

Research Article

The Looming Cancer: A Qualitative Study on the Experience of Living with Chronic Lymphocytic Leukemia (CLL) before the Initiation of Treatment

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Purpose. This study aimed to study the challenges and ways of coping with living with chronic lymphocytic leukemia (CLL) before the initiation of treatment. **Methods.** Semistructured interviews were carried out with 8 people living with CLL (4 males and 4 females) who had never received any treatment. Interpretative phenomenological analysis was utilized for the analysis of the data. **Results.** The following three themes were developed: (1) “Still waters run deep” highlights the contrast between living with minimal symptoms while experiencing high anxiety for the future, (2) “Surviving uncertainty” portrays participants’ supportive networks, communication challenges, and internal coping mechanisms to face the threatening overtones of CLL, and (3) “Turning over a new leaf” delineates participants’ realization of life’s finiteness and the way this acts as a nudge for psychological growth. **Conclusion.** Despite the limited physical discomfort, the CLL diagnosis and the watch-and-wait phase bring about psychological distress, which drives meaning-making efforts and an array of coping mechanisms, potentially leading to posttraumatic growth processes for people living with CLL.

1. Introduction

The cancer experience is associated with great levels of psychological distress [1–4], as it can impact every aspect of one’s life [5–7]. The physical effects of cancer and cancer treatments are often debilitating for patients [8, 9], leading to feelings of powerlessness, lack of control, and alienation. In addition, the whole cancer experience challenges patients’ sense of self, their sense of value, and their dignity [10]. As cancer confronts one with the finitude of life, one’s fundamental sense of security is also threatened, it limits their freedom, and autonomy is placed [11]. Thus, death anxiety, fears of recurrence, demoralization, and hopelessness often ensue [12–14].

Under such a threat, people struggle to find ways to cope and establish a sense of meaning [15]. It is evident that the

ability to cope and the cancer experience itself vary from person to person, owing not only to individual factors, e.g., demographics, personality, and available resources [16, 17] but also to the disease characteristics, e.g., the type and the stage of cancer. For instance, people who have been diagnosed with nonmetastatic cancer, especially in the earlier stages, are more likely to use adaptive coping strategies, compared to those living with metastatic or advanced cancer [18, 19]. Breast cancer survivors use a coping approach involving acceptance, whereas prostate and colorectal cancer survivors use avoidance strategies, such as denial or distraction [20].

This study concerns a chronic hematological malignancy, chronic lymphocytic leukemia (CLL). CLL is the most common adult leukemia in Western countries, with an average crude incidence rate across Europe of 4.8 per

100,000 people [21]. CLL is mostly diagnosed in people over the age of 50. Its incidence increases with age, and the median age at diagnosis is >70 years [22]. The unique characteristic of CLL is that the vast majority, around 70–80% of patients, is often asymptomatic or mildly symptomatic at the time of diagnosis and might not require treatment immediately [23]. They will remain under observation (“watch-and-wait”) for the first year [24], which entails regular hospital outpatient visits for undertaking medical examinations and consulting with a hematologist. A minority of patients (~30%) never show signs and symptoms of disease progression and remain under watchful waiting for the rest of their lives [23].

If disease progression occurs, patients may experience anemia, bleeding due to low platelet counts, fatigue, weight loss, frequent infections, night sweats, and swollen lymph nodes [25]. At that stage, specific clinical and laboratory criteria might indicate the initiation of treatment. There are several available treatment schemes, some with fixed duration and some that last for years. For many patients, treatment can lead to the alleviation of their symptoms and to a short- or long-term remission [26]. The remission stage initiates a new watchful waiting period with regular follow-ups and medical tests. The relapse of the disease and the reemergence of symptoms require the consideration of starting a new scheme or altering the current treatment regimen [27].

Despite the advent of new targeted therapies, CLL remains an incurable disease. In contrast with other types of cancer, people living with CLL never enter a “permanent survivorship” phase. They remain for the rest of their lives on the remitting-relapsing pathway and have to deal with the uncertainty that this entails. About 85% survive for 5 years or more after diagnosis [28]. The rate varies with age, being higher in younger ones and lower in those over 80 years old [28]. This places a considerable psychological burden on them [29]. Notably, people living with CLL in the “watch-and-wait” phase have been found to experience similar levels of anxiety, depression, and quality of life to people who receive active treatment [30, 31]. In previous studies involving people living with chronic hematological malignancies, the psychological impact of the uncertainty they experienced has been described as more difficult than the physical consequences of their condition [29, 32]. Along these lines, CLL has been characterized as an “incurable, invisible, and inconclusive” disease [33].

These include coping with distress [34, 35], struggling to maintain adequate levels of quality of life and well-being [36, 37], and striving to meet their spiritual needs [38]. However, there are also important particularities, and the unique nature of the disease and the challenges it poses to patients and the healthcare system [39] require a deeper understanding of their experiences in order to meet their needs [40].

To the best of the authors’ knowledge, there have been only two qualitative studies on the experience of people living with CLL, but the sample used was heterogenous since

it included patients in different phases along the CLL trajectory [25, 33]. Studying the experience of a more homogenous group of participants, i.e., people living with CLL in the “watch-and-wait” phase, allows for a more in-depth perspective on their particular needs and challenges (e.g., psychological, social, existential, and information needs). In addition, selecting this group of patients would allow a more focused approach on the psychological impact of living with a cancer diagnosis, irrespective of the physical symptoms of the disease and their implications.

To this end, this qualitative study aims to study the experience, needs, challenges, and ways of coping with CLL under watchful waiting before the initiation of any treatment. This can in turn inform more individualized patient-centered interventions in clinical practice and health policy.

2. Methods

2.1. Design. A qualitative methodology was utilized for this study. Semistructured interviews were used, in the interest of exploring patients’ perceptions in-depth. Interpretative phenomenological analysis (IPA) was considered the most suitable methodology for exploring the study’s research questions, considering the sample’s homogeneity, the interpretative depth it provides, and its theoretical underpinnings, i.e., IPA is concerned with the individual’s perceptions and interpretations of phenomena rather than the phenomena per se [41]. Thus, IPA is particularly relevant for the present study, as the absence of concrete physical symptoms for most participants highlights their subjective perceptions and experiences as the main focus of interest. Reporting of the study’s methodology and findings adheres to the consolidated criteria for reporting qualitative research (COREQ) [42] (see Supplement A) and the Standards for Reporting Qualitative Research [43].

2.2. Participants. Utilizing purposive sampling, 30 patients from public hospitals in Thessaloniki were approached over the phone. Since a small homogenous sample is considered more congruous for IPA studies [44, 45], only the interviews of 8 patients (four females) who had never received any treatment for CLL were selected for analysis. The time since participants’ diagnosis ranged from 6 months to 9 years, participants’ age ranged from 60 to 75 years, with the exception of one participant who was 40 years old.

2.3. Procedure. The qualitative data were obtained through semistructured interviews with open-ended questions to enable insight into participants’ experiences. The interview focused on the following: (a) reflections on receiving a CLL diagnosis, (b) various aspects of living with CLL, (c) changes in perspective and coping, and (d) participants’ thoughts about the future. Probing questions were asked when further exploration was considered necessary (see Supplement B for the interview guide).

None of the participants refused to participate or withdrew during or after the interviews. The one-to-one interviews were conducted in Greek as per the interview

guide by a female health psychologist (CK), who was a researcher with previous training and experience in semi-structured interviews in the field of health psychology and IPA. None of the researchers had prior relationships with the participants of the study, and participants were only informed that the interviewer was a health psychologist. Upon being briefed about the study's objectives, participants received a patient information sheet (see Supplement C) and provided their consent by signing a consent form (see Supplement D).

Interviews were held at the patient's preferred location; five interviews were conducted in the research institute where CK was employed, one in a participant's workplace and two in the researcher's private office. In all cases, the participant's privacy was ensured. The interviews were audio-recorded and lasted between 30 and 60 minutes. During the interviews, no field notes were taken and no one else was present besides the participant and the interviewer. The transcripts were not returned to the participants, and no-repeat interviews were carried out as spontaneous and instinctive answers would better ascribe their experience.

The collected data were considered complete when participants' accounts had been analyzed, and the conceptual structure derived from the analysis was of adequate in depth and richness for addressing the analytical goals and research questions of this study [46].

2.4. Analysis. The data were analyzed by utilizing IPA. A member of the research team (DK), a male clinical psychologist (MSc) with substantial experience in qualitative research, carried out the analysis. The input of a psychology undergraduate student (KS) undertaking training in qualitative research was utilized in several stages of the analysis as explained in more detail in the following section. CK was monitoring the whole process and consulting with DK and KS on a weekly basis.

First, the interviews were transcribed, and any personal information was anonymized. DK and KS then listened to the interviews and read the transcripts several times to achieve familiarization with the data. In order to enhance the reliability of the analysis, the first three interviews were analyzed independently by DK and KS. Along with this process, inductive coding was performed on the interview transcripts to mark preliminary concepts pertaining to the research questions. Some examples of codes in this step are "valuing elemental facts of living" and "worry and uncertainty about future progression." Subsequently, DK and KS reviewed and discussed the developed codes. Appropriate refinements were made until a consensus was reached.

Following this step, DK and KS developed themes and superordinate themes ensuing from the developed codes, through a collaborative and iterative process. First, the developed codes were grouped together to form themes that reflected repeated conceptual patterns across the data. Subsequently, the themes were clustered in higher-level categories to form superordinate themes that reflected central organizing concepts grounded in the data.

The remaining five interviews were coded independently by DK and KS, and the resulting codes were mapped by DK to the existing themes. No further refinements to the sub-themes and themes were made during this step.

The analysis was performed in Microsoft Office Excel.

2.5. Ethical Issues. Prior to the interviews, participants were informed about the purpose of the study and asked to sign a consent form explicating the protection of their confidentiality, the procedures for anonymizing any personal information, and their right to deny answering any of the questions or withdraw from the study at any moment. This study was approved by the Research Ethics Committee of the Institute of Applied Biosciences at the Centre for Research and Technology Hellas (CERTH) and the Research Ethics Committee of every participating hospital. The study was performed in accordance with the Declaration of Helsinki and is compliant with the European General Data Protection Regulation (GDPR).

3. Results

Following the analysis of the data, the three superordinate themes (see Figure 1) were developed: (1) "Still waters run deep" concerns how participants adapt to their diagnosis. It also portrays the sharp contrast between the limited physical impact of asymptomatic CLL and the intense difficult emotions that people living with CLL were experiencing; (2) "Surviving Uncertainty" portrays participants' efforts to cope with the threatening overtones of CLL. Barriers to sharing their diagnosis and receiving adequate support from their close ones are discussed, along with the hematologists' role in providing support and reassurance; and (3) "Turning over a new leaf" illustrates participants' confrontation with life's finiteness and the diagnosis' impact on their identity and outlook on life, which acted as a nudge for psychological growth and change.

The developed themes are discussed in more detail in the following sections. Participants' quotes are embedded to further illustrate and support the presented concepts. Pseudonyms have been used instead of participants' actual names, to safeguard their privacy.

The Greek quotes were translated into English by a C1 proficient English user (DK), and then another proficient English user of the research team (CK) checked whether each quote was translated such that the intended concepts were captured with accuracy. In case they were not, revisions were made until a consensus between the two researchers was reached.

3.1. Still Waters Run Deep. This theme portrays participants' first reaction upon hearing their diagnosis and the ways in which they adapt to it and move forward with their lives. It also highlights an emerging contrast, that is, the virtually intact participants' functionality, daily life, and absence of symptoms which made CLL seem just like a surface scratch, on the one hand, and the experienced uncertainty and

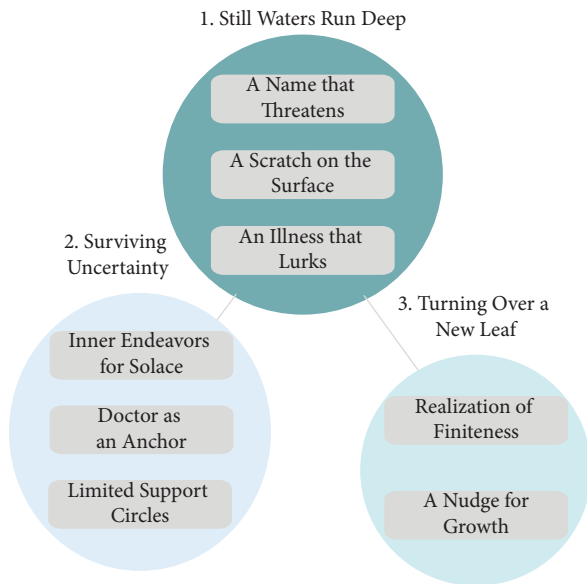


FIGURE 1: Themes and subthemes. Themes are presented as circles, and subthemes are presented in orthogonal shapes embedded in the circles.

anxiety regarding what their illness will bring in the future, on the other.

3.1.1. A Name That Threatens. Hearing the name of their diagnosis for the first time was a shock for participants. Feeling “frozen in terror” (Maria, 3 years since diagnosis) and “ambushed” and “losing the ground from under their feet” (Victor, 5 years since diagnosis) are indicative accounts of their initial internal reactions.

Everything stood still. Everything stood still. Because I didn’t know what this (chronic lymphocytic leukemia) was exactly. Of course, it is the word that’s really terrifying, “leukemia” and, of course, it was a hard day. (Maria, 3 years since diagnosis)

Two participants mentioned that the reactions and information from physicians outside the field of hematology shocked them and made them think they were soon going to die. For instance, Jim (less than a year since diagnosis), after being misinformed by a nonhematology resident that his life expectancy was 4-5 years, experienced an even bigger shock upon searching the term leukemia on the Internet. Contrastingly, Catherine’s (5 years since diagnosis) reaction was to spontaneously accept the diagnosis and reflect on every positive fact in her life.

When I heard the diagnosis, I didn’t feel sad, if that’s what you expect to hear, not because I’m a positive person, but because my nephew died of cancer at the age of 10. I consider myself one of the lucky ones because I had a very good childhood, a job that I love, and that is really rare these days. I have two daughters that I adore, and I feel life has given me back everything I have offered. I felt my

sickness was welcome, and that we will deal with it as we deal with anything that comes in life. (Catherine, 5 years since diagnosis)

As a result of the connotation carried, one participant (Victor, 5 years since diagnosis) could not accept the favorable prognosis presented by his hematologist and cross-checked the received information with a second physician. Another participant (Maria, 3 years since diagnosis) was met with disbelief by her family members when she explained her diagnosis to them, as they speculated there was a more serious health condition that she was hiding from them by lying.

3.1.2. A Scratch on the Surface. Being referred to a hematologist and trying to gather accurate medical information from all possible sources (e.g., Internet and physicians in their close circle) were important for patients’ understanding and coming to terms with their diagnosis. Their hematologist’s reassurance regarding the good prognosis of the disease was the greatest source of relief for participants, which consequently helped them overcome the initial shock and come to terms with their diagnosis.

And luckily when we went to (hematologist’s name), she said “There seems to be nothing going on, except from the white blood cell count. There is an underlying condition, but since the count is not high you are just fine.” Ahh, I felt calm, I ate, I drunk water (chuckles). (Barbara, less than 1 year since diagnosis)

One participant (George, 5 years since diagnosis) felt so much trust and was relieved to such an extent by his hematologist’s reassurance that he completely disregarded any threat and did not realize he had a malignancy. This led to subsequent shock and self-blame when he later found out from another individual with CLL.

I realized (that CLL was a malignancy) just a while ago I felt bad, I wondered ‘Am I so stupid, so ignorant, that I didn’t even read more (about CLL)? That is to say, OK, they told me “It is nothing, your health will be monitored and there is no need to be afraid,” but such was the magnitude of my reassurance (that I didn’t even realize CLL was a malignancy). (George, 5 years since diagnosis)

Despite its threatening overtones, participants were functionally unaffected by CLL and resumed their daily lives as normal. Their work, social, and family life remained intact as participants were not experiencing any symptoms, except for Catherine (5 years since diagnosis) who was experiencing fatigue and thus could not keep up with all she used to do in the past. As a result, she took more time daily to rest and adjusted her hobbies and habits accordingly (i.e., went out with friends earlier in the afternoon or chose to stay in). Due to the absence of symptoms, most participants were feeling healthy and did not report any changes regarding their self and body image, with the exception of Gloria (9 years since diagnosis) who had comorbidities and felt that she carried an

“illness” inside her body, and Jim (less than a year since diagnosis), a newly diagnosed participant, who described oscillating between a healthy and ill self-image.

3.1.3. *An Illness That Lurks.* Despite its limited physical impact, being diagnosed with CLL casts a shadow of uncertainty, anxiety, and fear for the majority of participants. Their main concerns were what the future might entail in terms of disease progression, symptoms, and treatments and how long it will take until their health deteriorates. Having received a cancer diagnosis, but not experiencing any signs or symptoms related to it, denoted a lurking quality to CLL.

The course (of my disease) and how it will progress (is what worries me the most). Will I suddenly start having symptoms? Will I wake up in pain one day, without knowing what’s going on, and I should immediately start. I don’t know what to expect. (Jim, less than a year since diagnosis)

This was reinforced by the absence of concrete symptoms, which made half of the participants vigilant and speculative on whether emerging physical and psychological signs and symptoms, such as fatigue, skin lesions, or even forgetfulness, were indeed symptoms of CLL or were caused by other factors, such as aging.

After understanding and accepting their diagnosis, participants returned to normal life, but uncertainty regarding their future remained in the back of their minds and was keeping some of them on guard. For instance, Gloria (9 years since diagnosis) was experiencing increasing worry in anticipation of the future, as many years since her diagnosis had passed and she had never received any treatment.

I am worried about the future, I don’t know what’s coming for me and I don’t know much regarding my own case, what happens next, when it will get much worse, what therapy will I get, what treatment. I am not sure whether it is a good or a bad thing that I don’t know, but it stresses me out, for sure it does make me anxious, that I don’t know what’s coming for me. (Gloria, 9 years since diagnosis)

Despite having managed to not think about CLL daily and indulge in worrying, certain conditions triggered participants’ anxiety. Medical check-ups reactivated participants’ fear and worry regarding their illness and instigated nervousness concerning the results, tapping on their apprehensiveness about the time when the “bell will toll” for treatment initiation. Seeing peers in a worse condition and receiving therapy was another triggering condition, which made participants uncertain with regard to the way they would manage to cope if they ever ended up in their peers’ shoes. In addition, as Catherine (5 years since diagnosis) mentioned, worry and attention from family members kept reminding her that she has CLL.

3.2. *Surviving Uncertainty.* This subtheme portrays participants’ ways of coping with the uncertainty that their CLL diagnosis entailed, which evoked difficult-to-manage emotions. Managing these emotions, CLL and the underlying idea of dying that seemed to whirl beneath it, became an ongoing challenge for participants. To this end, they mustered internal coping mechanisms, related to the way they perceive their illness, their identity, the future, and life in general. Lastly, external mechanisms, involving the acquisition of support from their hematologist and their close ones, were utilized.

3.2.1. *Inner Endeavors for Solace.* Participants adopted a variety of internal coping strategies to deal with the anxiety evoked by being diagnosed with CLL. A prominent internal strategy was to think that they were lucky or blessed, due to the positive prognostic factors of CLL. In addition, two participants contrasted the mildness and good prognosis of their condition with more serious forms of cancer. For instance, Maria (3 years since diagnosis) actively thought about others in a worse health condition when she experienced injustice and distress.

Another internal coping strategy was minimizing CLL and trying to repress relevant thoughts and negative emotions. Continuing to live a normal life and preserving their identity as healthy individuals helped participants keep CLL out of their conscious awareness. One participant even thought that CLL might disappear as time goes by.

Consider that there are people with acute forms of the disease. Okay, we shouldn’t complain, and one should accept certain things, that it was meant to be that way and it’s over, but you are lucky to be one of those people who have the chronic form (of leukemia). Recently I lost somebody, a man much younger than myself to cancer, so, you think, okay, I am grateful lucky in my misfortune, which I don’t consider a complete misfortune, because this disease progresses really slowly and I don’t know what will even happen I sometimes think that maybe nothing will ever happen, (laughs). I hope it may vanish, yes, maybe I am one of the lucky ones. (Maria, 3 years since diagnosis)

In that manner, when directly asked about their outlook on the future, three participants commented that they do not want to think about it and rather prefer to live in the present. Three others pointed to God’s protection and their trust in their inner strength for facing life adversities.

I’m not scared or anything like that, because I’ve had a very difficult life with three children and other circumstances. I’m not afraid of anything, only God knows. (Barbara, less than 1 year since diagnosis)

Finally, most participants mentioned that they found solace in certain existential beliefs, i.e., the universality of death and dying, the temporary nature of life, as well as the inescapable destiny or God’s will.

3.2.2. Doctor as an Anchor. Every participant emphasized the support, reassurance, and encouragement they had received from their hematologist since their diagnosis. In the absence of treatment, one participant highlighted that her hematologists' genuine interest and reassuring stance were what cured her emotionally.

I realized from day one that she knew, or she understood that we are not rich. She always does something extra (for us), (e.g.,) a discount and that was what I relied on. That helped me stay calm, I'm not stressed, I'm not stressed at all, God is above me and Ms. (Doctors' Name). (George, less than 1 year since diagnosis)

Besides reminding participants of their diagnosis, medical check-ups also provided them with a sense of having their disease under control. Some participants mentioned that their hematologists' encouraging and positive attitude buffered the stress they experienced before check-ups and walked out of the clinic room feeling calm and relieved. In the cases of two participants, complete trust in their hematologists fully buffered any anxiety regarding the future.

However, half of the participants mentioned that they had not discussed their inner worries with their hematologists. They expressed the need to learn more about possible future adversities as well as the course and manifestations of CLL, in order to accept their condition and better prepare themselves and their family members for what lies ahead. One participant (Jim, less than a year since diagnosis) wanted to know the exact symptoms of CLL in order to stop self-monitoring and constantly worrying about irrelevant symptoms that he feared were the onset of CLL's progression. The short duration of medical appointments was mentioned as the primary barrier to these discussions. Hence, Victor (5 years since diagnosis) suggested that there should be a CLL point of contact for emerging questions. This might be a source of support for patients without overloading hematologists' busy schedules. It is worth highlighting that half of the participants wished they could cultivate a more personal doctor-patient relationship, beyond a typical role or a hospital setting.

With my doctor we have the best relationship. I have had just two appointments as I am still in the beginning, but she is exceptional. Exceptional. And as time goes by, I want our relationship to become closer, warmer, not the typical relationship between doctor and patient. (Jim, less than 1 year since diagnosis)

3.2.3. Limited Support Circles. Participants faced several barriers that impeded helpful communication with their close ones. The mildness and "invisibility" of their condition, in conjunction with the impact they expected it would have on their interpersonal relationships, substantially limited the emotional support that was both sought and received.

Apart from their hematologists, participants acknowledged that their families were the main source of support to them. However, not everyone could get the support they

needed. Notably, Maria's (3 years since diagnosis) family blocked the expression of negative emotions, which led her to shut herself off and go through them on her own.

I may want to get it off my chest sometimes including my negativity and my sadness and they all tell you "don't think about it, don't think about it and they repel you, friends and relatives distance themselves, so you go through this alone." (Maria, 3 years since diagnosis)

Another participant (Catherine, 5 years since diagnosis) came across diverse reactions from family members; her daughter became overprotective by offering constant practical support, while her husband did not support her at all, as he perceived that she was completely healthy. Correspondingly, in order not to worry her family members, Barbara (less than a year since diagnosis) went through the stressful initial examinations without telling anyone, while Gloria (9 years since diagnosis) never expressed her concerns and worries to them.

Further to their families, three participants mentioned that they did not even disclose their diagnosis to their friends, afraid that they would take pity on them, become overprotective, or take their distance.

When I get emotional, I try not to let things really affect me (emotionally) or if they do, I try to just keep it to myself (. . .) I don't want to dwell on (it), neither (share it) with friends I don't want to make others pity me, I don't want anyone to think that I have a serious issue which makes me unable to hang out with a group (of friends). They might behave differently towards you, and I don't know, maybe they might even avoid you, I don't know what others may feel if they hear the word "leukemia" and "cancer" and all that. You can't know how others will treat you and for what reason. (Jim, less than 1 year since diagnosis)

Some participants mentioned the lack of symptoms and treatment as factors of holding them back from diagnosis disclosure. However, despite concealing his diagnosis from his friends, one participant (Jim, less than a year since diagnosis) felt that going out with them was a great way out of his anxiety for the future.

3.2.4. Filling the Gap: Peer Groups and Raising Awareness.

When asked about their possible participation in a CLL peer group, participants' replies indicated that attending peer-group meetings could offer them supportive elements that were missing from their current networks. Meeting peers could be a great source of information, as participants could exchange experiences, get a better picture of what lies in the future, and share ways of coping.

I want to see other cases that have been around longer than me, see their illness progression, whether they had visible symptoms and what kind because I don't have any yet but I want to see them as soon as possible. (Jim, less than 1 year since diagnosis)

Peer discussions could also provide solace stemming from a shared understanding of their condition. One participant (Maria, 3 years since diagnosis) highlighted the importance of raising awareness about CLL in order to extend such understanding outside the circles of peers, while another, who had already attended a peer meeting, took courage from seeing others in good health and experienced solace and relief.

I saw all these people who suffer from the same disease, it was a bit relieving because, first of all, I saw that everyone was ok and this gave me courage it gave me courage. (Gloria, 9 years since diagnosis)

Three participants highlighted that they felt confident in empowering, reassuring, and helping their peers develop a positive outlook on life.

3.3. *Turning over a New Leaf.* This theme describes the psychological and existential impact of being diagnosed with CLL on participants and its impact on their identity and outlook on life. Receiving a cancer diagnosis shook and challenged participants by pulling the carpet of safety from under their feet and spontaneously instigated internal processes that resulted in maturation and growth.

3.3.1. *Realization of Finiteness.* The diagnosis of CLL confronted participants with their finiteness and enabled them to experientially grasp the ephemeral nature of life. For Maria (3 years since diagnosis), this entailed regrets regarding the importance she had given to transient things in the past and how disappointed she was feeling when things went wrong.

(Before the diagnosis) I might not put my health first, and then I started to always put health first. I used to put my job ahead of my health, now I consider things at work as of secondary importance. I prefer to rest than finish things at work, just because they told me to do so. (Victor, 5 years since diagnosis)

Three participants referred to a deep change in perspective which encompassed that things can actually go wrong, that life is fragile, and can change at any moment. To highlight this shift in perspective, two participants mentioned that before their diagnosis, they were feeling invulnerable to illness and took their physical health for granted.

Realizing the fragile nature of life and perceiving having an “illness” inside her body made Gloria (9 years since diagnosis) experience reduced interest in caring for her physical fitness, appearance, and social interactions beyond her family, as these were currently perceived as futile.

3.3.2. *A Nudge for Growth.* Along with the realization of their mortality, the CLL diagnosis was described as a lever of growth and maturation by many participants.

Five of them mentioned that after being diagnosed, they actively started prioritizing their own health.

Until then (the diagnosis), you see things, you take life more easily. Since that moment I realized that, you know, everything is a fleeting moment. Everything can change at some point. And maybe I didn't put health first at times, and then I started to always put health first. (George, 5 years since diagnosis)

Many participants referred to an increase in their self-care behaviors and their engagement in a healthier lifestyle (e.g., adopting a healthier diet and reducing alcohol consumption). In addition, some participants mentioned that since health had become the most important value they held, they came to avoid getting worked up about life's mishaps (e.g., financial difficulties and family quarrels) that were previously a major source of negative emotions for them. This was notable, as half of the participants believed that psychological factors, i.e., stress, sadness, and pressure, contributed to the emergence of CLL.

The way I look at life has changed, meaning that I used to get upset if I had a conflict with my husband. Now I don't get upset at all because I believe I do what I have to, as a wife, as a mother, as a housewife. There are times when I feel the need to relax and I will do so. I will cook if I'm in the mood to do so; that used to be taken for granted. If I am not in the mood I will not do it. (...) That's what changed. (Catherine, 5 years since diagnosis)

Another change instigated by the CLL diagnosis involved decentering from the needs and demands of others and focusing more on, previously neglected, needs and desires of their own. For instance, Barbara (less than a year since diagnosis) who had dedicated her life to meeting the needs of her family members experienced her diagnosis as an important reminder from God to realize her self-worth and start living according to her own wishes. Increased acceptance of uncontrollable life contingencies and letting go of efforts to plan and have full control over the future were also described by participants.

Finally, three participants highlighted that getting a CLL diagnosis was a life-changing experience for them, which made them grow to savor each moment and value the elemental facts of living (e.g., breathing) and ordinary life experiences.

It is indeed a luxury to live, to breathe, to drink a cup of coffee in the same coffee shop (chuckles), with the same person and discussing exactly the same things. It changed me very much, I see things in a whole different way, I love myself and my body more. (Maria, 3 years since diagnosis)

4. Discussion

The interviews offered several insights into how CLL has impacted patients who are in a “watch-and-wait” phase. In summary, most participants were shocked hearing the

diagnosis and the term “leukemia.” Even though they were barely affected in their daily life, they had been experiencing intense and difficult-to-manage emotions such as uncertainty for the future and anxiety about their illness’s progression. For many, their family was the main source of support, yet the invisibility of their disease made it difficult to share it with their loved ones, leading to limited emotional support. Participants wanted to invest in a personal relationship with their hematologists, who provided substantial support, reassurance, and encouragement. In their endeavor to deal with uncertainty, CLL patients utilized internal coping strategies, such as rationalization, repression, and external support from their hematologist, and they were very keen on the prospect of participating in peer support groups. Being diagnosed with CLL triggered existential thoughts and impacted patients’ identity and outlook on life. Living with a life-threatening illness led to a different perspective, a change in priorities, and posttraumatic growth.

For most participants in the current study, there seemed to be a quite an intense negative psychological reaction after diagnosis, which was cushioned after they were properly informed by a hematologist. Yet even though hematologists provided reassurance, some patients felt reluctant to accept it. Furthermore, participants had upcoming unanswered questions which they wished to have time to discuss. Thus, the value of medical consultations and personalized information with the aim to not only inform people living with CLL but also to support them emotionally [47] is called to attention. People with CLL in the “watch-and-wait” phase might be in less need of medical care compared to those with other types of cancer (e.g., acute leukemia). However, healthcare professionals should be attentive to their psychological needs in order to help them manage the uncertainty they experience and improve their well-being.

Shock as patients’ first reaction upon a cancer diagnosis was reported in other types of cancer as well [48–50]. Of note is that participants’ reaction upon receiving their diagnosis mostly resembled reactions to diagnoses of terminal rather than chronic conditions [49, 50], in the absence of disturbing symptoms or treatment burden. In this context, feelings of shock and distress were probably stemming from the social representations of cancer as a fatal and painful medical condition [51]. This could be attributed not only to the initial shock imposed by the connotations of the terms “leukemia” and “cancer” but also by the way healthcare professionals outside the field of hematology inform them. These findings underscore the need for raising awareness for CLL among healthcare professionals and granting people living with CLL timely access to accurate medical information.

In contrast to patients with acute leukemias, who were experiencing burdensome and pressing physical challenges which compromised their ability to fulfil daily roles and their independence [52, 53], people living with CLL in the watch-and-wait phase did not experience a pressing need to focus on their physical condition. While patients with acute leukemias were in multiple trying to restore a sense of normalcy in their lives, e.g., by struggling to carry out a certain amount of everyday activities, participating in

medical decisions, or trying to establish support networks that would help them take distance from their disease [52, 53], people living with CLL in the watch-and-wait phase faced a different challenge, that is, to keep living in “normalcy” while anticipating a “looming cancer,” which would impact them in the future.

The findings of the present study are complemented by quantitative research in the framework of the common-sense model [54]. Once receiving a diagnosis or experiencing symptoms, people immediately develop mental representations about them and their meaning [55]. These then lead to ways of coping with the health threat. Contrary to other people with cancer, people with CLL may not start treatment immediately after diagnosis and remain unaware of how and when their illness would develop [24]. This deprives them of an important active coping strategy [56], which could give them the sense of directly managing their stressor. The absence of treatment has substantial psychological repercussions, as shown by the decreased perception of control for those who do not receive treatment for CLL compared to those who do [57]. Participants in this study struggled to adjust to living without being able to predict and control how their disease would progress and what implications this might have for their future.

Of interest is how participants tried to regain a sense of meaning in their lives after receiving a diagnosis characterized by an unknown etiology, an unpredictable course and constraints over patients’ capacity to control the future. According to the meaning-making model [58], when individuals experience a stressful event, they try to appraise its situational meaning along a variety of factors, such as threat level, controllability, etiology, and implications for their future. When there is a discrepancy between the situational meaning and the global meaning in one’s life (e.g., one’s sense of control, predictability, justice, coherence, and sense of purpose), distress is created, which drives meaning-making efforts to reduce such discrepancy, i.e., by altering the meaning of the stressful event, their global life meaning, or both. Several processes described by participants can be viewed under this prism. For example, feeling lucky and comparing themselves with patients in worse health conditions can be viewed as an attempt to render CLL less threatening. Avoiding reminders of CLL or thoughts about what the future entails can be seen as an effort to reduce the discrepancy between having received a cancer diagnosis and continuing to live as normal. Fully trusting their hematologists and finding solace in God’s protection and their inner strength for addressing life’s adversities can be seen as ways of preserving their sense of control and optimism regarding their future. In addition, altering their global beliefs regarding life’s finiteness can be seen as an effort to accommodate their worldview to their new diagnosis.

According to Brandstadter et al. [59], such an accommodation can be quite adaptive and lead to posttraumatic growth. Indeed, being diagnosed with cancer not only leads to negative emotions but may also lead to positive psychological changes, such as personal growth [60–63]. Thus, elements of the posttraumatic growth

model [64] such as personal strength, relationships with others, new possibilities, appreciation of life, and spiritual beliefs were apparent in the narratives of patients in this study.

In addition, this study further validates what the model describes as a “seismic event,” namely, a traumatic event that is so strong that shakes people up and results in change. Since the participants of this study were not having any major symptoms and did not receive any treatments, it is the diagnosis itself (the “seismic event”) that has led to the change.

Another significant finding of the current study was that patients often faced difficulty sharing their diagnosis with their environment and experienced limited emotional support. Since the presence of social support seems to be crucial for cancer patients’ psychological well-being and coping with their illness [65–68], a focus should be placed on enabling them to maintain interpersonal support. Thus, it is essential to sensitize informal CLL patients’ caregivers to recognize and address patients’ needs, through psycho-education [69]. Since the watch-and-wait phase usually entails minimal physical impact, the focus should shift to the emotional effects of the disease, utilizing dyadic communication and dyadic coping [70]. In addition, as watch-and-wait is characterized by feelings of uncertainty, interventions that focus on improving patients’ tolerance of uncertainty may be helpful. Similar interventions have been implemented for individuals and caregivers with breast cancer, brain tumor, leukemia, gynecological cancer, and ovarian cancer and have been found effective in uncertainty management [71].

Health literacy is another crucial factor for cancer patients’ communication and quality of life [72], and CLL patients’ associations could be a proper vehicle for enhancing CLL-related literacy. Increasing the knowledge of patients and caregivers regarding their disease and its phases has been associated with favorable clinical outcomes [73], better QoL [74], higher levels of self-management behavior, as well as lower fear of recurrence [75]. Such interventions could be tailored and delivered to people living with CLL. This can also not only enable patients to inform their family members but also their HCPs about their needs and how they could best be supported, thus improving their overall communication.

Future research should also test interventions aimed at communication training for HCPs, as effective doctor-patient communication has been found to be an important factor regarding patients’ well-being [76, 77]. Since patients in the present study reported having unanswered questions and experiencing difficulties in communicating their worries, such interventions could tackle communication barriers. In addition, providing personalized information and promoting timely referrals to psychosocial or spiritual services could assist patients in addressing their multifaceted concerns (e.g., medical information and existential concerns) and capitalize on posttraumatic growth processes. This leads to the need for tailored clinical programs for hematologists [40], focused on people living with CLL’s unique needs.

5. Conclusions

Despite the limited physical discomfort that people living with CLL experience during the watch-and-wait phase, living with the CLL diagnosis brings about psychological distress, which drives meaning-making efforts and activates several coping mechanisms. Based on this study’s findings and previous research, this has the potential to activate posttraumatic growth.

CLL patients in active monitoring could benefit from psychosocial interventions that focus on assisting them in managing uncertainty, utilizing interpersonal support resources, addressing their existential concerns, and capitalizing on posttraumatic growth processes.

Data Availability

The datasets generated and analyzed during the current study are not publicly available due to the fact that the interview transcripts are in participants’ native language, i.e., Greek, and therefore not suitable for deposit in a public repository. They can be available to anyone interested upon request to the authors of the study.

Ethical Approval

This study was approved by the Research Ethics Committee of the Institute of Applied Biosciences at Centre for Research and Technology Hellas (CERTH) and the Research Ethics Committee of every participating hospital.

Consent

Informed consent was obtained from all individual participants included in the study (see Supplement C and Supplement D).

Disclosure

The funders had no role in the study design, data collection, analysis, decision to publish, or preparation of the manuscript.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Authors’ Contributions

All authors contributed to the study conception and design. Material preparation, data collection, and analysis were performed by Dimitrios Kyrou, Nikolaos Vrontaras, Konstantina Stavrogianni, and Christina Karamanidou. The first draft of the manuscript was written by Dimitris Kyrou, George Koulierakis, and Nikolaos Vrontaras, and all authors commented on the previous versions of the manuscript. All authors read and approved the final manuscript.

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Supplementary Materials

Supplement A: COREQ criteria. Supplement B: interview guide. Supplement C: patient information sheet. Supplement D: patient consent form. (*Supplementary Materials*)

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