The illness reframing process in an ethnic majority population of older people with incurable cancer: Cultural- and existential meaning-making analyses

Abstract
Older, ethnic Norwegians with incurable cancer may experience different cultural processes, leading to different understandings and management of their clinical reality. Little is understood about how they reframe their illness experiences in light of existential meaning-making adjustments. This article, part of a larger qualitative study, focused on specialized healthcare contexts. Four case illustrations were analyzed, representing the range of belief frameworks from the total group of 21 participants. Kleinman’s medical anthropology cultural framework was adapted for the data analysis. The case illustrations represented heterogeneous cultural processes. Independent of cultural variation, the illness reframing contributed positively to: new constructions of illness and health; improved relating to the surroundings; and adjustments made in daily living. The results point to the need for including cultural- and existential meaning information in the clinical process for better understanding the patient’s framework of interpretations, and for identifying treatment planning resources.

Keywords: palliative care, end-of-life care, culture, existential meaning, aging, Kleinman, A., DSM-5
Introduction
An initial qualitative study of 21 older ethnic Norwegian participants with incurable cancer in the south-eastern part of Norway formed the study’s base. Exploration focused on participants’ reframing process from a cultural framework building from Kleinman’s model (1980) and elaborated and applied to palliative care in Scandinavia by DeMarinis (1998, 2003). Research question: How can cultural- and existential meaning-making analyses contribute to an understanding of the reframing process for an ethnic Norwegian majority population of older people with cancer?

The need for majority population focus emerged from the initial study’s findings (Haug, Danbolt, Kvigne, & DeMarinis, 2014): older people were strongly connected to life in their daily living, and that existential meaning-making and resilience were the overarching processes; yet, the patterns and contents of their existential meaning-making experiences were very different. This pointed to different cultural processes and orientations to clinical reality. (Kleinman & Benson, 2006).

Background
Despite the increasing number of older people living with incurable cancer as a chronic disease, research on culture’s influence in this patient group is scarce (Gysels et al., 2012b; Surbone, Kagawa-Singer, Terret, & Baider, 2007). European palliative care research has paid attention to culture’s role in public healthcare contexts through the action program, PRISMA, (Gysels et al., 2012b; Gysels M. et al., 2012a), supported by the European Commission (Harding & Higginson, 2010). Research exploring both socio-cultural understandings of illness experiences and caring, and an elderly population focus, is emphasized by WHO (S. Hall, Petkova H., Tsouros, Costantini, & Higginson, 2011). Guidelines exploring cultural aspects of palliative care through a holistic and culturally-embedded orientation for understanding patients’ illness experiences are needed (Selman et al., 2014).

In Norway people aged 70 and older comprise the largest hospitalized population, with cancer the second most frequent disease between ages 70-79 (Mundal & Thonstad, 2013). The situation represents a coming major challenge for specialized healthcare contexts, necessitating cultural knowledge for this group. The national guidelines for palliative care’s objective (Norwegian Directorate of Health, 2013) is to improve care for people with incurable cancer and to make sure the same high quality service is available throughout Norway. Though the guidelines include a spiritual domain, a cultural domain is just briefly mentioned. Two articles focusing on a clinical context in southern Norway (DeMarinis,
Ulland, & Karlsen, 2011 a; Ulland & DeMarinis, 2014) discuss the need for a culture-focused perspective for all patients for understanding the patient’s and family’s interpretations of illness and health. Existential meaning is understood as fundamental for how these interpretations are perceived and practiced. This approach to gaining cultural information for all patients, including existential meaning information, is consonant with culture’s importance in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) (American Psychiatric Association, 2013).

Research on the religion-health connection has expanded after the 1980s, especially in the USA (Hood, Hill, & Spilka, 2009; Koenig, King, & Carson, 2012). General finding there show a positive and complex relationship. In a Norwegian quantitative study on patients with cancer, no associations were observed between ‘Seeking God’s help’ and ‘Life Satisfaction’ or ‘Disease-Specific Quality of Life’ (Sørensen et al., 2012). This highlights the need for conducting research with cultural awareness.

*A cultural understanding of clinical reality*

Prominent medical anthropologist Arthur Kleinman argues that culture influences all aspects of human experience (2006). Thus, culture affects perceptions of illness, disease, and health for patients, practitioners, and healthcare service delivery. Kleinman’s clinical model is based on a distinction between disease and illness (2013). The aim is to strengthen care by better understanding patients’ illness experiences. While disease refers to the medical system with diagnostic classifications and specific treatment interventions, illness represents the patient’s responses to disease, including psychosocial experiences and meanings ascribed to illness. Experience, understood as a flow of social activities and communications, moves both between persons and within each individual, and is facilitated by complex mediating processes connecting the inner world to social forms, “a local way of being human” (1992, p. 129). This allows for experience-near analysis on an individual level, exploring psychosocial processes and patterns of meaning in local worlds.

In Kleinman’s framework clinical reality means “the socially constituted contexts that influence illness and clinical care” (1980, p. 41). The contexts consist of different types of realities: social; symbolic; psychobiological; and, the physical environmental context. These are included in the cultural framework, and have been further elaborated as five dimensions, and adapted to palliative care in Scandinavia by DeMarinis (1998, 2003). The five dimensions are: biological-physical; psychological; social; ecological; and, existential (2003, pp. 44-46), see description under data analysis and Fig 1. Symbolic reality and the existential dimension
are seen as functionally synonyms in the modified model (De Marinis, 1998, 2003). This dimension is understood as fundamental as it influences the other dimensions, in making adjustments and interpreting circumstances. If the interpretation processes are temporarily blocked or dysfunctional, this may negatively affect patients’ experiences of illness, disease, and care. Palliative care research has integrated cultural importance, particularly the understandings of illness and disease in clinical contexts (Crawley, Marshall, Lo, & Koenig, 2002; Gysels et al., 2012b; P. Hall, Stone, & Fiset, 1998; Payne, 2007; Surbone et al., 2007).

Framing the different cultural dimensions in a clinical situation is dynamic, as reframing and adjustments to the changing conditions and impact on daily living are on-going. The psychological term reframing rooted in the psychotherapeutic tradition is relevant for understanding these changes (Mattila, 2001). Reframing is understood as: changing the concepts and/or emotional settings or viewpoints in relation to which a situation is experienced, placing it in another frame which fits the ‘facts’ of the same concrete situation equally well or even better, thereby change its entire meaning (Watzlawick, Weakland, & Fish, 1974, p. 95). Reframing’s aim is to help patients in relabeling the meaning or implications attributed to behavior. This may in turn facilitate positive effects on attitudes, responses, and relationships (Mattila, 2001).

The cultural-clinical context

Historically, the study’s participants were children or adolescents in World War II under the German occupation. After the war the country was united in the common task of development (Sejersted, 2014). During the next decades Norway became a solid welfare state, implying that for most people life became better and safer. The welfare system, similar across Scandinavian countries (Christensen & Berg, 2014), is characterized by the following principles: expectation for all citizens to work, participation in society, civic duties, paying taxes, and equal rights for all, including access to education, cost-free public healthcare systems, and economic security in case of health problems (The Directorate of Integration and Diversity (IMDi), 2014). In the latest European survey on life satisfaction Norway was included in the highest rating group (Statistics Norway, 2015).

Regarding church membership, the two counties in this study differ from the national profile. While here 84 percent are members of the main Lutheran church, Church of Norway, the proportion nationally is 75 percent (Statistics Norway, 2014d). Beyond infant baptism, there are no requirements when it comes to type of belief frames or frequency of church-related activities. Consequently, people with non-religious belief frames are also included.
Thus, a multidimensional and broad understanding of existential meaning-making experiences is needed in clinical research in Scandinavian contexts in order to gain more insight into the diversity and complexity of these phenomena (Ahmadi, 2006; DeMarinis, 2008).

Research on socio-cultural understandings of illness experiences and caring, and targeted research on elderly persons are important in palliative care. However, research is scarce about how members of this group, from the ethnically-dominant majority population, experience cultural processes related to illness and health in general, and specifically to the framing and reframing of cultural experiences related to the existential dimension in a Norwegian context.

**Method**
For the specific research question guiding this study, we chose to concentrate on four case illustrations representing the variation in existential meaning-making expressions from the initial study: atheistic/humanistic; religious; and, spiritual (Haug et al., 2014). Thus, the breadth in the data was represented. In a Swedish qualitative study on patients with cancer aged 25-83 a similar categorization was made based on their outlook on life (Ahmadi, 2006). In a deductive way we applied the cultural-dimension framework from Kleinman (1980), further elaborated and applied to palliative care contexts in Scandinavia (1998, 2003) as presented in the data analysis section.

**Location**
The study was conducted through two hospitals, representing the two counties in the south-eastern part of Norway. Population base per January 2014 was 402 072 (Innlandet Hospital Trust, 2013). The counties have the highest share of the elderly in the country (Statistics Norway, 2014a).

**Ethics**
The study was approved by the Regional Ethical Committee for Medical and Health Research Ethics, south-eastern Norway (reference number 2011/920) and The Privacy Protection Department at Oslo University Hospital.

**Participants and demographic information**
The larger study’s inclusion criteria were: older people age 70+ including all cancer types; diagnosed with cancer in the palliative phase; being informed and having an understanding of
the diagnosis; living at home; and, not having reached the terminal phase. Of the four patient cases included here, three were outpatients from oncological day clinics, and one was an inpatient, temporarily hospitalized due to distance from home concerns. The four case illustrations represented the three types of belief frames in the sample: atheistic/humanistic frame; religious frame; and, belief without a religious frame (Haug et al., 2014). The latter was renamed ‘a spiritual belief frame’ in the present article. Two participants with a religious belief frame were selected because this frame comprised the most dominant type in the data, and exhibited a wide variety of expressions. Both genders were equally included and there was some age distribution, ranging from 72-83 years old. One lived alone and three in partnered relationships. Three had children and grandchildren. The time living with incurable cancer varied from six months to six years.

**Data**

The original project data and first study, used here, consisted of an initial fieldwork period at the recruitment sites and semi-structured interviews with each participant (see Haug et al., 2014). The case selection for this article was based on the initial study’s results.

**Data analysis**

The data analysis for this study involved two steps. First, the five-dimension cultural framework was applied broadly to each case for an overview of content and patterns. Second, the interaction of information among the dimensions was analysed, with special attention to the function of the existential dimension. The comprehensive analysis was extracted and summarized as case illustrations. The smallest unit of analysis was illness experience. Illness represented the patient’s responses to disease in cultural context (Kleinman, 2013). Similarly, the concept experience was understood as expressions of “a local way of being human” (Kleinman, 1992, p. 129). Reframing the illness experience was in focus here. The participants provided both retrospective and current accounts of daily living and experiences of living with incurable cancer treatments, which permitted following reframing and reframing processes in the five dimensions, with special focus on the existential dimension of the cultural framework.

The five-dimension cultural framework is both described (DeMarinis, 2003, pp. 44-46), and illustrated in Fig 1 below (DeMarinis, 1998, p. 22).

- The biological-physical dimension is focused on the body’s way of functioning, meaning both physiological processes and bodily reactions to surroundings.
- The psychological dimension is focused on the ‘inner world’, how the psyche functions and reacts in its surrounding context, involving a dynamic interaction between the individual’s personality structure and thoughts, actions, and emotions.
- The social dimension is focused on the relational world in which the individual participates and negotiates. In particular this includes the institutions, representing power systems with normative and meaning-giving systems.
- The ecological (natural) dimension is focused on the individual’s interaction with the natural environment”, including structures, space in both natural and constructed environments.
- The existential dimension is focused on the individual’s understandings of existentiality/spirituality and ways of creating and expressing meaning. The dimension includes worldview conception, life approach, decision-making structure, way of relating, and way of understanding. In addition, it includes practices related to symbols and rituals. Essential in this understanding is that each individual has an existential dimension. As portrayed in Fig.1, the existential dimension is understood differently than the other dimensions. The arrow points both towards and away from the centre, illustrating that the dimension interacts with and to some degree coordinates the information related to interpreting illness experiences, disease as well as health for the patient in cultural context and through daily living in his/her local world.

Insert Appendix 8, The relation between the dimensions in the cultural framework about here

**Results: Four case illustrations**

A summary of the cultural existential meaning-making analyses is given for each case. The illness reframing citation, emerging out of the existential dimension, is placed in each case headline. A case summary notation is included on the illness reframing process through the existential dimension. An overview of the results, presented in Table 1, includes four categories: type of belief frame; illness reframing; constructions of illness and health; and, adaptations in daily living.
Hans: humanistic belief frame, “Now I just want to enjoy the time that is left and releasing my responsibility”.

Hans was in his early eighties and diagnosed with incurable cancer six months earlier. He lived together with his wife in a small city. The family including children, grandchildren, and great-grandchildren lived nearby. He related the illness reframing to his experiences of receiving help and support from specialized healthcare, seeming relieved in a way that affected him deeply: I feel more relaxed. This is hard to explain but I don’t feel as the most important person any more. I know the end will come, but there is no hurry. The reframing was a physical experience in the sense that he could feel in his body the symptom-reducing effect of radiotherapy treatment; feeling at ease. These experiences were in stark contrast to his background, being raised in a religiously-based orphanage where he was subjected to physical and psychological abuse. He had worked hard in order not to let the trauma destroy his life. His social background was difficult in that his family was poor. The reframing mediated a process where centre of attention was on daily living; spending time with wife and family, and going for outdoor walks. He could allow himself to feel that he had succeeded in his main goal and value in life; being a provider. The fact that spring was approaching represented a reinforcement of the reframing: Right now, I get flashes of light because I see that the sun is shining longer every day.

Illness reframing: Both family and healthcare institutions played a large role in the reframing process that led to changes in Hans’ existential meaning-making process, especially concerning a re-valuing- and re-prioritizing of time, and a re-framing of his life story as fulfilling his primary obligation of family provider.

Dag: religious belief frame, “I feel fit as a fiddle. I am always optimistic, never pessimistic”.

Dag was in the beginning of his seventies, and had lived with incurable cancer for almost four years. He lived in a small city together with his wife. The close family with children, grandchildren and one great-grandchild lived in a city nearby.

Dag expressed clearly that he did not feel sick (symptoms) and that he had a positive life attitude. Despite several treatment periods, he had not experienced negative changes in his body. He considered the positive attitude to be a gift from God, believing in life after death and that his length of life was under God’s control. He thought of his life attitude to be a heritage from his parents. From experiencing several losses, he had learned that mourning
over time or looking backward was useless, when considering the unchangeable facts of life. His belief frame had been confirmed and strengthened by a specific supernatural experience he had experienced together with his wife; seeing Jesus passing by. The illness reframing was in accordance with his life previous to the cancer, and it corresponded with common understandings in his religious context. To maintain living as he used to was most important. He was preoccupied with a sick family member, hoping for his recovery, and engaged in a church in which he previously had organized some of the aid work. He was still supporting it financially. Dag was satisfied with specialized healthcare contexts; even the leader is in a good mood. He was aware of the high costs of the treatment, noting the importance of paying taxes so everyone can receive good healthcare.

Illness reframing: For Dag the illness reframing involved an intensification of his existential meaning framework, which clearly included a perspective of relationship to God and other worldliness. Dag’s daily rituals of prayer as well as care activities and church engagements contributed to the strengthening of his meaning-making process.

Liv: spiritual belief frame, “I don’t understand how but I’ve just accepted the colostomy. Hence, later this year I will go abroad”.

Liv was in her mid-seventies and had lived with incurable cancer for almost six years. Three years earlier, she got a colostomy, a sequelae of the cancer disease. She lived alone in an apartment close to the city center, and her daughter and grandchildren lived nearby. Liv wondered if the reframing towards acceptance of the colostomy happened in conjunction with a leakage episode in a hospice day clinic a couple of weeks earlier. A nurse helped her, and then the change had occurred. Soon she had started making travel plans for the near future. Her hectic treatment schedule and experiencing that time was running fast was a part of this. She described the adaptation to the colostomy as extremely difficult: From the beginning I thought the stoma was awful, I did not dare to look at it, I said please open the window, I couldn’t imagine dealing with it. In the period afterwards, she avoided trips and certain social gatherings due to the fear of leakage. Now she also dared to participate in social gatherings. She wondered how the acceptance could occur, while also telling about the context where it took place, good atmosphere and tasty food. The illness reframing occurred after receiving palliative care from all three levels of public healthcare systems for several years, experiencing her life as sitting pretty, because she was not used to be taken care of by others. Her belief frame was referred to as a kind of confidence that somebody was taking care of
her. Her relationships with her daughter and grandchildren were the most important aspect in her life.

Illness reframing: Liv’s existential meaning-making process involved a very clear reframing of how life could be lived even with the colostomy. As noted, interaction with healthcare workers was essential for this change. Visiting the healthcare context where she felt cared for became a positive, ritualized experience for her, which enabled more energy for family interactions.

*Nina: religious belief frame, “I am not optimistic by nature. However, since the doctor hasn’t given up on me I think I haven’t become pessimistic. I try to hold on to hope, enjoying what is possible to enjoy”.*

Nina was in the early eighties, diagnosed with cancer six years ago, had undergone surgery, and had been healthy up to the previous year when the cancer recurred. She lived with her husband in an agricultural area not far from forest- and mountain areas. She referred to the last year as an absorbing experience in every respect: *the cancer illness requires all of me,* involving conspicuous decline in physical capacity: limitations in daily activities; feelings of alienation; and, being forced to let go of plans. In this situation, her reframing was directly linked to a healthcare professional, a doctor in specialized healthcare, providing her with hope of life-prolonging effect of treatment and support. Concretely, her hope was based in a certain place in the mountains, which she yearned to visit the coming summer. Originally, she had planned to move back to the area. The recurrence of the cancer illness put an end to the plans. She considered her Christian belief frame to be private and personal, describing it as: *a handle to hold on to when dealing with difficulties.* She had a couple of good friends she talked to about these matters. The enjoyable sides of life were: visits from good friends; helpful neighbors; living at home; nature experiences; and, hobbies.

Illness reframing: Nina’s existential meaning-making process was strongly coupled to nature and memories of places. Her faith framework helped her make adjustments and preserve hope. The relation to healthcare staff also helped in the maintenance of hope and reframing of goals.

*Place Appendix 9, Four case illustrations: Illness experiences analysed in the cultural framework about here*
Discussion

Despite that the older people in this article belonged to the dominant ethnic group in Norway they experienced heterogeneous cultural processes in relation to their illness experiences. In agreement with other studies (DeMarinis et al., 2011 a; Kleinman, 1980) the results also showed that the illness reframing, linked to the existential dimension, led to changes in the other dimensions in the applied cultural framework. Independent of the variation in the belief frames, these changes facilitated cultural processes in relation to: dealing with the cancer illness; understandings of both mental- and somatic health aspects; the surroundings; and, adjustments made in daily living. Hence, the case illustrations point to the importance of cultural- and existential meaning-making analysis, also for majority populations, in order to understand both problems with- and identifying resources for living with cancer.

At an early stage in his research Kleinman addressed the narrowing focus on diagnosis, treatment, and cure in public healthcare at the exclusion of patients’ illness experiences (Kleinman A., Eisenberg L., & B., 1978); while now Kleinman (Kleinman, 2013) is even more critical to developments, highlighting the importance of keeping caregiving central in health care, focusing on the moral and emotional core of experiences related to human suffering. Due to the increasing number of older people requiring palliative care in specialized healthcare contexts, this challenge is both relevant and essential. Hence, we addressed this challenge by interpreting illness experiences from a person-centered perspective (Kleinman, 1992; Kleinman & Kleinman, 1991). That illness and health experiences are multi-dimensional and dynamic was supported in these case illustrations.

In the four case illustrations here, the cultural processes seemed to be independent of the variation of the belief frames: atheistic/humanistic; religious; and, spiritual. No differences were identified that could indicate more positive or more negative connections between belief frames and illness reframing with implications for illness and health constructions and daily living. This contrasts with the general, positive finding in research on the connections between religion and health (Hood et al., 2009; Koenig et al., 2012), supporting the importance of conducting research in other cultural contexts and with cultural understanding (Sørensen et al., 2012).

Two common and interrelated characteristics of the illness reframing were especially noted. First, the reframing contained a proactive attitude to the future by means of making the time left as good as possible. The attitude was mainly characterized by adjusted hope and reframed optimism. The reframing entailed a process of connecting the illness implications to
daily living, enabling them to focus on what seemed most important, particularly close relationships, certain meaningful activities, and daily existential meaning-making concerns. By reframing the meaning or implications attributed to their illness experiences over time, they created new existential meaning narratives and experienced adjusted positive effects on attitudes, responses, and relationships in accordance with a psychotherapeutic understanding of reframing (Mattila, 2001; Watzlawick et al., 1974). Regardless of belief frame or length of time living with cancer, the process of reframing occurred.

Second, in all four cases the illness reframing was affected by the welfare system in general and palliative care in specialized healthcare contexts in particular. Essential for this cultural analysis was that the case participants, as all patients in the larger study, had experienced the changes in Norway after World War II. Now, as incurably sick with cancer, they experienced that the welfare system, especially represented by palliative care in specialized healthcare contexts, was functioning. These available clinical contexts contributed in large measure to helping the patients, and their families, make needed adjustments for improving daily living and maintaining life quality. This role of the welfare system, which is similar in the Scandinavian countries, differs from that of other western countries such as the USA and forms a part of the social- as well as existential meaning-making processes.

The findings confirm the usefulness of cultural and existential meaning-making analyses as applied to the palliative healthcare field. The adapted Kleinman framework worked well as an analytical tool. The findings confirm the importance of having a multi-dimensional framework, and seeing the framework content in a process-oriented perspective. The findings related to older people needing palliative care as an emerging public health concern (S. Hall et al., 2011), confirm the need for attention to the role of culture in health services, and socio-cultural understandings of illness experiences and caring, (Gysels et al., 2012b; Gysels M. et al., 2012a). In the Norwegian guidelines for palliative care, (Norwegian Directorate of Health, 2013) patients’ experiences are viewed as central for communication. However, the role of culture is not developed.

This study confirms the importance of cultural analysis for patient care and for understanding the existential dimension in the cultural framework as pivotal for negotiating changes made in the other dimensions. This approach is in line with the understanding of cultural- and existential information in research in Norwegian mental healthcare (DeMarinis et al., 2011a; Ulland & DeMarinis, 2014), and in the recommendation in Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) to use the ‘Cultural Formulation Interview’ with every patient.
Further testing of the cultural framework used here in specialized palliative care contexts is important, as its results may provide essential information for the clinical process itself, and contribute to an effective means for including the existential dimension in palliative care. The clinical application of information gained through this type of cultural analysis, for treatment planning and for identifying additional resources for patient and families appears to be an important research area for developments in specialized palliative care. Finally, the study supports the need for the development of guidelines relating to cultural aspects of palliative care (Selman et al., 2014).

**Methodological consideration**

The cultural dimensions’ model was applied to previously collected data, where information for each of the dimensions was found, but not explicitly asked for in the interviews. Including questions on each of the dimensions would have contributed to more substantial data. In future studies the inclusion of these dimensions in data gathering would be useful. The main selection criteria of the four case illustrations, representing the range of belief frames in the total sample was one out of several possibilities for categorizing existential meaning-making experiences. As described in the first study (Haug et al., 2014), there was wide variation within each type. The belief frames are illustrations and representations of certain outlooks on life, and not fixed entities or prototypes. For the four case illustrations the reframing facilitated favorable cultural processes. However, reframing might also include problematic psychological interpretations such as denial and illusion that may negatively affect patient’s experiences of illness, disease, and care. These aspects were present to a limited degree in some cases in the larger study, but not included here as they focus on dysfunctional belief frames, a separate topic.

**Conclusion**

The four case illustrations underscore the need for including cultural- and existential meaning information in research with all patients, including the majority ethnic population. The main finding was that patients’ cases reflected heterogeneous cultural processes while living with incurable cancer. Independent of the variation of belief frames, represented the reframing of existential meaning-making contributed positively to: constructions of illness and health; the relation to the surroundings; and the adjustments made in daily living. Thus, the existential dimension served to connect and in many ways coordinate modifications in the other
dimensions in relation to experiences of illness, disease, and health in their local worlds. Information gained through cultural- and existential meaning-making analysis at the individual level, supported by cultural information at the national and local context levels, contributed to a more nuanced understandings of patients’ varied interpretations and modifications of living with incurable cancer. The results point to the need for including these types of information, analyses and resulting information into the clinical process for understanding the patient’s framework of interpretations, and for identifying treatment planning resources.

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