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The meaning of the lived experience of hope in patients with cancer in palliative home care

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Abstract: The aim of this study was to illuminate the meaning of the lived experience of hope in patients with cancer in palliative home care. Narrative interviews with 11 patients were interpreted using a phenomenological–hermeneutic method, inspired by Ricoeur. The findings revealed a tension between *hoping for something*, that is a hope of getting cured, and *living in hope*, that is reconciliation and comfort with life and death. This tension is highlighted, according to the views of the French philosopher Gabriel Marcel, as a state of ‘recollection’. The interviewees told of the hope of living as normally as possible and of the experience of confirmative relationships as dimensions of their lived experience of hope. These findings show that hope is a dynamic experience, important to both a meaningful life and a dignified death, for those patients suffering from incurable cancer.

Key words: hope; palliative care; home care; incurable cancer; lived experience; phenomenological–hermeneutics; narratives

Sammandrag: Syftet med studien var att belysa innebörden av den levda erfarenheten av hopp hos patienter i palliativ hemsjukvård. Berättande intervjuer med 11 patienter tolkades med en fenomenologisk–hermeneutisk metod, inspirerad av Ricoeur. Resultatet visade en spänning mellan *att hoppas på någonting*, dvs ett hopp om att bli botad och *att leva i hopp*, dvs försoning och tillfredsställelse med livet och döden. Denna spänning beskrivs som ett tillstånd av ‘recollection’ av den franske filosofen Gabriel Marcel. De intervjuade berättade om ett hopp att leva så normalt som möjligt och att uppleva bekräftande relationer som dimensioner av deras levda erfarenhet av hopp. Detta resultat visar att hopp är en dynamisk upplevelse, som är viktig för ett meningsfullt liv och en värdig död, för de patienter som lider av obotlig cancer.

Sökord: hopp; palliativ vård; hemsjukvård; obotlig cancer; levd erfarenhet; fenomenologisk–hermeneutik; berättelser

Introduction

Hope in palliative care is built on the belief that better days or moments can come.¹ This is in line with the findings from a study involving 30 terminally ill

patients,² in which the meaning of hope was revealed as ‘an inner power that facilitates the transcendence of the present situation and movement toward new awareness and enrichment of being’. This study showed that the presence of aims fostered hope. The aims were revalued from being personal and narrow as long as the patients could manage their daily living by themselves (for example, ‘a relief of pain just for the day’) to aims directed out-

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side themselves involving family and friends, when physical symptoms became dominant (for example, 'the best for my two young sons as they grow up'). When death was imminent, the aim for inner peace and rest was revealed.

In a study of adults undergoing bone marrow transplantation for leukaemia, it was found that maintaining hope was the most important goal.³ This was possible from dealing with the disease, by being confronted with the negative consequences of the disease and accepting it as a threat and allowing emotional response. Another strategy was to keep the disease in its place, by retaining a sense of control, managing uncertainty and being able to focus on the future. Post-White *et al.*⁴ revealed themes of hope in interviews with patients from a haematology/oncology unit: finding meaning, affirming relationships, using inner resources, living in the present and anticipating survival.

Hope was also a dominant component when terminally ill patients described their experience of health.⁵ A multidimensional model of hope for palliative care⁶ emphasizes the personal intangible experience of hope, consisting of three dimensions: *personal spirit* revealing personal experiences of meaning, *risk* referring to the specific situation of being in palliative care, that is the balance between predictability and uncertainty, and *authentic caring* highlighting, for example, comfort.

There are, however, few studies aimed at in-depth revelation of the meaning of the lived experience of hope from the perspective of patients with incurable cancer. A systematic literature review revealed nine studies with acceptable reliability and validity with this focus.⁷

The aim of this study was thus to illuminate the meaning of the lived experience of hope in patients with cancer in palliative home care.

Methods

Subjects and settings

The inclusion criteria for the patients in this study were: having incurable cancer (documented in medical records), being cared for in their own homes, being over 18 years old and being aware of their fatal situation. Eleven patients (four women and seven men, 54–83 years of age, median 65 years) participated in the study. Six patients could manage their daily activities, while five patients needed help. They had all chosen palliative home care for the remaining days of their lives. They were cared for in their homes by staff from the primary health care and the hospital-based home care and/or by a palliative care team. Details of the primary cancer site, treatment and time of interview before day of death are shown in Table 1.

Procedure

Nurses from primary health care, hospital-based home care and a palliative care team were informed about the study. Consecutive patients who entered palliative home care were asked by the nurses to participate in the study, except for those whom the nurses considered too sick to be interviewed. The nurses asked the patients' permission for the researcher to contact them. Oral and written information about the study was given to the patients interested in participating. Four patients declined to participate, as they considered themselves too sick to be interviewed; four patients died before the agreed time for the interview.

Ethical aspects

Interviewing patients in palliative care demands that consideration be given to ethical issues. The researchers in this study did not consider the interview

Table 1 Localization of the cancer, treatment, and time between interview and day of death

Localization of the cancer (<i>n</i> =11)		Treatment (<i>n</i> =11)		Time of interview before the interviewees' day of death (<i>n</i> =11)	
Lung	3	Cytotoxic drugs	3	9–12 months	5
Prostate	3	Alternative medicine	3	5–9 weeks	4
Breast	2	Radiation	1	2–3 weeks	2
Liver	1	Not offered further treatment	2		
Ovary	1	Declined treatment	2		
Duodenum	1				

as violating the patient's integrity, even if the topic could be emotionally demanding. The interviewees were also told that they could break off the interview at any time. The study was approved by the Ethics Committee at the Health University in Linköping (Dnr 96335/96).

Interviews

Tape-recorded narrative interviews were conducted in the patients' homes, each lasting about 75 min. This narrative interview approach is seen as a discourse between speakers and is a way for the interviewees to reflect on and understand their own experiences.⁸ The opening question was: 'Would you please tell me how you felt when you were first diagnosed as having cancer?'. Thereafter, the patients were asked to narrate their lived experience of hope by narrating situations where they had experienced hope. The researcher encouraged the interviewees to narrate as freely as possible with a minimum of interruption. Conducting interviews using an open approach means listening to life stories. The interviewees narrated their life stories in a humble and honest way, despite being tired, needing to drink or having a break during the interviews. Many of the interviewees told the researcher after the interviews that they now understood themselves better and that the interview had helped them formulate their own thoughts and feelings.⁹ In fact, no one had asked for their stories before. These reflecting stories strengthen the credibility of this study.

Analysis

The interviews were transcribed verbatim. A phenomenological–hermeneutic method, inspired by Ricoeur,^{10,11} developed at Umeå University¹² and the University of Tromsø,¹³ was used for analysis. This form of interpretation is a spiral process and starts with an initial reading to gain a sense of the whole and to obtain suggestions for the structural analyses, where the text can be explained by identifying meaningful parts and patterns. The text is divided into meaning units, condensed and organized in themes. The final step is to interpret the text as a whole once again, considering all the steps in the interpretation as well as the pre-understanding of the researcher, to achieve a comprehensive understanding.

In addition, after the initial reading an overall thematic content analysis was performed¹⁴ to de-

scribe aspects of living with incurable cancer, which were considered part of the context of the study looking at the concept of hope. These parts of the text were extracted and categorized, and notes about possible general themes were made. Headings were written down and reduced to broader categories. The findings from this part of the analysis are presented in the next section.

Making the analysis open, by showing the steps in the structural analysis, increases trustworthiness.¹⁵ The trustworthiness of the interpretations is related to appropriation, that is the way an interpretation is addressed to someone and the extent to which the reader finds the interpretation adequate for his or her life and work.^{16,17}

Interpretations and findings

Initial reading

Having read the interviews several times, the impression was that it is important to understand the interviewees' life situation, that they are living with the awareness of having incurable cancer, in order to understand the meaning of the lived experience of hope. The transition from a healthy life to a life awaiting premature death is to experience bewilderment and suffering, involving, for example, deterioration of the body and dealing with the ultimate questions about life and death.

The meaning of the experience of hope seemed to be a will to live for a while longer. The text also contained attitudes of living for the day, as normally as usual, the importance of significant relationships and a reverence for human life.

Living with incurable cancer – findings from the content analysis

Life changed in a dramatic way for the interviewees when they were informed that no curative treatment was available. At the time of the interviews, all interviewees were aware of their limited future and therefore claimed they were living for the day, in the present, without thinking too much about the future. The expression '*we take each day as it comes*' was frequently used. Their current daily life was also limited in the sense that they were not able to do the things they could before.

Living with incurable cancer also meant a narrowing of their frame of reference and a re-evaluation

of what is important in life. The interviewees now had other priorities in life and found joy in doing things that they had previously considered dull.

The interviewees were aware of their imminent death, but claimed that they had to live as long as they were alive. They could not escape from life even if they wanted to. They were doomed to live. They felt torn between a will to live and the awareness of a final capitulation to death, because they were also doomed to die. The experience of belonging both to life and death was out of the interviewees' control and something they just had to accept. Many took comfort in thinking that life is a process: we are born and we die.

Experiencing the deterioration of their body, in terms of lost weight and changed appearance, caused their own body to become a stranger to them. This made them feel dependent on others as they became physically disabled. They were all afraid of being totally dependent and did not want to end up in a vegetative state.

The interviewees lived in great uncertainty, which was focused on the progression of the disease. They could get worse at any moment and this created an avoidance of thinking too much about the future. The uncertainty was also related to lack of information, especially about the disease and its prognosis.

The awareness of living in the terminal phase of life also gave rise to thoughts about spiritual things, for example the meaning of life and whether there is a life after death. The interviewees seemed to have a great need to formulate these questions.

These experiences of living with incurable cancer were homogeneous, irrespective of age or sex.

The meaning of the lived experience of hope – findings from the structural analysis

The structural analysis revealed four themes: *a hope of being cured, a hope of living as normally as possible, a presence of confirmative relationships and reconciliation with life and death* (see Table 2).

The lived experience of hope was narrated as a will to find meaning, to envision something better or to make life easier. According to the interviewees, this is dependent on personal attributes, such as personality, attitudes, outlook on life and values. One man said:

If hope disappears, you have nothing.

However, it did not seem to be easy to experience hope. He continued:

I try to keep hope as the uppermost, but I do not always manage, because there are so many factors that play a part in this, such as my mood.

A hope of being cured. The hope of being cured was the most significant experience. The interviewees argued that they were intellectually aware of their situation and that they knew and did not believe they were going to recover, and therefore, initially, they claimed they had no hope. The presence of hope was essential for their will and their ability to go on living. The hope of being cured or at least getting better, was a fundamental experience. Although the chances were very slim, the interviewees wanted to believe that miracles can still occur or that some new medicine could be developed:

Table 2 Examples of the structural analysis

Meaning unit	Condensed statements	Theme
'The most important thing is that everything should be as normal as possible ... that I'll be able to get back to how I was before ... that it doesn't stop me, because the more I can live like normal the easier it is for me and [wife's name], then we can live more normally'	When everything is normal, it is easier to live	Hope to live as normally as possible
'I've resigned myself to the idea that I'll die soon ... that's life ... I can't do anything about it, no ... I've resigned myself to it and it feels good'	Have accepted the life situation and can face death without fear	Reconciliation with life and death

Obviously I hope I'll get well, or at least better, you have to have hope ... that's what keeps people going.

It's not that I think there will be some miracle, but obviously you want to get well, the hope remains, you never know ... perhaps someone will come one wonderful day and say they've found a new medicine.

The hope to be cured was strongly related to palliative treatment being offered. As long as any kind of treatment was ongoing, such as cytotoxic drugs or alternative medicine, there was an experience of hope. Two interviewees, who had undergone difficult treatment, did give up on further treatment. They wanted to live out their remaining days as comfortably as possible. For these patients, saying 'no' was one dimension of their experience of hope:

... they asked if I wanted to join a study by a French pharmaceutical company, they were going to test something new, so I did ... you try anything, anything that's offered.

After the previous treatment I had hallucinations, I thought I'd never get up again, but now I'm here ... I did get a bit better but I said no to any further treatments ... I refused to have them.

Facts presented about the disease were related to the interviewees' experience of the hope of being cured. The development of the disease was important as to whether or not they felt hopeful. The interviewees paid great attention to the results of their blood samples, for example. Every degree of change towards a normal value deepened their experience of hope:

Then I was told that the tests were fine and that perhaps I could have another operation, obviously hope sprang up again, it was something to do with the white blood corpuscles.

The interviewees narrated that it was of decisive importance to have good symptom control, as when the symptoms became more prominent, their hope of being cured diminished.

The interviewees also noted a relationship between the seriousness of the disease and the presence of disease-related symptoms. One man said: *'It is the symptoms that decide how much you hope'*. The experience of pain was frequently considered. The interviewees hoped that they could be able to live the rest of their life without pain and suffering:

I take a lot of painkillers morning and night and in between I have injections of fast-working morphine.

Otherwise I wouldn't manage. It's essential to hold the pain in check.

A hope of living as normally as possible. The struggle to live as normally as possible was a consequence of the feeling of being stigmatized. The hope of being 'normal' again was strongly emphasized, emerging from the strength of their will to go on living. They even argued that they could influence their own survival. Despite being aware that they were not able to lead a normal life, they had accepted their situation and were glad about the small things in life. They had lowered their sights concerning what could be realized. The patients suffering from pain emphasized that pain constantly reminded them of their vulnerable situation:

The most important thing is that everything should be as normal as possible ... that I'll be able to get back to how I was before ... that it doesn't stop me, because the more I can live like normal the easier it is for me and [wife's name], then we can live more normally.

When it's as painful as this I can't do anything, can't go out or ... it's even difficult to get out of bed. It's not normal to suffer pain, it really isn't ... to live a normal life.

For those interviewees who liked being out in the open air, it was important to be able to experience these sensory impressions. It was also important to keep up interests and activities as much as possible.

The hope for living a normal life also included setting goals. The interviewees talked about short-term goals, directed to the same or the next day. None of them mentioned long-term goals. However, there was always a great uncertainty about whether these goals could be achieved. Before they received their diagnosis, achievement of goals was taken for granted. Now, goals were often set in the morning, when the interviewees could decide if they felt well enough to do what was required to achieve the goals:

Now I think, I hope I can sit up this afternoon, I'm going to have a visitor, I hope I have the energy.

A presence of confirmative relationships. The experience of confirmative relationships was an important dimension of the experience of hope. These relationships included *self, significant others, milieu, pets* and a *transcendent relationship*.

The interviewees said that it was important to have a good relationship with themselves. It was not always easy when their body and mental functions were changed in such a negative way. It seemed, though, that the relationship to themselves was important for their ability to maintain good relationships with others.

Close family and friends came into all narratives and, as the interviewees had chosen to be cared for at home, relatives were always close to the patient:

It means a lot, almost everything, that you have a family to support you and good friends, that you have someone to listen to you and help you when you need it. Obviously it's important for having hope.

The relationship with other patients with incurable cancer gave the interviewees an experience of belonging to a group. They could no longer identify themselves with healthy people. Together with other patients with incurable cancer, they could share feelings and thoughts and be acknowledged. Sometimes it was also a consolation to see that 'others may be worse off':

The contact group was good because you could talk about whatever you wanted to. They had so many different tumours, in the brain and the liver. You need to talk, although I find it hard, but we were all alike there, all ill in the same way. There were also those worse off than me. One man couldn't be there the whole time, but I managed.

The staff were important people for the interviewees. Their professional treatment, for example the way they gave information and answered questions, had a great impact:

That nurse she was so nice, yes everyone is really nice in that clinic ... of course you have to have trust in the doctors, otherwise it wouldn't work, still I was angry and upset about the way he told me what my diagnosis was [in the lift on the way to the ward] ... he hit me really hard.

The interviewees paid great attention to their immediate milieu and claimed that their own home was a secure and familiar place, and an important dimension of their experience of hope. Living in their own home made it possible for them to participate in taking decisions about their care and the way to deal with their daily living. There were no rigid routines as in the hospital. None of the interviewees wanted to be cared for or to die in the hospital, if it could be avoided. Some of the interviewees had pets, whom they loved and who were

important for their experience of hope:

It's really nice to be at home. I've chosen to be here. Here I have all my own things and I get help with going to bed and to the toilet. I decide when I want to get up in the morning and I can set my own pace. I want to be here to the end if possible.

The interviewees also said that it was important for them to experience a relationship with something beyond their present situation, for example using their imagination and in some way entering a transcendent state. They also stated that it was important to have dreams, to envision themselves as healthy and living in a world without problems. Dreams, such as seeing oneself in beautiful clothes in younger days or participating in interesting courses, were a way of 'entering the healthy world':

Sometimes I let myself imagine that I'll live until Christmas and sometimes in the night I lie and think about where to put the tree. I know it's silly but it feels good to think about myself sitting there by the tree with everyone ... a lovely picture.

All the interviewees spoke about a relationship to something beyond their present life, called faith or 'something out there'. Although they claimed that they were not religious, thoughts of and talks with God occurred. One woman was astonished, when she discovered in the middle of the night, that she was praying without being aware of it:

One night I know ... I've never prayed before, but then it came to me that I should pray to get well, with clasped hands, it was a bit scary, I've never dared to say it before, what would people think, my children would be mad.

Reconciliation with life and death. The interviewees said that their experience of hope was to be well prepared for death both in a practical and an emotional way. Most of the interviewees had taken care of the practical financial and legal issues in the family and had prepared their funerals:

I've already written down ... my ... what I want my funeral arrangements to be ... with those closest to me, and found a suitable poem and so on and she [wife] has learned to deal with my part of the household finances ... and the insurance.

Another way of preparing themselves for death was to look back and summarize their life. This seemed important in bringing life to a completion, making all the pieces of the puzzle fit together. Talking over memories with friends and relatives and

looking at photos were conducive to their experiencing hope:

I'm only 54 but ... I think I got a great deal out of life and the best thing is that I've been a parent ... and we've danced a lot and travelled, so I don't think it's the length of life that matters but what sort of life and we've had a good life, a good marriage.

In spite of the hope of being cured, the interviewees showed an acceptance of and/or had reconciled themselves to their life situation, that is both with an ending of life and an inevitable death:

I've resigned myself to the idea that I'll die soon ... that's life ... I can't do anything about it, no ... I've resigned myself to it and it feels good.

Interpreted whole

The interpreted whole and reflections embrace the findings from the content and structural analyses. The findings indicate that the meaning of the lived experience of hope is related to the interviewees' life situation of living with incurable cancer. The experience of belonging to both life and death is a disunion and a puzzling situation. This dialectic experience of belonging to 'two worlds simultaneously'; the world of the sick and the world of the healthy, is also expressed by women with fibromyalgia.¹⁸ The experience of a narrowed frame of reference, of a deteriorating body, as well as the need to think about spiritual things, was also related to the lived experience of hope for the interviewees in this study.

The lived experience of hope is a tension between various dimensions of hope; to *hope for something*, that is the hope of being cured, and *living in hope*, that is reconciliation with and comfort with life and death. Which dimension is prominent varies over time. This play of dimensions could at first sight seem to be contradictory, but, according to the philosophy of Marcel,¹⁹ this is the ontological mystery, to hope against all hope. How can 'being' reside in harmony with 'acting'? Marcel¹⁹ believes that the understanding lies in viewing hope as a mystery, i.e. 'I cannot place myself outside it or before it ... I am inside it'. This can be accomplished only in a state of recollection, by joining 'being' and 'acting' or, in other words, transcending the dualism between the two (Figure 1). Recollection means to 're-collect' myself as a unity, which also includes relaxation and

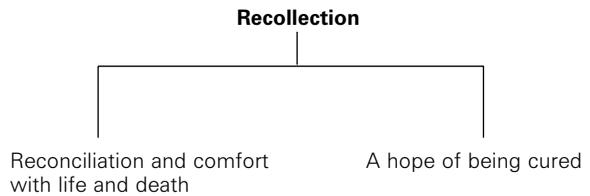


Figure 1 The meaning of the lived experience of hope: a state of recollection

abandonment. Within recollection 'I become capable of taking up my position – in regard to my life; I withdraw from it in a certain way ... it is an inward hold, an inward reflection'.¹⁹ Recollection points out that hope has no specific referent but a general orientation to reality that makes it possible to live in hope. Recollection is possible from confirmative relationships with others.²⁰

Another way of understanding the ontological mystery is to recognize the assertion of hope, that in a person's very being, beyond all facts, there is a mysterious principle that one person's will is also the will of other people.¹⁹ The person with incurable cancer might think that it is not the aim of reality to be hostile, because his or her belief is that reality is good, and there would be other people who also want him or her to be cured. That thought is possible, as hope transcends the reality of, for example, medical proofs. Being doomed to death does not mean giving up, being a useless creature, but entering into the state of encountering oneself beyond all judgements of life.¹⁹ To experience hope is a way of coming out of the dark.²⁰

Discussion

The findings in this study are partly in line with previous interpretations of hope in palliative care.^{2,21} Living with an incurable illness does not mean living without hope. Although the hope of being cured is judged impossible, hope can still be maintained. The strong will of being cured is a sign that hope is inexhaustible.²⁰ The possibility that miracles can still occur ensures that hope is never vanquished.^{3,22} The narratives of the interviewees consisted of a conviction that it is possible to influence the time of death by hoping to live until a certain

significant time in life.^{5,23} Living with incurable illness means living in uncertainty, for example due to the progression of symptoms. Lack of information is a source of uncertainty and a gap between expectation and the true situation. The lack of information as one contributory factor to uncertainty in patients with cancer in palliative care is also highlighted by others.²⁴

The strong hope of being cured generates a confidence in the treatments offered. The narratives showed that declining offers of treatment requires courage. Oncology nurses have also perceived that patient confidence in treatment is one factor in their hope.²⁵ However, having the possibility to decline treatment is also a way of maintaining hope. If the decisions taken are perceived as meaningful, it seems to deepen a person's experience of hope.²⁶

Good symptom control may be seen as a prerequisite for acknowledging hope as a mystery. The most common symptom related to advanced cancer is pain, but other symptoms must also be alleviated such as diarrhoea²⁷ and dyspnoea,²⁸ in order to make room for hope. The severity of the symptoms is related to the perception of the progress of the cancer. On the one hand, several studies have presented a relation between increasing symptoms and diminished hope.^{29,30} On the other hand, physical health was found independent of hope in a sample of women with breast cancer.³¹ However, a study of health in terminally ill people showed that their diseases were not the cause of feeling unhealthy, but the fact that they could not do the things they wanted to or live their lives as fully as they wished.⁵ The present study found that the hope of living as normally as possible was a significant dimension of hope, as was also emphasized by the findings of other studies.^{4,5}

Confirmative relationships with relatives, staff and significant others are important, as previous studies have also found.^{2,4,32} A confirmative relationship is only experienced as confirmative if there is a reciprocal presence in the encounter. Presence is something that reveals immediately in a handshake or in a look, and it is only in the interaction between a giver and a receiver that hope can emerge.²³ Confirmation means, for example, recognizing the other's existence and acknowledging a relationship of affiliation with the other.³³ This is described in encounters between nurses and guests

in a hospice:³⁴ 'in the midst of sorrow and fears one is embraced by a spirit of respect, beauty, ... making one feel worthwhile, one who is not abandoned, but closely connected to others and the world'. This kind of presence can be found when encountering support groups, where confirmation is given from other people in a similar life situation. The encounters with the staff are, however, not always considered confirmative but as an encounter where a person stands in front of them, physically at their disposal, but not spiritually.²⁰

The themes revealed in this study should be seen as being related to each other like the units in a mobile. If one unit moves or changes its appearance in one way or another it affects one or more of the other units. For example, if there is a lack of confirmative relationships, the experience of living as normally as possible is reduced. This indicates that the lived experience of hope should be seen as multidimensional and not as a linear experience.³⁵ The model of hope by Nikolaichuk and Bruera⁶ is in line with the findings in this study.

This study was carried out in home care, where effective symptom control can be accomplished.³⁶ Their own home is a safe and comforting place, where the dying have control and can lead their daily life according to their own rhythm, that is living in hope. One study³⁰ showed that control of the environment also underpinned the hope of controlling the cancer. Their own home may be chosen for the remaining days in a person's life when caring relatives and enough support from the health care are available. To die in one's own home makes death less medicalized.

Conclusion

The lived experience of hope for patients in palliative home care is not only hoping for something, but also living in hope. Living in hope means having confirmative relationships and an experience of being at home, with all their loved things and pets. One's own home is a source of 'feeling at home'.^{12,37}

Further research is needed in order to foster patients' experiences of living in hope, that is which nursing activities are required in order to facilitate the patients' entering into the state of recollection?

What kind of confirmative relationships are needed? These questions call for studies with a longitudinal approach to identify the processes preceding recollection.

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