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“I Got My Diagnosis on a Yellow Post-it Note”

Young Adult Cancer Patients' Experiences of the Process of Being Diagnosed With Cancer

KEY WORDS

Diagnosis process
Qualitative study
Transitions
Young adult cancer patients

Background: Cancer in young adults is rare but young adult cancer patients (YACPs) are at an increased risk of severe physical and psychosocial impairments during cancer treatment and survivorship. However, little is known about the onset of this process. **Objective:** The aim of this study was to explore how young cancer survivors experience the process of being diagnosed with cancer. **Methods:** A qualitative method founded on a phenomenological-hermeneutical approach was used and included in-depth interviews with 20 young adult survivors (aged 24–35 years) with different cancer diagnoses, analyzed by Systematic Text Condensation. **Results:** The participants' experiences of the diagnosis process were elaborated according to 3 main themes: (1) “I felt something was wrong, but...,” (2) “The traumatic uncertainty,” and (3) “The day my world collapsed.” **Conclusion:** The findings indicate that the YACPs experienced a diagnosis of cancer as a highly traumatic and long-lasting process, characterized by lack of information and uncertainty. The findings indicate that healthcare professionals do not acknowledge the vulnerable phase of life and transitional challenges of YACPs. **Implications for Clinical Practice:** The findings highlight the need to raise awareness of cancer in young adulthood in the public and in the primary healthcare system, to shorten the diagnosis process, and to clarify responsibility for age-related information and psychosocial follow-up during the diagnosis process. Further research is highly warranted.

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Cancer in young adulthood (between 18 and 35 years of age) is rare,^{1,2} but research documents that young adult cancer patients (YACPs) face unique physical and psychosocial challenges and unmet needs during treatment and survivorship.^{3,4} However, little attention has been given to YACPs' experiences from the process of being diagnosed with cancer. This is crucial knowledge for healthcare providers to facilitate suitable information and psychosocial support and to promote YACPs' coping and well-being throughout the remainder of their cancer trajectory.

■ Previous Research

Cancer in young adulthood comprises only 2% to 4% of new cancers and brings a unique biology, etiology, and pathogenesis.⁴⁻⁶ Based on this, and being in a particularly vulnerable period of life,⁷ YACPs face unique physical, psychological, social, educational, and economical challenges during treatment and survivorship.^{8,9} Even though YACPs report a high degree of cancer-related distress, uncertainty for the unpredictable illness course, and unmet information and communication needs,^{6,10,11} little attention has been given to the onset of their cancer trajectory.

Research indicates that YACPs face distinct challenges related to early detection and diagnosis because of their reluctance to seek medical care and a lack of cancer awareness and health insurance.¹²⁻¹⁴ In addition, general practitioners (GPs) lack knowledge and experience of cancer in young adulthood, whereby cancer symptoms are often underrecognized and diagnosis is delayed.^{4,15-18} As a consequence, YACPs often present with an advanced stage of disease and lower survival rates.¹²

Receiving a cancer diagnosis in young adulthood is described as a traumatic moment, representing a period of confusion and emotional turmoil with a stunning loss of normalcy.^{19,20} Consequently, "coping with the diagnosis" is shown to be a distinct challenge of the cancer trajectory.^{11,21} Disclosing a cancer diagnosis has direct consequences at psychological, emotional, and relational levels, as well as representing a critical step in establishing a trust-based relationship between the patient and healthcare providers.^{22,23} Research suggests that YACPs place high importance on receiving information about medical, physical, practical, emotional, and psychological issues during diagnosis, although these information needs are largely unmet, and they experience little care in respect of their emotional and psychological concerns.²⁴ Young adult cancer patients seem to be especially dissatisfied with the physician's communication at diagnosis as this often is experienced as being delivered in a cold, aloof, or patronizing manner²⁵ and dominated by medical information with less attention placed on the emotional aspects of the diagnosis.²⁶ The unmet needs of YACPs are mainly explained by a fragmented and poorly coordinated healthcare system with insufficient access to age-appropriate information, communication, emotional and psychosocial care, and treatment settings.²⁷⁻³¹ However, more knowledge about YACPs' own experiences of the diagnosis process is important to be able to meet their needs and thereby to promote trust and coping ability throughout the cancer trajectory.

■ Theoretical Framework

Young adulthood is characterized as a vulnerable and transitional phase of life with a high degree of heterogeneity and instability, an extended length of education, and identity exploration with respect to love, work, and worldviews.^{7,32} Cancer in this period of life adds a tremendous burden and disruption to life^{1,33,34} and is also described as a transition with increased risk of negative health outcomes.³⁵ Thus, one could claim that YACPs experience a dual transition. The Cognitive Activation Theory of Stress (CATS)³⁶ states that a challenging situation (stressor), for example, being young and diagnosed with cancer, is evaluated considering the individual's previous experiences and subjective perceptions, producing a stress response that activates physical, emotional, and behavioral reactions. If the individual has positive coping experiences, expectations, and capabilities, the stress response becomes one of coping and short-term stress. A stress response via "noncoping" may lead to prolonged and constant stress, negative experiences, helplessness, and hopelessness.³⁶ Being in a dual transition with limited experiences, YACPs are particularly vulnerable and are at risk of experiencing increased stress, helplessness, or hopelessness and negative health outcomes.^{32,35,36} Therefore, healthcare providers have a crucial role in facilitating positive coping experiences during the diagnosis process and in supporting YACPs to develop adequate coping abilities for the cancer trajectory to come.

■ Aim

The overall aim of this study was to generate knowledge and insight into how young adult experience the process of being diagnosed with cancer.

■ Methods

The study embraces a qualitative method using a phenomenological-hermeneutic design.^{37,38} This design is especially suitable when the research attempts to understand the lifeworld from the individual's point of view, here, YACPs' experiences of being diagnosed with cancer. It involves an iterative process between the YACPs' expressed experience of their lifeworld and the researchers' interpretations (the hermeneutic cycle), whereby the researchers reflect upon how their own preunderstanding shapes interpretation throughout the interpretative course. This process continues until a consensus is reached, representing a new understanding.³⁸

■ Participants

The participants were enrolled in a larger study of cancer rehabilitation³⁹ where the eligibility criteria were (a) YACPs aged 18 to 35 years, (b) finished cancer treatment within the

last 5 years, (c) all cancer diagnoses, and (d) referred to the study by an oncologist or GP. All the 20 eligible and invited participants agreed to join this study, representing a variety of demographic and medical variables as outlined in Table 1.

■ Data Collection

The first author conducted face-to-face interviews with all the participants in a quiet office at the rehabilitation center at the start of their rehabilitation program. Each interview focused on retrospective reflections based on a semistructured interview guide outlined in Table 2. The main question was: “Can you please tell me about your experiences of being diagnosed with cancer?” Follow-up questions were related to symptoms, the diagnosis process, how the diagnosis was disclosed, reactions, and information. The interviews lasted between 45 and 70 minutes and were audiotaped and transcribed. To conceal the identity of the participants, no name or background data were transcribed, and a pseudonym was given to each participant.³⁷

Data Analysis

Systematic Text Condensation was used to analyze the data.⁴⁰ NVivo 9 software was used to code and sort the data (www.qsrinternational.com). Following Systematic Text Condensation's 4 steps, we first read the interviews to obtain a general impression. Second, we reread the interviews and extracted 5 units or codes of meaning. Third, these codes were condensed into groups and subgroups, engaging the researchers in an analytic circle between the identified codes and the transcribed interviews. Discussions between the researchers included several

☀ **Table 2 • The Semistructured Interview Guide**

Main Questions	Period	Follow-up Topics if Necessary
Can you please tell me about your experiences of being diagnosed with cancer?	Symptoms, diagnosis process and diagnose	Symptoms before Investigation process How the diagnosis was given Initial information Own reactions

facets of the analyses.³⁷ The first and third authors analyzed and coded the transcribed data separately to enhance validity. These analyses were then discussed until all interpretations reached consensus.^{37,40} At the conclusion of this process, 3 main units of meaning or themes had been agreed, each having 2 subthemes. To validate the analysis, the fourth step entailed comparing the findings against the interviews to ensure that we had captured the informants' expressed and intended meanings. In addition, the first author discussed the findings with a group of 4 female YACPs (20–30 years of age) who had not participated in the study, and they unanimously validated the findings. Table 3 outlines the analysis process.

■ Ethical Considerations

The Western Norway Regional Committee of Research and Ethics approved the study. The participants gave written consent, and the researchers followed established guidelines in preserving anonymity and the safe handling of the data.⁴¹

■ Findings

Three main themes emerged from the analysis as essential elements of YACPs' process of being diagnosed with cancer: (1) “I felt something was wrong, but...,” (2) “The traumatic uncertainty,” and (3) “The day my world collapsed.” Each theme was elaborated by 2 subthemes. The main findings are outlined in Table 4 and described as follows.

Theme 1: “I Felt Something Was Wrong, But...”

From a retrospect perspective, all but 2 of the participants expressed that their cancer trajectory was initiated by a feeling that something was wrong and that this feeling was based on a variety of vague physical symptoms. These symptoms included a cough, pain, night sweats, fever, dizziness, reduced appetite, bleedings, mouth ulcers, weight loss, diarrhea, hearing loss, lumps, and so on. Tiredness was a frequent symptom: “I was very tired... And I was tired ALL the time. I used to be very

☀ **Table 1 • Demographic and Medical Presentation of Study Population (N=20)**

	n	Mean or Percent	SD/ Range
Gender			
Female	15	75%	
Male	5	25%	
Age, y	20	31.1	3.9/24–35
Civil status			
Married/cohabitate	11	55%	
Single/divorced	9	45%	
Highest fulfilled education			
Senior high school	6	30%	
University/university college	14	70%	
Cancer diagnosis			
Lymphoma	5	25%	
Gynecological	5	25%	
Breast	4	20%	
Testes	2	10%	
Colon	2	10%	
Sarcoma	1	5%	
Head and neck	1	5%	
Months since diagnosis		24.6	16.0/4–71

Table 3 • Overview of the Systematic Text Condensation Analyzing Process in the Study

Step 1: Getting a Total Impression	Step 2: Identifying Meaning Units	Step 3: Abstracting the Contents of Individual Meaning Units	Step 4: Summarizing the Findings
Process	Process	Process	Process
(a) The authors read the transcribed interviews separately	(a) The authors coded the data separately	(a) The authors analyzed the contents separately	
(b) Discussed the total impression to consensus	(b) Discussed the codes to consensus within the codes	(b) Several discussions to consensus	(b) The authors discussed the findings against the transcribed interviews (c) Each author found direct statements to elucidate units of meaning and discussed to consensus
Identified Total Impression	Identified Meaning Units	Abstracted Contents/Themes	Summarizing
Vague symptoms GPs did not take their symptoms seriously	Code^a Delay in diagnosis	Source^b 11	
Long and often painful investigations	References^c 43	Experiences from the diagnosis process	Summarized findings and presenting direct statements within the abstracted contents
Difficult waiting time		1A: "I tried to ignore it"	
Diagnosis given in different ways—often alone		1B: "My GP ignored it"	
Shock reactions	How the diagnosis was given	20	68
Information about diagnosis and treatment, not psychological support	Reactions	17	39
	Information	14	33
		Elaborated by the 2 sub-themes: 2A: "But no one would tell" 2B: "To live in suspense"	
		Theme 3: "The day my world collapsed" Elaborated by the sub-themes: 3A: "I got my diagnosis on a yellow Post-it note" 3B: "Only the hard facts"	The findings were discussed and unanimously validated by 4 young adult cancer patients who had not participated in the study

^aIdentified meaning units.

^bNumber of informants talking about the code (N = 20).

^cNumber of quotes related to the code.

social, but I couldn't do that... I struggled hard..." (Wenche). Most participants did not link these symptoms to cancer, and each reacted differently to their symptoms as elaborated in the 2 subthemes "I tried to ignore it" and "My GP ignored it."

SUBTHEME 1A: "I TRIED TO IGNORE IT"

Most of the participants reported that they had experienced diffuse symptoms over time. Initially, they were not worried but most commonly ignored or displaced the symptoms or they tried, in diverse ways, to explain or trivialize them: "...I had coughed over an extended period. I was very exhausted, but I thought I probably had some debris in my system. And the cough varied (...), and I could not run (...), and every-

thing was heavy (...). It's completely insane when I think about it now, but during the entire spring, I woke up at night bathed in sweat, but I just thought it was warm. I was incredibly good at blaming things..." (Linda). Similarly, some participant related the symptoms to a stressful life situation, for example, a relocation, a new job, exam stress, or a breakup: "I had lost weight and felt tired and... But at the same time, I went through a breakup.... So I thought it was THAT, right?" (Mette). Other participants related the symptoms to other diseases, for example, mononucleosis, something they had eaten, or natural body changes: "I found a lump in my breast, so I first thought it was something hormonal or the cycle or... So, I thought. 'It's probably nothing.' And I talked with others as well, and they said the same thing..." (Mary). A few participants

**Table 4 • The Study's Main Findings**

Main Themes	Subthemes
"I felt something was wrong, but..."	(a) "I tried to ignore it" (b) "My GP ignored it"
"The traumatic uncertainty"	(a) "But no one would tell" (b) "To live in suspense"
"The day my world collapsed"	(a) "I got my diagnosis on a yellow Post-it note" (b) "Only the hard facts"

even thought it could be cancer but found the symptoms to be too weak: "I thought it could be cancer, but because I did not hurt or had any other bother with it, so..." (Astrid).

The time between the onset of the symptoms and the contact with their GP varied from a couple of weeks to more than a year. Some made the GP appointment on their own initiative; others were ordered to do so by family or friends, whereas a few made the appointment for other medical problems and presented their symptoms as a sub-issue. Four participants did not seek medical help before the symptoms were critical and severe: "One morning I coughed blood... and then I thought that now I have to take care of this..." (Linda), and "And when I could eat only liquid food, then I realized I had to get a grip..." (Astrid).

SUBTHEME 1B: "MY GP IGNORED IT"

Eventually, when the participants visited their GPs, the doctors' reactions to their symptoms varied. Several found that their symptoms were trivialized or explained away: "I went to my GP and was told that there was certainly nothing to [worry about]... and 'certainly not cancer, as you are too young'" (Ingrid). Consequently, most paid several visits to their GP before further inquiries were initiated. They were asked to wait until the symptoms disappeared by themselves, or alternatively, they were treated symptomatically: "I began to lose hearing in my right ear, but then I was told that they should just drill holes in the eardrum (...). I went to the GP 3 times... (...) They told me it was pressure from the inside... and it certainly was..." (Wenche). To be on the safe side, some of the participants were referred to a specialist: "I was told it was most certainly was an infection in the epididymis, but for the sake of the safety, I should go to the hospital" (Arne). For other participants, their GP did not react, and their symptoms became more severe, eventually being admitted to emergency: "We swapped tires on our car, then I got a really strong bleeding, it just flooded! And then it was straight to emergency... And then, then they started to... understand that it was something more than just something normal that only went over by itself... However, I didn't think of cancer. Not at all! It did not occur to me that it could be..." (Mariann).

Theme 2: "The Traumatic Uncertainty"

Eventually, most of the participants were referred for further investigation. In general, this process was described as the worst

phase as it was experienced as a traumatic and lengthy process. This period was elaborated by the 2 subthemes "But no one would tell" and "To live in suspense."

SUBTHEME 2A: "BUT NO ONE WOULD TELL"

Referred from their GP, most of the participants went through more or less painful examinations and tests, for example, x-rays, computed tomography scans, one or several biopsies, colonoscopies, and spinal punctures: "The doctor was very aggressive... who yelled me out because I had a lot of trouble taking the gynecological examinations... And it was several such situations where they forced themselves on... It has been very painful, and I have cried, and they got very angry with me. It was quite traumatic" (Pamela).

Many participants were not prepared or did not understand the purpose of the different tests or that these were tests to confirm or disprove a cancer diagnosis. For some participants, the suspicion of cancer was first awakened as a result of receiving a letter from the cancer hospital or cancer unit or by nonverbal hints from professionals: "I felt it was something between the lines. It was just trivial things, such as if she said that I should have checked this out before... Things like that. And when I was at the ultrasound. The doctor, she SAID nothing, but she looked very concerned in her face. It's actually the body language that tells you the most" (Mary).

However, a common feature of this period was that the participants experienced a dearth of information and considerable worry and uncertainty: "I wish that they had told me what they suspected... and given information. Because the big deal was that, you did not get any information. And it's worse to sit and wonder... Then, I went home and searched all my symptoms on the Web. And that's much worse than being told that we suspect this or that... Tell me at least that! It was nothing specific... I had to interpret. It was very frustrating... I felt that they REFRAINED from telling me... It's worse not to know... they should rather tell. It was absolutely awful" (Mette).

In contrast, a few participants received information that the doctor thought it was cancer, although the tests could not confirm it. These participants found it especially traumatic to be given a considerable amount of information about a diagnosis or invasive procedures, which in the event turned out to be unnecessary. "First you get the bomb that it is 99% for sure that you have cancer, but we can't find anything on the biopsy (...). And the surgeon said to me, 'Yes, for sure we have to pull out all your teeth and operate on your jawbone...' They didn't know it was cancer... Yes, they dramatized it way over. ...A LOT of it turned out not to be real... It was the worst case all the time. I was full of anxiety (...). It was awful" (Kirsten).

This perceived lack of, or inaccurate, information seemed to be connected to the number of healthcare professionals and different hospitals that were involved in the different examinations and tests, and the participants were not told, or could not figure out, who was in charge: "I was sent as a package between the different units... No one took responsibility, and I was sent around. It was terribly exhausting!" (Kirsten).

SUBTHEME 2B: "TO LIVE IN SUSPENSE"

Many of the participants reported weeks of waiting before they received their final diagnosis. This time of waiting felt unreasonably long, and it significantly raised their levels of anxiety and uncertainty: "And then he took the biopsy, and it was the day before Easter. Then, it needed to be cultivated and... It took all the Easter and... not to know anything. Just that you have cancer. That's it. All this time was hell" (Wenche).

Several participants were very frustrated and used a lot of energy in trying to find out who was in charge and who could provide them with the results: "It was like no one would take it [my case]. None of the units. All the waiting... I called about 27 times to the hospital... Three months passed before I got help... Then I called my GP, and he got furious. Then they called... but it had to be a GP to get through..." (Kirsten).

For some participants, the waiting time was increased because of lost papers or unclear lines of communication, whereby they lost confidence in the healthcare system: "I called on Friday, but then the outpatient unit was closed... Then, I tried to call again on Monday (...) but did not get through. When I finally got through, I had fallen out of their system... my entire journal. I did not understand what they had done. I waited and just felt extra alone... (cries). I got extra anxiety based on that" (Pamela).

A few participants reported that the prolonged waiting time had led to a more serious disease: "Now, in the aftermath, I find it quite outrageous. Based on what I know now, I most certainly would have got much 'easier' treatment if it had been caught earlier.... Now it had spread, and I had to go through a much more comprehensive treatment than most others with this kind of cancer do" (Per).

Most of the participants were disappointed and surprised over the prolonged investigation process, the amount of professionals involved, and the unclear communication lines: "I found it to be too long. It surprised me. I had thought that you should be admitted to the hospital based on the suspicion... So, take me in, if nothing else as an outpatient. DO the tests, and get it done! (...) I had thought better about the healthcare system... it lacks a system around cancer patients. Definitely (...). You get afraid, insecure" (Mette).

Theme 3: "The Day My World Collapsed"

Following their journeys to the final cancer diagnosis and the time that had passed, all the participants described in detail where and how the cancer diagnosis was communicated: "It was Friday, March 13th, 12 o'clock" (Pamela). Overall, the participants experienced this as a traumatic and overwhelming situation, repeatedly describing it as "The day my world collapsed." This situation was elaborated by 2 subthemes: "I got my diagnosis on a yellow Post-it note" and "Only the hard facts."

SUBTHEME 3A: "I GOT MY DIAGNOSIS ON A YELLOW POST-IT NOTE"

How the participants were informed about their cancer diagnosis varied considerably. Based on the investigation process,

quite a few had prepared themselves for the "worst news," and some were even relieved to receive the final diagnosis: "I was mentally prepared; I had been that for 3 weeks. Therefore, I just waited for them to tell me that I had lymphoma... And then [when he told me], actually, I was glad because I first thought I had lung cancer..." (Linda).

For 2 participants, the diagnosis came unexpectedly as they had been examined for other issues, for example, infertility: "I was told everything was OK (...). It was the head physician at the hospital; he came in and was very determined that 'this must be removed and the ovaries as well, and be done with it.' It was a shock... (...). My basis was a wish for a child..." (Christine).

However, most participants were quite critical to how their cancer diagnosis had been revealed, ranging from a telephone call from the hospital, a formal letter with details of the commencement of cancer treatment, the visit of a doctor on a hospital ward with other patients present, in the preoperative unit, still drugged by medications, or by accident from a nurse. Sixteen of the 20 participants were alone when they received the diagnosis. Some were alone because they were not aware that they were about to receive their final diagnosis, and others did not want, for example, their parents, to join them: "He [my father] waited outside. I didn't want him to be with me. It's like I KNEW what was to come... However, when I got the diagnosis, it was like 'Yes, it is Hodgkin lymphoma. You are going to the cancer hospital on Monday.' Then, I got my diagnosis on a yellow Post-it note, and then he said 'You'll find a lot of information about the diagnosis on the Internet.' Only that... He said that they had not classified it yet... that there were many subgroups, but that I could search on the Internet. I don't know if it was that he did not have any knowledge or... (...). But I got that note, and I was perhaps in that doctor's office for 10 minutes, then I left..." (Mette).

Only 3 participants experienced that they were informed about their diagnosis in an empathetic and satisfactory manner, receiving their diagnosis from the surgeon or GP, together with their partners: "He called the hospital, and (...) then he put the phone down, raised his eyes, and said: 'Unni, you have cancer. (...) The next year (...) is a year with the focus on full recovery. (...) I want you to sit here... I'll cancel all my patients this afternoon, and we'll call your husband. I will not let you go now. I want your husband to come, and I want to talk with him'" (Unni).

SUBTHEME 3B: "ONLY THE HARD FACTS"

Despite the way in which the diagnosis was communicated, all the participants described their initial reaction using words such as disbelief, shock, unreal or surrealistic, catastrophe, being hit to the ground, being outside of themselves, or that their world had collapsed: "It was like... I have always thought it was bullshit. You feel that you are on the outside... But just then I remember that I could see myself standing outside..." (Unni). "Then the world just collapsed and you didn't know what to do" (Grete).

The participants had different experiences of the initial information communicated by their physician. A few stated that

the information was good in that they were given time to ask questions and their next of kin were present: "I asked him a lot of questions (...). And my husband came and we talked (...). Therefore, I find him quite fantastic. And I think that everybody ought to have such a GP if something happens..." (Unni).

However, in the experience of most participants, the information was revealed in a technical and impersonal way, emphasizing facts about the diagnosis and the upcoming treatment: "He said: 'Yes, I do not have any good news for you... You must have your breast removed, and you must have chemo and so many cycles....' He said a lot. 'You will lose your hair.' (...) He said it in a way... (...). Surgeons are like that.... They are hardly human..." (Mary).

"It was pang, pang, pang. You have cancer. Pang. You should be admitted to the hospital at once. Pang. It is a harsh treatment. Pang..." (Wenche). Some informants reported that the doctor used highly "medicalized" and unfamiliar language. Consequently, the information was difficult to understand: "They said it was a tumor, and then I breathed out because then it certainly wasn't dangerous. I did not know what it was. (...) But, eventually I understood that it was...cancer" (Kristian).

The participants underlined that both the use of language and the way the doctor behaved highly influenced their trustfulness: "Actually, he said straight out that they had very little experience with this.... (...) You get a sense of insecurity. It is gross. (...). Yes, you need to know that they know for sure what they are doing. Perhaps I was unlucky with the doctor... He appeared to be very insecure... It affected me greatly. I did not think it was OK. He could barely finish any sentences... and started repeatedly... When you are uneasy to begin with, then it does not get any easier... You need a sense of security in such a situation" (Marianne).

A few participants even felt that the doctor had trivialized the diagnosis and upcoming treatment: "But you can have a new tit!" (Kari), whereas some got a sense of guilt because they had not come earlier: "If you only had gone to check it up more often, then we would have discovered it" (Astrid).

For many participants, their initial shock reaction was linked to the fact that cancer is a deadly disease: "The first thought is that you don't want to die and leave your kids. That, first of all..." (Kari). How the doctor elaborated on the prognosis added to their level of anxiety: "She is an amazing doctor. I know that she is at the forefront of her field, but she is so COLD that I... She is straight on... (...). I don't know why she said it, but she said that she couldn't guarantee anything because the rate of relapse was high (...). She wouldn't give any false hopes... I think I cried for 4 hours in a row that day. (...) They are very much like... they will not give any [false hopes] (...)... it is... a bit too much. (...). But I have also thought that it MUST be like that [the doctors being cold] to be able to do a decent job. At least I try to comfort myself with that" (Wenche). Furthermore, the doctor's specific outlining of the prognosis was often interpreted ambiguously: "He said (...) with my stage of disease, they reckoned it to be a 50% to 80% 5-year survival... I took it with composure... look at it as an 80% chance... But you can never say... Yes, 8 out of 10. If you put 10 balls into a bucket, 2 red and 8 green, and then

draw 1, then the chance of drawing a red one is quite big even if it's only 20%" (Jack).

Overall, in this situation, the participants experienced a severe lack of interest, empathy, and concern from the physician. This was elaborated as a lack of psychological support and comfort and a lack of questions related to their private civil status or living conditions. In the experience of several participants, they did not have enough time to ask questions, or based on the shock and the totally unknown situation, several did not know what questions to ask. Consequently, most participants kept their reactions to themselves until they were out of sight of the healthcare providers: "I felt that they did not see the shock I was in. They ought to know a bit more... (...). They should have listened to me... I should have been heard and acknowledged for how I was... I just wanted to be met as I had it THEN. I didn't want to talk about the future..." (Kari). In keeping their reactions to themselves or not being allowed to express them, several physicians complemented them on taking the diagnosis in such a courteous manner: "...they said: 'You coped very well receiving the cancer message! You were very calm! It is not a message you want to receive when you are 22... (...) I think I just ... that my way to cope with it was to shut it out and not take it inward.... However, it was not easy. I think I cried myself to sleep nearly every night" (Unni).

In summing up the findings, the participants expressed that being diagnosed with cancer was experienced as a challenging, lengthy, and traumatic process. Kristian summed up the entire process like this: "I have to say it has been frightening. I could have written a BOOK about it. Many people I meet say that this must only count for you. But the more I speak with others, then everybody has such stories... and they talk about the thing that didn't work as it should and... (...) And the communication, THAT is not present..."

■ Discussion

The aim of this study was to generate knowledge and insight into how young adults experience the process of being diagnosed with cancer. The findings show that the YACPs described this process via 3 main themes and concurrent subthemes: (1) "I felt something was wrong, but..." (2) "The traumatic uncertainty," and (3) "The day my world collapsed." Confronted with the dual transition of young adulthood^{7,32} and being diagnosed with cancer³⁵ and in light of CATS,³⁶ these findings raise concerning issues about the onset of YACPs' cancer trajectory.

"I Felt Something Was Wrong, But..."

The findings revealed that many of the participants had experienced a range of vague symptoms over time, which they mostly ignored, displaced, or trivialized in diverse ways. These findings may have several explanations. Young adults are already dealing with specific challenges related to physical and psychosocial development, education, and secession from their parents,^{6,7,32} which means that the capacity to pay attention to vague symptoms may be limited. A further explanation may be that young

adults strive to conform to their social group, and thus, they prefer not to report their symptoms to anyone.^{6,34} Furthermore, research shows that people, in general, have limited experiences and awareness of potential cancer signs and symptoms in young adults, which, in line with our findings, may lead to a lengthy symptom interval.^{14,16}

In keeping with our results, several international studies indicate that young adults are more reluctant to contact their GPs than are older individuals; young women show more reluctance than men do.^{13,17} Internationally, this reluctance is often explained by young adults' lack of health insurance or by financial barriers and less access to medical care.^{6,12,42} However, Norway has a public healthcare system where all citizens have an assigned GP; thus, cost or accessibility cannot explain this reluctance. From the experiences of our participants, a more trustworthy explanation may be related to young adults' geographical relocations related to work or studies and their failure to change their GP to their new location.

However, an even more concerning finding is that several participants experienced that their symptoms were not taken seriously on their first contact with their GP. This finding is supported by international research, documenting an under-recognition of cancer symptoms by medical professionals^{4,17} and less timely referral to specialists.¹³ Supported by our findings, this may lead to a delay in diagnosis, resulting in a more advanced stage of the disease.¹² Some participants first received medical help in the emergency room, because they, or their GP, had trivialized the symptoms. This is also concerning because patients presenting to emergency may be 3 times more likely to die of their disease.¹⁷ Together, these findings highlight the importance of raising cancer awareness, educating the public (eg, via information campaigns, the education system, and social media), and providing information about vaccines and screening programs (eg, cervical cancer).^{14,15} Furthermore, there is a need to integrate this knowledge into the education of medical professionals, as well as to develop education programs to raise awareness of cancer and cancer risks in young adults.⁴³

“The Traumatic Uncertainty”

Most participants reported that the process, from being referred to specialists for investigation through to the final diagnosis, was characterized by traumatic uncertainty based on a profound lack of information and living in suspense. Information has been shown to reduce uncertainty and anxiety, to help patients to gain control over their lives and to facilitate coping and enhance self-care ability.⁴⁴ In contrast, and in line with our findings, research documents that young adults' information and communication needs are largely unmet and that they experience difficulty in navigating the healthcare system.^{3,24} To live in suspense for a long period and to be unclear about who was in charge added to the participants' worry and their experiences of uncertainty. Xu et al¹⁷ found that the time from the first contact with a healthcare professional to the point of diagnosis was the largest contributor to the delay in diagnosis for YACPs. According to CATS, such negative experiences and prolonged stress across time may lead to negative health outcomes.³⁶ Documented delays in

diagnosis^{12,17} show that YACPs are at greater risk of psychosocial difficulties⁶ and that lack of control and unmet information needs are associated with impaired quality of life for YACPs.³⁰ This emphasizes the point that increased attention should be placed on the diagnosis process of YACPs. The findings indicate that the healthcare providers did not take account of the participants' dual transition challenges, placing them at increased risk of negative health outcomes and coping.³⁵ These participants were diagnosed prior to 2015 when Norway introduced standardized cancer pathways. The pathways aim to speed up patient assessments and cancer treatment, to secure information, and to make the assessment period as predictable and stress-free as possible.⁴⁵ However, these pathways are diagnosis based and do not address young adults' specific needs and challenges.

“The Day My World Collapsed”

Overall, the participants described the situation of being diagnosed with cancer as a traumatic experience, especially based on the way in which the diagnosis was communicated and the subsequent information. Similarly, research documents that cancer in young adulthood is particularly traumatic and life changing and that a proper disclosure is crucial.^{19,33,34} In contrast, the study's most disturbing finding is the diverse ways in which the cancer diagnoses were disclosed, mostly characterized by impersonality, bad planning, 1-way communication, and lack of privacy and time. Knowing that disclosing a cancer diagnosis has enormous consequences for a young adult's life, as well as being important in establishing a trust-based relationship between the patient and the healthcare system,^{22,24} such disclosures seem to be highly inappropriate. One explanation could be that several professionals may be involved in the diagnosis process. This means that the responsibilities for information and communication may become fragmented, and the professionals involved may not have adequate communication skills or any knowledge regarding youth friendly communication.^{6,27} A further highly worrying finding is that 16 of the 20 participants were alone when they received their diagnosis. Being diagnosed with cancer is a traumatic and life-changing moment,^{19,20} as is clearly illustrated by the participants' descriptions of their world collapsing. Being alone in this situation may add to the traumatic experience and perceived stress and consequently leave the individual with fewer coping abilities.³⁶ These findings also illustrate young adults' vulnerability, being in a transferal period of life with increasing independence and secession from their parental home.^{6,33,46}

In line with previous research,^{22–24} most participants found that the subsequent information about their diagnosis and treatment was revealed in an impersonal and technical way, emphasizing facts and lacking emotional support. The most horrendous example is how a young woman received her diagnosis on a Post-it note and was told to search for further information on the Internet. Similar to our findings, previous research has documented that YACPs experience less care about their emotional and psychological concerns and receive less information about their diagnosis and treatment. Consequently, they call for a greater focus on physical, practical, emotional, and psychological issues during the diagnosis.^{25,45} According to CATS, both information and

psychological support may be helpful in reducing the patient's perceived stress and supporting positive coping experiences.³⁶

■ Study Limitations

Even though this study's findings provide new and important knowledge of how YACPs experience their diagnosis process, it also has some limitations. Because of the qualitative design, the findings cannot be generalized to the broader population of YACPs. The study also had an underrepresentation of men and of the youngest age group (18–23 years). However, a significant strength of the study is the enrolment of a diverse population of informants across the country, with varying backgrounds, life circumstances, ages, and cancer diagnoses. Furthermore, the common themes were consistent, suggesting that we captured a valid sample of the experiences of being young and diagnosed with cancer that may help direct both future research and clinical practice.

■ Implications for Clinical Practice and Recommendations for Further Research

In general, the participants experienced the process of being diagnosed with cancer as a lengthy and traumatic process, and this has several clinical implications. First, the findings show that to prevent delays in diagnosis it is necessary to raise cancer awareness in people in general and especially in young adults, as well as to educate GP and primary healthcare nurses in cancers in young adulthood. Second, the period of diagnostic assessment should be as short as possible, allocating clear responsibilities for age-appropriate information and follow-up. Third, the cancer diagnosis should be delivered face-to-face in an appropriate setting with next of kin present, and there should be sufficient time to focus on information about medical, physical, practical, and emotional issues. Preferably, a nurse with specific knowledge of the particular needs and challenges that YACPs face should participate, providing the opportunity to repeat the information and to follow up in times of crisis. The study's findings suggest that more research within this field is warranted, particularly larger surveys to examine whether the new cancer pathways have addressed the problem of delays in diagnosis and the provision of information, as well as YACPs's perceived distress during the diagnosis process. A study of this type in other countries and cultures would also be an important contribution to the literature. Furthermore, randomized controlled trials providing YACPs with age-appropriate services are also highly welcomed.

■ Conclusion

The findings from this study indicate that the YACPs experienced being diagnosed with cancer as a highly traumatic and lengthy

process, elaborated according to 3 main themes and 2 subsequent subthemes. (1) "I felt something was wrong, but..." was elaborated by the 2 subthemes "I tried to ignore it" and "My GP ignored it." (2) "The traumatic uncertainty" was described by the subthemes "But no one would tell" and "To live in suspense." (3) "The day my world collapsed" was explained by the 2 subthemes "I got my diagnosis on a yellow Post-it note" and "Only the hard facts." The findings indicate that healthcare professionals do not acknowledge YACPs' transitional challenges. Consequently, the findings highlight the need to raise cancer awareness among the public, as well as in the healthcare system, to shorten the diagnosis process and to clarify responsibility for age-related information and psychosocial follow-up during the diagnosis process. Further research is highly warranted.

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