

Essay

Isabelle Wienand*, Milenko Rakic, Sandra Eckstein, Monica Escher, Nadia Pacurari, Susanne Zwahlen und Bernice Elger

The variety of hope: findings in palliative care patients' medical records

<https://doi.org/10.1515/spircare-2017-0039>

Vorab online veröffentlicht 7. Dezember 2017

Introduction

There is a widespread consensus about the importance of hope for human life (Dalferth 2016). However, opinions diverge greatly when it comes to defining the essence, the function and the value of hope (Woschitz 1979). The ancient Greek culture illustrates the different perspectives on hope (*elpis*) eloquently: according to the Greek myth of Pandora's Box, hope is the only blessing mankind has left to bear the toil and suffering of life. Interestingly, the ancient narrative recalls the harshness of life, and less the extraordinary human capacity not only to endure suffering, but also to make sense of it (Most 2006). A similarly negative evaluation of hope is to be found in the Greek fabulist Aesop. The moral lessons of his fables is that it is unreasonable to give up a present good – how small it may be – for the sake of something we do not have yet, i.e., we hope to get (Aesop 2008). But Theognis of Megara and the Hippocratic writings give a more favourable account of hope by stressing the supporting effect of hope. According to the Greek physician, hoping that patients recover or feel better is the doctors' *raison d'être* (Gallois 2005).

The following essay is an attempt to understand what hope is in the context of palliative care: wishful thinking, i.e., a reactive attitude or coping strategy to face bad news, as it is often mentioned in the literature (Shirado et al. 2013; Olsman et al. 2014; Koopman et al. 2016) an active will for something to happen, an expression of faith or

trust in a beneficent transcendence, a form of inborn optimism, a positive feeling (Hilpert 2017; Wienand et al. submitted)?

Sometimes we associate hope with denial of reality, for example when a person says they continue hoping for their complete recovery despite their imminent death. In a palliative care context, a similar tension is noticed time and again: despite prognosis of death, some patients and their family do not give up their hope of complete cure. But this example illustrates only one particular – and in fact relatively rare – form of hope qua wishful thinking. Yet, there is a variety of hope as our study has documented. The analysis of hope in a palliative care context should therefore be undertaken with greater interpretative caution in order to understand the patient's inner perspective (Dalferth 2016). In other words, a preconceived opinion on hope prevents from grasping what patients and family actually mean when they speak about hope (Bühler & Peng-Keller 2014). This stumbling block drew our attention while reading and analysing 300 palliative patients' medical records collected at three Swiss university hospitals between April and September 2016. Since qualitative research design helps to investigate medical staff's written statements about patients in more depth than quantitative research (Green and Britten 1998), we used this approach to understand patients' perspective. More precisely, we used content analysis for analysing the data (Vaismoradi et al. 2013). Details on the data extraction sheet and data collection are described elsewhere (Rakic et al. under revision). The quotes cited in this essay are verbatim texts written by the medical team into the patients' medical records. The passages were copied and translated from French or German into English. We obtained the ethical approval from the local research ethics committee ([EKNZ]; Nr. EK 2015–197).

*Korrespondenzautorin: Isabelle Wienand, Basel,

E-Mail: isabelle.wienand@unibas.ch

Milenko Rakic, Basel

Sandra Eckstein, Basel

Monica Escher, Geneva

Nadia Pacurari, Basel

Susanne Zwahlen, Bern

Bernice Elger, Basel

Results from an empirical study on patients' hope in three university hospitals

In the record notes written by the medical team we found a number of references to hope. During analysis, the term “hope” was further divided into five themes, which are presented below.

Hope as a coping strategy

When hope appears as a coping strategy, hope implies a chronological and immanent dimension. Patients have a representation of present and future, and hope for recovery or improvement in a near future. Hope is always *prospective*. In palliative care, hope is used to implement a goal-oriented therapy called “living with hope” (Kylmä et al. 2009). Also Olsman et al. (2015) suggested in their interview study that palliative care patients relate hope to a gain in the near future. Furthermore, hoping appears to be *redemptive*: no patient in the analysed data hopes for deterioration, but for an improvement of their present condition, for alleviation of symptoms:

“Patient hopes for possible radiotherapy of the arm in order to reduce the pain; talk with patient and partner: patient exhausted, does not participate to the talk” (Medical Record [MR] Patient [Pat] 81).

In this quote, hope appears to offer a response to cope with pain, and possibly with exhaustion. Hope allows the patient to envisage a better future – reduction of pain, and less tiredness – in order to improve their present quality of life. Here, excessive pain seems precisely to be that with which the patient attempts to cope: they hope to get rid of pain and – albeit not explicitly mentioned in the records – of the related effects of pain, such as exhaustion. Patients appear to hope for “something” and they adjust their hopes to the changing circumstances of their condition. A further similar statement confirms that hope is seen as a coping strategy to face life-threatening diseases:

“Patient knows that her illness in the liver is metastasized and is progressing rapidly, but she hopes for an improvement of her present situation, so that she can receive further chemo” (MR Pat 91).

Hope is sometimes expressed with other terms, such as ‘optimism’: “Patient expressed that she wanted to fight with the disease and she was optimistic” (MR Pat 69). In other cases, hope is not named as such, but it can be guessed

from the patient’s mental state as described in the medical records: “*The patient had a lot of motivation and interest in life: work, people that she could meet at work; she loved reading and culture. Conserving her cognitive faculties was important for her, while she affirmed being able to adapt to a mobility loss*” (MR Pat 24). Implicitly, one can assume that the patient hopes to feel better and to continue doing these activities.

Hope as an active will for health improvement to happen

When hope expresses an active will for recovery to happen, it seems to be right, as Capps (2005) claims, that it makes little sense of speaking of ‘false hopes’ because the object of hope, by definition, is perceived to be realizable. Capps (2005: 193–194) adds that “to say that hope envisions the realizable does not mean that it is bound by the practical, the sensible, the proven, or the tried and true”. What is more, Rosenfeld et al. (2011: 326) note a diverging understanding of ‘hopelessness’ among clinicians and researchers of whom “many assume that the presence of a terminal prognosis is synonymous with hopelessness and that the absence of hopelessness merely reflects a lack of insight into one’s prognosis (i.e., naïve optimism)”. Yet, as the authors note, the understanding of hopelessness in palliative care settings is different. Terminal prognosis does not necessarily precipitate patients into a state of hopelessness: “Clinicians who work in palliative care settings often readily acknowledge that many patients retain considerable hope and are able to shift to more realistic albeit often short-term goals” (Rosenfeld et al. 2011: 326).

The following quotes express patients’ concrete objects of hope:

- to be operated: “Patient hopes that his [blood] values will become better, so that he can be operated” (MR Pat 30);
- to receive an organ transplant: “Patient wishes further clarification for another liver; patient sees her severe illness and hopes for further years of quality of life and a further transplantation” (MR Pat 74);
- to have a better functioning organ: “Patient speaks of his hope that his intestine will function normally again” (MR Pat 55).

Hope in conjunction with other feelings

However, the active will to recover can coexist with feelings of fear, anxiety, and resignation within the human

psyche. Olsman et al. (2015) also emphasize this aspect in palliative care settings. The following quotes exemplify this important feature of hope qua psychological disposition: hope can accommodate other, even opposing feelings, such as anxiety or despair. Hope can also be accompanied by a lucid awareness of the situation. The particularity of hope as expression of desire is that, as Descartes writes in § 165 of his *Passions of the Soul*, hope and anxiety, “although opposed, may nevertheless occur together, namely when we think of reasons for regarding the fulfilment of the desire as easy, and at the same time we think of other reasons which make it seem difficult” (Descartes 1985: 389).

“Patient oscillates between hope (transplantation of the lungs) and the awareness of having reached his ‘final destination’ ” (MR Pat 60).

“Patient hopes time and again that the situation will improve and that he can go home; actually he knows, too, that this will not be possible” (MR Pat 92).

“Patient admits a form of resignation in her state, even though she asserts preserving the hope for a better state” (MR Pat 27).

Hope as an expression of one’s relation to transcendence

There is a further type of hope in the medical records we analysed: hope appears in some medical notes less related to the actual situation, and more as an expression of faith in transcendence, a particular receptivity to an overwhelming reality. Confidence in the efficacy of the “good energy” for the healing seems to be deeply anchored:

“Son speaks of the family’s hope for recovery, for a miracle, and also of the belief in the good energy which allows healing” (MR Pat 81).

Family’s hope

Shirado et al. (2013) stress that hope is important for patients but also for families: “Maintaining a sense of hope is important in the face of death not only for patients but also for their family members” (Shirado et al. 2013: 849). The following quotes do not tell whether partners and spouses have the same kind of hope – quote of MR Pat 4 seems to point at a potential conflict. But what these medical records confirm is that hope expresses the partner’s desire of a prolongation of life, or a stabilisation of

the patient’s condition. Here too, hope appears as a resource for the patient to live as well as possible until the end. As for the family, hope helps them to endure the situation. Hope seems also to be a precious support for the family members themselves to accept that death is part of life.

“She [partner] hopes that with the relief of pain, the wish to die will be ‘stabilized’ ” (MR Pat 4).

“Spouse considers the situation critical: he has great hopes that the patient will stabilize and can become mobile” (MR Pat 32).

“Partner hopes very much that a therapy can be found to prolong the life of the patient” (MR Pat 36).

Discussion

On the face of our analysis of palliative care patients’ medical records, it seems to be reductive to claim that hope is only a kind of wishful thinking (Mattingly 2006) for a number of reasons.

First, by interpreting patients’ recorded occurrences about hope as signs of epistemic neediness, we might be missing something important. For it is typically inferred that hope is of less or low epistemic value, because hope seems to be at odds with evident, accountable facts (Mattingly 2006). The English expression “to hope against hope” catches very well the apparent paradox of hoping “where there are no reasonable grounds for doing so” (Oxford English Dictionary, online).

That is, hope is not an inferior surrogate for rational thinking, but an essential fuel for humans to imagine, change and improve the world as well as their lives. Hope implies concern, commitment or even love towards the world and our own lives. Indeed, hoping for a better world is imagining how the world could or should be, but is not yet. It is relevant to recall that “to hope against hope” is quoted after Paul’s letter to the Romans (Röm 4, 18)¹. In the context of palliative care, hope for a more efficient treatment might also indicate an ingrained commitment to, and love in life.

Second, hope might not just be a reaction to suffering and death, but also an active attitude in order to give suffering and death a meaning in human life (Breitbart et

¹ Who against hope believed in hope, that he might become the father of many nations; according to that which was spoken, so shall thy seed be (King James Bible).

al. 2015; Olsman et al. 2015). Hope seems to be so intimately wrought into human nature that it lasts until death.

Third, it has perhaps become more difficult for us to discern spiritual features within the human nature (Voll et al. 2017). If we look at the modern development of Western philosophy we find good arguments to dismiss the soul qua something purely mental and eternal as a myth (see Kim 1998; Goetz & Taliaferro 2011). However, although the paradigm of the soul is no longer of scientific relevance, we still need to understand what patients and their families convey when they hope for recovery, for going home, etc. (Brandt & Besson 2016). Even if modern medicine is sceptical about speculative soul-theories, talks about the soul have not disappeared, as Asma (2010) reminds. It should not prevent from being attentive to the expressivity of ‘soul talk’:

Like other expressive forms, soul talks in ordinary folk language have much theoretical interest, because it is rarely, if ever, trying to explain a phenomenon. In the same way that a poem is not trying to explain a phenomenon, soul talk is equally uninterested in induction, hypothesis, prediction, and corroboration. Instead, soul talk tries to express our hopes and aspirations, e.g. ‘I hope I see my family again in the afterlife’ (Asma 2010).

Fourth, it is important to recognize hope as a distinctive human capacity as necessary as inferring, calculating etc. are, in order to lead a meaningful life. In his *Passions of the Soul* (1649) the rationalist thinker Descartes defines hope as a “disposition of the soul to be convinced that what it desires will come about” (Descartes 1649/1985: 389). The American theologian Capps also defines hoping as a “perception that one wants to happen will happen, a perception that is fuelled by desire and in response to felt deprivation” (Dykstra 2005: 189).

Finally, the medical records we studied did not document patients’ hope to die soon. This might be a limitation of our analysis, as the wish to hasten death is a recurrent topic for palliative care patients (Monforte-Royo et al. 2012; Guerrero-Torrelles et al. 2017). Very often, the hope to die soon is motivated by the experience of intolerable pain. This particular kind of hope which seems *prima facie* death-oriented might however also express feelings of gratefulness towards life, a wish to die in dignity, or an indirect request for a more adapted care (Sulmasy 2002; Glawischmig-Goschnik 2017). Patients’ hope to die soon also confirms our suggestion that there is a variety of kinds of hope.

Conclusion

We have seen that there is a variety of kinds of hope which cannot all be subsumed under the general umbrella term ‘coping strategy’. The variety of expressions, functions and purposes of hope, as our analysis shows, is partly reflecting the complexity and perhaps even mystery of the human psyche when facing suffering and death. Indeed, hope is not a mere coping strategy, but also a positive commitment towards life, a disposition which can accommodate fear, anxiety, and lucidity, and is sometimes related with confidence in or reliance on transcendence. Hope, like imagination and belief, gives patients a kind of mental robustness or resilience to have life-oriented goals until the end of their life. Capps (2005) reminds us of the difference between ‘realizable’ and ‘realistic’. The analysis of the medical records suggests, however, we should diminish the contrast between the realm of the imagination (the realizable) and the realm of ‘cold facts’ (the realistic). Patients move from one realm to the other without great difficulty (e.g. MR Pat 92). We have also seen that hope is often mixed with, or followed by other sentiments (confidence) and sometimes contrasting feelings (e.g. fear, despair, anxiety). The coexistence of hope with other feelings is in a palliative care setting particularly important for healthcare professionals to recognize, as families are confronted with suffering and end-of-life issues, and experience hope and despair concomitantly.

As Cole et al. (2015: 368) rightly indicate, the line between “realistic and realizable is sometimes hard to locate”. Mattes & Sloane (2015) underline the “challenging task of balancing optimism and realism.” More than just a strategy which patients can resort to in order to help them cope with suffering and a life-limiting condition, hope is an essential part of human life, in the very same way as pain is.

From the patients’ and relatives’ perspective, hope seems to be a sustaining resource to keep meaning in end-of-life contexts. However, hope was not mentioned very often in the patients’ records. The reasons for a relative low amount of occurrences are likely to be various although they cannot be pinpointed precisely: either the medical staff did not have the time to write it down, or did not think it was medically relevant, or the patients infrequently spoke to the medical team about hope. Yang (2004: 351) suggests that patients with hope might fare better than desperate patients as hope might stimulate “the release of internal painkiller molecules”. Our study also often points at positive effects of hope for patients and their relatives in palliative care settings. It is therefore crucial that palliative care teams are aware of the pervading presence of hope as

well as its supportive and comforting benefit, in order to foster and sustain it. This is already anchored in the Hippocratic corpus we referred to in the introduction (Lloyd 1983; Gallois 2005): hoping that patients recover or feel better is the physicians' *raison d'être*.

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