Hope in palliative care: A longitudinal qualitative study

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Chapter 5: A Relational Ethics of Hope

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Abstract
The ethics of hope has often been understood as a conflict between duties: do not lie versus do not destroy hope. However, such a way of framing the ethics of hope may easily place healthcare professionals at the side of realism and patients at the side of (false) hope. That leaves unexamined relational dimensions of hope. In addition, the relational-ethical dimensions of hope have hardly been explored empirically. The objective of this study was to describe a relational ethics of hope based on the perspectives of palliative care patients, their family members and their healthcare professionals. Semi-structured interviews on hope were conducted with twenty-nine palliative care patients, nineteen friends or family members, and fifty-two healthcare professionals. Several researchers thematically analyzed data on hope and interpretations of hope were checked with participants. When participants spoke about hope, they referred to power, like the powerful bonding of hope between patients and physicians. They also associated hope with the loss of hope and suffering. Several participating healthcare professionals tried to balance both sides, which involved acknowledgment of hope and suffering. Moral philosophies were used to articulate the ethical dimensions of the empirical findings. Hope and power were reflected in the ethical concept of empowerment, whereas suffering and the loss of hope were reflected in the ethical concept of compassion. Empowerment and compassion can be balanced in solicitude. In conclusion, a relational ethics of hope requires solicitude, in which healthcare professionals are able to weigh empowerment and compassion within particular relationships.
Introduction

The ethics of hope has often been described within the context of truth telling, for instance when healthcare professionals have to break bad news. They may have to tell patients that a treatment failed to work or that patients suffer from a serious disease. In situations like these, healthcare professionals may want to tell the truth and respect patient autonomy, while simultaneously maintaining patients’ hope (1,2). This perspective may be connected to deontological theories, in which healthcare professionals experience a conflict of duties.

However, “hope versus truth” only reflects a realistic perspective on hope (3), which may easily place healthcare professionals at the side of realism and patients at the side of (false) hope. That leaves unexamined relational processes underlying shared hope (4,5). Furthermore, only a few authors have addressed relational-ethical dimensions of hope (6–8), and these dimensions have hardly been examined empirically.

The objective of our study was to describe a relational ethics of hope based on the perspectives of palliative care patients, their family members and their healthcare professionals. The central question was as follows: what does a relational ethics of hope consist of? Our approach was informed by the ethics of care and narrative ethics, in which relational dimensions, among other dimensions, are significant (9–14). The research question was answered from an empirical-ethical point of view (15,16), which involved that we examined what participants stated about hope within relationships. Moral philosophies were used to articulate the ethical dimensions of these findings.

The findings of this study may help healthcare professionals to see various sides of what is at stake when they work with hope, which may widen their reflective equilibrium (17). Furthermore, the results may support healthcare professionals to deal with hope in such a way that the quality of their relationship with patients is maintained or reinforced.

Method

Being part of a longitudinal qualitative study on hope in palliative care
(18), this paper focuses on the ethics of hope.

Data Collection

Semi-structured interviews on hope were conducted with palliative care patients, their family members and healthcare professionals. Sampling of participants aimed to obtain variation in gender and age. Eligible participants were eighteen years of age or older and they were informed about the study both orally and by letter.

Nurses, chaplains and physicians were approached through newsletters and palliative care networks. During the interview they were asked to tell about their own hope and the hope of their palliative care patients and patients’ family members. Then, participating healthcare professionals were informed about the sampling of patients and they were asked to approach eligible patient participants. When patients agreed to be approached by the researchers, they received information about the study. They were asked for their preference for being interviewed alone or with a family member or friend. In the latter case, the friend/family member was also informed about the study. After the interview they were asked for written and oral consent for interviewing their healthcare professional and/or their family members about them.

Palliative care patients were included when they suffered from incurable cancer, severe chronic obstructive pulmonary disease (COPD), or from severe heart failure (HF). Severe COPD means gold (Global Initiative for Chronic Obstructive Lung Disease) 3 or 4, and severe HF means NYHA (New York Heart Association) III or IV. These three diseases were selected because they are some of the most prevalent causes of death in Western countries and because they follow different trajectories (19).

Interview guides were developed on the basis of three pilot interviews and on the basis of literature on hope in healthcare (see Supplementary File 1, pages 95–97). The interviews were audiotaped and transcribed. Definitions of hope were not formulated prior to the study because of the various definitions and approaches of hope in healthcare and philosophy (20–25), and mainly because the researchers were interested in participants’ ideas about hope.
Participants were interviewed a maximum of three times with average intervals of six months. One interviewer (E.O.) interviewed all participants, which provided a relative constant factor in the research process and was important for building trustful relationships with participants (26). He was an experienced interviewer and had followed several courses on qualitative data collection and analysis.

**Research Ethics**

According to Dutch law our study did not need an ethics review (27). Although severely ill patients may benefit from participating in research, risks include the potential for emotional distress in participants and the main researcher, and difficulties around serial consent (26,28). These risks were discussed within the research team and the main researcher constantly attuned to the needs of patients and patients' family members.

Eligible participants received information about the study both by letter and orally, and when they took part in the study, patient and family participants signed an informed consent form. In The Netherlands healthcare professionals only have to give oral consent (27). In a few cases patient participants were unable to sign an informed consent. In these cases the informed consent was read aloud and patients gave oral consent, which was audiotaped, and a witness confirmed that patients participated voluntarily. Issues of confidentiality were explained to participants and patient participants were asked for written and oral consent for interviewing their healthcare professional and/or their family members about them.

In order to guarantee the anonymity of all participants in this paper, demographics are presented collectively (Table 1), and the characteristics of two participants in this paper were changed. However, these changes did not affect the presentation of the findings.

**Data Analysis**

Fragments, in which participants explicitly referred to the word “hope” and derivatives thereof, like hopelessness and despair, which include the word “hope” in the Dutch language, were thematically analyzed. MAXqda
software was used to analyze the data. For examples of the code trees, see Supplementary Files 2 (page 98) and 3 (page 99). The main researcher (E.O.) analyzed the interviews and six researchers (four females) with backgrounds in sociology/nursing, religious studies, general practice/ethics, humanistic studies/ethics, or neurology co–analyzed a total of twenty–six interviews. Results were discussed until researchers reached consensus.

In many instances, interpretations of participants' hope were checked by telephone or during subsequent interviews. Transcripts were returned to participants and memos were used to reflect, analyze and capture ideas on hope. Saturation was reached when no new themes appeared in the data and when around twenty–four patient participants had been included. Inclusion of patients continued until twenty–nine patients had been included (26,29).

**Results**

**Participants**

Of the participating patients (n=29), eleven suffered from incurable cancer, ten from severe COPD, and eight from severe HF. Nine partners, four friends, three children, two brothers, and one sister–in–law were interviewed (n=19). Around one half of the friends/family members were interviewed together with the patient participants. The included healthcare professionals (n=52) were twenty–four physicians, among whom general practitioners, geriatricians and specialist physicians, eighteen nurses, among whom community, hospice, and specialist nurses, and ten chaplains with a Protestant, Roman Catholic, non–denominational, humanistic, or Muslim background. See Table 1 for demographic information.

The semi–structured interviews lasted an average of one hour and took place between December 2010 and November 2012. Patient and family interviews took place at their living place, like home, hospice or home care institution, whereas most interviews with healthcare professionals took place at their work place. Reasons for dropping out and non–participation of patient participants were fatigue and death, whereas the main reason for non–participation of healthcare professionals was a lack of time.
Hope and Suffering

When patients, patients’ family members and healthcare professionals in our study addressed hope, they often spoke about power. They also associated hope with suffering and loss of hope. For examples of the code trees, see Supplementary Files 2 (page 98) and 3 (page 99).

Hope and Power. Talking about hope, participants often referred to power. The wife of one of the included patients spoke about hope: “It has to do with a sort of power” (family 12). One of the patient participants addressed power as well and related it to healthcare professionals’ ethical obligation to give hope: “You always have to give your patient hope, offer him something to cheer him up by telling him: ‘Have confidence! Be open for the forces and powers that accompany you’” (patient 6).

Several healthcare professionals described hope as a powerful bonding between specialist physicians and patients. One healthcare professional referred to hope and told about this bonding: “The specialist physicians say: ‘Well, the patient asks for it, you know, to go to the last.’ (…) Patients sometimes tell me: ‘Yes, well, the doctor expects me to do it. The doctors are willing to do so much for me’” (physician 5). Another physician told about a patient’s hope for an experimental treatment: “His hope is that it will help. Well, that absolutely is false hope. Because he gets an
experimental chemotherapy and in my view the effect is zero.” This physician explained how hope was nourished by the bonding with the patient’s oncologist: “If you [as oncologist] deal with patients for such a long time, it is very difficult to take some distance and say: ‘Well, now it’s really finished.’ They are not capable of doing that, or they don’t want to do that” (physician 4).

Hope and the power of hope were limited when hope was reduced to hope for cure. One patient told about the inborn nature of his heart failure and added: “Hope is not possible for me. There is no hope” (patient 3). According to several participating healthcare professionals hope for cure was dominant. One participating physician told how she searched for ‘second best’ hopes, like hope to see the daffodils grow or to experience the birth of your grandchild: “So these kinds of new little hopes arise when the big hope for definitive cure, when that door has been closed. Then, a circuit of second-rate little hopes arises” (physician 12).

**Loss of Hope and Suffering.** When discussing hope, many participants spoke about suffering and loss of hope. Participants also gave clues about good ways of dealing with loss of hope and suffering. A chaplain in our study stated: “To be able to deal with that suffering, that hopelessness of life (...) [you should realize] that there is never one appropriate answer” (chaplain 9). A specialist physician asserted that the suffering of losing hope often involved sadness: “With patients with cancer you very often deal with sadness as a response to the situation. That has something to do with the loss of hope” (physician 7).

A patient participant expressed that he had lost hope and everything that had been important in his life: his wife and his health. He told that he suffered from hopelessness. However, he felt supported by his psychologist: “She is open for that, you know. She immediately takes that seriously” (patient 1). A participating specialist nurse took seriously the loss of hope as well, by not downplaying emotions: “You reckon with the fact that sorrow or emotions come up while losing hope, and I’ve learned to allow that, not to immediately downplay that” (nurse 11).
Hope and Suffering within Relationships

Participants had different experiences with hope and suffering. Whereas some participants emphasized suffering, others emphasized hope, and yet others tried to pay attention to both suffering and hope.

Patients – Family Members. Patients and family members sometimes emphasized different sides: either hope or suffering. A patient participant was interviewed together with his wife. He asserted: “I hope that it will continue this way, as long as possible (…). But she said: ‘Maybe you could have better died.’ But please not! This period is worth living it” (patient 17). His wife responded: “Well, I thought: then he doesn’t have to dread it, then he won’t suffer.” She no longer emphasized his suffering: “He says: this is better with respect to his experience. Well, that’s true. And I’m better prepared now” (family 19).

Another patient participant told how her parents “kept saying” to her: “You’ll make it!” She explained it as: “They maintain hope and want their daughter to continue her life. But well, that won’t happen. That’s heavy.” She herself mainly experienced suffering: “I won’t make it. My heart says: this is the end. I’ve fought so much, every time again! Every time again” (patient 21).

Patients and Family Members – Healthcare Professionals. Differences were also found between healthcare professionals one the one hand and patients and their family members on the other. In one case a patient was interviewed together with her husband. She (patient 10) always hoped for a “better tomorrow”. Her husband explained that she could talk “in a very hopeful way” (family 12). They explained how their cardiologist, in their view, thought that they had “false hope” and how the cardiologist, as a consequence, focused too much on her suffering. They made clear to their cardiologist that she focused too much on the suffering and since then, the cardiologist took a different approach. The husband concluded: “The relationship is very good now” (family 12).

In another case a physician told about her hospice patient who hoped for a miracle cure. She tried to discuss what the patient “expected of her
future”. However, this evoked anger because the patient felt approached only as sufferer: “She said: ‘Everybody only tells me bad news. I don’t need to hear that because I will continue praying that a miracle will happen’.” The physician continued: “So then I told her: ‘I would like to talk about it at least once and after that I will stop nagging.’ So after that I haven’t talked about the future for a very long time” (physician 3).

**Reflections of Healthcare Professionals.** Several healthcare professionals tried to pay attention both to hope and to suffering. One participating nurse spoke about one of her patients: “The degree you appeal to her power has to do with hope (...) but if you ask too much of her, then you would deny her suffering” (nurse 9). Another healthcare professional asserted: “Disease and hope don’t go along very well. So it is the person and hope. It is the art of not focusing too much on the disease.” He added: “You need to pay attention to that [symptoms], of course. But also take into account: what else is playing a role here?” (physician 15). Some healthcare professionals expressed how they needed hope while facing suffering of patients. One of them stated: “Nurses don’t find it easy to give chemotherapies because you make your patients ill and you decrease their quality of life, because you hope that they will have quality of life after their treatments” (nurse 13).

**Discussion**

The results of our study suggest that palliative care patients, their family members and their healthcare professionals associate hope with power, and with suffering and the loss of hope. The results also suggest that within relationships both hope and suffering may play a role and that healthcare professionals try to balance both sides.

**Strengths and Limitations**

One of the strengths of this study is that it empirically examined hope from several perspectives: patients, family members, and healthcare professionals. Another strength is that – because of the study’s longitudinal character – interpretations of hope during previous interviews
were checked during subsequent interviews. In addition, the fact that one interviewer interviewed all participants reinforced trust between interviewer and participants, which is significant in longitudinal qualitative approaches (26).

However, our study only examined the micro level of individual stories and future studies should scrutinize hope at social levels, like others have done in hospitals (30), and hope at political levels, which includes issues such as justice and allocation of (financial) resources. In addition, future research is necessary in other healthcare settings than palliative care, in order to sharpen or revise the findings presented in this paper, which may reinforce the external validity of the results found in our study. In the last place, the concept of suffering should be empirically scrutinized in future research.

**Moral Theories**

The empirical findings presented above will be further articulated from a moral point of view.

**Hope: Empowerment.** The findings on hope and power reflect social–psychological and critical–sociological perceptions of empowerment. Social–psychological theories have described empowerment as a process of personal growth (31), and self–efficacy of palliative care professionals may indeed increase their hope (32). From a critical–sociological theory perspective, empowerment means the liberation from ties of oppression and inequality (21,33), which is a useful concept in order to critically approach the oppression of dominant hopes, like the hope for cure. The critical–sociological theory perspective on empowerment may furthermore help to critically approach the powerful bonding of hope between specialist physicians and patients, which was also addressed by others (4,5). Empowerment and hope in these cases entail deconstructing dominant or taken for granted hopes and reconstructing new hopes, like one of the physicians in our study did (see above).

**Suffering: Compassion.** The findings of suffering and the loss of hope,
and taking seriously the suffering of another person, are reflected in the ethical concept of compassion. Martha Nussbaum (34) defined compassion as “a painful emotion occasioned by the awareness of another person’s undeserved misfortune.” It includes three cognitive beliefs: 1) the suffering is serious, 2) the person does not deserve it, 3) similar possibilities of sufferer and compassionate person – the suffering could happen to both of them. Compared to empathy, compassion is not morally neutral: a torturer may be empathetic but is not compassionate (34). However, a critical comment should also be made: “If reason is used to justify the validity of compassion then compassion becomes a slave to reason. Subsequently, compassion becomes a slave to an abstraction, an idea of the good life like Nussbaum’s eudaimonistic conception” (35). This remark should remind healthcare professionals that their own eudaimonistic evaluations and those of their patients may be different, which requires exploration in clinical practice.

**Empowerment and Compassion: Solicitude.** The data suggested that hope and suffering are related themes and others have also addressed these themes (36,37). Several healthcare professionals in our study tried to balance both, which did not mean that they always ended up in the middle but rather expressed their capacity to weigh both sides. Empowerment and compassion can be balanced in solicitude.

Erik Erikson’s reference to solicitude helps us to understand how solicitude includes the care for others, from which hope, power and empowerment may arise. According to Erikson, hope is the most basic and earliest human power that is rooted within caring relationships (38). Animals also care for their young, “only man, however, can and must extend his solicitude over the long, parallel and overlapping childhoods of numerous offspring united in households and communities.” He concludes: “Care is the widening concern from what has been generated by love, necessity, or accident; it overcomes the ambivalence adhering to irreversible obligation” (38). For Erikson, hope remains a central factor in developing ego identity and autonomy (39), which relates to empowerment.
Solicitude also includes compassion. Paul Ricoeur wrote that solicitude resembles friendship and aims at the good life (40). Friendship is characterized by “a fragile balance in which giving and receiving are equal, hypothetically.” Solicitude, however, is first dissymmetrical: the suffering of the other evokes my “benevolent spontaneity” and compassion. Although compassion may lead to dissemetry, “this is perhaps the supreme test of solicitude, when unequal power finds compensation in an authentic reciprocity in exchange, which in the hour of agony, finds refuge in the shared whisper of voices or the feeble embrace of clasped hands.” According to Ricoeur the re-establishment of equality requires the recognition of the superiority of the other’s authority, and a shared recognition of fragility and mortality. “A self reminded of the vulnerability of the condition of mortality can receive from the friend’s weakness more than he or she can give in return by drawing from his or her own reserves of strength” (40).

In summary, solicitude includes the power of hope and empowerment, which are supported by mutually dependent relationships. On the other hand solicitude includes compassion, which is the shared recognition of fragility and suffering, in which the difference between giving and receiving is transcended.

**Conclusion**

In conclusion, an ethics of hope requires solicitude, in which empowerment and compassion are balanced. The results presented in this study may help healthcare professionals to develop relationships characterized by solicitude, in which healthcare professionals have the sensitivity to weigh compassion and empowerment within particular relationships. The results may also help them to reflect on their normative arguments and considerations, ultimately leading to reciprocal caring relationships between palliative care patients, their family members and their healthcare professionals.
References


18. Olsman E, Leget C, Duggleby W and Willems D. A singing choir: understanding the dynamics of hope, hopelessness and despair in palliative care patients. A longitudinal qualitative study. Accepted for publication by *Palliat Support Care*.


Supplementary File 1. Interview Guides

Interview Guide Patient and Family Participants

1. Opening
   a) Could you tell me what your first ideas were when you heard about the topic of this research: hope?
   b) Answers (and stories) were further explored by explorative questions: ‘What do you mean by …?’ ‘Could you tell something more about…?’ et cetera.

2. Concept of hope
   a) What does hope mean for you and what is its relation to hopelessness or despair?
   b) Are there other themes related to hope?

3. Dynamics of hope
   a) Have there been changes in your hope? Prompts: If yes, in what way? Did your hope, for example, increase, decrease, or remain the same? Could you tell me more about that?
   b) Have there been changes in your hopelessness? Prompts: If yes, in what way?
   c) Have there been changes in your despair? Prompts: If yes, in what way?
   d) Did other themes play a role in these changes? Prompts: If yes, which themes?

4. Social dimensions of hope
   a) What is the role of other persons in your hope? Prompts: which actions, responses or relationships help you to keep hope? Who threatens your hope? How did other respond to (changes in) your hope?
   b) Is hope the same for you, your family and healthcare professionals? If not, in what way is it different and how do you deal with that difference? If yes, how do you notice that it is the same?

5. Ethics of hope
   a) What do you see as a good way of dealing with (changes in) hope?
   b) What do you see as a good way of dealing with hopelessness?
   c) What do you see as a good way of dealing with despair?
      Prompts: Could you give an example? Could you tell me more about that?
Interview Guide Healthcare Professional Participants

1. Opening
   a. 'What were your first ideas when you heard about the topic of this study, which is: hope in the lives of people who suffer from a disease from which they will sooner or later die?'
   b. Answers will be further explored by explorative questions: 'What do you mean by ...?' ‘Could you tell something more about...?' et cetera.

2. Concept of hope
   a. What is hope and what is its relation to hopelessness or despair?
   b. (How) does hope relate to emotions like fear, joy, sorrow, etc
   c. (How) does hope relate to religiosity or spirituality?

3. Dynamics of hope
   a. Do you see changes in hope in palliative care patients and their friends/families? If yes, in what way? Prompts: in what way does hope change? What are factors that influence changes in hope?
   b. Do you see changes in hopelessness in palliative care patients and their families/friends? If yes, in what way? Prompts: in what way does hopelessness change? What are factors that influence change in hopelessness?
   c. Do you see changes in despair in palliative care patients and their friends/families? If yes, in what way? Prompts: in what way does despair change? What are factors that influence changes in despair?

4. Social dimensions of hope
   a. Could you give an example of a situation in which hope of patients and family members was different? How did you deal with that difference?
   b. Could you give an example of a situation in which hope of palliative care patients and/or their friends/families was different from your own hope? How did you deal with that difference?

5. Ethics of hope
   a. What is a good way of dealing with hope?
   b. What is a good way of dealing with hopelessness?
   c. What is a good way of dealing with despair?

Prompts: Could you give an example? Which values are important for you in this example?

6. Hope and disease
a. Do you see similarities and/or differences between (changes in) hope among different palliative care patient groups? (e.g. between severe COPD/other chronic diseases and cancer) *Prompt:* If yes, in what way?

7. Hope of professionals
   a. Could you give an example of things you hope for yourself? *Prompt:* think about hope in your own life and/or in your contact with palliative care patients or patients’ families or friends.
   b. What are situations in which you experience hopelessness or despair in relation to palliative care patients? *Prompt:* could you tell something more about that?
**Supplementary File 2. An Example of the Code Tree: Hope and Power**

<table>
<thead>
<tr>
<th>Quotations</th>
<th>Themes</th>
<th>Hope associated with</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;Well, that [church] was like: keep hoping, allow yourself time, be strong and powerful, things like that&quot; (patient 21)</td>
<td>keep hoping: allow time, be power strong, powerful</td>
<td></td>
</tr>
<tr>
<td>&quot;She was so powerful because of her hope that she didn't leave any space for saying goodbyes.&quot; (nurse 15)</td>
<td>powerful because of hope, power no space for goodbyes</td>
<td></td>
</tr>
<tr>
<td>Let's say: that hope, which people have had, I also think it is a sort of motivator, a sort of power, like: I will go on.&quot; (physician 10)</td>
<td>hope is motivator, power power</td>
<td></td>
</tr>
<tr>
<td>&quot;Hope is: I wanna stay alive. That will to survive is very strong in human beings, no matter how ill they are. They cling to that&quot; (patient 6)</td>
<td>Hope: strong will to survive strong will → power</td>
<td></td>
</tr>
<tr>
<td>&quot;Hope also includes a desire and courage as well, you make an inventory of power, and hope also gives power&quot; (physician 12)</td>
<td>hope includes desire, courage and gives power</td>
<td></td>
</tr>
<tr>
<td>&quot;Some people [with hope] try to keep themselves on their feet with thoughts like: it's not as bad as it seems. And: I want to do many things. I also think that we as healthcare professionals sometimes are more negative than patients&quot; (chaplain 10)</td>
<td>hope keeps people on their feet keeping yourself on your feet → power</td>
<td></td>
</tr>
</tbody>
</table>
### Supplementary File 3. An Example of the Code Tree: Loss of Hope and Suffering

<table>
<thead>
<tr>
<th>Quotations</th>
<th>Themes</th>
<th>Loss of hope / no hope associated with</th>
</tr>
</thead>
<tbody>
<tr>
<td>Then they've lost hope (...) at the point that they say: 'It's ready now. I'm done with struggling.'&quot; (nurse 6)</td>
<td>lost hope: done with struggling</td>
<td>struggling --&gt; suffering?</td>
</tr>
<tr>
<td>[During desperate moments I think about:] losing control. That I won't be any longer who I used to be. I think that's the word. That I won't have any control over my body. That you're pissing, shitting and stinking&quot; (patient 12)</td>
<td>desperate moments: losing control over body</td>
<td>no control over body and losing yourself --&gt; suffering</td>
</tr>
<tr>
<td>&quot;First they hope for cure. Then you've lost the hope for cure and then you hope to live for another year (...). You may deny it to a certain degree but the disease's nature is that that won't work anymore at a certain moment&quot; (physician 7)</td>
<td>lose hope because of physical suffering</td>
<td>suffering</td>
</tr>
<tr>
<td>About her hope, our puzzle is: how do you simultaneously acknowledge her suffering and take things over from her? (nurse 9)</td>
<td>hope versus suffering</td>
<td>suffering</td>
</tr>
<tr>
<td>&quot;We [man with COPD and I] saw each other during coffee, tea (...). He had always played [a wind instrument] in orchestras (...) so that man misses that a lot [pause]. Well, he had fun at that moment [with me]. No hope, but now again he had hope&quot; (patient 29)</td>
<td>no hope because he missed his favorite hobby --&gt; hope again</td>
<td>missing favorite things, no fun --&gt; suffering?</td>
</tr>
</tbody>
</table>