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Facing mortality: A qualitative in-depth interview study on illness perception, lay theories and coping strategies of adult patients with acute leukemia 1 week after diagnosis

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Abstract

In patients with acute leukemia we investigated the illness perceptions, lay theories and coping strategies 1 week after diagnosis. Semi-structured *in-depth interviews* were conducted with 12 patients. The transcribed interviews were analyzed by methods of qualitative research. Dramatic narrations of overwhelming threat in younger patients contrast to rationalization in elderly patients. Feelings of helplessness and efforts of normalization become apparent. Intense descriptions of physical injury due to invasive procedures allow verbalizing the fear of the disease. While coping strategies are complex, the overall importance of trust is recognized. Mortal fears are indirectly indicated. The results have consequences for psycho-oncological training and patient education.

Keywords: Illness perception; Lay theories; Coping strategies; Acute leukaemia; Quality of life; Qualitative research

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1. Introduction

Immediate diagnosis, prompt initiation of systemic therapy and direct access to supportive measures are prerequisites for a successful outcome in patients with acute leukemia. From a patient point of view, the severity of the disease and the urgency of the initial situation represent a trauma-like experience, while the invisible character of the disease is a challenge to his or her trust. It is therefore a delicate task to reach an optimal level of cooperation between the patient and the physician, which requires adequate insight on both parts.

While quality-of-life issues of patients with acute leukemia have been assessed [1–4], some of which have been reported in this journal, little is known about illness perception, patient's understanding of his/her disease, and individual coping strategies. Given the differences in personality, socio-cultural background and age, a uniform pattern of patient's readiness to seek and ability to understand medical information (health literacy) cannot be expected and does not exist in clinical reality [5,6]. Although promoted by clinicians, relatives and society, detailed medical information usually given during the initial phase of the disease may not meet the patient's immediate need and surpass his momentary ability of comprehension.

It was postulated earlier that qualitative research methods should help to improve the understanding of our patients [7,8]. In contrast to questionnaire measurements, diagnostic narrative interviews allow to portray the complex structure of lay concepts more adequately in their entirety including their multifaceted nature, dynamic aspects and emotion dependence. Moreover, qualitative research leads to the recognition of phenomena that, up to this point, were neither considered nor expected [9,10]. Therefore, we conducted and analyzed interviews with patients suffering from acute leukemia using

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the qualitative paradigm. Due to the large amount of information provided by each interview and the in-depth character of the analysis, it was not intended to study a large number of patients, but rather a limited sample, thus permitting to concentrate on the individual's reactions to the vital threat imposed by the disease.

2. Patients and methods

To investigate the objectives of the study, semi-structured interviews were carried out with 12 consecutive adult patients hospitalized for acute leukemia within the first week of diagnosis. Topics included the patients' interpretation of prediagnostic symptoms, perception of diagnosis and treatment, comprehension and controllability of the situation. After approval of the study protocol by the ethics committee of our faculty, written informed consent was obtained from all patients. Only patients with sufficient knowledge of the German language and with the intention to receive intensive antileukemic treatment were included. Induction therapy for patients with acute myeloid leukemia (AML) consisted in anthracycline with either low-dose cytarabine over 7 days (3 + 7 protocol) or intermediate dose cytarabine on days 1, 3, 5, and 7 [11]. Patients with acute lymphoblastic leukemia (ALL) received a multi-agent induction protocol according to the GM-ALL Study Group [12].

Six patients were suffering from ALL and six from AML. The median age was 59.5 years ranging from 21 to 70 years. Four patients were 32 years or younger. Seven patients were female, five were male. Regarding school education, five patients had finished secondary school, four had Realschule degree and three had a graduated from high school. At the time of the interview, all patients had been notified of their diagnosis and had started induction chemotherapy. Patients' characteristics are listed in Table 1.

The interviews were conducted by a medical member or by a board-certified psychologist of our team. All interviews were audio recorded. According to the patients' readiness to communicate, the duration of the interviews ranged from 30 to 75 min, corresponding to a size between 4985 and 14,654 words (mean 9649, S.D. 3139). The entire text corpus was 115,794 words or 290 single-spaced, descriptive pages of transcript material. A sample size of 12 persons was chosen, since this has been proven to be sufficient for enough variance in other research projects [13], i.e. theoretical saturation as established by the logics of the grounded theory analysis was achieved, and the collection of more data would not have lead to a substantial increase in insight [14].

A complete *verbatim* transcription of each interview was carried out according to the guidelines of Mergenthaler and Stinson [15]. To evaluate the transcribed interviews, a combination of grounded theory [14] and qualitative content analysis [16] was applied. To allow inter-individual comprehensibility (which presents the core criteria for the quality of qualitative research), guidelines were established with regulations for coding, definition of the categories and a selection of supporting anchor examples. Using these guidelines, specific text segments were assigned to the individual categories and were then condensed and increasingly abstracted (paraphrasing, bundling, etc.) according to the rules of qualitative content analysis. The reduced data made up the basis for inter-individual comparison tables. All individual evaluations were critically discussed and adopted by the team in order to meet the requirements of investigator-triangulation regarding the expansion of subjective interpretations. The inter-individual comparisons took into special consideration similarities and contrasts, forming the basis for the construction of prototypes or ideal types [17]. Ideal types are thought constructs which focus on relevant aspects of concrete reality. They are constructed by empirical description and synthesis of the core features of the phenomena under investigation in order to guide a detailed theoretical understanding of the individual.

In order to secure the quality of our data presentation and interpretation, and to allow comprehensibility to the reader [18], the original transcript of one entire interview (ID 011-M) is available at the website of the journal. Furthermore, Appendix A of this paper contains the condensed statements of one patient (ID 011-M) concerning the relevant areas of this study; an inter-individual condensed comparison table derived from all 12 interviews is shown in Table 2.

Table 1
Patients' characteristics

ID	Diagnosis	Age	Sex	Education	Profession	Word count
001-L	ALL	50	Female	Realschule	Wages clerk	12431
002-L	ALL	69	Male	High school graduation	Security agent	6067
003-L	ALL	25	Male	Realschule	Baker	6648
004-L	ALL	58	Male	Secondary school	Driver	7071
005-M	AML	21	Female	High school graduation	Callcenter agent	10724
006-M	AML	76	Female	Realschule	Nurse	12669
007-M	AML	61	Female	Secondary school	Farmer	10937
008-M	AML	70	Female	Secondary school	Cook	12563
009-L	ALL	32	Male	Realschule	Carpenter	14654
010-M	AML	73	Female	Secondary school	Farmer	9615
011-M	AML	63	Male	Secondary school	Forest manager	4985
012-L	ALL	21	Female	High school graduation	Accounting clerk	7430

Table 2
Condensed inter-individual comparison table

Pt-ID	Original complaints	Diagnostic procedure	Cause of the disease	Control of the disease	Treatment experiences	Prognosis
001-L	Heavy complaints, patient's explanation: viral infection	Factual description of the diagnostic process, shock at diagnosis, horror of puncture	Unknown cause, it was meant to be so (fate)	No medical comprehension of the disease, medicine helps, however underlying impairment of trust, personal strategy: fighting	Rapid onset of therapy, drastic side effects of chemotherapy put into perspective, fear of port-à-cath placement	The topics death and dying indirectly alluded to, hope and doubt, the aim: to become a little healthy
002-L	Heavy complaints, patient's explanation: internal disease	Factual description of the diagnostic process, no shock at diagnosis, factual description of the puncture	Unknown cause, risk factors chemicals and toxaemia not applicable	No medical comprehension of the disease, medicine helps, however underlying impairment of trust, personal strategy: fighting	Factual description of side effects of chemotherapy, uncertainty	The topics death and dying not an issue, hope and doubt
003-L	Heavy complaints, patient's explanation: blue spots due to increased sensitivity to sun	Factual description of the diagnostic process, shock at diagnosis, horror of puncture	Unknown cause, risk factors chemicals, irradiation or genetic risks not applicable	Relatively much knowledge about the disease, medicine helps, full confidence, personal strategy: wait and see	Chemotherapy, its side effects and associate emotions extensively described, problems with loosing hair, fear of port-à-cath placement	The topics death and dying not an issue, hope = expectation
004-L	Minor complaints, patient's explanation: diabetes	Factual description of the diagnostic process, shock at diagnosis, puncture bearable	Unknown cause, why me?	No medical comprehension of the disease, medicine helps, however underlying impairment of trust, personal strategy: wait and see	Factual description of side effects of chemotherapy, uncertainty	The topics death and dying indirectly alluded to, hope bound with treatment
005-M	Heavy complaints, patient's explanation: pyelonephrits, blue spots due to a blow during sleep	Factual description of the diagnostic process, shock at diagnosis (not yet recovered), puncture was horrible (cried)	Unknown cause, risk factors chemicals, irradiation or genetic risks not applicable	Relatively much knowledge about the disease, medicine helps, however underlying impairment of trust, personal strategy: specific individual initiative	Rapid onset of chemotherapy, side effects and associated emotions extensively described, problems with loosing hair, fear of central venous access placement	The topics death and dying indirectly alluded to, hope = expectation
006-M	Heavy symptoms	Factual description of the diagnostic process, shock at diagnosis (not yet recovered), puncture was horrible	Unknown cause, genetic risks not applicable	No medical comprehension of the disease, medicine helps, personal strategy: fighting	Rapid onset of chemotherapy, factual description of side effects	The topics death and dying not an issue, hope bound with treatment, the aim: to become a little healthy
007-M	Minor complaints, patient's explanation: cold	Factual description of the diagnostic process, shock at diagnosis (not yet recovered), factual description of the puncture	Unknown cause, genetic risks not applicable	No medical comprehension of the disease, does not want to brood, medicine helps, full confidence, personal strategy: fighting, specific individual initiative	Factual description of chemotherapy and side effects fear of central venous access and port-à-cath placement	The topics death and dying indirectly alluded to, hope and doubt, the aim: to live a few more years

Table 2 (*Continued*)

Pt-ID	Original complaints	Diagnostic procedure	Cause of the disease	Control of the disease	Treatment experiences	Prognosis
008-M	Minor complaints, patient's explanation: consequence of bike accident	Factual description of the diagnostic process, shock at diagnosis, puncture was actually bearable	Unknown cause, fate	No medical comprehension of the disease, does not want to brood, medicine helps, however underlying impairment of trust, personal strategy: wait and see, faith, specific individual initiative	Rapid onset of chemotherapy, factual description of side effects, fear of port-à-cath	The topics death and dying not an issue, hope bound with the fact that relatives became old
009-L	Minor complaints, patient's explanation: dandruff, splinter in his eye	Factual description of the diagnostic process, shock at diagnosis (not yet recovered), puncture was horrible	Unknown cause, risk factors chemicals, irradiation or smoking not applicable. Why me?	No medical comprehension of the disease, does not want to brood, medicine helps, however underlying impairment of trust, personal strategy: wait and see	Rapid onset of chemotherapy, extensive description of side effects and associated emotions	The topics death and dying indirectly alluded to, hope = expectation, break from normal life
010-M	Major complaints, patient's explanation: influenca, not healed up	Factual description of the diagnostic process, shock at diagnosis (not yet recovered), puncture was horrible	Unknown cause	No medical comprehension of the disease, does not want to brood, medicine helps, personal strategy: wait and see, faith	Factual descriptions of chemotherapy and associated side effects, fear of central venous access placement	The topics death and dying indirectly alluded to, hope bound with health of the heart
011-M	Minor complaints, patient's explanation: bad teeth	Factual description of the diagnostic process, shock at diagnosis, factual description of the puncture	Poisoned well, water of Saale river was poisoned	Relatively much knowledge about the disease, medicine helps, full confidence personal strategy: fighting	Rapid onset of chemotherapy, factual descriptions of chemotherapy and associated side effects	The topics death and dying indirectly alluded to, hope and doubt
012-L	Heavy complaints	Factual description of the diagnostic process, shock at diagnosis, puncture was horrible	Unknown cause, risk factors chemicals, irradiation or genetic risks not applicable. Why me?	Relatively much knowledge about the disease, medicine helps, personal strategy: specific individual initiative	Factual descriptions of chemotherapy and associated side effects, fear of central venous access placement	The topics death and dying indirectly alluded to, hope = expectation, break from normal life

3. Results

3.1. Illness perceptions

3.1.1. Prediagnostic complaints

In the narratives of the initial complaint, the patients could be separated into one group who strongly perceived the complaints, e.g., extreme weakness, tiredness and bone pain. These seven patients described major restrictions in their everyday life including the inability to carry out their jobs: "I would be at work for two or three hours and then I went home. I was completely exhausted" (003-L). In the other group, all patients described only minor complaints, e.g., feelings of dizziness and feeling unwell. These five patients admitted, they had not been worried, and that their daily routine had not been disturbed: "I never really cared too much about that" (004-L). An astounding discovery was that in the text material, there was no transition between the two extremes, one being the dramatic description of major complaints and the other a trivialized playing down.

3.1.2. Diagnostic procedures perceived as measurements

At first mention, the general portrayal of the diagnostic process in connection with the illness was predominantly technical, sober, and objective. Diagnostic measures were described with regard to timing and location, often without reference to their medical function. On the whole, the story rather described the *measurement of the body*, whereas emotional aspects were hardly dealt with.

3.1.3. Diagnostic procedures as threat

In contrast, when diagnostic measures were discussed in detail, descriptions of the bone marrow puncture gained considerable importance. Two-thirds of the patients spoke about the tap in detail and plastically described the fears, pain and reaction, as can be seen in the following quoted interview: "what hurt the most is this withdrawal of the bone marrow, you notice that, it pulls—it pulls down to the little toe and then they pull this stuff out of the bones and at the end when they pull out a bone chip, they go with some sort of an instrument into the hole and then they rip out a piece of bone from the edge and that too, that hurts like hell" (009-L). On the occasion of the invasiveness of the procedure the disease-associated experience of threat was perceived. In part, the puncture was experienced as an increase of the already existing threat, because, on the way to the expected medical help, the patient had to endure another violation.

3.1.4. Communication of the diagnosis perceived as overwhelming

In contrast to the diagnostic procedures, when the communication of the diagnosis itself was described, experiences were expressed solely on an emotional level. The disease was not only perceived as a threat to the body, but to the entire person as well. With the exception of one patient, who at no point in the interview spoke about feelings and denied any burden, all the others described the experience of hearing the diagnosis as a dramatic penetration of their inner life. "That was a shock! then I knew it is! cancer, right? In, in that! moment I was scared! I knew it is! cancer. It's not a game, it is not a wrong diagnosis, it is really! cancer" (001-L; exclamation mark indicates emphasis of the previous word according to transcription rules [15]). Both the formal language (broken sentences, rise in voice) as well as its content, show that, in this exceptional situation, the patient was overwhelmed, speechless, bewildered. The patients were displaced from their lives, the situation in the hospital appeared unreal, as in a film.

3.1.5. Treatment as threat

Patients described a very quick onset of their treatments, which they took as evidence of the risk associated with their illness. Regarding their treatment, they commented primarily on chemotherapy, which was often critically assessed because of its side effects. Comparatively, medical and non-medical measures intended to alleviate or to prevent complaints were described objectively and without assessment. Insecurity was addressed in part of the patients, who attributed their lack of control to their lack of knowledge, as the following quote clarifies: "so, I don't know! So, I had to take that!" (002-L). Fear and pain concentrated around procedures such as placing a central venous access, the taking of blood samples and the application of medicine. This was expressed in the following quote: "I die many hells there" (001-L).

3.1.6. Age-dependent perception of side effects

The interview partner described different side effects of the medication, for example, "throwing up," "listlessness," and "pain." Of those who mentioned "losing hair," only two younger patients reported concern and feelings: "when you're bald you feel so naked, insecure!" (005-L). Only one-third of the patients reported about side effects in detail. These were the four younger patients from our sample (<33 years). They reported a lot of brooding and wearing themselves out. They experienced all complaints as depressing and tried to estimate the seriousness of their situation based on circumstances. The utilized chemotherapy is "weird stuff," since it comes in black, light-protected pouches, "so, that's not a mansy pansy medicine, because they are always checking my blood, ... that won't exactly be sugar water that comes in" (009-L). In contrast to the younger patients, the older patients (>50) seemed to overlook the emotional side of the treatment and restricted themselves to the reporting of the physical aspects. These patients rejected brooding and utilized stereotypical coping clichés such as: "you start being sick and it has to be this" (010-M).

3.2. Lay theories and health literacy

3.2.1. Explanation of the symptoms

Two different patterns in studying the patients' attribution to the subjective origins of their illness emerge: a small part of the patients look for a different origin for each complaint, whereas half try to find a global explanation for the totality of their symptoms. Patients with insignificantly perceived complaints attribute their symptoms to minor illnesses, for example, to a cold, dandruff, or bad teeth. As opposed to this, patients with seriously perceived symptoms tended to consider serious illnesses, for example, pyelonephritis, viral illness or "internal diseases" as causes.

3.2.2. Possible causes: disorientation and helplessness

The basic tenor of almost all answers to the question of the cause for their illness signalized helplessness, which is reflected in the following quote: "No one knows where it comes from" (012-L). The patients reflected and brooded about the causes of their illness, and, with one exception, they explicitly admitted a momentary lack of success in their study of causes. The lack of ideas about the causes of their own illness was frustrating for the majority of the patients and put the meaning of life in question.

3.2.3. Understanding of the disease

Regarding a basic medical comprehension of their illness, only four patients presented themselves as well informed. The remaining patients, in contrast, had no differentiated understanding about their disease. This could not be only attributed to a question of education, since several patients explicitly did not want to receive detailed information in order to avoid brooding. A large part of the patients helplessly faced the hematological terminology (e.g., "neutropenia"). The terms were taken into their own vocabulary without question and without their exact meaning being known.

3.3. Coping strategies

3.3.1. The role of trust

Despite considerable deficits in understanding the illness, all patients comment on the conviction that they can positively control their disease. By far, the largest effect is attributed to chemotherapy and the work of the medical personnel. Trust is understood as the most important factor for coping with the situation. However, there is an underlying impairment of the trust in the treatment through doubt and reservations. These reservations are reinforced in patients who primarily suffered only little and who than felt massively restricted in their quality of life (QOL) by the chemotherapy experience.

3.3.2. Possibilities of personal influence

Whereas all patients expected improvement with medical treatment, possibilities to take personal influence were only occasionally acknowledged. Three strategies were distinguishable: (1) waiting; (2) fighting against the disease; and (3) specific individual initiative. Four patients were waiting and seemed to be resigned to the new life situation; they concentrated on their role as patient, trying hard to fulfill all the medical expectations. They seemed to find stability through adjustment to the normality of institutional courses and routines. Two of these patients sought additional strength in personal faith. Five patients faced their illness by fighting it. For them, fighting meant not giving up, being hard and not showing any feeling in the sense of "I can't let myself" (001-L). Complaints were negated or minimized, information and conversations about the disease were actively avoided. "Fighting! means I throw it away! The disease! . . . just out of the head!" (007-L). Four patients described efforts, which served the purpose of preventing or alleviating complications. These activities took different directions, comprising, for example, breathing exercises, physical movements to prevent weakness, avoiding certain foods, allowing only visits from healthy persons and always wearing a protective mask.

3.3.3. Dealing with the fear of death

Although all the patients described hope in the interviews, great insecurity and uncertainty was implied in quotes such as, "you can't expect anything," "one makes it, the other doesn't," "it could all be over soon." Only one male patient used the words "death" and "dying." The other patients spoke of the threat to their own life only indirectly, dodging the issue, for example: "not everyone can live to be 100" (011-M). In this way, they created distance to the experience of their personal threat. In addition, this created distance was expressed in the often used "you" form. One-third of the patients did not speak at all about the current threat to their lives, thus protecting themselves against the subject.

3.3.4. Expression of hope

With respect to their prognosis, hope and confidence was expressed much more than the feeling of threat. Especially in the older patients (>50 years), however, a consciousness of threat resonated implicitly. Hope was bound with general predictors for a long life expectancy, for example, with the fact that the heart was still healthy or that many of their blood relatives had become very old. Also, the fact that an extensive treatment was taking place at a university hospital was assessed as being grounds for a positive prognosis: "otherwise the doctors don't need to do all this" (004-L). Patients expressed their expectation, that the doctors do "everything" to make a normal life possible, but they spoke of healing only exceptionally. Three patients expressed the goal, "to get a little healthy" and "to enjoy their last days of life." In contrast, the four younger study participants (>33 years) expected a good prognosis and a positive course of the disease, seeing the momentary situation only as a temporary interruption to their daily life, which became clear in the following closing quote: "oh well and so I have a year break now and then it goes on. Then I'll just pick up where I left off. Maybe then more intensively, I don't know" (012-L).

4. Discussion

The aim of our study was to describe phenomenologically, and to generate inductively insight into the existential crisis, in which patients with acute leukemia find themselves shortly after initial diagnosis. In a qualitative analysis of interviews with a sample of patients suffering from acute and chronic leukemia, Berterö et al. [4] found *uncertainty* to be the core category. These authors focused on quality of life and interpreted uncertainty as an important factor to explain differences in experiencing QOL. We have described how the patient's identity *as a whole* is altered by the global loss of their former references and orientation points. The experience of diagnostics and therapy is massively burdened with the fear of a potentially mortal disease verbalized at the occasion of visible and tangible violations of the integrity of the body. Because of the narrow time interval between the initial diagnosis and the interview, the patients find themselves in a state of being intrusively run over, which, at this point has not yet allowed to reflect the situation and to adapt emotionally or intellectually. Friis et al. describe an unexpectedly reduced need for medical information in patients with acute myeloid leukemia [5]. These authors explain the patient's avoidance of information as a strategy to maintain hope.

Other more unconscious strategies include the use of protection and denial potentials intended at the normalization of daily in-hospital life. Individually chosen more active coping strategies are the decision to adapt a fighters' mindset or to choose individual possibilities of the remaining freedom to act within the personal environment.

4.1. Conclusions

Resulting from the data of this study, a deeper understanding of the patient's experiences, comprehension of the disease and individual coping strategies should focus our physician-to-patient communication especially in the initial phase of the disease. In this respect, psycho-oncological training of physicians [19,20] can now be further developed and the findings may serve as a basis to shape psychological interventions for patients with acute leukemia. Finally, the data communicate to patient education and support group programs [21] that there is a physician-driven tendency to strengthen the patient's individual role in the therapeutic process.

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Appendix A. Condensation of interview 011-M

A.1. Original complaints

During the flood the basement needed to be emptied. He filled bags with sand and secured the house, carried wood, worked for 4 days. His hands became blue and weak. He felt a traction in his left chest. Blue spots on his body which he did not notice himself.

A dental problem was suspected.

A.2. Diagnostic procedure

After the first signs of the disease the dentist suspected his teeth as the origin. Because of a pain in the left part of his chest he went to see his general practitioner (GP); electrocardiography (ECG) was OK. The ECG nurse noticed blue spots all over the body. The GP visited the patient at home, performed a blood sedimentation rate (BSR) and sent him to hospital due to poor blood results; a lack of blood was suspected; bone marrow puncture was performed. Result; anaemia, blood and serum transfusions became necessary; after 14 days he was discharged, stayed 10 days at home, was hospitalised again after this. Referred to another bone marrow puncture. "And then I asked whether he did not want to do it right away? And he said, it may not even be necessary." Finally the bone marrow puncture was performed. After 3 h, the result showed blood cancer with 99%. Another examination needed to be done. Referral to the hospital. The diagnosis was a shock.

A.3. Cause of the disease

Many people have died in his village (in the 1980s); the water of the Saale river was poisoned 6 km into the countryside; the problems are poisoning of a well, the cause is certain.

A.4. Control of the disease

Relatively good knowledge about disease and his personal condition, e.g., with respect to his specific blood counts. Control by chemotherapy and medical stuff; complete trust in medicine; fighting, do not show your emotions, be hard, do not ponder too much about it; "it must be," "I need to get through it."

A.5. Treatment experiences

Received blood and thrombocytes on the first day; "I am not afraid of blood transfusions, I am not afraid of anything; Friday is the last day of chemotherapy." Side effects were fever (received a drug), upset stomach (received an injection), loss of appetite (has to force himself to eat, especially in the morning and in the evening); "if you get to know the people, you are pushed into it and you know nobody; from one hour to the next things may change completely and then, well then you have to get used to it and I like to say that I got used to it."

A.6. Prognosis

Topic of dead and dying was addressed indirectly; hope, but also insecurity; nothing about cure of the disease; "I am not afraid of anything, not even of the therapy no matter how it comes and what's the end (. . .) not everybody can live to be 100 (. . .) but to be able to live for a couple of years that would not be bad."

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