

The Temporal World in Caregivers of Cancer Survivors: Intertextual Analysis of their Experiences about the Perception of Time Compared with Excerpts from the Book "Einstein's Dreams"

Rafael Vargas^{1,*}, Andrés Camargo²

¹Facultad de Medicina, Universidad Antonio Nariño, Bogotá, Colombia.

²Facultad de Medicina, Universidad de Ciencias Aplicadas y Ambientales, U.D.C.A, Bogotá, Colombia.

Abstract

Purpose: The perception of time and its measurements depend on subjective constructs that vary according to changes in health. The evidence has shown that cancer diagnosis induces new relationships with time in patients and caregivers. The purpose of this study was to propose a multifaceted view about time perception referred by caregivers of cancer survivors.

Methods: This study used a qualitative phenomenological methodology including semi-structured interviews with caregivers of cancer survivors. Transcripts of the interviews were analyzed using an approach for intertextual analysis, taking as reference the book "Einstein's dreams".

Results: The analysis of transcripts shows changes caregivers' time perception. Participants were grouped into three essential moments related to each stage of the disease. The variations found in the perception of time in caregivers can be explained by common physiological and behavioral responses associated with the diagnosis of a chronic disease (i.e. stress, anxiety, fear, unhappiness, and sadness), which can be modified in the course of the disease.

Conclusions: We propose that a holistic approach to patient and caregiver care should include management of time perception, thus establishing interventions that facilitate a change in the experience of time perception into a more pleasant experience after a cancer diagnosis. The above may result in increased quality of patient care and possibly increased quality of life of caregivers.

Corresponding author: Rafael Vargas, Facultad de Medicina, Universidad Antonio Nariño, Bogotá, Colombia

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Introduction

Cancer disease. Cancer is a major cause of morbidity and mortality worldwide, over 90% of deaths are related to metastatic disease; its impact is expected to increase in the future¹⁻³. A cancer diagnosis has been related to increases in life expectancy and progressive aging of the global population, which, in addition to advances in early detection and the development of curative and/or palliative therapies, has led to an increase in the number of cancer survivors. The term "cancer survivors", according to Vijayvergia & Denlinger (2015)⁴, includes both the person diagnosed with cancer as well as their family, friends and family caregivers (FCGs). The survivors, who may or may not include the patient, depending on the outcome of the disease, represent a challenge for health systems. These survivors often develop serious health problems, including primary cancers, adverse effects of chemotherapy and radiotherapy (active or passive exposure for patients and FCGs), psychological and emotional problems and socio-economic difficulties^{4, 5}.

Even though the diagnosis of cancer is not equivalent to an imminent death, cancer as a disease represents an unknown situation and is interpreted as the possibility of short-term death, by both the patient and the FCGs; which generates in many cases, behavioral disorders including anxiety, aggression, isolation and suicidal thoughts. The family environment, work, and social life are also affected. These behavioral effects determine the diagnosis of rejection, compliance and adherence to treatment and ultimately the possibility of overcoming the disease^{6,7}.

The role of FCGs is essential to reducing anxiety, mood swings, supporting and helping in the treatment process and adaption to new routines that the disease imposes on the patient⁸. Although there are multiple types of cancer, the caretaking of these patients has several points in common, including the extremely high physical and emotional demands to which FCGs are exposed⁶.

Alongside the progression of the disease, patients and FCGs' needs exponentially increase⁹. Cancer progression has a great impact on patients and FCGs' lives; in the FCGs group, this is because their routine is conditioned by the patient's life and they are

largely responsible for administering medication and supervising their diet. They are also responsible for the patient's commute to health institutions and for providing specific daily care for the sick person. This responsibility must be balanced with personal obligations, family, job roles, and financial obligations¹⁰. In the clinical course of cancer, changes in time perception are perceived since diagnosis. These variations seem to depend on many factors including stress, depression, anxiety, pain and fear of death, which in turn are related to family, social, economic and cultural aspects.

Is time perception merely biological? Time and space are fundamental dimensions for living beings. In humans, time is the conscious experience of the processes that allow it to adapt to their environment sequential relations, these lapses are measured in intervals, which are time-wise cortical representation products of high-level cognitive functions. Time intervals perception, in the range from seconds to minutes, is crucial for physiological, cognitive and behavioral processes¹⁰⁻¹².

In the last decade, the perception of time has had a resurged interest¹³, since the ability to estimate the passage of time is critical for perceptual and cognitive processes. From the point of view of individuals, there are two times: the external, measurable and constant and a subjective or internal, which is variable and depends on biological aspects, cultural issues and the experience of the individual. The perception of time is not isometric to physical time¹⁴ and many factors including attention, memory, arousal and emotional states are potential modulators.

The ability to estimate subjective time, i.e., the inner experience that indicates how quickly time passes or how much time has passed since a certain event, is a stable and robust brain function that requires the use of an internal clock. The subjective duration of an event may be overestimated systematically; this phenomenon is called "*time dilation*", "*expansion of subjective time*" or emotional "*chronostasis*"¹⁵⁻²⁰. Humans have at least two different types of internal clocks, one that synchronizes and positions at different times of the day (circadian system) and another one that becomes important regarding the perception of time²¹. The

perception of time in terms of milliseconds is crucial for reflex responses, anticipatory responses, motor control, speech recognition and generation, among other functions²². The perception of time in the range of seconds to minutes (known as interval timing) determines cognitive processes such as attention and memory²³. Circadian rhythms operate in the range of 24 hours and are involved in a variety of physiological and behavioral functions²⁴. In a variety of animal models, it has been observed that an essential component of cognitive function is the ability to extract and represent the temporal information from the environment because quantifying and processing time is essential for adaptation^{25, 26}.

Time estimated in the range of seconds to minutes is vital for many forms of sensorimotor processing that determine emotional states and thought processes in the individual. It has recently been proposed that dilation of time depends on the predictability of what is expected and it is mediated by levels of attention, excitement, expectation, and context of the stimulus²⁷.

A particular mood changes the time perception in everyday life²⁸. It is known that the sense of time is affected by different moods; sadness, for example, can influence the perception of time, slowing it down^{16, 29-31}. There are differences in the perception of time in individuals with neurological and psychiatric disorders compared with healthy subjects^{32,33}, specifically in patients with alterations in dopaminergic pathways, such as individuals with Parkinson's disease, Huntington disease, Multiple System Atrophy, depression, anxiety, drug dependence and schizophrenia^{19,23,34,35}.

In a patient diagnosed with cancer, anxiety and depression are adaptive reactions to the diagnosis of the disease, interpreted as a stressful life event, which has an uncertain prognosis³⁶. In these circumstances, distortions of time may occur aggravating mood alterations in the patient and the FCGs³⁷.

"Einstein's Dreams". Is time merely cultural, historical and social? Physicist and novelist Alan Lightman poses in his book, *"Einstein's Dreams"*, different possibilities of conceiving the experience of time³⁸. The book recounts thirty different stories, each of which tells a fictional dream of Albert Einstein on the

concept of time. Lightman poses multiple possibilities for perceiving time as a sensory phenomenon without a precise definition of time, which is one of the most challenging and elusive aspects for human thought^{39,40}.

The aim of this study was to propose a multifaceted view about the perception of time referred by FCGs of cancer patients, comparing their reported experiences with the stories in the work of Alan Lightman "Einstein's Dreams"; and to provide a study model of the perception of time not only as a quantitative but also a qualitative experience.

Methodology

This study used a qualitative phenomenological methodology including semi-structured interviews with FCGs of cancer patients, in order to gain a deeper understanding of the experiences about the perception of time in this population. For the development of this work, the authors conducted semi-structured interviews with FCGs. After being transcribed and analyzed, the interviews were compared with various concepts of time that are exposed in the book "Einstein's Dreams", using intertextual reading⁴¹. Considering the subjective component of time perception, which has been little studied, the aim of the phenomenological approach of this paper is to further enrich the concepts of time perception that have been developed so far, including the personal experiences of the participants and their interaction with their environment^{42,43}.

Subjects. Participants included five FCGs of cancer patients who accompanied their relatives during the diagnosis, treatment and outcome of the disease. These patients attended a cancer unit at a hospital in Bogotá, the capital of Colombia, and were selected by relevance criteria, appropriateness and availability. The inclusion criteria were: (1) being over 18 years old and (2) having no history of neuropsychiatric diseases that can alter the subjective perception of time^{14,16,44-46}. The number of participants was defined by the point of thematic saturation, i.e., when no new information appears in interviews, or when the information provided is repetitive⁴⁷.

Interviews. Data collection was conducted between January and December of 2017, using a semi-structured interview that began with descriptive questions, then structured questions and finally

cross-check questions. Each interview about the experience on time perception during the care of cancer patients lasted an hour. The interview was recorded, transcribed and analyzed simultaneously by researchers. In order to maintain the anonymity of the respondents, they were coded sequentially I1, I2, I3, I4, and I5. Finally, the interviews were translated into the English language.

Analysis of the information. For the phenomenological analysis, we used the steps proposed by Amadeo Giorgi⁴⁷: a reading of all materials (interviews) to get an overall idea of the information; then the significance units were specified from the description provided by participants about the phenomenon studied. A connection was established from a psychological view in every significance unit; and finally, all significance units were processed into a coherent statement regarding the participants' experiences⁴⁸. A second analysis was performed to carry out an intertextual reading, contrasting the significance units analyzed in the interviews with the concepts expressed in Alan Lightman's book³⁸. In his work, the author considers different ways of perceiving time and raises the idea that the time phenomenon is one but perceptions of time can be multiple and all of which are valid⁴⁹. The study of intertextuality has important implications for constitution of subjects through texts, where intertextuality and constantly changing intertextual relations in discourse are central for understanding subject's constitution process⁵⁰.

The methodological rigor of the study was given by meeting the following criteria: credibility, dependence, transferability, and confirmability^{51,52}. The Research Ethics Committee, of the University, approved this study. The present study also met the international standards of ethical chronobiology research and all subjects gave informed consent⁵³.

Results

Participants included five FCGs of both sexes, with an average age of 37 years (range of 25 to 62 years), three of them whose parents had the disease (two women and a man), and two were husbands of the patients. The average time of care was 4.5 years. All participants revealed that they had gone through a difficult process that generated major changes in their

lives.

The content analysis of the speeches shows three essential moments in the experience of FCGs, which is in line with different stages of disease: cancer diagnosis, treatment, and outcome of disease-related survival. Regarding the experience on how FCGs perceive the passage of time, three main themes emerged that may relate to essential moments of their experience. The diagnostic phase, which is related to the perception of time, is expressed as overwhelming. The treatment phase that is related to the perception of time is described as "ephemeral" and the outcome phase, which is related to the perception of time, is defined as uncertain and/or changing. Table S1 (supplementary material) shows a comparison between the descriptions about time perception expressed by FCGs and excerpts from the book "Einstein's Dreams".

Topic

Time is overwhelming and it chains individuals when the disease starts or reactivates. It represents procedures, treatments, and the hospital.

Subtopic Time is a local phenomenon. Regarding diagnosis and disease, the FCGs must change activities and synchronize their times with the needs of the cancer patient and their care. In addition to meeting with family, work and personal commitments, they acquire the commitment to care for their loved ones. Time is perceived as a local phenomenon that varies according to the location of the subject.

"After the doctor told us that my mother had cancer, I thought about my parents whenever I was not with them: at work or even when I went out with my friends. I thought about how they were and I just could not wait to be with them. Since then, I started calling them more often and I even felt guilty for getting home late for any reason." (I2).

Subtopic

A world in which people live only one day. The signs and symptoms caused by the disease as well as the side effects caused by medical examinations and treatments, generate various feelings: fear, uncertainty, sadness. All of this makes life seem very short. In addition, the disease progression and the side effects of interventions are visible in the physical appearance and

mood of the survivor; the passage of time is also noticeable, that is to say time is visible. Regarding the diagnosis of disease, the most common thought is "death"; usually those thoughts are accompanied by sadness, hopelessness, and anguish of not knowing how much time is left:

"I wish time had stopped and I had never received the news that my wife had cancer, I wish that moment had never happened." (I4).

Subtopic

Time is absolute. Days turn into a series of events, defined by the routine of the disease and its progression; dates are defined by medical appointments, days by hospitalization times, and hours by visitation schedules or dosing of medication. However, time is absolute and always elapses in the end. This situation is associated with the patient survival, which is generally defined by the type of cancer and the stage of diagnosis.

"Now, life revolves around fighting every minute against the disease. It was simply about: the chemotherapy day, the radiotherapy day, time of medication, we started living to maintaining life and just waiting for the passage of time. I remember my mom telling me that there is not time that does not come, no debt that is not paid. It is only now, after she died, that I begin to understand what she meant." (I2).

Subtopic

Time is regular. However, as life changes according to the routines, evolution of the disease, treatment, and prognosis, time is perceived as irregular:

"In the hospital, a day seemed eternal. We had to leave behind our routines. We left behind our family and we slipped into a routine of examinations, medicines and procedures." (I1).

Topic

Time is fleeting. You must make the most of happy times when the disease is in a period of dormancy.

Subtopic

Time, quality not quantity, and time is only a moment. During the course of the disease, every moment is quality time. According to the results of the

qualitative analysis, for FCGs the most valuable aspect was to spend and enjoy family time, because before being FCGs they were sons, husbands, brothers or fathers, therefore family roles continued to exist. Time became a resource in which every moment of happiness was unique and in which the quality of happy times was measured by the joy of those times. The FCGs also reported significant changes in the speed of time in the happy times, when the disease was in remission and there were no medical treatments, which is evident in the stories:

"My wife and I used to travel a lot, we would usually go to the beach. A few days before she died, she remembered a trip in which we went to an island. One day when we woke up, it was raining just like that day in the hospital. I remember she smiled." (I4).

Subtopic

Infinite time. The analysis showed that, in addition to sharing quality time and living for the moment, for FCGs it was very important to immortalize the calm and happy moments without thinking about the progression of the disease, thus making time infinite:

"At that time, it was important for my wife to do the things she had postponed, probably because of childcare. We returned to many plans we had as a couple and that had been postponed for a few years; however, I never stopped thinking about how it would be when cancer got worse, I tried not to think about it and I said to myself that we would have time to deal and face the situation when the moment came." (I4).

Topic

The inevitable. The outcome very fact that there is a conflict between order and chaos in the first place

Subtopic

Freezing time. Over time, FCGs are witnesses of the patient's physical deterioration, pain and fear of death caused by the natural progression of disease. For these reasons, a common desire is to stop time. In interviews, a feeling of powerlessness was perceived in FCGs as the disease progressed and the perception of time was revealed as an accomplice in this situation:

"I was filled with anguish of thinking that my dad was dying at an accelerating pace and doctors could not do anything to stop the disease. One day the

oncologist saw the tests and told us that treatment was no longer working. That made me very sad because I realized that my father's death was near. I thought: why did we fight so hard if he was going to die anyway? Sadness, impotence and fear consumed me during the following months until my father died." (I3).

Subtopic

Time is sticky. In the end, time passes and only memories of experiences during all phases of the disease remain, including good and bad moments spent with family and health professionals, specially doctors and nurses who are present during different stages of the disease:

"After the first surgery my mom had, she asked the doctor: So, what is next? He tenderly replied: to be happy. I will never forget the way she smiled that day"; (I2).

Subtopic

Time as a constant flow and as a multidimensional phenomenon. In the interviews, the FCGs questioned retrospectively their actions, evaluated their strengths and weaknesses and expressed actions they did or did not do during the time they took care of their loved ones. Likewise, they expressed their desire to go back in time and be able to correct or change aspects, which now generate feelings of guilt or frustration.

They also made explicit their desire to travel to the past by evoking special moments. Given that the doubt about whether they did the right for the patient is always present, they mentally speculate and hypothesize about the effect of possible decisions that were not taken.

"If I could turn back time, I would tell my father how grateful I was for all the good things he did for me, my brothers and my mom. I did not think that the disease would progress so fast and that he would die that soon." (I3).

Subtopic

Time and order. The outcome very fact that there is a conflict between order and chaos in the first place. A retrospective look allowed FCGs to deduce that time is an essential factor at each stage of the disease. It allowed them to understand the different situations

and adjust to them. They learned, from their experience, how the time gives order and shows the sequential pathway that cancer survivors must follow:

"In the family of my wife, there was never a history of cancer. She was always a very healthy and active person, she rarely went to the doctor. During the years following her diagnosis, while I was caring for her, I imagined how things would end. I realized how much our lives changed, and even though she died, she fought until her last day. I feel that the disease brought us closer. Now, for the people who are still alive like us, it only remains to be strong and move on as long as we can. (I4).

Subtopic

Time as a judge. Physical time does not stop, it waits for no one; nevertheless, without time there is no life.

"I always thought about how the final stage of the disease would be. I had the time to prepare myself and be strong and, above all, I had the time to care for her as long as necessary. I remember that the month before my mother died, my brother and I were celebrating our birthdays and also Father's day, I guess she waited for this month and even though she fought, perhaps her forces were running out" (I2).

The Other Side of the Coin

the perception of time in cancer patients. Although in this study patients were not interviewed, it is they who most acutely perceived changes in their personal time, in their perception of time. This could be partially and indirectly evidenced by the stories of the FCGs, who evoke phrases and feelings of patients they cared for, which often coincide with the experiences or perceptions of the caregivers.

"In the last stage of disease, in the hospital, the nights seemed eternal for me and my wife. In fact, she was afraid of nightfall because it was then that pain and anxiety increased, she asked me for the time very often, I do not know why". (I4).

Discussion

The diagnosis and progression of cancer is an event that interrupts reality not only for the person with cancer but also for those who are close to that person, especially the family. In general, the responsibility of

caring for these patients falls upon family members, mostly members of the immediate family, such as their spouses, children or siblings². In this sense, the care of a patient with cancer constitutes a direct and continuous 24-hour activity involving family and health professionals. This activity must be adapted to the requirements and needs of the patient, which vary in time expressed in seconds, minutes, hours, days, weeks, months and years. From this perspective, the relationship between care versus time is usually approached from a mechanistic vision marked only by the clock and the calendar.

Given the above, it is possible to think about the possibility that the perception of time in FCGs of cancer patients may be influenced by their own experience of care and by the way they interpret and deal with the illness. That is to say, how the perception of the past, the present, and the future can be influenced by their current interpretations and conclusions about the patient's health and even their own physical and mental state of health⁵⁴.

In the current study, it was observed that the experience of the perception of time was described by the FCGs as a struggle between two time periods characterized by being too fast or too slow, and too short or too long in the course of the disease⁵⁵. This dichotomous perception of time probably corresponds to the normal functioning of the internal clock³⁸. The experience of time perception experienced by cancer survivors follows a particular logic since the medical condition makes time follow an apparent variable, and an unstable and insecure sequence⁵⁶. For instance, it has been found that current problems in patients are combined with past events and future plans^{57,58}. The perception of time experience in cancer patients without evidence of disease compared to patients with advanced cancer is significantly different and may vary from diagnosis of the disease to its outcome⁵⁴. These patients must live with numerous physical and psychosocial complications induced by the disease and treatments, including the dilemmas of death and the dying process⁵⁹. Also in the FCGs, these changes can be associated with distress, anxiety, and depression^{60,61}, which could alter their perception of time, given that the experience of time depends on a complex set of brain-body factors;

including cognitive, emotional and physical states⁶²⁻⁶⁴.

It has been found that, in patients and in FCGs, the perception of cancer as a deadly disease is common and this idea persists despite the improved prognosis of the patients. This can be explained by the fact that the diagnosis, the treatment, the prognosis, and the recurrence of the disease generate many questions and fears about the remaining time of life^{65,66}.

An important feature that emerged from the narratives was the fragmentation of time made by the FCGs during the disease process. As was found in a previous study with cancer patients⁶, time was fragmented into smaller parts by the FCGs and possibly also by the patients, which made the disease more manageable in terms of experience: the remembered past, the perceived present, and the imagined future.

Following this hypothesis, it can be thought that the disease survival and the weight of the perceived present become the object of focus for both caregiver and patient, which arises from the need to satisfy the demands of the treatment and the disease management. Taking into account these demands of time, surviving the present with the disease is a matter of great importance for patients, caregivers, and families, since the hope of recovery depends on it^{33,34}.

Thus, it is possible that the patient and the caregiver can cope more easily with the emotional burden caused by their experience of their illness if interpreted in a fragmented context. Such time-illness reconciliation probably occurs because the diagnosis of cancer significantly changes the way in which the patient and the caregiver think about themselves and their lives^{6,8,33}.

Interestingly, with regard to the foregoing, another study including patients with chronic disease shows how the patient fragments time in their experience of the disease; notable dates (i.e, diagnoses, end of treatment and anniversaries) are used as markers for the beginning or the end of specific time periods³⁴.

On the other hand, the current study found that support and constant communication with the medical staff during all stages of the disease were important for the patient and their family. Probably these processes generated tranquility, reduced stress and overload⁶⁷,

changing not only the perception of the disease but the experience in the perception of time³⁸. In this way, we start from the idea that time is a construction from multiple information sources²⁰. Time representations and measurements also depend on subjective constructions that vary according to changes in our concepts, beliefs, and experiences⁶⁸. In fact, the sense of time depends on the intrinsic context such as emotional state and the extrinsic contexts such as the pace of the activity of others. For instance, conditions of stress increase the level of arousal, which in turn accelerates the biological clock speed, resulting in an overestimation of the length of time. This effect has been also observed in anger and fear; which allows humans to anticipate an event and to act quickly⁶⁹.

Conclusions

It is known that time influences the physiological, psychological and social functions of the human being, and arises as a variable to consider in the care that is provided to patients⁷⁰. However, there has been little studies about the perception of time in people who are going through a situation of disease such as cancer. In this sense, a holistic approach to patient care should include time perception, not only understanding time as the number of hours dedicated to the care or survival as a number of years. Therefore, including individual assessments of patients' time perception is relevant to identify how pleasant or unpleasant the experience is at every stage of the disease⁷¹⁻⁷³.

We found that the experience in the perception of time in FCGs of cancer patients changes by various internal factors such as fear, anxiety, hopelessness, depression or even joy, happiness, peace, and hope. In addition, it varies depending on external factors such as stage of disease, treatments, tests and hospital stays⁷⁴.

In human health care, time perception is critical, understanding the perception of time as an experience where time does not exist without events (cancer) and in turn, it makes no sense without observers (survivors and caregivers)⁷⁵. Besides, it is necessary that hospital staff be more sensitive and learn more to how their definitions, perceptions, and experiences concerning time can differ from those of patients⁷².

The main limitation of the present study was the small size of the sample interviewed. In spite of this

fact, the present study is relevant because it explores the perception of time as a determinant of the health-disease process, a topic that could have important repercussions in the design of therapeutic strategies for the patient and the mitigation of the burden of disease for the caregiver and their family⁷⁶.

For future studies on this topic, it would be relevant to inquire about the differences in the perception of time according to different types of chronic disease, taking into account factors that could alter this perception in caregivers (previous care experience, schooling, and even anxious and depressive symptomatology); and in patients (medication, chemotherapy, and previous diagnose). In addition, it could be relevant to investigate the differences in time perception between patients and caregivers and how they affects the progress of the disease or recovery.

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Conflict of Interest

The authors confirm that this study has no conflict of interest.

Supplementary Material

Supplementary Table 1. Topic, subtopic that emerged from interviews and intertextual reading of Einstein's Dreams.

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