). Within relations, people seek to be accepted; stories are shared in order to be heard and encountered. Yet, the hearers of the stories can be other people or transcendent (Ganzevoort 1998; Ganzevoort 2010).

Further, physical bodies are related to our thoughts and knowledge. Therefore, cognitive processes cannot be detached from bodily experiences.



Bodies include the physical body itself. Additionally, emotions and passions are embodied experiences (Miller-McLemore 2013). As embodied experiences, emotions include a physical and cognitive dimension. Emotions motivate us to search for and live a meaningful life; emotions motivate us to make changes when needed (Moschella 2016, 25–27). Rituals are also connected to emotions; in crisis situations rituals assist in grasping the reality of life and constructing meaning in the midst of chaos. Moreover, the tactile element of the ritual makes it a strong bodily experience, and rituals are likely to carry “symbolic and existential significance” (Dambolt & Stifoss-Hanssen 2011, 30).

The experience of meaning is related to the experience of hope (Saarelainen 2017). In the relational theological understanding of hope it is important to note that hope has two dimensions. First, hope in earthly life focuses on relations to other humans. Second, the spiritual dimension of hope covers eternal life and relations to God during earthly life (Moltmann 2003). Hope is easier to identify by its contradictions and negations; Hope builds on belief in God, whereas despair is an outcome of sin (Moltmann 1967). Yet, hope and despair are often intertwined, as in difficulties a tinge of hope appears when individuals plead with or curse God in their misery (Lester 1995).

For cancer patients, hope is constructed from the mental distance kept from the disease, the soundness of the body, the treatment, a positive attitude that includes future plans or projects, downward comparisons, and the existence of a positive model (Salander, Bergknut & Henriksson 2014). Whereas people with HIV have been reported to live “in the empty present” (Davies 1997), trauma was still tangible. Further, Davies (1997) describes his HIV positive interviewees as locked in the past. Earlier illness narrative studies show a relation between the crisis and time (e.g., Davies 1997, Ezzy 2000, Frank 1995). Nevertheless, if the research focuses only on the linearity of time, the complexity of the illness process is easily neglected (see Bülow & Hydén 2003). To be able to share personal illness experiences and to be provided with emotional support rather than consumption of time, seem to explain the experience of finding meaning in life during and after cancer crises (Saarelainen 2017).

This chapter encompasses experiences of two different life-threatening illnesses and two different contexts. The narrated experiences of life-threatening illness are from cancer and HIV/AIDS.

Our aim is to discover how the occurrence of despair and hope can be interpreted from a Christian perspective.

Data and methods

The empirical data for the present study is formed from three different field works. Auli Vähäkangas conducted interviews with people living with HIV/AIDS (PLWHA) in Finland in the year 2006 and in Tanzania in 2009. Both data collections were sponsored by nongovernmental organizations (NGOs) working with PLWHA. In Finland the NGO called The Positives, a nationwide peer support organization of PLWHA, was the sponsor. Five PLWHA were interviewed, four men and one woman. The sponsor for the interviews in Tanzania was the Selian Palliative Care Program. Eight people were interviewed, four of each gender. In addition, Suvi-Maria Saarelainen interviewed sixteen emerging Finnish adults, aged between 18 and 35, in 2011 and 2012 after their cancer treatment. The timing between the treatment and interview varied from a few weeks to five years. These interviewees were recruited with the assistance of Finnish Cancer Society. Twelve females and four males were interviewed for the study.

All of the interviews had an autobiographical approach with a focus on the impact of the disease on their life story. Furthermore, the interviews of emerging adults with cancer began by drawing a life-tree drawing (see Saarelainen 2015, for visual-narrative analysis). The interviews were tape-recorded and transcribed. The translations of the direct quotations from Finnish and Swahili are done by the authors. The processes of analysis began by reading and open coding. As a result, several categories and themes were found, including fear of death, importance of support, impact of the context, and significance of the worldview. The findings of the tree drawings followed a similar analysis pattern.

These different cases are not intended to be generalized to a broader population. Rather, they provide an in-depth perspective which may contribute to an understanding of hope in the context of a health crisis. Nor do we directly compare the experiences of cancer and AIDS patients. We do, however, point out general differences and similarities in the patients' narratives of hope. Three main experiences were found from the data: the importance of social relationships as a source for hope, the difficulties of stigma and suffering during severe illness,



and the importance of rituals during the crisis of an illness. These three main findings give the structure to the following sections.

Social relationships as a source for hope

In the context of severe illness, hope cannot simply be considered an individual expression of emotion, but rather is a social construct. Realities and subjectivities are constructed in and by language and, in one way or another, in a community with others. Moltmann (1967, 303) brings out that the “co-humanity” provided by the Christian community becomes highly important during the hardships of human life; the Christian calling for the priesthood of all believers actualizes as a shared intention to create a meaningful future together. Within our studies, the significance of important others was described within all the informant groups. The participants spoke in their narratives especially about family and peer support.

Moreover, within the life-tree drawings of emerging adults with cancer, the support was strongly drawn. Most often, the support was depicted as roots as of the tree that symbolized the importance of family during the cancer process. For instance, Tom narrates that the roots symbolized “the outstanding support provided by significant others.” In Tom’s drawing, the tree itself has strong roots and the roots of other trees keep the tree standing. This type of description also highlights a tangible—embodied—description of this support. In addition, for some the support was drawn as a sprout that balanced the tree, or as leaves of the tree. Every now and then, the roots were not actually drawn, but the drawer stated that there were “supposed to be roots” that represented the family, significant others, and their importance. When the emerging adults talked about the received support, the support included emotional and practical aspects that were found to be equally important. Emotional support was described as being given the opportunity to discuss and share one’s thoughts. The practical support received included the relief of not having to worry about daily responsibilities, as many of them moved back to their parents’ house. Only for a few did emotional support include an aspect of religious support.

The importance of peer support was expressed in various narratives of the HIV positives. As Tanzanian Pascalina expressed it: “I feel great when I am close to people. Then I always feel comforted. Then I

feel that I am fine. I get hope from what I am doing.” The importance of peers also became significant for those emerging adults who received active peer support from former patients. From the meetings with peer patients, emerging adults discovered encouragement; from the others they could see how life can be lived after cancer. Previous research on peer support found that such support improved the psychosocial well-being of the participants while some peer support groups have transformed the lives of their participants (Kumakech et al. 2009).

In the context of HIV/AIDS, hope was conveyed not only as an individual experience, but also as a communal expression. Communal expressions of hope gave individuals the chance for a new life. The feeling of not being left alone was an important expression of hope among the Tanzanian PLWHA, as Furahini explains: “I get hope mostly from what you are doing here. I am encouraged by you. I feel that you give me courage.” These Tanzanian expressions show the importance of human relationships for healing. Social relationships are also important for relational counseling and in building feelings of hope. Further, some of the Finnish emerging adults expressed that their cancer suffering carried an existential meaning when they understood the importance of significant others (Saarelainen 2017).

Experiences of bodily stigma and suffering

Stigmatized HIV/AIDS victims, deepening poverty, and other more negative aspects have been emphasized many more times than hope in connection with the pandemic. Moltmann’s reading of eschatology and hope is helpful in the context of life-threatening illness because it recognizes the need to transform the present. Christian hope is in essence the hope of resurrection and differs from other hopes in that it deals with past, present, and future (Moltmann 2003).

Olli, an HIV-positive man in Finland, no longer goes to his church because he feels rejected and unworthy because of his sexual orientation: “Why are some people worthy of being in God’s image and others are not? I was born just as I am.” He had a strong bodily experience of being stigmatized because of his sexual orientation. For young people with cancer, the bodily experience of stigma was highest during the cancer treatment. The interviewees described challenging changes in their body im-



age such as losing weight and simultaneously having swelling in their face. Moreover, losing hair (all the body hair), not recognizing oneself in the mirror, having fertility issues, and having physical scars that will never heal made them feel different from others. The roughest and longest-term embodied stigma were also visualized as part of the life-tree drawings, as Thea described her life tree by saying: "The tree is mentally stronger than before, but physically it is riddled." She connected her physically demanding operations and months of rehabilitation with being "riddled," since it was likely that her body would never be the same again; the dead branch symbolizes cancer and it is a substantial part of the drawing. Moreover, the falling brown leaves stand for elements of the self that she wishes to shake off from herself. Still, she concludes that she is "mentally stronger" than before. Overall, changes in one's body were strongly linked to the experience of the self: when one's physical body was healing, the experience of recognizing oneself was regained.

Daniël J. Louw has written on the theology of the cross during the era of HIV/AIDS: "[It] does not inspire HIV people to ignore their suffering: it seeks to encourage people in their struggle and urge them to find meaning in their suffering. Resurrection hope fosters the courage to be, and impels us to resist evil. Hope is only hope within suffering, not a flight from suffering, nor an attempt to bypass suffering." (2006, 110–111) Christian hope is the basis for counseling those who suffer. Hope connects healing with social responsibility and helps the counselor assist in the struggle against suffering and promotes discovering meaning in life. These notions reinforce the ideas that hope is rooted in human dignity and that both hope and dignity are socially strengthened. Often, the stigma was alleviated among loved ones who provided their love without any conditions.

Yet the self longs for meaningful social relations in order to stay healthy (McClure 2010, 22–27, 47). Others (e.g., community or significant others) can provide consolation, which helps to deal with the pain. Loneliness and pain are rooted in the feeling of being abandoned (Lester 1995, 94–96; Zylla 2012, 114–122). Therefore, painful stories are always shared in the hope of their acceptance and to obtain a response from the audience (Ganzevoort 1998). This indicates that relations are essential while people suffering from life-threatening illness are searching for meaning in life in spite of stigma and suffering.

Embodied rituals

The interviewees shared various narratives on embodied rituals. Most of these rituals were religious and some were more helpful for coping with life-threatening illness than others. Only one emerging adult, Sophia, included church attendance in her story. Sophia explained that after the diagnosis she and her mother searched for alleviation "everywhere they could" and one of the places of comfort was a local charismatic movement. She was given a blessed linen cloth to bring comfort and God's protection. She said that she carried the cloth with her to the treatment and that she believed that the cloth brought her protection. The importance of tactile elements was also highlighted by Thea and Chloe who carried angel figures to their treatment. Thea described an incident where she accidentally dropped her angel and was scared that she had broken "something," something besides the angel figure. These angel figures strongly carried protective powers and the figures were related to a perception of having protection. Further, these tactile elements carried long-lasting value. Five years after treatment, Sophia reflected on the importance of the blessed cloth by saying: "I still believe that the cloth carries protection." The angel figures were also described as carrying important symbolic meaning years after the treatment. These anecdotes illustrate the importance of tactile elements in meaningful rituals. Moreover, the tactile can be seen as an embodied element of the presence of God or a higher power and bring comfort during and after health crises.

The HIV positives had quite similar experiences to the cancer patients on the importance of embodied rituals. For instance, Pekka's experience shows the embodied experience of positive support from the Christian community: "Warmth, power, hope have clearly arrived, really concretely, even though my mind says that I am a sinful person not worthy of anything... It is certainly something bigger." Arja's experience, however, indicates denial and stigma: "In a prayer meeting I wrote my special prayer request. Nobody read it or took any notice of it. I was disappointed." Arja explains that she looked for another parish and went to a bigger prayer meeting with a famous Finnish prayer healer Pirkko Jalovaara who she thought would accept her situation and pray for her. This new prayer was especially important after the first disappointing experience: "Jalovaara prayed for me and took part in my inner suffering and it felt so good." This second experience



was comforting even though she was not physically healed through prayer. Through this prayer recognition she felt she was accepted by the church community and by God himself.

For emerging adults with cancer, the first moments of despair often included “why” questions in terms like “why would God allow this?” Even though the young people rarely found themselves as Lutheran or Christian, still, most of them turned to a higher power or God in both asking for a reason and searching for comfort. Most of them prayed and these prayers took place when they were scared of the treatment, during the nausea, or when they were worried about survival from cancer. Once, as Sarah recounted, God’s support was tangible as she explains: “I had such a strong nausea that I thought I have to go back to the hospital ... I went to the living room, I curled up and prayed. Then I fell asleep and when I woke up, I felt much better. So it was really concrete.” As Sarah demonstrates, praying as a ritual was strongly linked to alleviation of bodily agony.

In Chloe’s story, bodily rituals became intense by communing with nature. Chloe narrated how she discovered her personal relationship to God through the embodied experience of these nature walks. During the deepest misery, Chloe kept walking in the woods; after weeks of extensive walking, she suddenly understood that there is no need to worry or feel powerless; she found that life itself and God would take care of her. Still, Ava was the only participant who captured her worldview in the life drawing; she drew a red thread with hearts and the thread runs through her tree from the roots up to the leaves. As Ava explains her tree: “the thread symbolizes my inner power ... the way I have always believed that life itself carries ... Moreover, it symbolizes God and his guidance in my life.” It can be interpreted as her belief that her personal strength becomes interwoven with God’s comfort.

Embodiment was found to be important and a form of physically touching AIDS patients is a central part of spiritual counseling in the studied Selian Hospice and Palliative Care Program in Tanzania. As explained in the interviews, touching, not just talking, breaks the stigma of HIV/AIDS. This reflects traditional African ideas of the value of human encounters. Physical touch is used during prayer for the sick at the end of each counseling session. Another element in contextualizing the counseling in the program studied here is that the counselor blesses the medicine given to a client already beforehand when a client consults the medical personnel of the

team. The program leaders interviewed pointed out that their patients had no need to approach the traditional healers for blessing of the medicine because the ailment had already been cured with spiritual power. What is practiced in the Tanzanian end-of-life care clearly follows Emmanuel Lartey’s reflection: “What seems significant about all researchers and writers on African pastoral care and counseling is that they engage with indigenous people’s beliefs and practices of traditional healers in their attempt to evolve a truly African approach to pastoral care that is relevant and effective” (2006, 66).

The Christian understanding of hope does not pretend to give solutions. However, it provides a meaningful framework for proceeding with life. Louw further analyses: “Theologia resurrectionis provides pastoral theology of a paradigm that can contribute to the healing of life and the human attempt to signify life within the realm of suffering, death and dying” (Louw 2014, 8). Christian understanding thus stresses the significance of the salvation on the cross as a part of the personal experience of hope. Moltmann (2003, 150) emphasizes that Christianity is a hope for the hopeless, and he wants to emphasize that all humans need God’s salvation; Resurrection means a broad space of freedom, a fresh new beginning of being born again to living hope. The eternal hope, as seeking comfort from God, provided rays of hope in the midst of the despair of the health crisis with the help of the above-discussed embodied rituals.

Hope is based on relationships

According to our findings, hope itself is a process. In the theology of hope, human dignity and value are emphasized through Christian faith and the theology of the cross. Perfect human value is seen only through God’s salvation. Moltmann writes: “Nobody is required to be perfect, but everyone must be able to start anew. All that matters in life and death is the new beginning. If a child falls down, it learns to stand up again. Failures and disappointments are not a problem, but it is important to stand up and try again” (2003, 157–167). A human being is perfect in the eyes of God through the salvation of Jesus Christ; salvation on the cross is a channel that leads from a feeling of unworthiness to the understanding of human dignity. Dignity has been defined as “an inherent characteristic of being human, which can be felt as an attribute of the self, and is made

manifest through behaviour that demonstrates respect for self and others” (Jacelon et al. 2004). Street and Kissane additionally argue that “dignity is relational and constructed through relationships with others” (Street & Kissane 2001, 97). The people suffering from life-threatening illness found hope in the feelings of dignity through significant relationships and embodied rituals as is seen in the following figure:

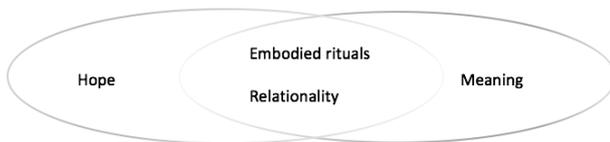


Figure 1: Hope and meaning in life during life threatening illness

Overall, as the figure above sums up, our studies showed that hope was needed in order to experience meaning. Hope and meaning were closely connected to hopelessness and meaninglessness. Yet, embodied rituals provided a tangible means to alleviate the troubled mind. Besides the stories we live by, the bodies in which we live are also products of culture. When the body is seen as a cultural product, it leads to the understanding that bodies are culturally contested and that body images are accepted by negotiating with cultural master narratives. Then it is the cultural master narratives that have an impact on an individual’s body image, embodied practice, and the way that the individual expresses bodily gestures. Furthermore, when countering a life-threatening illness, it was common to question meaningfulness in life.

The experience of being accepted had an embodied dimension that was described as a part of the narratives and drawings. The bodily changes were rarely drawn, even though stories of a challenged body image were often narrated. Crises that arose from physical changes in the body focused more on the treatment period; therefore, the bodily changes were expressed only in the drawings of those who had longer-lasting or permanent changes in their bodies. Furthermore, some of the drawers had had demanding operations, requiring long-term physical rehabilitation. Besides the manifold aspects of hope and despair, the narratives of the emerging adults pointed out something about the nature of a crisis with cancer. The body-related changes were linked to the experience of stigma.

Hope is hope in suffering, not a way of getting out of suffering (Louw 2006, 110–111). Jesus himself

suffered on the cross, and through this suffering he understands those who suffer. Through the theology of the cross, human dignity is emphasized. Hope is seen in the narratives of suffering (Moltmann 2004, 90–93). The theology of hope is based on the relationship between the human being and God in a situation in which a person sees an opportunity to share despair and pain with the suffering of God himself. Christian hope without the theology of the cross is impossible but this type of hope was not central to all of our interviewees.

Conclusion

The aim of this chapter was to discuss embodied experiences during life-threatening illness. The aim was reached in studying narratives of two different life-threatening illnesses, namely experiences of cancer and HIV/AIDS. Our data from two very different contexts has shown the importance of or difficulties in relationships during life-threatening illness. AIDS still carries stigma which was seen in the narratives of HIV positive people both in Finland and in Tanzania. The strongest support for the HIV positives was peer support. One reason for lively peer support was that many of them had not revealed their HIV positive status to those close to them. The stigma with cancer was found to be different, as the negative experience, at least partly, toned down with time. The emerging adults suffering from cancer in Finland had experienced mainly positive support from their family and friends they were able to feel belonging instead of exclusion. The emerging adults described their cancer as an embodied experience that exposed them to emotional effusion, changed their identity, and affected their physical bodies.

Our studies show that hope was needed in order to experience meaning. The experience of being accepted had an embodied dimension that was described as a part of the narratives and drawings. The people suffering from life-threatening illness found hope in the feelings of dignity through significant relationships and embodied rituals. Hope itself is a process and it refers simultaneously to hope, despair and hopelessness. These findings show that both hope and despair grow from the experience of belonging; hope builds on social relationships and human dignity, whereas despair deepens with the experience of being different. Some relations increase suffering rather than help the process of searching



for hope during life threatening illnesses. This negative side of relations is also important to keep in mind when re-formulating relational theology.

A traditional relational theology like Cooper-White's model focuses mainly on the relationship between a counsellor and a counselee but our research findings indicate the importance of peer and family support during life threatening illnesses. In which way these different relationships influence the process of the search for hope and meaning needs further study.

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