Why we suffer? Existential challenges of patients with chronic illness. A Kierkegaardian inspired interpretative phenomenological analysis.

Introduction

“Starting reflecting makes it easier to take ownership of your life, your illness, your choices. That’s the way life is.” (DA, female, diagnosed for five years).

When human beings are confronted with life-changing experiences such as chronic illness, the existential dimensions of human life such as identity, freedom, meaning, suffering, loneliness, and death may appear clearer (Frankl, 1982; Yalom, 1980). Consequently, the individual often employs different secular, spiritual, and religious strategies aiming to handle the existential challenges (la Cour & Hvidt, 2010). This article presents a qualitative interview study exploring the existential, spiritual, and religious experiences of patients living with multiple sclerosis or chronic pain.

To understand how people handle life-changing experiences in relation to chronic illness, the transactional stress and coping model (Lazarus & Folkman, 1984) has been introduced and is widely employed in healthcare. The transactional stress and coping model points to the cognitive appraisal of the stressor in relation to the specific context and to the different problem and emotion-focused strategies that patients use to manage their illness-related stress and crises. However, specific aspects of coping such as spiritual and religious strategies have been found challenging to assess when using general coping assessment instruments (Pargament et al., 2013). Specific measurements to assess diverse spiritual and religious forms of coping have been developed and studied through a variety of quantitative measures, including studies of multiple sclerosis and chronic pain (Koenig et al., 2012; Wachholtz & Pearce, 2009; Wirth & Bussing, 2016). The coping model itself has been expanded by the concept of meaning-making to emphasize the cognitive structures included in how people
strive to make meaning, especially when coping with unsolvable events such as loss (Park, 2005). As a supplement to the concepts of coping and meaning-making in relation to chronic illness, we suggest a perspective focusing specifically on how human beings relate to themselves and to their lives with chronic illnesses. In this paper we focus on multiple sclerosis and chronic, complex pain conditions.

The Danish philosopher Søren Kierkegaard (Kierkegaard, 1849 /1962) can be interpreted to have contributed to the aspect of coping since his thinking provides a psychological understanding of how a “stroke of fate” imposes the human being to relate to oneself and to one’s own existential situation. The “stroke of fate” has been set into relation with the crisis experienced by human beings who suffer from severe, somatic illness (Jacobsen, 2000). In the Kierkegaardian understanding, the severe illness forces the patient to relate not only to the inherent physical challenges, but also to the existential challenges of one’s own situation as a human being (Jacobsen, 2000; Kierkegaard, 1849 /1962). Kierkegaard’s approach suggests that these challenges might be solved from an existential, spiritual, and religious perspective.

Kierkegaard is viewed as the founding father of modern existential philosophy and psychology (Cooper, 2011). His work has inspired scholars also in existential psychotherapy, for example Spinelli’s understanding of “existential angst” (Spinelli, 2008) and van Deurzen’s understanding of the “Überwelt” and “leap of faith” (van Deurzen & Adams, 2012). Most analyses inspired by Kierkegaard’s concepts in health and medical psychology are of a theoretical rather than of an empirical nature, based in the humanities (Katz, 2004, 2018; Oaks, 2016), or employed to discuss findings derived from a narrative analysis (Missel & Birkelund, 2011). Exceptions include the case study analysis of a long-term psychotherapeutic treatment (Peteet, 2017) and the analysis of patient experiences of cancer-survivorship (Knox, 2019).

In the current article, we aim to explore if and how a Kierkegaard-inspired psychological
analysis contributes to the understanding of the patients’ different ways to experience and respond to the existential challenges of living with multiple sclerosis and chronic pain.

**Theoretical Underpinnings and Definitions**

To comprise the complexity of different experiences and approaches to the existential dimensions, we employed a broad frame of concepts that needs to be defined. *Existential challenges* cover existential conditions, such as the identity formation or search for meaning in life. *Secular* approaches cover a worldly-minded approach based in values such as altruism without reference to the supernatural or God (DeMarinis, 2011; Frankl, 1982; Yalom, 1980). *Spirituality* includes a persuasion of a transcendence either as a supernatural, cosmic power or as this-worldly that might be sustained by practices such as going for walking meditations in nature or reflecting regularly on the good in the world and in other people (Ahmadi & Ahmadi, 2017; Schnell, 2012, 2017). *Religiosity* relates to transcendent beliefs, experiences, and practices developed over time within a community that are understood as having a sacred character incorporating also non-theistic expressions for example when ones family or the environment comprise a sacred character (Koenig et al., 2012; Pargament et al., 2017).

Employing a Kierkegaardian-inspired analysis as a theoretical frame reflects the attempt to embrace the possible complexity of human experience, since the Kierkegaardian aesthetic, ethical, and religious stages open for both secular, spiritual, and religious meaning orientations as possible choices when confronted with suffering in life.

The Kierkegaardian *self* is argued to be a relational and dialectical self (Nielsen, 2018):

> A human being is spirit. But what is spirit? Spirit is the self. But what is the self? The self is a relation that relates itself to itself or is the relation’s relating itself to itself in the relation; the self is not the relation but is the relation’s relating itself to itself (Kierkegaard, 1849/1962, p. 73).

When Kierkegaard uses the term “spirit”, it is to be understood in relation to his definition of the human being as a self; not to be confused with the formerly defined understanding of the
term “spiritual”. Kierkegaard characterizes the human being as a synthesis of opposing existential dimensions:

A human being is a synthesis of infinite and the finite of the temporal and the eternal, of freedom and necessity, in short, a synthesis. A synthesis is a relation between two. Considered in this way, a human being is still not a self (Kierkegaard, 1849 /1962, p. 73).

To realize oneself, the goal is not to choose between the two existential poles, but to make a synthesis. The human being is not per default a self but bears the possibility to become a self, what Kierkegaard would term coming into existence. To become a self, the human being needs to synthesize the opposing existential dimensions such as freedom and necessity. The existential dimensions are extremes in each end of a continuum which makes neglecting one of the opposing dimensions possible (Nielsen, 2018). The human being often avoids synthesizing the opposing poles and instead lets him/herself be consumed by either of the two. To be engulfed in the necessity, finite, and temporal means living a concrete life, limited by the temporal, and absorbed in what is expected to be necessary. To be engulfed in possibilities, infinity, and the eternal defines a life consumed by imagining without connection to a bodily, concrete everyday reality. In both extremes, the human being is not realizing the self, but is mis-relating the self’s relation to itself which leads to despair (Nielsen, 2018). Most of us, Kierkegaard would say, live a life in despair without knowing it (Kierkegaard, 1849 /1962, p. 182), because it is more convenient to fulfil the expectancies of our time without taking a subjective stance to our-self and our lives. We live a straightforward, unconscious or ‘spiritless’ life (Nielsen, 2018) until something from outside stops us and confronts us with the existential conditions in life that have been there all the time without us recognizing them.

The Kierkegaardian concepts have been widely discussed across disciplines, but in psychology, especially the aesthetic, ethical, and religious stages, and the notion of the other have been a subject of debate (Nielsen, 2018; Nordentoft, 1972). In the current article, the
stages are understood not as psychological, developmental stages to be followed, but as ideal possibilities and as life-spheres, as Nordentoft argues in his comprehensive study of the Kierkegaardian psychology (1972, pp. 35-36), and as employed in psychological analyses of the crisis related to somatic illness and of a psychotherapeutic case study (Jacobsen, 2000; Peteet, 2017).

In the work “Sickness Unto Death” (1849/1962), Kierkegaard describes how the human being becomes a true self by relating to oneself as a relationship through the other. The notion of the other might open for a broad interpretation; however, later in the text, Kierkegaard clearly understands the other as the Christian God. Consequently, the other and the Christian God have been understood from different perspectives in philosophy and psychology; as an interpretation of the other as God but also as inter-subjectivity (Habermas, 1995; Nielsen, 2018), as a commitment to the community (Kirby, 2004), or simply marginalized (Nielsen, 2018; Nordentoft, 1972). Debates within academic psychology about the religious dimensions in Kierkegaard’s work are understandable, since Kierkegaardian philosophy makes statements about existential and religious dimensions such as love that can only be believed and not academically verified (Jacobsen, 2000). On the other hand, when we want to understand individual experiences of patients and these experiences include faith, it would be at the expense of the first person’s perspective if we precluded such dimensions that can only be believed (Boyd, 2000). Consequently, also dimensions of faith and belief, must be included in academic psychology as a part of human experience. From a psychological perspective, the current article takes as point of departure the meaning of the patients’ experiences as they appear in the individual accounts, including their religious meaning orientations, wherefore the truth value of their beliefs will not be discussed (Gonsiorek et al., 2009; Pargament et al., 2017).

To analyze religious and spiritual aspects in our interviews and to understand our patients, we
argue for the following interpretation: The human being can become him/herself by resting
“transparently in the power that has established it” (Nielsen, 2018, p. 71), which may
comprise a broader interpretation of “the establishing power” than in Kierkegaard’s original
work. Kierkegaard’s other is the Christian God as the creative power and symbol of
unconditional love. This implies a theological stand that goes beyond the psychological
profession. Viewed from a psychological and non-confessional perspective, Kierkegaard’s
other and definition of the self can be used as a psychological, analytical tool if interpreted as
representing all these relationships that generate foundations for human life. Being a self
through the other thereby implicates resting on or surrendering oneself to something bigger
than oneself, and might not only encompass individuals considering themselves to be
Christians, but all human beings who ground themselves in something beyond their own
power such as, e.g., a greater cause or love as an existential choice in life. In this sense being
a self through the other is only possible through the religious life-sphere, understood broadly
as something beyond the individual human being. This broader interpretation of the other also
resonates with earlier philosophical and sociological understandings (Nielsen, 2018) and with
a philosophical analysis of patient-experiences (Knox, 2019).

Methodological Considerations
The analysis in this article is based on 23 semi-structured patient interviews. The interviews
were conducted as part of a research project investigating how physicians and patients with
multiple sclerosis or chronic pain communicate about existential, spiritual, and religious
experiences (Andersen et al., 2019, a+b). As part of this research project a further eight
interviews were conducted with physicians treating one of the two illness conditions. Analysis
of the physicians’ experiences is presented in a separate paper (Andersen et al., 2020). The
study employs a qualitative methodology in order to explore how the patients explain
existential challenges in relation to the course of illness. The patient interviews yielded a
deeper insight into the dynamics that led to existential challenges along with how patients lived with these challenges.

The analysis of patient experiences was guided by Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009). With a hermeneutic-phenomenological approach, the patients’ descriptions of their experiences are primary and comprise the foundation for the interpretative analysis to explore subjective meaning-making. Following the recommended steps of IPA, we initially tried to bracket our pre-understandings and familiarized ourselves with the data, and to keep an openness while developing themes. Each interview transcript was analyzed in its own right before summarizing similarities and differences across interviews.

Data Generation
The semi-structured interviews were conducted by the first author between November 2018 and April 2019. The interviews lasted between forty-five and ninety minutes and were subsequently transcribed. The interview guide centered on the patients’ experiences of existential, spiritual, and religious issues in relation to their illness and treatment (for the interview guide please see Andersen et al. (2019,a)).

Researcher Reflexivity
The first author, a trained clinical psychologist and a researcher, conducted all interviews. The patients were informed about the professional background of the interviewer. A clinical, therapeutic conversation and a research interview do share common traits, e.g., the necessity of establishing a trustworthy and asymmetric relationship in which personal issues can be shared. Still, there are differences between these kinds of interviews which are ethically important to be aware of, such as their purpose of sharing (for personal change or knowledge
production) and who determines the subject of interest (the client or the researcher) (Hall, 1996/2003; Kvale & Brinkmann, 2014). The author group includes researchers and therapists experienced in the area of health psychology, health communication, religious sciences, and theology. A researcher and psychologist not previously involved in the project was included in the group at a later stage. This would challenge some of the taken-for granted ideas and assumptions among the consolidated group members, hereby fostering a climate of renewed researcher reflexivity (Malterud, 2001).

**Participants**

The 23 patients were diagnosed with severe, non-life-threatening, chronic illnesses such as chronic pain or multiple sclerosis. Patients were recruited primarily through the treating hospital wards, but also through a snowballing sampling technique, (Smith et al., 2009) and they received written and oral information about the study before giving written consent to participate.

The patients were aged between 32 and 66 (mean age 51 years), all patients were Danish citizens, of which two had prior citizenship in another country (a European and a Middle East country), seven were males and 16 females, and 17 lived with a partner or a child, six were living alone. The educational characteristics of the patients were diverse with three completing 10-12 years of education, five craftsmen, nine with a medium long education, and six with a university background. The patients had lived with their diagnosis between 1 and 33 years (8½ years in average) and over half of them were retired due to age or disease. To assure anonymity, the patients will appear with anonymized initials, years with the diagnosis and gender as the only identification.

**Analytical Strategy**

During the process of interviewing, transcribing, and taking initial, analytical notes, the patients’ stories about existential struggles with identity and self-relation were recurrent. As
recommended in IPA, we employed the concept of “double hermeneutics” (Ricoeur, 1970; Smith et al., 2009) where suspicion is practiced using theories (Smith et al., 2009, p.36). After analyzing each interview in its own right followed by looking at themes across cases (please see the steps of IPA above), we searched for a theory that could serve as a further key to explore the meaning of the patients’ experiences. We wanted the theory to comprise the multiple ways the patients were found to live with and respond to the illness-related challenges. Reading Kierkegaard made the first author go back and read the interviews and the analytical themes again to study the Kierkegaardian concepts’ potential applicability for deepening our understandings of the patients’ experiences. We thereby combined our initial interpretive phenomenological understandings with specific Kierkegaardian concepts as a further step in abstraction and to further explore the existential struggles of patients. Adding a specific theoretical frame of analysis to the interpretation is in line with IPA (Smith et al., 2009, p. 36) and reflects the iterative process of interpretative analysis in qualitative studies: How theoretical understandings interact with empirical materials to explore the phenomenon of interest by systematically adjusting the methods (including analytical approaches) and theories to the subject-matter and research questions under investigation (Huniche & Sørensen, 2019).

Findings

The themes relating to the patients’ existential, spiritual, and religious illness-experiences were found to be prevalent in both groups of patients and were therefore not specific to any of the two illnesses. The findings appear in two parts: The first four themes - Illness as a stroke of fate, Illness and despair, Struggling to relate to oneself, and Becoming oneself - describe different aspects of struggling to identify and relate to oneself after receiving a chronic diagnosis. The next themes – the Aesthetic, Ethical, and Religious Life-spheres - unravel the patients’ different ways to respond to the existential claim.
Illness as a Stroke of Fate

Repeatedly across the interviews were the patients’ spontaneous illness-stories as an unwelcomed interruption of their lived everyday life. Illnesses as chronic pain and multiple sclerosis interfered with the patients’ everyday-life in a way they experienced as totally life-changing; from a former active to a restricted lifestyle with the risk of reducing their capacities to participate in work and social life and threatening their whole identity. The related feelings were expressed as shock, chaos, sadness, or as an emotional limbo.

Receiving the diagnosis was like falling from a bench. Suddenly, I could not go on with the things I did. And it took some time before I really understood that I actually was in a totally different situation (EV, female, diagnosed for eleven years).

The illness was not only a question of somatic symptoms and physical disabilities. It did not only interfere with the psychosocial life, but with their whole existence, “it interferes with everything” (ST) as another female patient framed it. The illness as an interruption, as something from outside that has a disturbing effect on life as it used to be, can be seen as an analogy to what Kierkegaard describes as “a stroke of fate” that makes it impossible for the individual to enroll in a straightforward and obvious way of living (Kierkegaard, 1849/1962, p. 107). As one female patient said about receiving her diagnosis: “the rug was pulled out from under me. I was in shock” (DI). A male patient explained how he thought his physical challenges could be resolved by an operation and a following retreat until the physician told him he could work no longer:

I broke down, because it has never been me to have a last day of work. I have always been doing things, day and night, always. And it still hurts, I’m suffering because it is difficult for me to gear down far enough, and it is hard (JE, diagnosed for 5 years).

The characteristic of the Kierkegaardian ‘stroke’ is that it disturbs the straightforward and well-known life in such a way that the human being cannot continue but will be thrown into existential despair. The illness functions as such a “stroke” bringing the patients into despair;
evoked by the embodied pain and suffering and furthermore evoked by the physicians’ message of the chronicity of their illness (Jacobsen, 2000).

**Illness and Despair**

In Kierkegaard’s terminology, despair is not primarily to be understood as an emotional feeling, but as an existential condition defined as a fundamental mis-relation in the self (Nielsen, 2018). The ‘sickness unto death’, as Kierkegaard entitled the book unfolding the concept of despair (Kierkegaard, 1849 /1962; Kierkegaard, 1980), is clarified as a condition of life which the individual first recognizes with the “stroke of fate”. Despair as an existential condition that first becomes clear with the illness resonates with the following experience of a woman recently diagnosed:

*I’m totally lost about what makes sense. I wasn’t before; it was my job that gave me quality in life, it gave me identity... I got such a kick out of being part of that inferno (DI, diagnosed for one year).*

The patient goes on to explain how she never stopped before and constantly had to move on to new activities. Nowadays she has come to enjoy just being with herself, sensing where she is at. Through the lenses of Kierkegaard, she had let herself be absorbed in work-life preventing her from working on becoming her-self, and this is, according to Kierkegaard, the despair of the spiritless life, of not-willing to be oneself (Kierkegaard, 1849 /1962, p. 78). The confrontation with the chronic illness shocked her and led to a sense of hopelessness and despair. At the time of the interview, this patient had lived with the diagnosis for one year and was still in a process of how to respond to the “existential call”, spinning out from recognizing the fundamental changes in her life. Her experience resonates with other patients in our study:

*I experience myself as a reduced version of myself. I have had some good dialogues with psychologists, and we have talked about how it’s a stupid thing to say or that it is not very smart of me to say; it sounds so negative. But actually, God damn it, it is a really negative thing that many of the things I once thought I was able to do, have*
been able to do, I can simply not handle anymore. And physically, the pain is there, but the psychological part I feel even more (GE, diagnosed for one year).

I use all my energy just to endure the day. I can do nothing. I’m nicely and easily being eroded as a human being (FI, male, diagnosed for one year).

In the first quote, the patient is holding on to his own perception of the negative experience of being a “reduced version” of himself not capable of handling what he used to be able to do. In the next quote, the chronic illness is explained as a breakdown of the patient as a human being because he experiences that he cannot do anything but endure the day. In this way, they both stress how the illness is critically influencing not only the physiological part but their entire self-experience. The experience of the significant negative illness-effect on the self can be understood as Kierkegaard’s despair and mis-relation to the self: When illness is a constant reminder of the restrictions in life shadowing former possibilities, illness becomes an obstacle to synthesizing life between the existential poles of necessity and freedom.

To clarify the need for synthesizing, Kierkegaard speaks of the lack of freedom and possibilities as being “dumb”: “Necessity is like a sequence of consonants only, but in order to utter them there must in addition be possibility” (Kierkegaard, 1849/1962, p. 95; Kierkegaard, 1980). Freedom and possibility are achievable through the human ability for imagination or fantasy; or as Kierkegaard puts it: “The self is reflection. Imagination is the possibility of all reflection” (Kierkegaard, 1849/1962, p. 89; Kierkegaard, 1980). To be ourselves requires our ability to fantasize about our possibilities; to imagine ourselves in the future. The existential struggle of becoming oneself is a challenge of imagining one’s own possibilities in the future.

**Struggling to Relate to Oneself by Synthesizing the Existential Poles**

To relate to oneself, in the terminology of Kierkegaard, is to synthesize between necessities and possibilities. Staying in the tension between the opposing existential poles is described as suffering (Kierkegaard, 1844/1962, p. 68). When we as human beings cannot project
ourselves into the future, when we experience extreme suffering, we are at risk for hopelessness and suicidal thoughts:

"Sometimes I’ve thought it would be okay if I did not ever wake up again, because some days are so hard. But I always think of my children, and I will never do anything to hurt myself" (MA, female, diagnosed for one year).

This quote illuminates how some days are experienced as meaningless, the female informant having thoughts of vanishing, escaping suffering and pain; in Kierkegaard’s words such days, where one cannot imagine oneself in the future, result in a profound struggle to be oneself. Experiencing illnesses as multiple sclerosis and chronic pain can be a constant reminder of the body and the necessities of life to a degree that challenges the ability to envision oneself in the future. Although a female patient explained she has a list of concrete illness-related problems she wants to solve and tick off (how she is going to earn her living and where she can live), she also explains how her unknown future is anxiety provoking; as a land of no dreams, as if she is losing sight of her future:

"This is what makes you move on, to have a dream, knowing what you are after…. I want to see what is out there, but I get frustrated. What am I going to do? The land is totally open, it is a large plain, and I try not to think about it, because I get stressed. So, I try to think about the small everyday matters… drinking coffee at a café or going on a trip (DI, diagnosed for one year)."

On the one hand, this patient experiences a need for resolving some practical issues for her future life, as a scaffold to hold onto in times of chaos. But with a newly diagnosed chronic illness she does not know what her future possibilities may be, nor what new goals she can realistically set for her life. It seems as if she is stuck in necessities expressed as “I have to…”. Struggling to synthesize as a way out of the despair, she starts to think about the daily possibilities for sense-making of the small things that could bring pleasure in her life. Instead of passively turning to either of the extremes, such as being absorbed in necessities or possibilities, it seems that the demanding task of trying to synthesize the opposite poles of necessity and possibility, of the finite and the infinite is what makes sense and helps her move on.
One of the patients, a woman with ten years of experience living with the chronic illness, voiced the struggles to come to terms with necessities like this:

_We all have so many facades, but when you have a chronic illness and pain, then it is not realistic anymore, but we don’t know. We hold on to the routines: “I have to because one ought to, and I’m used to do that”. And if you could prevent that, I think you could pick up more people before they are out of their depth. There are a lot of patients who can’t let go. It’s so depressing to have pain. But if you could realize in some dialogues that maybe my goals have to be something else, something I’ve never thought about before...(GR)._

The tendency described is to hold on to the necessities and routines from life before the illness, though it is not possible and realistic anymore. When illness is a constant reminder of the limitations and necessities of life, there is a need for change in order not to be depressed. Depression becomes a synonym for the despair of necessities (Oaks, 2016). In the patient’s account, the process of realizing new goals can be facilitated and unfolded by dialogue “because you can’t get there by yourself” (GR), and another one adds “putting this realization into words makes me realize it properly” (DI).

Stressing dialogue as an important part of realizing and as bearing the possibility for facilitating an existential choice, point to the relational understanding of the Kierkegaardian self:

_Such a derived, constituted, relation is the human self, a relation which relates itself to its own self, and in relating itself to its own self relates itself to another (Kierkegaard, 1849 /1962, p. 73; Kierkegaard, 1980)._

Therefore, to relate to oneself and thereby relate to the other can be interpreted as the individual actualization of oneself through a communicative engagement with the other (Nielsen, 2018).

**Becoming Oneself as an Existential Process**

The core existential struggles of the chronically ill patients in this interview study is that of becoming and being oneself:

_When you are in good health, you have a goal with your life and some routines... and with a chronic illness, you have to rethink your life... I wasn’t prepared for how many things that would change in my life, no one told me about it... You really take some_
rolls and it’s my job to figure out what I’m going to do, it is hard... It has actually taken me a lot of years...
Now I have another approach to life, I appreciate it, do not take it for granted anymore. I would never have come this far if I hadn’t been ill. It’s been an eye-opener and it’s kind of scary: Only when you really stand on the edge and look down the slope... (GR, female, diagnosed for ten years).

Though there are no clear-cut phases, it seems that the earlier in the process the more frustration and struggle is involved. A patient diagnosed for one year voices an experience of losing herself and of the sorrow related to a mis-relation in the self:

I have lost my-self, and I will not keep looking at the one I was but look at the one I can be, the one I am in the process of becoming. I don’t want just to be the sick one, I want to be me (KA).

The experience of losing oneself, understood as the self that one used to be, is a consequence of the chronic illness, and the patient here personifies the process of being. She cannot be her old self but must become what she already is including pain and disabilities; she realizes that she must choose herself as she is – her new self that is herself now. How can we identify the new ‘me’ as a self? Employing the Kierkegaardian understanding of the self, this patient is struggling to synthesize between being sick - and thereby constantly reminded of the finite, necessity, and temporality in human life - and being me, understood as a reflection of being more than sick (infinite), opening possibilities (freedom) and imaginations of what she would like to become (eternal). Through the pain of letting go of her old and well-known self, she is taking her-self seriously, by trying not to escape and taking on the complicated task of living her life as it is.

Living with her illness for 18 years and looking back, a female patient describes the first years like a profound identity struggle:

My whole world and my identity collapsed. Not being able to finish my education, which was really hard. It is the worst thing in my life, I think, worse than receiving the diagnosis. So, I struggled a lot with my identity. I spent a couple of years identifying as just me (JA).

The excerpt explains a change in the foundation of her identity towards accomplishing to be the person she is without performing. In Kierkegaard’s words, she changes from focusing on
the exterior values to the inward values.

In these interviews, the possibility of realizing the existential conditions, always inherent in human nature, becomes evident when a chronic illness, such as multiple sclerosis or chronic pain, forces patients to abandon their established everyday routines, to face existential realizations and a painful struggle to find themselves anew in order to live. They stress taking individual responsibility as an essential part of finding their existential way of being. The subjective responsibility for responding to the existential calling is a main issue in the theory of Kierkegaard.

Responding to the Existential Claim through the Aesthetic, Ethical, and Religious Life-spheres

The participants’ painful experiences echo Kierkegaard’s concepts of despair as a mis-relation in the self. A further Kierkegaardian-inspired analysis of how to become oneself can deepen the understandings of how patients integrate the existential challenges into their lives. Kierkegaard outlined three different life-spheres (Nordentoft, 1972) as ways to respond to the existential confrontation: through an aesthetic, an ethical, or a religious life-sphere (Kierkegaard, 1845/1962). Our applicable aim was to understand the patients’ different ways to approach the existential challenges. Therefore, the patients’ experiences will be analyzed through Kierkegaard’s concept of life-spheres, not as normative solutions, but as a model of different possible ways each human being can subjectively choose (Nordentoft, 1972, p. 35).

The aesthetic life-sphere

The aesthetic choice implies a life with focus on pleasure and the here-and-now. Individual freedom is praised and everything beautiful is enjoyed. The aesthetic choice also implies leaving behind a “spiritless” life where one follows the routines and fulfils the expectations from society. After being halted by their health conditions, it seems that the majority of the patients in our study do not return to the “spiritless” life. Instead, they focus on aspects of life
that afford pleasure here-and-now as a way of living with the existential challenge of how to be a self under these altered and often painful circumstances, as in the following quote from a female patient:

*I’ve reached the point, and this is something that has changed, where I don’t care what people think. What matters is how I feel and that I’m doing fine. I don’t know my future, so I must have it all right now, that’s how I have to live my life and it’s my choice* (GR, diagnosed for ten years).

Several patients from our study mentioned being in nature as significant for their well-being, as a need for fresh air, nature, and space around them growing with the illness:

*It helps letting go of pressure, things that hurt, the pain. When I’m outdoors, I can relax better, the sky’s the limit. I’ve become more conscious about this, that I need it, as my illness has worsened* (DA, female, diagnosed for 5 years).

Nature provides possibilities - being in nature helps her being her-self understood as synthesizing the existential extremes of necessities and freedom: Her illness is a constant reminder of limitations and necessities in her life, and being outdoors reminds her of freedom and possibilities. Kierkegaard’s understanding of the synthesis of the existential poles as a precondition fits well with her desire to be her-self between these poles.

While living with multiple sclerosis or chronic pain is characterized by necessities and the finite life, a male patient emphasizes aesthetic values as a way of synthesizing with freedom and infinity:

*When you become chronically ill then it’s ...important that the times when I feel well is quality time; enjoying, experiencing things and doing things with my family. It is about optimizing your spare time to as high a level as possible, within the scope of your possibilities, of course. For me, going on a boat trip is freedom: Out there we are all equal. It’s been an awakening to me the last four years. You can’t do anything but eat, drink and feel good* (JE, diagnosed for 5 years).

Leaving behind the values of the former and spiritless life appears inherent to the aesthetic life-sphere; cherishing the here-and-now of being in nature and with others as opposed to living through external and material values such as image, work life, and appearance for the sake of other people.

**The ethical life-sphere.**
In the ethical life-sphere, choosing actively what the individual wants to be is more important than focus on what to leave behind. The ethical is a positive choice of taking one’s life seriously; taking responsibility for being oneself by choosing oneself implies obligations, responsibilities, and values such as trustworthiness and safety. A female patient explains how she actively make choices as a consequence of the illness:

*It makes me choose. Relationships have always been important, but I didn’t focus on it. Now I engage in what really means something. Before I was just led by something work-related... Now I stop and reflect about if this really is what I want or if there is something at home that is more important... During this long course of the illness, I might have given it a lower priority... but I think it is important to realize that you really have to choose and hold on* (ST, diagnosed for four years).

At some point, this patient realized that the illness had determined her life and that she had not prioritized what was important to her, thereby personifying Kierkegaard’s notion of turning back to the spiritless life where the individual just follows the expectations from the surroundings; in this case the perceived expectations and necessities related to living with the chronic illness. Although she knew that relationships were important to her, she just followed the expectations from the surroundings until she realized the importance of making an active choice about her prioritizations and realizing this choice in her everyday practice.

Furthermore, this choice was explained as an ongoing process as she switched between her old way of living and her new priorities.

From the despair following the illness, our patients explain how they take an active choice:

*I think I have hit rock bottom and that I am on my way up. It is also an existential decision: I live with the pain... I have a mantra: “I'm alive” – there are no negations in it. I'm alive and I hold on to that. It's me who hold the reins* (FI, male, diagnosed for one year).

This quote also illuminates an existential struggle of meaninglessness and an attitudinal stance towards his own conditions in life that resembles Frankl’s work on the human will to meaning (Frankl, 1982), which is also inspired by the Kierkegaardian writings (Frankl, 1970). Some patients refer to a meaningful and positive choice they wished they had integrated earlier in their life:
I want to help other people, to see that my family is doing fine. I regret that I did not think about what I wanted to do with my life before I got ill. I will recommend others to do so (GE, male, diagnosed for one year).

A patient, who had lived with her chronic illness for eleven years, clarifies the differences between her former life focusing on material values and her actual life by saying:

'It's how you are doing that's important. I learned that the hard way, but I would have liked to have paid more attention to it before I reached this point. Somehow it gives me more peace of mind and room for myself (EV).

By making an active, subjective choice of what is important in her life, she synthesized the necessities of her bodily limitations with the actual possibilities of her life resulting in a new and more attractive relationship to herself. The despair following from the illness and associated interruption of life as it used to be was released by the ethical choice of prioritizing internal values such as relationships above external, material values. The actualization of the choice seemed to be an ongoing process in several patients’ lives since their illness and pain were constantly reminding them about the necessary and finite extremes of lives. To resolve this despair demanded a constant choice of focus on freedom and infinity, as in the ethical choice of the patient quoted above.

**The religious life-sphere.**

When the patients described how they managed their life with a chronic illness such as multiple sclerosis or chronic pain, several referred to spirituality and a belief in something bigger than themselves like a higher purpose of life. To a certain degree, the religious life-sphere overlaps with the ethical life-sphere’s focus on choosing what is important in life; but where the choice in the ethical life-sphere can consider individual aspects, the religious life-sphere contains a dimension that transcends the individual. A patient summarizes his experiences: “There is probably more than meets the eye” (JA, diagnosed for 30 years). To another patient, the positive implications that spirituality and love as an active choice had on his relationships with other people extended to his illness-experience:
Its forgiveness... you get help from outside, that’s what I experience. It was later I realized it was spiritual. Love is an intelligent solution. Now it’s easier to keep the pain in check (LA, diagnosed for three years).

For some of the patients, the ground beyond their own power is a mixture of close relationships, reading literature, and being able to help other people as a responsibility to a Christian principle. Some patients also reveal faith or religion as being significant for them to gain comfort or relief, like a patient practicing Buddhist meditation: “When I meditate, I don’t feel the pain” (CA, female, diagnosed for one year); or as significant for them in order to be themselves during the illness-experiences:

I use my religion to be calm sometimes, but it doesn’t take away my pain. I live by my religion, because I believe in the religion, and in our religion, we think of Paradise if you take care of your-self and your family and everything (UW, male, diagnosed for one year).

Here, religion is explained as a convinced faith in an afterlife that provides peace regardless of whether the pain is relieved on earth. Another patient, diagnosed for 20 years, sees herself as a believer and uses God as the one she relieves her mind with: “I won’t say that I pray, but I forward thoughts and frustrations... such as ‘why doesn’t he help right now?’” (ME). In this way, her faith and relationship to God provide relief regardless of her concrete experience of help.

Talking about the deep frustration and suicidal thoughts during the first year of illness, a female patient explains how a religious experience became the turning point:

It was a very religious experience, I thought it was God who said he was with me. And then I did not take it so hard any longer, because though I felt my family wasn’t supporting me God was. I consider myself a Christian, but don’t go to church or believe in the Bible, but I got an affirmation that I had someone on my side (HA, diagnosed for seven years).

The growing importance of existential and religious values with hard times is further confirmed:

Before, if I thought too much, I just went out shopping, tried to run away from it. But I have experienced that I cannot, I have to do something else. And I sing, play music, and pray. And I go to church, it gives me peace and presence. To have a place outside
myself and outside my network to put the dark things I don’t know where else to put (CA, female, diagnosed for ten years).

Here, the patient repeats the abovementioned point of not being able to run away and distract herself from thoughts, as she did before. Instead, she seeks to something bigger than herself such as music, going to church, or going for a walk. The meaning of “going for a walk” and being in nature, is explained further as a room for reflections regarding the illness:

I went out for walks and looked at the stars and thought; I’m not going to die from this, it can be really bad, but we still have each other.

Being in nature and looking at the stars here became the bigger frame of reference through which she understood herself and were able to relate to her new situation in life. Furthermore, nature became a place where she could just be without any purpose:

Now, I give myself breaks, where I’m just happy to see the winter aconite blooming soon. I don’t think it was important to me before. It is really important for me now, to go for a walk, spend time for myself to... just to be.

Nature here not only represents an aesthetic pleasure in life, it becomes the frame in which she can truly be herself; the bigger frame in which she can rest. Other patients also described being in nature with another purpose than exercising or enjoying the beauty. For them, nature seems also to function as the bigger frame of reference that reflects the notion of the other as something bigger than themselves through whom they can relate to be able to relate to themselves.

All the patients mentioned relationships as the source of meaning, and relationships were fundamental for their existential choices. However, some also explained how their relationship to themselves went through close, faithful relationships with others. A patient explained at first how the illness forced her to take her life up for reflection and work with what she called: “Finding peace in myself” (DA). Later she revealed an example that indicated how relationships were fundamental for her process of relating to herself not only as an ethical choice but as trust:
I called a friend and cried for half an hour and then I felt the things she had asked me about meant that I could... (breathes out) I could make a choice... She knew how to inquire so I could “man up” and not only feel sorry for myself.

In this example, through the communication with a friend, the patient changed from being a victim to be an independent self by taking herself seriously and taking responsibility for her life. The foundation for the communication, however, was trust: she surrendered herself and all her misery to the relationship with her friend believing in her friend’s caring and benevolent attitude. Faith in their relationship was the reason for her to surrender herself to open and honest communication, and trusting her friend was significant for her to reflect on the questions, make a choice, and thereby be her-self.

In different ways the patients describe how they, through spirituality or religion, became able to relate to themselves as human beings staying in the tension between the necessary, finite, and temporal parts of life and the free, infinite, and eternal parts of life (Kierkegaard, 1849 /1962). Furthermore, some patients also described nature or relationships with other people as significant in a way that are similar to the characteristics of faith in a transcendence and with the Kierkegaardian “relating to oneself through the other”: nature as something bigger than themselves to interact with in times of crises and resting faithfully in relationships for them to be able to relate to themselves.

Looking across the whole analysis, the patients experienced the life-spheres of Kierkegaard in different ways, at different points during their process and sometimes, life-spheres were experienced simultaneously. In one of the cases, both the sense of freedom from being in nature (aesthetic life-sphere) and trust in close relationships characterized by benevolence (the religious life-sphere) were significant for the patient to be able to find peace in her-self. Based on this analysis, the three different life-spheres can be represented in the individual in different ways, to varying degrees, and from time to time.
**Discussion**

The patients of this study living with chronic pain or multiple sclerosis were found to experience illness as “a stroke of fate” resulting in *existential despair*, as analyzed with the concept of Kierkegaard. Despair was unraveled as a struggle to find out how they could identify and relate to themselves in their new life-situation. Struggling to become oneself was described as a long process including failed attempts to go back to the old way of being. Several of the participants were struggling and describing despair at the time of the interview, some of those recently diagnosed. However, in lives restrained by illnesses, the patients fought to find ways out of their despair; they struggled to exist by living with both existential poles of necessities and possibilities, not letting themselves be absorbed in either. The way they responded to the existential challenges were by subjectively choosing aesthetic, ethical, and religious life-spheres, and they solved the despair by realizing themselves as human beings through *the other*, understood as relationships, nature, spirituality, or God.

Our analysis shows how Kierkegaard’s concepts of the human self and the life-spheres as possible solutions to inherent despair are valuable in order to understand patients’ experiences of multiple sclerosis and chronic pain in an existential-psychological frame of reference. The theoretical analysis of the patients’ existential struggles provided a deeper understanding of the complicated and significant process of finding new ways to relate to oneself after receiving a diagnosis.

The current existential-psychological analysis illuminates the patients’ ways to live with their illness-related challenges as going beyond the psychological concept of coping and meaning-making: The patients’ ways of responding to the existential challenges involve their whole life; it is more than an emotional or problem focused, psychological strategy (Lazarus & Folkman, 1984) and more than a cognitive structure of meaning-making (Park, 2005): it is a
way of being, of existing. When life is fundamentally transformed by severe illness, it seems that the existential struggles cannot simply be “managed” but require a subjective and ontological stand in life in order to live as oneself, to be oneself.

Emphasizing the existential dimensions and inherent struggles of a life with multiple sclerosis or chronic pain makes room for acknowledging suffering as an experience that cannot be medically cured or otherwise fixed. On the contrary, suffering, as described by the patients during interviews, is an existential concern that needs reflection and dialogue. It is not a question of how to learn to think positively or a cognitive process of acceptance or reappraisal. How to live with suffering and limitations is a long process of actualizing possibilities (synthesizing between possibilities and necessities) by relating to oneself through the other. Thus, the current study indicates that a broader frame of reference is needed to supplement the cognitive coping and meaning-making theories in order to grasp the existential struggles of patients suffering from multiple sclerosis or chronic pain.

Kierkegaard’s self is not a private self that human beings need to develop individually - as in the humanistic tradition focusing on a self-contained individual (Nielsen, 2018). According to Kierkegaard, the self is rather a relational self that relates to itself through the other, and ultimately through the ultimate other, God (Oaks, 2016). The Kierkegaardian claim that the human being has to relate to oneself through the other in order to really exist can be compared to Buber’s notion of the encounter between an I and a Thou as a precondition to be an I (Buber, 1923/1997). This encounter is characterized by an intense, unconditioned presence of an I and a Thou, in a moment without purpose and means. Such moments may occur also in health care contexts when the professional brackets own biomedical assessments and is present in the intersubjective contact (Andersen et al., 2019,a; Buber, 1923/1997). Buber argued that a Thou can present as both nature, other human beings or spirituality and God. This article’s interpretation of Kierkegaard’s other as a relationship with something bigger.
than oneself as a precondition for being oneself can be compared to the Buberian meeting between an I and a Thou as the precondition for being an I. Further, the characteristic of the Buberian meeting is the unconditional presence without purpose and means, which also characterizes the Kierkegaardian understanding of the other as unconditioned love.

The traditional interpretation of the religious life-sphere is in the current analysis expanded by the inclusion of nature and relationships. In the Kierkegaardian understanding, the other is God. However, when applying Buber, we can distinguish between relating to nature as an aesthetic value where the purpose is to relax and enjoy, and as a religious value without any other purpose than being present as oneself. In our analysis, we saw that nature for some of our patients comprised an aesthetic value. For others, nature was the place that generated a sense of being and the bigger frame of reference through which they understood themselves. In addition, relationships to other people further comprised a ground to trust other than themselves that was significant for the patients’ relation to themselves. The Buberian notion of nature, relationships, and the spiritual world, or God, as constituting the possible Thou thus adds to the Kierkegaardian understanding of the patients’ experiences by stressing nature and other people as equal opportunities through which to relate to be oneself. Our empirical findings support the broadening of the intersubjective and relational understanding derived from Kierkegaard’s other to include human relationships and nature.

**Clinical Implications**

Bringing the Kierkegaardian concepts to the analysis enabled us to unravel the distinct feelings and experiences of existential despair and of struggling to relate to oneself that cannot be limited to either the physiological condition or the psychosocial consequences of illness, although these have a significant impact. The process of how to relate to oneself and to live with multiple sclerosis or chronic pain seems to profoundly affect the patients’ illness
experiences and their psychological health. Stressing the self as relational and the dialogue as essential for realizing oneself might therefore call for a broader approach to clinical practice. To initiate such an existential conversation and assessment implies asking open questions possibly in connection with a short explanation such as: “We know from research studies that when you suffer from chronic illnesses, such as multiple sclerosis or chronic pain, it can be challenging to figure out which person you are becoming and how you can find meaning in life given the new life circumstances. Is this something you have been wondering about too?” With this short communication, the health care professional acknowledges and normalizes the possible existential struggles related to the illness; and by inviting to an open dialogue, s/he paves the way for establishing a relationship in which the existential struggles can be shared. In this manner, healthcare professionals can identify those patients who would welcome a dialogue about the existential illness-related struggles for the benefit of their health. Our results reveal that bringing an existential awareness to patient treatment may be foundational for adequate care that addresses the whole-person and supports them to uncover meaning through an illness that has the potential of creating a high level of distress. All patients may not respond positively to existential concerns, but for those that do, it could make an immense difference in their quality of life and recovery process.

**Methodological Considerations**

Combining the analytical, inductive strategy from the interpretative phenomenological approach with Kierkegaard’s conceptual framework may be questioned as deviating from the inductive, phenomenological methodology and therefore considered a limitation. However, the interpretive phenomenological approach stressing the primacy of each individual’s experiences corresponds with the subjective emphasis in a Kierkegaardian approach. In practice, we have been true to the case-based approach in IPA by analyzing each individual interview before comparing across interviews. Employing this iterative approach is equivalent
to IPA’s “double hermeneutic” in which additional theories can serve to disclose the meaning of experiences (Smith et al., 2009, p. 36).

An added theoretical framework can be criticized for restricting the possible findings to those applicable to its theoretical concepts. In this study, however, derived from the first inductive analyses, the Kierkegaardian approach was chosen to explore further the broad spectrum of patients’ experiences. Furthermore, while analyzing with a theoretical focus, the first author continuously reread the interviews to ensure the empirical foundation for the analysis.

Research is needed in order to explore whether the findings are transferrable to patients suffering from other chronic illness conditions.

**Conclusion**

The analytical framework inspired by Kierkegaardian concepts may give us a deeper understanding of the complex existential challenges in chronic pain patients’ experiences of illness as an unwelcomed, fundamental change of their lives. Patients with multiple sclerosis and chronic pain are existentially challenged in being themselves and with the concepts of the aesthetic, ethical, and religious life-spheres, we have illuminated the different ways through which they respond to and live with this challenge.

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