

Stranger Times. Heterotemporality and the Spiritual Experience of Illness

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Abstract

As highlighted in the medical humanities and narrative medicine the onset of a severe pathology constitutes a biographical disruption that on the one hand alters the patient's temporal perspective throughout the therapeutic process, and on the other can trigger existential and spiritual questions and needs. The direct connection between temporality and spirituality in the subjective experience of illness is, however, little investigated in the sociological literature.

Based on the analysis of personal illness narratives collected through qualitative interviews using the creative technique of time-box with cancer patients in Piedmont, this article shows how the relation with the disease is inscribed as an “other” time or “heterotemporality” in the patient's life course, producing estranging effects on identity and agentivity from which emerges a spirituality focused on time as a resource for coping with suffering. These results can provide indications for implementing spiritual care strategies in healthcare and clinical contexts.

Keywords: illness narrative, spirituality, time.

1. Introduction

The COVID-19 pandemic has actualized the link between time and illness and highlighted the vulnerability of ordinary forms of the social organisation of time (Venkatesan & Joshi, 2022), resulting in a loss of habitual references during the “suspended” time of lockdown restrictive measures (Velasco et al., 2022). While the health emergency has been an unprecedented opportunity to observe the temporal implications of illness on a collective level, the incidence of pathology on individual biographies has been an established object of study within the sociology of health and the medical humanities. As highlighted by

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these studies, the onset of a serious illness signals a turning point, a discontinuity in the life trajectory that marks a biographical disruption between a “before” and an “after”, following which the subject’s identity, the relationship of immediacy with his or her own body and the given-for-granted meanings with which the world is habitually interpreted are altered and put into crisis (Bury, 1982). Pathology thus determines a transition to a new and unexpected state that leads to a reorientation, even a profound one, of everyday life (Cardano, 2008; Frank, 1995). In affecting the life course, pathology also alters the patient’s time horizon, leading to a contraction of his or her expectations of the future (Giarelli & Venneri, 2009).

This article focuses on the relevance of temporality in the emergence of a spiritual attitude in the face of illness, through the reading of personal illness narrative of patients suffering from a serious disease such as cancer. In the following pages I will examine in particular the relationship, still little explored in the literature, between time, illness and spirituality: these three terms define the field of investigation of a research conducted on two groups of oncological patients in Piedmont with lung and breast cancer, whose illness stories were collected through qualitative interviews with the help of the creative method of the “time box”. From the analysis of the exemplary cases of three spiritual illness narratives, it will be shown how the clinical time of disease is inscribed in the patient’s biography as “other” time, or “heterotemporality”, which produces estranging effects in that it leads the narrator (a) to assume a new point of view on everyday reality and, as a consequence, (b) to develop a new spiritual attitude centred on time as a fundamental value of the experience of illness. In the conclusions, it will be suggested how attention to temporality can contribute to the understanding of the disease pathways in the oncological context.

1. Time, illness and spirituality

In the case of terminal or chronic illnesses such as cancer, temporality becomes a defining feature of their very name (Ostrowska, 2008). Pathology with a terminal outcome significantly alters the patient’s perception of the temporal rhythm, which at the end of life is centred on the day-after-day experience (Lövgren et al., 2010) and an orientation focused predominantly on the past, as a healthy phase of life, rather than on the future (Rovers et al., 2019). Chronic illness, for its part, exposes not a single biographical fracture, but a recurrence of multiple fractures that vary as the clinical course progresses (Williams, 2000). More and more previously terminal diseases are becoming

chronic as a consequence of advances in medical therapies and the general aging of the population especially in Western countries (Atella et al., 2019; Hale et al. 2014). Statistical data provided by the World Health Organization indicate that chronic non-communicable diseases constitute the main cause of mortality for more than 70% of deaths worldwide, with a higher concentration in countries with low to middle income¹.

If, therefore, the onset of a chronic or terminal illness induces an overall reorganization of habitual behaviour, interpersonal relations, and the cognitive frameworks, it not infrequently prompts an unprecedented reflection on identity, life, and death (Charon, 2006). “Why me?” or “what have I done?” are the most frequent questions from which the individual starts a research pathway with which to give meaning to the experience of illness and recompose a sense of continuity and unity in his or her existential trajectory (Kleinman, 1989; Riessman, 2002). Critical or traumatic situations can indeed foster spiritual reactions (Harper & Pargament, 2015) and in particular conditions of “total suffering” (Wood, 2022) produce forms of spiritual distress whose symptoms are emotional states such as fear and loss of confidence in the future (Roze des Ordons et al., 2018). The suffering that connotes illness can thus give expression to questions of a spiritual nature (Puchalski, 2004; Timmins & Caldeira, 2017) in terms of a search for meaning, purpose, transcendence and connection with the self, others and the world (Puchalski et al., 2014). Spiritual dimension is at the heart of the practice of “spiritual care”, a model of care developed in the field of medical humanities consisting of professional attention on the part of health professionals to the need for spirituality that arises in the face of illness (VandeCreek, 2010). This is a holistic and centred-patients model of care that considers spirituality as a resource to promote well-being in the case of severe diseases (Lucchetti et al., 2019; Timmins & Caldeira, 2019). Satisfying the spiritual needs of patients can indeed have relevant benefits on their clinical journey and on improving their quality of life through personalised interventions (Lazenby, 2018), with positive spillovers in terms of increased chances of recovery and participatory involvement in the clinical relationship (Taylor & Johnston, 2019).

The model of spiritual care is widely elaborated in theory but poorly implemented in healthcare contexts (Hawthorne & Gordon, 2020; Timmins et al., 2022). A renewed interest in it is being registered just recently in the wake of the COVID-19 pandemic (de-Diego Cordero et al., 2022). It should be emphasised, however, that many tools for detecting patients’ spirituality and

¹ [https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases#:~:text=Noncommunicable%20diseases%20\(NCDs\)%20kill%2041,%2D%20and%20middle%2Dincome%20countries](https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases#:~:text=Noncommunicable%20diseases%20(NCDs)%20kill%2041,%2D%20and%20middle%2Dincome%20countries) (accessed: 6 April, 2023).

planning care interventions do not duly take into account the processuality of the illness experience and thus the need to monitor this change over time (McSherry et al., 2019). Spiritual care requires specific attention to the patient's subjective experience of time during the course of the illness: this temporal dimension is qualitatively different from the objective and abstract time conceptualised by clinical knowledge and adopted in care protocols by healthcare professionals (Toombs, 1990). Understanding the ways in which the patient represents the different phases of time, finding in the anticipation of the future a reason for hope or fear, in the memory of the past a support and comfort, and in the present a source of meaning to live the experience of illness with more awareness (Leder, 2021), can provide guidance for designing treatment interventions and formulating strategies to cope with the disease (Robertson, 2015).

2. Methods and materials

The data of the present study were collected during a research project aimed at studying the illness experience of cancer patients living in Piedmont. The analysis presented here is based on a corpus of 20 qualitative interviews collected in 2022 and conducted with two groups of patients, 10 suffering from lung cancer recruited through the leaders of the association WALCE (Women Against Lung Cancer in Europe) at the San Luigi Gonzaga hospital in Orbassano (Turin) and 10 suffering from breast cancer recruited through the leaders of ANDOS (Associazione Nazionale Donne Operate al Seno) at the Molinette hospital in Turin². The two groups were selected according to the most different system design, a research strategy that allows the comparison of dissimilar cases to check for a common effect or behavior (Seawright & Gerring, 2008). In the context under consideration, the two groups of oncological patients correspond to opposite clinical profiles in terms of life

² The WALCE sample of interviewees was formed from a list of patients' names drawn up by the referring doctors that included both members of the association and other patients treated at the San Luigi hospital. The ANDOS sample was formed following an initial group meeting day in which the researcher presented the study to the members of the association and in which the signatures of patients willing to participate were collected. In total, 16 female and 4 male patients were identified, with an age range between 35 and 65 years. With respect to the religious variable, relevant for this study, all the interviewees had a Catholic background, but only 2 were believers and practitioners already before the illness, 1 declared himself an atheist and 17 were "nominal" Catholics who lived their faith with detachment or critically, or had begun non-Christian spiritual quests.

expectancy, with a more favourable prognosis for patients with breast neoplasia who, in Italy, survive in 88% of cases 5 years after the onset of the disease, against 19.5% on average between men and women for patients with pulmonary neoplasia³: in the face of this difference, the hypothesis put forward is that in both cases there is a significant incidence of severe pathology on biographical time and on the emergence of questions or needs of a spiritual nature as a resource for coping with the experience of illness (Batstone et al., 2020).

The interviews, lasting on average about an hour, were conducted by the researcher both in-presence and online on the basis of an outline consisting of three open-ended questions: (a) “how has the illness changed your life?”; (b) “how are you coping with this change?”; (c) “if you had to take stock of your experience, what do you think the illness has taken away from you and what has it given you?”. In order to enable these questions to be answered, the interviews involve the use of the “time box” technique, a creative research method that aims to foster the involvement of participants engaged in the study through a performative activity (Giorgi et al., 2021) that leverages the collaborative dimension of playful practice (Langley et al., 2022). The time box solicits the autobiographical narrative of illness, or “pathographies” (Hawkins, 1999; Nesby, 2019) through the use of meaningful objects that the interviewee freely chooses to illustrate their personal experience. The researcher, during the first individual contact by telephone or e-mail with the patient, invites the participant to fill the time box with objects, which will then be used at the interview in the next meeting. Object-mediated interviewing and the use of the box encourage, more than a narrative solely focused on verbal stimuli, the emotional and embedded expression of the patient’s point of view (Brown, 2019; Fleetwood-Smith et al., 2021; Ravn, 2021; Woodward, 2015) and foster a narrative that accounts for the processuality and changes over time of the illness experience (Calman et al., 2013).

A total of 14 of 20 interviewees agreed to the suggestion of constructing the time box. In the other 6 cases, interviewees had difficulty with this task, opting for a different solution, such as preparing written sheets of paper or selecting only one object or, again, not utilizing any kind of object. All time boxes were photographed by the researcher.

The online and in-presence interviews were video and audio-recorded respectively and manually transcribed by the interviewer; the transcribed texts were subsequently examined using the thematic analysis approach which involves the selection of statements and the coding of keywords in order to

³ Report *I numeri del cancro in Italia, 2022*, available at: https://www.aiom.it/wp-content/uploads/2022/12/2022_AIOM_NDC-web.pdf (accessed: 20 April 2023).

extrapolate the recurring patterns of meaning that structure patients' narratives (Naeem et al., 2023).

3. Illness narratives in a time box

In this section I will examine in detail the spiritual illness narratives of three oncological patients: P.B., a woman with lung cancer diagnosed in February 2022 and with a brain cancer relapse in the summer of the same year; F.D., a woman with breast cancer dating back to 2007; S.A., a woman with breast cancer diagnosed in 2017. These stories exemplify recurring aspects in the biographical paths of the patients belonging to the two oncological associations involved in the study, relating to the impact of cancer on the relationship with time in everyday life and the way in which a form of spirituality emerges from this relationship that values temporality as a constitutive dimension of the personal experience of illness. The selected stories recount the three main spiritual paths prompted by the event of the disease which can be recognized in the overall corpus of interviews collected: in the case of P.B., the experience of cancer leads to a rediscovery and a revitalization of one's Catholic faith, up to that moment lived with detachment (4 other stories belong to this category); in the case of F.D., the illness leads to a highly critical reworking of Catholicism, which leads to a personal faith lived outside the Church (this characteristic is present in 5 other stories); finally, in the case of S.A., cancer urges the acquisition of a new, secular spirituality, focused mainly on nature and human relationships (as happens in 8 other stories).

To return in detail through qualitative analysis the discursive structuring of the patients' storytelling, the next sections will focus on these three stories, referring to more general considerations on the entire corpus of interviews in the Conclusions.

4.1 The estranging time of illness

The following accounts show how the clinical time of the illness - the chronological course of the pathology and the guidelines of the treatment interventions in the medical context which impose periodic visits, hospital admissions and the taking of drugs (Terenziani et al., 2008) - is inscribed in the narrator's biography as an "other" time which pushes one to reorganise the rhythms of daily life in relation to the therapeutic course. This heterotemporality time produces an alienating effect from which the patient tends to assume a new point of view on the given ordinary reality. The

estrangement, which accompanies the transition from the familiar state of health to the unexpected and critical state of cancer disease, is a condition in which the subject renegotiates the relationship with the body, the self and the others within the framework of a representation of time marked by uncertainty and fear towards the future, by the need to live the present as best as possible, and by the reinterpretation of the past as a period of normality (Broom et al., 2020).

In P.B.'s account — a 54-years-old woman, married and currently employed as a company accountant —, the estranging effect caused by the irruption of the illness is described with the image of the 'world fell apart around me', which metaphorically expresses the destabilising impact of the diagnosis, from which a path marked by "fright" begins, the key-word that the interviewee writes by hand on a sheet of paper and inserts in her own time box. The metaphor employed here testifies to the way in which illness produces a fracture in individual biography (Bury, 1982): the fracture interrupts the linearity of time in the same way as a *suspension* in the flow of ordinary life. This is what occurs for P.B. in the initial days after the first suspicions about the illness, days spent waiting for the results of the medical tests confirming the diagnosis of the first lung cancer and then the relapse in the brain. It is a phase in which the interviewee plunges into an emotional and cognitive condition of disorientation that completely disrupts her routines:

It had become a nail in my head, because that was the first thought in the morning and also in the evening before falling asleep [...]. During that time I enjoyed the work. I worked even better because it kept my head busy and helped me a lot.

In those days, the thought of illness becomes a "fixed nail", the main concern that subordinates all other daily activities, and against which professional commitment proves to be an antidote to keep "the head busy". During this suspended time, P.B. finds himself in a liminal condition marked by fear for the future in which sufferers typically attempt to safeguard the integrity of the self threatened by pathology (Du Plooy, 2014). The liminality that connotes the suspended time of illness is also addressed by F.D. — a 60-year-old woman, who lives with her husband and works as an employee —, in the second story examined:

I helped myself with découpage; it was a way for me to occupy time. I used to do it with friends and it was a way to get together, however, that kept me company enough because it was a way to do something different than walking up and down the hallway and that helped me a lot because it was a

way to do things, for me it was important to distract myself [...]. I spent nights playing this game by myself, that you can play by yourself, it's a very simple board game and my husband could hear the noise of these dice on the table because the *fil rouge* of this whole thing is loneliness that started especially with illness hours and hours at home alone. It filled so many nights because the nights were long.

From her time box, the interviewee pulls out an old paintbrush used for découpage and the dice from a board game, two expedients that allow F.D. to counteract the sense of loneliness associated with her illness by “filling” the night time. Nighttime hours are a liminal time, habitually not experienced by the interviewee in her health condition, but an integral part of her daily experience since the onset of illness. The daytime hours, on the other hand, punctuated by the rhythm of professional commitments, are those in which the difficulties of managing the clinical time of the disease are most apparent. As the cancer worsens, the respondent requests leave from work, after which she returns to the office with part-time hours:

I had no problems with leave or anything, no pressure of any kind. The big difficulty for cancer patients is getting time off work [...]. After lunch is the most difficult time, being able to be home after lunch to manage the afternoon, which is the heaviest time.

In this excerpt F.D. raises the issue of reconciling work schedules and care needs, a practical issue that in her case finds a solution, but in that of other cancer patients can be a serious obstacle. On the other hand, for the interviewee, some moments of the day, for example the early afternoon, remain the most tiring to manage along with professional commitments.

In S.A.'s narrative — a 40-years-old woman, married, with one daughter, who works as a physical education teacher in primary school —, the onset of illness constitutes an unexpected event against which the protagonist intends to struggle, even with the awareness that this struggle entails an inevitable interruption of ordinary life that can only be recovered later:

I really did not expect it, the breast. I knew right away that I would have to go through chemotherapy, but I am not one to cry, to complain, that is, one thing I was taught is that crying is almost a shame, a weakness. So I was impassive, not because I didn't feel or hear, but because it's just in my nature, complaining is not part of me. I said to myself, okay, it's a long thing, if I come out of it, it was a hard thing, a battle, however, then I get my life back.

In the liminal time of suspension, which manifests itself in histories of cancer illness as a loss of control over the self and the surrounding reality (Little et al., 1998), the problem of interruption of daily life coexists with the foreshadowing of an uncertain future. As P.B. states, resorting to the second sheet with the keyword “confusion”: “I did not know what the future would hold for me”. More specifically, after her brain tumor diagnosis in May, the respondent is thrown into despondency:

I think I have never felt something like that in my whole life because at that moment I realized that this disease had taken away my future. At that time I could not see beyond June, July [...]. I couldn't see a future, I didn't even recognize myself anymore, I looked in the mirror, I didn't recognise myself anymore, I felt strange. If you make speeches at the age of 80, I say, who knows if I will still be alive at 80? Instead maybe once I could think I will make it to 80, I will do this. Disease takes away the future.

Disease takes over in the course of everyday life as an otherness that subtracts planning toward the future and deconstructs the sense of personal identity, even to the point of altering the perception of one's own face in the mirror, in front of which, P.B. recalls, “I no longer recognised myself”. It is the occurrence of a change in the point of view about herself. This biographical fracture reverberates in multiple turning points that affect different aspects of daily life and that, on the whole, weaken the respondent's agentivity under the banner of “not being able to do” - not being able to work or not being able to drive -, thus decreeing a partial loss of autonomy and a condition of dependence on others.

The suspension of ordinary time exposes one to a condition of liminality in which ordinary frameworks lose plausibility so as to alter even one's body image on which self-perception rests (Featherstone, 2010). The episode of the mirror according to which F.B. sees an alienating reflection in which she does not recognize herself is, in this regard, illustrative. In S.A.'s story, the change in self-perception is given by the relationship between a “healthy self” of the past and a “sick self” of the present, described through a series of pointed oppositions involving both character and body planes:

I was always very active, always the one who ran from morning to night, independent, alone. I was full of hope, patience, I was a very, too patient person, and this patience has gone with my hair [...]. I'm not a patient person anymore, I don't have that sweetness and understanding that I had before. All those things, like an identity card, I don't find them anymore, I don't like myself as a person.

The image of an active woman drawn by S.A. is immediately tested by the unexpected consequences of pathology, and the battle metaphor depicts the clash between the idea of a healthy self and that of a pathological self that will have to prepare for clinical treatment. The interviewee continues her reflection on character change, recalling the concomitant change in physical appearance, exemplified by hair loss from chemotherapy and wig wearing:

My physical characteristic was my hair: they called me sheep or Bob Marley, because I had this very frizzy hair, I never had it short. And without batting an eyelid, I had my first chemotherapy and they said, 'within the week she will lose her hair'. So I went to the hairdresser friend of the family with my mom and my daughter, putting it almost on the line-even because with my daughter I had to say that [...] I had a bad disease and I was going to lose my hair. Ninety percent of women make it a hair issue. I didn't make a big deal out of it, even though it was a feature of mine.

S.A. adds that in the time box she would have included the hair itself, as one of the symbols of the illness experience. Hair is 'a symbol, in the sense that it's just blatant, even from the outside, that you don't come back the way you used to', After all, wearing a wig has never been a solution for her, as:

I used to put the wig on more for my daughter, to go out and about. Now I gave it away, I had anxiety every time I had to go out and put on this wig because it was not part of me and I put it on more for others, not for myself.

The wig thus becomes an outward symbol with which the interviewee intends to convey, to her daughter and to others, an image of apparent normality, although this accessory is felt as a foreign element to her own body. S.A. performs identity work, a strategy of repairing and revising that which pertains to the individual's sense of distinctiveness (Mathieson & Stam, 1995). The respondent's identity work is a way for coping with the erosion of a bodily trait that physically expresses the female sense of self, as frequently found in the biographical journeys of breast-operated women, to whom social stigma may be attached as a sign culturally associated with the sickness condition (Trusson & Pilnick, 2017; Williams & Solbrække, 2018). However relevant, hair represents for S.A. only a secondary component that does not exhaust the identity work she performs as a consequence of body transformations. In this regard, S.A. continues:

It is a phase of life that kills your person, because we are made of cells anyway. This good cells so basically it kills a part of you and that part there

doesn't come back anymore because it changes you too much, it changes you at the level of everyday life.

The identity reworking that goes hand in hand with the process of personal transformation, due not only to the disease but also to the clinical treatment, leads the interviewee to formulate a microscopic identification of herself with the very cells of which the organism is made up: the outcome is a gradual deconstruction of the former healthy self that takes place along with the 'killing' of the sick body operated by chemotherapy. Based on this view of the "cellular self", S.A. must therefore admit the caesura between past and present, between who she was before and who she has become after cancer. The biographical rupture that sharply separates the before and after narrated by S.A. is complementary to the *overlap* of past and present on which F.D. focuses:

The impact of the disease I always have it present because they removed all the lymph nodes in my armpit, consequently my arm swells, so it is a present stuff. You have to be very careful, you can't buy the clothes you want, I don't really care about dressing up however if I see a stuff I would like to be able to take it, one doesn't think that for women it is important instead it is.

What emerges here is the inscription of the disease in the body as a scar that lasts over time and is a trace in the present of past suffering: the before and the after, which although they oppose each other in the narrator's biography, can coexist in that swelling with which, in the manner of a somatic memory (Eli, 2016), the body remembers the operation undergone (the removal of lymph nodes) to the point of making the past of the disease never definitively past, but 'always present'.

4.2 The consciousness of time: loss and reconquest

The estranging effects caused by the breakthrough of cancer in the narrator's biography prompt the acquisition of a new point of view with which to interpret the self and the surrounding reality. In the three stories under consideration this point of view leads to a spiritual consciousness that matures over time and values time itself as a constitutive dimension of one's personal trajectory. This consciousness is expressed discursively in the form of a life review (Haber, 2006; Ng et al., 2022), the recapitulation of past experience that is subjected to evaluative judgment in light of life conditions in the present and expectations regarding the future.

The emergence of a spiritual attitude in the biographical journeys of cancer patients offers a source of meaning for coping with suffering and can take different declinations depending on the patient's value orientations. This spirituality, while it may draw on the narrator's prior religious faith, is usually not reduced to it, being the specific and innovative bearer of the illness experience. One of the possible forms of spirituality that emerges along the therapeutic journey is the *rediscovery* or revitalization of the initial religiosity, experienced with detachment until the time of illness. This is what happens in the account of P.B., a Catholic educated, believing but non-practicing person. His rediscovery of Catholicism begins with the consideration, already recalled in the previous pages, that 'illness takes away the future'. These are words that denounce a perception of time as a scarce resource in the face of the possible inauspicious outcome of pathology (Fitzpatrick et al., 1980) and that testify to the contraction of the time horizon within which illness narratives move (Giarelli & Venneri, 2009). This is the starting point that triggers in the interviewee a reflection on biographical time:

I realized that all these years I spent in the office, I realized that I had no particular hobbies, I didn't know what to do, I couldn't watch television, I couldn't read [...]. Sometimes I have regrets because one says 'when I later maybe retire or get older' we used to say with my husband, we can go here and there, and I regretted not doing it when I could because now I don't know if I will be able to do everything I had planned in my mind.

The consciousness of past time as "lost" time counterbalances the fear of not having time in the future to fulfill one's dreams and desires. P.B. resorts to religion several times: initially she turns to Buddhism and relaxation techniques, as suggested by some of her colleagues, but without gaining the hoped-for benefits. She then realizes that she must look inwardly for the right motivation to cope with the illness: "because I needed to spend hours at home alone [...] and this allowed me to regain hope, to regain strength". Along with introspection, the interviewee finds support in her Catholic faith:

I attended elementary and middle school in a nuns' home, so they kind of directed me in that direction. Then I didn't attend anymore [...]. In this period I realized that maybe a prayer or these roses that my friends brought me, a thought that maybe a person who brings me this bracelet that a friend of mine got me a little Madonna, here they gave me and are giving me support in this period [...]. This relationship with religion has always been there but maybe in this period I feel it more.

In particular, the rediscovery and strengthening of the Catholic faith in which she was born and raised is expressed in her devotion to saint Rita of Cascia, the saint of the “impossible causes”:

As a child I went to school to the nuns however I did not know Saint Rita and there were a number of things that led me to this saint [...]. In May my colleagues came in turn and filled my house with these roses of Saint Rita, which are blessed, and which I didn't even know what they were.

Cancer urged P.B. to recover his faith, giving it new meanings and values. This religious component is part of a more general and profound reevaluation of life time, which is the paradoxically ameliorative effect brought by the disease itself:

[The illness] gave me the opportunity to live more quietly, with my family, live more outdoors, gave me a better life in that sense, I found benefit, freer, less stressful. I have learned to live more by the day, I enjoy the things of the day [...]. During this period I gained in quality of life, because I used to be very stressed. I used to go out at 8 o'clock in the morning and arrive at 6:30 at night, so now I don't have these stress problems anymore. My desire was to go for walks but I couldn't do them because I didn't have time and instead now every afternoon I go for walks, so I'm living in a different way that maybe I like even more.

This theme is reiterated by a third note contained in the time box, which carries the phrase, “the life I live now is stress-free”, which preludes a meditation on the value of time lived and a comparison with past time, heterodirected by work rhythms. Cancer, therefore, can be a valuable learning opportunity for the interviewee. Also in F.D.'s story, the emergence of the spiritual dimension is linked to uncertainty for the future and fear of death:

[The disease has] taken away some of my serenity. If you still had an ounce of lightness it takes it away because it puts you in front of a reality: the reality of dying we all have it present but it's not so present because when you have it instead it's different. The fear of dying we all have, the near certainty is different. It sounds like a catch phrase 'we all have to die', yes, I have to be honest, dying of a heart attack is something I would subscribe to, it's just this thing of time, you could die but from here that you die you have time and that's deadly stuff to me. You say you can use it, yes yes, then fortunately years have passed and one then regains hope [...]. Let's say that all experiences are valid, as a life experience I think people like me have a more open mind, think more than those who haven't had it, it's an experience that opens up new visions of what life can be like.

Death and dying, which in ordinary life remain abstract and distant concepts, in the experience of illness acquire salience and become tangible concerns. Confrontation with the risk of death cracks the linearity of chronological time in everyday life and raises awareness of the value of time and the need to use it to live in the best way possible (Rasmussen & Elverdam, 2007) as a “recovered” time for self-actualization. In F.D.’s story, illness thus opens the door to a different way of understanding spirituality as a wholly personal and intimate experience, to be lived outside formal adherence to an organized religious tradition:

I am not a believer and therefore spirituality, I don’t know what spirituality means to me, it is a meaning I can’t understand, I can’t internalize spirituality by looking at nature and then there I feel at peace? I can only be at peace under certain conditions in the midst of greenery, nature. It is a condition that makes me feel good. I really envy those who believe I really envy them. I believe a little bit in introspection, talking to oneself to get better if I want to solve something I have to talk to myself, I have to try to internalize things a little bit, I find the strength more inside me than outside, it’s clear that in hard times it’s hard to find it, the way I am help yourself that heaven help you, that speech is very valid. In fact if I think about the various gurus, hermits are always people who are alone with themselves. If I have problems I have to walk alone.

Finally, in S.A.’s story can be found a distinctly lay conception of spirituality that moves from an explicit awareness of the temporality of one’s experience of illness:

For me it was really a matter of time, I would put in an hourglass. This is an awareness that I have gained over time. Yes, time is long, however, it is not that when it ends you go back and anyway this time in the meantime has passed, you have perhaps even aged, right? So it’s not a parenthesis and you start from there, no, you don’t start again, so it’s not true that it stops, that it’s a pause and you start again. From that moment it completely changes your life and it will never be the same again [...]. So this time has passed, it has passed badly, because you go through a sickness both psychological and physical, and that time there is not going to give it back to you, but you can’t complain because thank you that you had that time and you continue to have time, however that time there is no more, that person there is no more.

In this passage the interviewee gives voice to an awareness that she has developed over time and that has in time its own object of reflection. The years of illness profoundly affect the biographical path and mark it in such a radical way as to imprint not only a clear turning point between the “before” and the

“after”, but a direction to the progression of life time that appears to S.A. to be irreversible, ‘with no return’ to the starting condition. Despite the suffering of the disease, the interviewee acknowledges that she ‘cannot complain’ about the fact that she was nonetheless able to have that time, following a “survivor pattern” that recurs frequently in the stories of cancer patients (Hannum & Rubinstein, 2016; Little et al., 2002). The time of illness is an heterotemporality which enters the everyday time and permanently cracks it, installing itself in the biography as a caesura, as a “no more”. In light of this, the interviewee explains her own way of practicing spirituality, which also channels in her case toward alternative directions to institutional religion:

Seeing these comrades and friends of mine who didn’t deserve to die because they really fought so hard. I and others hated it when one would go to funerals and say ‘now finally rest in peace, amen’. That’s just something I always hated because one really goes on 5, 10 years, but even just 2 years: do they do all that to rest in peace? No, that’s not the purpose, otherwise he rested before he suffered hell or one after a long battle, however he was sick for so many years, however all these years he spent trying not to reach that end, so these things I always found very contradictory and annoying. I perhaps attached myself more on the level of my own spirituality as my own thing, maybe about the moon, about nature. I always loved nature however not like this, this has changed. Maybe I didn’t have the conception of it before.

This is a pagan sensibility centered on the sacralization of nature that gradually emerges in the path of illness. The inner and spiritual self becomes in this story a discovery that occurs during the experience of oncological illness and transcends the conflict between the healthy self of before and the sick self of after, pointing to a possible source of peace, well-being and meaning to overcome the trauma of cancer.

4. Conclusions

The stories presented in the preceding pages attest to the dual relevance of temporality in the experience of severe pathology such as cancer told by the patients of the two oncological associations: on the one hand, they narrate the identity change of the patient and the relationship with the disease *over* time, during the clinical process; on the other hand, they elaborate a discourse *about* time that expresses the emergence of a spiritual attitude of the patient marked by the recognition of the existential value of daily time. The emphasis on temporality and change posed by these stories and by the overall corpus of the

20 interviews collected allows us to note some methodological limitations of the quantitative and qualitative research tools suggested in the nursing literature for investigating the spiritual needs of the patients and for designing spiritual care interventions (Timmins & Caldeira, 2017). In fact, these tools do not adequately account for the subjective time experienced by the patient over the treatment course (McSherry et al., 2019). The attention paid to this subjective dimension can usefully complement the perspective of the biomedical model in which the time of illness experienced by the sick person is transposed into the abstract and formal framework of hospital practice (Frankenberg, 1988), a practice that involves coordination among health care figures, employment of technologies and planning of interventions and procedures in order to optimize and standardize the time of care (Pedersen & Obling, 2020).

The previous cases also illustrate how pathology translates from organic event into biographical experience, generating multiple temporalities, that is, different ways of relating to the experience of time (Dolina et al., 2014; Robertson, 2015). The clinical time of disease becomes part of the existential journey as “other” time, generating alienating effects because it alters the patient’s perception of the passage of time and his or her relationship with it, with repercussions on the definition of self, body and agentivity (Good, 1994). The consciousness that emerges leads to an ambivalent evaluation of the past and future. The balance between the past and the future, between what the illness has given and taken away, lead, in a seemingly paradoxical way, many patients interviewed to affirm that ‘now my life is better than before’, seeing the present moment as a recovered and propitious time to realize one’s self and one’s desires. The reasons given to explain this apparent paradox are diverse, but they invoke a new sensibility that allows, in the opinion of the patients themselves, to live with more depth, to enjoy the ‘little things in life’ more, and to assign value to time, not in spite of illness, but because of it.

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