

THE SEARCH FOR MEANING IN MEDICINE WHEN CONFRONTED WITH LIFE-THREATENING ILLNESS – HOW TO INCLUDE A BIO-PSYCHO-SOCIAL MODEL INTO HEALTH-CARE

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SUMMARY

This paper aims to discover and discuss the place of spirituality in the meaning-making process for patients with life-threatening diseases like cancer. Does the search for meaning serve a specific role, or is it purely subjective? Finding constructive coping strategies can improve the quality of life. Meaning-making might be an essential coping strategy. Research has confirmed that spirituality is an integral part of meaning-making for many patients.

To understand the findings of studies and their relevance for oncology and healthcare in general, definitions of religion, religiosity, and spirituality are presented. The main theoretical framework is shown in theories of the psychology of meaning. The search for meaning is discussed conceptually in psychoanalytic terms alongside developing a supporting super-ego. It aims to clarify the psychological effects and implications of faith, religion, religiosity, and spirituality on individual, interpersonal and social levels.

The influence of illness on life and the impact of life on illness have to be considered, as cultural/societal challenges influence change processes. Internalization of a supportive super-ego, adequate self-regulation, and subjective illness perception/ "truth" influence (social) behavior (un)consciously. Therefore, a systems-theoretical view of the ability to accept boundaries should accompany the supporting super-ego in the process of the search for meaning.

A bio-psycho-social model integrates all aspects of human life which are involved in dealing with a disease. The interest in the bio-psycho-social model is neither outdated nor new. The model is often supplemented by the factor of spirituality, which has been part of human experience throughout human history.

Key words: spirituality - bio-psycho-social model – coping – meaning - life-threatening illness

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INTRODUCTION

It is proven that patients struggle with questions about the deeper meaning of their lives, values, and relationships. Confronted with a life-threatening illness like cancer, patients suddenly face "profound existential challenges, including issues of control, identity and purpose." (Rabow & Knish 2015, p.919). Studies with terminally ill patients have documented how questions about spirituality, meaning in life and transcendence emerge (Benzein et al. 2001, Murray et al. 2004). Sulmasy (2009) called the questions that arise "spiritual questions," and these often concern transcendence.

A large body of literature suggests that religion and/or spirituality (R/S) is important for cancer patients and is frequently used as a coping resource (Camargos et al. 2015, Haußmann et al. 2017). Studies have revealed a significant association between R/S and lower levels of anxiety and depression (Braam & Koenig 2019), better physical health (Jim et al. 2015), a better quality of life (Chaar et al. 2018) and increased well-being (Kaliampou & Roussi 2017). It is also well known that R/S gives hope, comfort and strength (Thuné-Boyle et al. 2013, Tsai et al. 2016). Religions offer meaning, values, relationships, rituals, and rules for life bound to the culture's ethics. For example, all the world's religions have explanations and traditions concerning a person's death (Sulmasy 2009). There is a desire for or attachment to

something higher and transcendent in crises. This trend is also particularly evident nowadays in the corona crisis, where people are increasingly finding hope, security, meaning and trust in their religion (Kowalczyk et al. 2020). The question of health and illness is universal; it concerns people worldwide.

How health and illness are handled and interpreted depends on the cultural framework and the social characteristics of a society (Ahmadi & Rabbani 2019), and the relationship between spirituality and medicine differs in different cultural contexts (Inthorn 2009).

In medicine, the bio-psycho-social model is a known construct, but is it necessarily a holistic model if it does not include spirituality? Sulmasy (2002) argues that since "spirituality concerns a person's relationship with transcendence, genuinely holistic healthcare must address the totality of the patient's relational existence – physical, psychological, social and spiritual". Healthcare would, in this sense, benefit from including the spiritual domain of human life explicitly into its definition of holistic care and developing holistic care from a bio-psycho-social-spiritual model. If medicine and healthcare workers ignore the reality and actuality of the concept of spirituality there is a risk of losing sight both of the resources that can be found in the concept, as well as the possible strains.

Spirituality is recognized as a factor that contributes to health in many persons. The concept of spirituality is

found in all cultures and societies. It is expressed in an individual's search for ultimate meaning through participation in religion and/or belief in God, family, naturalism, rationalism, humanism, and the arts (see also Zinnbauer & Pargament 2005). All of these factors can influence how patients and health care professionals perceive health and illness and how they interact with one another (Association of American Medical Colleges 1999, referred to in Puchalski 2010) and might be conceptualized as (medical) humanities. There are many reliable and valid tools for measuring the health effects of spirituality (Pargament et al. 2000, Peterman et al. 2002, Büssing & Koenig 2008), but none have given a clear definition of the concept of spirituality and therefore further research (e.g., systematic reviews) is necessary. Besides, spirituality often is mixed with religion, positive aspects can be stressed, but religion might also be a risk, when specific affects as guilt or punishment are stirred up (Linke 2013). Therefore spirituality has to be clearly distinguished.

This article aims to clarify the role of spirituality in the meaning-making process while dealing with a life-threatening disease, such as cancer. In addition, the paper wants to highlight the importance of spirituality as an essential element that should be added to the bio-psycho-social model. Finally, it will point to possible consequences for holistic, compassionate healthcare care.

On this basis, we have the following research questions: 1. What is spirituality in the context of creating meaning for cancer patients? 2. Why are R/S essential aspects of the bio-psycho-social model? 3. What are the consequences of implementing R/S in medicine?

METHOD

In order to prepare a review or to define search terms for the meaning of spirituality we conducted a focus group including clinicians (N=6), who had gathered long-standing working experience with patients suffering from life-threatening diseases. We asked for concepts and theories, literature, that seemed relevant for their work in order to understand patients' processing of their illness. Further, we questioned the utilization of concepts of spirituality and religion. Two clinicians (internal medicine) working in palliative care, one as psychiatrist, one as neurologist, one clinical psychologist and one oncologist had all more than 35 years working experience in the field. The transcript of the focus group was analyzed by two independent raters according to a deductive approach in order to figure out conceptual framings, concepts and the stated literature around spirituality.

RESULTS

The following topics and argumentation lines could be recognized.

Clarification

Mostly, these two phenomena - religion and spirituality - are seen as deeply intertwined and often used as synonyms. It is important, though, to distinguish the term spirituality from the term religiosity. One way to establish the relationship between the two is to say that spiritual people are not necessarily religious, but religious people are spiritual. Spirituality is traditionally understood as mankind's search for the unseen and the transcendent in a broad sense. According to Streib & Hood (2016), "the connotations of "spirituality" are more personal and psychological than institutional, whereas the connotations of "religion" are more institutional and sociological" (p.14). These connotations clarify important differences in how spirituality and religion are understood. Spirituality is generally recognized as involving both, the beliefs, values, and behaviors of a person, while religion is more associated with the personal involvement with a religious tradition and institution (Streib & Hood 2016).

Transcultural perspective

Over the last decades, the term spirituality has become a popular and much used word, and it is common to refer to "spirituality" instead of "religion" without drawing any clear distinction between the concepts (Hood et al. 2018). More and more spirituality has been separated from religion as a distinct construct. This trend is rooted in a movement away from the authority of religious institutions in modern social life, together with a growing emphasis on individualism, particularly within Western cultures. These combined social forces have fostered beliefs and practices that are less linked to traditional, communal practices and belief systems and more linked to individual experience and expression. As a result, the terms religion and spirituality now are more frequently seen as referring to separate phenomena. On the other hand, Steinhäuser et al. (2017) found that most of the US population regard themselves as both spiritual and religious, and the terms religion and spirituality therefore seem to be overlapping constructs in the US.

Puchalski et al. (2009) noted that "spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and the significant or sacred." In other words, "Spirituality includes both a search for the transcendent and the discovery of the transcendent and, as such, involves traveling along a path that leads from non-consideration to questioning, to either staunch non-belief or belief, and if belief, then ultimately to devotion and finally, surrender" (Koenig et al. 2012). Eastern and Western traditions have different names for the transcendent, which is found both outside the self and yet also within the person. Eastern traditions refer to it as Brahman, manifestations of Brahman, Buddha, Dao,

or the ultimate truth or reality. In contrast, in Western cultures, the transcendent is referred to as God, Allah, Hashem, or a Higher Power (Koenig et al. 2012).

Transcendence

Puchalski & Romer (2000) argue that religiosity is related to the transcendent (personal or impersonal transcendent powers), whereas spirituality can be understood as relating to a transcendent meaning. Whether linked to a religious belief or not, spirituality “allows a person to experience transcendent meaning in life. This is often expressed as a relationship with God, but it can also be about nature, art, music, family, or community – whatever beliefs and values give a person a sense of meaning and purpose in life.” An important question is whether an atheist can be spiritual if spirituality only refers to transcendence? Puchalski (2010) suggests that “the challenge in defining spirituality is that any definition does not give justice to the full complexity of the human spirit and the transcendent, howsoever people understand and mean exactly”. Spirituality can also be defined as man’s inclination to search for and find meaning through one’s perceived relationship with or connectedness to a transcendent source whether this source is a religious one or not (Assing et al. 2013). Of course, the transcendent power has to be differentiated also according to other religious traditions. The European Association for Palliative Care (EAPC) offers the following definition: “Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and / or the sacred” (Nolan et al. 2011). Although the evidence base has grown, the field lacks consistency in the definition and methodological approaches, as well as an overarching framework for future research priorities (Steinhauser et al. 2017).

The search for meaning and health

From definitions of religion, religiosity and spirituality, the focus now shifts to how these concepts are linked to health. Can religiosity and spirituality represent resources for coping with a life-threatening disease? The relationship between religion and health is complex: “We no longer ask whether there is a relationship between religion and health, but rather under which conditions does religious participation affect health. We no longer ask whether religious involvement is good or bad for health, expecting an either/or answer” (George 2012). In 1902, William James (1842-1910), published his great classic of the psychology of religion. The varieties of religious experience and his book are permeated by his profound concern with the philosophical justification of religious faith (Wulff 1997).

Life-threatening diseases – Cancer as an example

Facing a life-threatening disease, for example cancer (Rassoulilian et al. 2021), raises existential questions whether the person has a belief or not (Puchalski 2000, 2010, 2012, Rousseau 2000, Büsing 2006, Sulmasy 2009, Surbone & Baider 2010, Van der Weegen et al. 2019). These questions may concern identity, meaning and what will happen after death (Balboni & Balboni 2018). In qualitative interviews, advanced cancer and end-stage heart failure patients, mentioned the need for love, meaning, purpose and transcendence (Murray et al. 2004). Sulmasy (2006a) concluded that these questions “about meaning, value and relationship” are questions of a transcendent nature - “spiritual questions” which are important for every human being and inevitably emerge when facing death (p.1385).

In a meta-analysis of qualitative studies, Edwards et al. (2010) documented how, at the end of life, questions of meaning and an awakening of the spiritual dimension increase. Additionally, Sulmasy asserts that “illness is a spiritual event” (Sulmasy 2006b). It can be argued that for some people religion/spirituality might provide explanations for the experience of illness and thus promote better coping mechanisms (Puchalski & Romer 2000, Sulmasy 2009, Balboni & Balboni 2019). Likewise, in qualitative interviews, cancer patients emphasized R/S as a main coping strategy which helped them to reframe their experience with illness (Asgeirsdottir et al. 2013, Pérez-Cruz et al. 2019, Peteet & Balboni 2013, Rochmawati et al. 2018, Stein et al. 2015, Thuné-Boyle et al. 2013, Ursaru et al. 2014).

DISCUSSION

R/S as an important frame of meaning-making

In a study with women with breast cancer, 71% of the participants reported a close relationship with God. The women who had a close relationship with God showed higher psychological well-being, less psychological distress and a higher sense of meaning in life (Meraviglia 2006). In line with this, Visser, Garssen and Vingerhoets (2010) emphasized that the essential component of spirituality is the meaning of life. Meaning can also be found in experiences of music, sports, nature, connection with others and in the beauty of nature (Mount et al. 2007). In a study with 350 terminal cancer patients, Bovero et al. (2021) discovered that meaning was the main predictor for feelings of hope. Additionally, hope was strongly correlated with less feelings of anxiety and depression and a higher quality of life in these patients. Studies have documented that R/S can affect the coping process during the cancer experience by giving meaning and peace during their time of illness (Cha et al. 2018). Zavala, Maliski, Kwan, Fink and Litwin (2009) found that meaning and peace aligns closely with greater spirituality

and a better health-related quality of life, including physical, mental health and energy in men with metastatic prostate cancer. It has been stated that meaning and peace are related to a better QOL in cancer patients, influencing the physical, psychological, social, and spiritual domains (Bai et al. 2015). Visser et al. (2010) examined spirituality and well-being in cancer patients in a literature review. The results showed that most of the cross-sectional studies documented a positive relationship between spirituality, meaning in life and well-being. But having a sense of meaning in life can also affect satisfaction with life and psychological well-being. Studies also show an association between meaning and peace and positive psychosocial well-being in cancer patients (McClain et al. 2003, Meraviglia 2006, Bai et al. 2015).

However, religiosity and spirituality are not seen as an essential component for cancer patients alone. Camargos et al. (2015) demonstrated that R/S were not only important for the majority of cancer patients (99.6%) but also for the health professionals working in the field of oncology. When facing difficulties and uncertainty in times of illness, it is well known that religious and spiritual beliefs can create an inner landscape of strength and comfort (Sloan et al. 1999, Herbert et al. 2001, Holt et al. 2009, Yanez et al. 2009). The results showed that spirituality strongly supported the coping process of the patients, and their caregivers, and provided strength, hope, optimism, and comfort.

Again, what is spirituality? The search for meaning elaborated

“Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred”. (Puchalski et al. 2009) Numerous studies have documented that for cancer patients the search for meaning in life or in the cancer experience itself is a very important element of their coping process (McClain et al. 2003, Murray et al. 2004, Alcorn et al. 2010, Zamanian et al. 2015). McGrath (2002) discovered in interviews with survivors of hematological malignancies that their battle with challenges concerning their physical health, their relationships, their identity, and existential questions can threaten their meaning-making concept and creates a painful void in them. Therefore, a strong meaning-making framework is essential.

Cancer as an example - a limitation or more?

In a study with cancer patients, Asgeirsdottir et al. (2013) concluded that “spirituality was understood broadly as a vital element connected to seeking meaning, purpose, and transcendence in life and touched the core of their existence” (p.1448). For cancer pa-

tients, meaning is an abstract, complex, and multifaceted concept (Gravier et al. 2019). One way to find meaning is in the experience of transcendence, in relationship with a personal God, or in unity with something larger than oneself. The meaning and experience of transcendence cannot be better said than in this quote from Cassell:

“Transcendence is probably the most powerful way in which one is restored to wholeness after an injury to personhood. When experienced, transcendence locates the person in a far larger landscape. The sufferer is not isolated by pain but is brought closer to a transpersonal source of meaning and to the human community that shares that meaning” (1991). Meaning can also be found in experiences of music, sports, nature, connection with others and in the beauty of nature (Mount et al. 2007).

In Rassoulilian et al. (2021) cancer patients were not explicitly asked about meaning in life. Instead, they were asked what gives them hope, inspiration and orientation. 64.5% of the patients answered that their beliefs help them to manage life more consciously. It can be argued that being conscious about one's life helps a person to be more aware of one's values and thereby get access to one's own understanding of meaning in life. In 2019, Gravier et al. explored the meaning in life among 728 advanced cancer patients and found a strong relationship between meaning in life and higher optimism and less psychological distress. Other researchers conclude that a strong feeling of meaning in life leads to lower anxiety and depression levels (Bovero et al. 2019). A longitudinal study of 418 breast cancer patients showed a significant association between meaning and peace as well as fewer symptoms of depression and higher vitality (Yanez et al. 2009). In the same study, Yanez et al. (2009) found in 2.156 cancer survivors that meaning and peace were correlated with better mental health combined with reduced cancer-related distress. Additionally, results of a meta-analysis demonstrated that both meaning in life and a sense of coherence can buffer distress in cancer patients (Winger et al. 2016).

Meaning was significantly positively associated with functional well-being, a fighting spirit and social well-being (Whitford & Olver 2012). Meaning was also shown to promote a less helpless/hopeless coping style. Whitford & Olver (2012) argued that cancer patients might experience their difficult circumstances as an opportunity to change their life goals; they thereby find meaning in ordinary things, resulting in greater optimism and an experience of growth in their lives. Likewise, the German-Swiss poet, novelist, and author Hermann Hesse (1877-1962), noted: “I have always believed, and I still believe, that whatever good or bad fortune may come our way we can always give it meaning and transform it into something of value.” (Hesse 1922).

In interviews with cancer patients, Mount et al. (2007) described a tendency for patients to seek deeper meaning and connectedness in their experiences with suffering. The search for meaning is not only a

postmodern quest; the well-known psychiatrist Victor Frankl related the quest for meaning to pure survival: “there is nothing in the world, I venture to say, that would so effectively help one to survive even the worst conditions as the knowledge that there is meaning in one’s life” (Frankl 1959). It is shown that in times of stress, illness and dying, meaning is paramount to survival (Puchalski 2012). According to Mount et al. (2007) and the results of their study: “meaning was not an end in itself, but a by-product of a related experience, a sense of connectedness. It was not meaning, per se, that brought the person alive but the underlying experience of being part of something greater and more enduring than the self” (p.383). Connectedness then is a vital part of meaning. Of course, different cultures might deal differently with their seek for meaning and coping style using spirituality. Nevertheless, when coming to existential questions and existential anxieties, unconscious processes dominate behaviour, as around 80% of our behavior is influenced by non-conscious processes (Roth 2019). For these processes no cultural differences were found (Cowen et al. 2021). Nevertheless, different cultures might deal differently with their search for meaning and spiritual coping.

Outlook

Due to the expanding literature highlighting the importance of meaning, it is recommended that health care professionals address these issues (Mehnert 2006, Rassoulilian et al. 2016). This is also supported by a literature review which documented that half of the questionnaires which examine the quality of life included items of meaning or purpose of life (Albers et al. 2010). Recent findings of a meta-analysis indicated that psychosocial interventions foster meaning and purpose in cancer patients (Park et al. 2019). Existential distress caused by a loss of meaning can result in more psychosocial distress (Gravier et al. 2019). Therefore, meaning-centered interventions can be a possibility to reduce distress in cancer patients (Winger et al. 2016).

As spirituality or meaning is a complex and personal theme in the life of individuals, sensitive and qualitative studies are needed to understand what helps and what is harmful, what gives a person meaning, and how we - at best point of service and interest for the patients - can include these aspects in the clinical context. To be confronted with a life-threatening, and in some cases incurable, disease is one of the biggest challenges of a person’s life. To understand and support patient resources should be one of the main goals in the practice of patient-centered medicine, and its relevance to the healing process should be attended to much more extent. The need is clearly mentioned also by medical students (Rassoulilian et al. 2016). For considerations on how to provide the best point of service and patient-centered care, the surrounding and social network of patients has to be included (Tretter &

Löffler-Stastka 2019). Attitudes of relatives, friends, students, and medical staff play an important role when it comes to strengthen patients’ resources (Rassoulilian et al. 2016).

The development of meaning – consequences for health-care

Meaning and epistemic trust is one essential component of a mature personality and can be disequibrated in life threatening disease processes. In patient/therapist interactions defense mechanisms, coping style, all affect-cognitive aspects can be observed, but also beliefs and illness perception have to be considered. Since interactions take place with sometimes limited possibilities to reflect and analyze what is going on, there is a great need for capabilities and also tools (Löffler-Stastka et al. 2021) to identify and enhance meta-cognitive processes. Altogether, cognitive- and affective (self-)regulation should be facilitated in therapeutic interactions, especially in patients with chronic and life-threatening conditions in order to stimulate activation of internalized processes of epistemic trust and meaning to cope with chronic conditions properly.

Known factors for possible loss of meaning, complications and mistrust are: distress that is specifically related to the illness, depressive disorders, post-traumatic stress disorder, avoidant coping, feeling a lack of control, characteristics of the treatment regimen, chronicity (Lieber et al. 2015). Most importantly a lack of empathy and information and lack of trust have been shown to be risk factors for such processes of loss of meaning (Lieber et al. 2015).

On the other hand, development of meaning also depends on a self-observing capacity as a component in self-regulation that is conceptualized in psychoanalytic terms as a main superego (conscience) function. Depending on the quality of working alliance, trust in doctors, and reflective functioning the observer’s position can be internalized and utilized with individually achieved balance of supportive and punishing (judgmental) functions. In order to help patients to establish and use their supportive superego functions to adequately deal with their illness, it is necessary to contain anxieties towards death, deficiencies or malfunctions. This implies the acceptance of boundaries, which is normally established within a normal psychic development, but is shattered or altered during illness processes. A reliable, empathic and stable doctor-patient-relationship with an adequate holding, affect-marking, reflecting and containing function (Fonagy et al. 2004) can help to work through difficult moments and re-establish meaning. In psychoanalytic theory this process especially has been investigated in Winnicott’s theory of holding (importance of the external object), Bion’s theory of container/contained, and Klein’s theory with a particular focus on the internal and phantasmatic experience (Aguayo 2018).

CONCLUSION

Physicians are well trained for coping with biomedical aspects of patients with desperate conditions, but their understanding of the psychological, social, and cultural dimensions of illness and health is often vague/limited. As a matter of facts, clinicians play an important role in motivating and helping patients to maintain healthy coping skills, meaning and trust. One reason for mistrust in individuals' with chronic and/or life-threatening conditions is that patients conceptualize their disease, its treatment, and their role in the treatment plan in very different ways. For example illness representations are one's beliefs about the illness, including its effects on daily life and treatment (Pereira et al. 2018). Moreover, recent research demonstrates that there is an association between illness perception and affect-cognitive parameters (Bock et al. 2016). But illness perception is a very subjective parameter, influenced by cultural factors, associated with fears, dysfunctional beliefs which have to be addressed as well, for example through strengthening/establishing mature coping mechanisms (e.g. sublimation).

Establishing a supporting super-ego - also in a systems-theoretical way - is necessary (Löffler-Stastka & Steinmair 2021) to take optimal responsibility for the autonomous patient (Löffler-Stastka & Krajic 2021) and not to let patients feel lost in ideological spaces. With the help of the patient's surrounding, e.g. the caregivers (Applebaum et al. 2018 and appropriate interventions (Breitbart et al. 2018) adequate care can be established: either provided in form of group therapy (van der Spek et al. 2017, Rosenfeld et al. 2017) for the suffering patients or as a more general request in training and/or refinement of attitudes (Schnell 2021). Shown for cancer patients suffering from life-threatening illness, it becomes more and more essential nowadays as due to the current pandemic a variety of foundational transformations in the very definition of mental health/disorder, with a frame-shift towards more liberal understanding of values, comprising e.g., coherence and quality of life, that individuals' subjective experiences are followed to dig into people's resilience, recovery and affect-cognitive containment possibilities.

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Contribution of individual authors:

Anahita Rassoulilian conceived the topic and gathered oncological studies.

Henriette Löffler-Stastka reviewed iteratively and added the conceptual psychoanalytic clinical viewpoint.

Both discussed the conceptualization of the topic iteratively and always based on their clinical experience.

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