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ORIGINAL RESEARCH

The Beneficence of Hope: Findings from a Qualitative Study with Gout and Diabetes Patients

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Abstract This paper explores the importance of hope as a determining factor for patients to participate in first-in-human trials for synthetic biology therapies. This paper focuses on different aspects of hope in the context of human health and well-being and explores the varieties of hope expressed by patients. The research findings are based on interview data collected from stable gout and diabetes patients. Three concepts of hope have emerged from the interviews: hope as certainty (H1); hope as reflective uncertainty (H2); hope as self-therapy (H3). The purpose of the paper is twofold. First, it aims to underline the significance of hope in patients' medical decision-making, as well as the beneficence of hope for patients' well-being, and for progress in research. Second, it shows how philosophical investigations—in particular Descartes—explore the phenomenon of hope and provide medical empirical research with profitable insights and tools.

Keywords Hope · Certainty · Optimism · Self-therapy · Virtue · Well-being

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1. Introduction

Hope is crucial for human lives and particularly for those affected by ailments (Hammelstein and Roth 2002; Scioli and Biller 2009). And yet, it is not easy to determine the specific nature of hope, as it is a diffuse phenomenon. Indeed, researchers have identified forty-nine different definitions of hope (Schrank et al. 2008). As Eliott has noted, the perception of hope differs markedly across time and culture. For instance, Ancient Greece defined hope as a divine evil "that encourages foolish optimism" (Eliott 2005, 2). In the Latin Christian tradition (e.g. 1 Corinthians 13:13) hope (*spes*) is a virtue among the three theological virtues (faith, hope, and charity). It is viewed as a God-given disposition—or infused virtue—to direct us to God and thus guides us through our journey on earth. Whereas the Medieval thinker Aquinas insisted that without this infused virtue, we would not feel the emotion of hope (Aquinas 1920), modern philosophers such as Camus (1942) and Bloch (1959) conceive hope in immanent terms. Psychologists and medical scholars do not generally explain hope as an effect of divine grace. However, they do not completely give up the idea that hope is a virtue (Miller 2012). Miller reminds us that, for the 19th century English physician Thomas Percival, the physician is a "minister of hope and comfort to the sick". Miller endorses this view as "still apt" (Miller 2012). In general, researchers focus their attention upon the psychological mechanisms that generate emotions of hope (Averill, Caitlin, and Chon 1990). Indeed, in the last four decades an increasing number of empirical

studies—conducted mainly in psychology and psychiatry—have developed tools for measuring hope, for example "The Hope Scale" (see Roth and Hammelstein 2007). This measures the effect of hope on bodily ailments and illnesses (see Snyder 2000). Andresen et al. (2003) demonstrate that hope can play a role in shortening recovery processes. Huguelet (2014) adds that hope may be both a motivating *factor* for healing more promptly and a *consequence* of healing. Maier and Shibles (2011) define hope as an emotion which produces positive bodily feelings. Maier and Shibles also establish a direct link between hope and humor:

> Both hope and humor take and run around life's problems. A negative situation may not be within our control, but humor is. […] The most hopeless situation is death, which is why humor is one of the few ways in which it can be coped with or explored. (Maier and Shibles 2011, 150)

Rivka Jacoby (1993) shows that hope is also a resourceful aid for coping in stressful situations. Particularly for terminally ill patients, the significance of hope has been abundantly documented (see Cooper et al. 2015; Rocker et al. 2010). As Cotter and Foxell note, health professionals in palliative care widely agree that,

> … although hope tends to change in people with terminal illness, maintaining a delicate balance of death and hope for a cure often remains an important task up until the time of death, even when people acknowledge that cure is virtually impossible. The dying person needs to envision future moments of happiness, fulfilment, and connection. (Cotter and Foxwell 2015, 7)

In a similar vein, recent empirical research in psychiatry has showed hope to be important for the recovery process of schizophrenia patients, even when their chances of reintegration into society are limited (see Schrank et al. 2012).

The significance of hope can also be identified in the context of first-in-human (FIH) trials, as we observed in thirty-six interviews conducted with stable gout and diabetes patients. The aim of the interviews was to have a better understanding of patients' attitudes towards hypothetical participation in cutting edge biotechnology research with a special focus on synthetic biology. Hope emerged as a distinctively rich theme—explicitly or tacitly present in many interviews with stable, but chronically ill patients with decreased life expectancies. The present paper attempts to clarify the importance of hope for patients who participate in clinical research and particularly in FIH trials. This article thus explores a novel research question that has hardly been discussed in the literature (Eaves et al. 2014; Jansen 2011). Based on the patients' narratives we identified three kinds of hope: hope as certainty (H1); hope as reflective uncertainty (H2); hope as self-therapy (H3). As the interviews illustrate hope can express a strong confidence in the goodness or beneficence of the scientific research's outcome, whether for the patient or for future patients (H1). Yet, hope can also imply scepticism, fear, and concerns about the outcome of scientific research (H2). Finally, hope can also function as self-therapy allowing patients to remain positive despite uncertain health outcomes (H3). The purpose of the paper is twofold. First, it aims to underline the significance of hope in patients' decision-making and to encourage the promotion of hope, as beneficent not only for patients' well-being but also as a component of research. Second, it shows how philosophical investigations—in particular Descartes—explore the complex phenomenon of hope and provide medical empirical research with useful theoretical insights and methodological tools. Descartes emphasizes the plasticity of hope: hope is a psychological coping strategy; hope can coexist with uncertainty; and hope is a great incentive to recover health.

2. Various Understandings of Hope

As Albert Camus writes in his philosophical essay *The Absurd*, hope arises when meaningfulness is at stake, that is, when we have to deal with purposeless events, or more fundamentally when we try to make sense of the vulnerability and finitude of our lives: "Absurdity, hope and death carry on their dialogue" (Camus 1942/2013, 25, our translation; see also Marcel 1947). In a similar vein to the existentialist way of evaluating hope as a way to comprehend the apparent absurdity of human existence, the atheist Marxist-inspired conceptions of hope such as Ernst Bloch's utopic model shares with Camus that hope is an immanent principle of moral agency. In his influential book *Das Prinzip Hoffnung* (1959) Bloch shows that hope is a strong motivating force of political actions. Without hope for a more just society, no dialectic change in history would be thinkable, no political reform would ever take place.

Despite their evident contrasts, the transcendent religious and the immanent atheistic models of hope agree on hope as confidence in the good that humans can potentially achieve. Being hopeful seems to be *prima facie* a beneficial trait of character, for it encourages committing oneself to noble causes such as childcare, education, and healthcare in the world. In this regard, hope has a critical normative dimension as it challenges unfair conditions: for example insufficient childcare and societal exclusion of people with mental conditions (Schranck, Wally, and Schmidt 2012). As well as being a strong motivational drive to positively change aspects of one's own life or to contribute to modify the course of history for the better, hope also generates a generally positive outlook on the potential of humans. An interesting consideration of hope raised by Aquinas concerns whether one can teach and learn hope. Aquinas thinks it is the effect of divine grace, whereas Bloch defends the view that it can be acquired by human efforts. Recent literature reports that a variety of hope-therapy programmes have been designed (Lopez et al. 2000).

In contrast to despair, hope turns us into optimistic people. However, the idea of "hope" is not fully interchangeable with "optimism."[1] Averill, Caitlin, and Chon (1990) suggest we should distinguish hope from optimism. Hope is a positive attitude toward desirable but unlikely events, whereas optimism expresses confidence in events which are likely to take place. So for instance we do not need hope for tomorrow to come, but we need hope in order to think that a fairer distribution of medical care is possible. More importantly, one needs hope, and not optimism, to defend a lost cause, for hope is not about evaluating the world as it is in a positive way but about believing that the world could be better than what it is. Optimism is a *Weltanschauung* which considers the world as predominantly good. In contrast, hope is a belief that the world as it is, is not predominantly good and that it could (or should) be different. Another difference highlighted by Averill and colleagues is that the events we are hoping for *matter* a lot to us. This personal involvement need not be the case for optimism. This latter distinction is harder to substantiate and we tend to disagree with Averill on the point, as both hope and optimism seem to imply a certain amount of personal engagement with the world. Indeed, a favourable course of events matters as much to the optimist as to the hopeful person. Hope differs from optimism in that hope implies that certain states of affairs should be avoided, even if it seems *prima facie* unlikely, if not impossible, to change them. In contrast, an optimist would typically look for the positive in any state of affairs, on the premise that the world as it is, is fundamentally good. In other words, hope has a stronger utopian dimension that is more critical of cultural, social, and political affairs than mere optimism. Hope evaluates the present in view of a possible and better future, while the optimist is content with the existing condition, the *status quo*. Our suggestion is that these distinctions between hope and optimism can also be relevant within a medical context. Consider this sentence from a physician to her/his incurable patient: "although there is little reason for optimism, don't lose hope" (Averill, Caitlin, and Chon 1990, 96). Smith et al. (2011) confirm the common occurrence of this statement in their study. The authors explain that the more honest and precise information patients receive, the more hopeful they can be. A recent study shows also that "disclosure of prognosis by the physician can support hope, even when the prognosis is poor" (Mack et al. 2007, 5636). For certain persons, to be hopeful means to believe in miracles. Cooper et al. (2015) also remind us that "many people, including healthcare providers, believe that miracles can and do happen, even in the most traumatic experiences." (2) The authors add that the belief in miracles can refer to at least two different conceptions:

> Some writers note that the belief in miracles is based on irrationality, meaning that something will occur despite the laws of sciences. Others frame the belief in a miracle as a statement of faith or piety. (2)

However, there is also good reason to doubt whether hope can be given any epistemic value and has any quantifiable use at all, since even the optimist recognizes the medical fact that the patient is incurable. So what is the point of hope? In certain ways hope seems to be the last evil in Pandora's Box, an illusion which we should fight against, as recommended by Hesiod and Aesop (Eliott 2005). Should we not be more suspicious about the psychological twist of hope, as Ludwig Feuerbach (Feuerbach 2008) showed in his critical analysis of

[1] We are not speaking here about the classical form of metaphysical optimism, as it is defended by Leibniz (1952) in his *Theodicy* (published in 1710). Optimism is understood here in a more psychological sense, that is as a tendency to interpret positively what happens and will happen to others and oneself.

religion? For the German philosopher, hope, particularly Christian hope is an infra-conscious projection of our desires for divine immortality (see Godfrey 1987). Seen in this light, hope is a kind of defiance and denial of our finitude.

Indeed, there are some cases in which hope seems to be an inadequate or even bad habit, a self-deceptive behaviour (Averill, Caitlin, and Chon 1990). Psychologists speak of "false hope" (Snyder and Rand 2003; Eliott 2005). The English language has a word to depict this out-of-place confidence: "pollyannaism." The *Oxford English Dictionary* defines pollyannaish as "naively cheerful and optimistic; unrealistically happy" (OED Online 2018). Ruddick (1999) emphasizes that physicians should avoid supporting patients' false hopes, as this attitude amounts to a "paternalistic violation of patient autonomy" (343). In the field of research ethics, unrealistic optimism can lead to what is called "therapeutic misconception," when the patient conflates research with therapy; when s/he believes that "every aspect of the research project […] is designed to benefit him [or her] directly" (Horng and Grady 2003, 12; see also Jansen 2006).

To sum up, hope plays a key role in human lives as it helps us face uncertain or fatal outcomes and interpret them in a pro-active sense. We have seen that philosophers and ethicists are wary of the potential harm of hope, as it rests on belief about improbable events and can lead to self-deception. However, our empirical data illustrate that the epistemic poverty of hope does not seem to be a problem for the interviewed patients. First, the medical knowledge that there will be little or no improvement in the patients' condition can coexist with the hope for a better outcome for future generations. Second, patients use hope as a measurable good ("little hope"), i.e. to indicate a low level of knowledge. Third, they seem to conceive of hope as a kind of therapeutic tool helping them to get through the day and envisage their near future cheerfully. While trying to identify the different combinations of hope in our collected material, we realized that Descartes made similar distinctions regarding hope in his private correspondence with Princess Elisabeth of Bohemia. The next section analyses our empirical data on hope in light of the philosophical insights of Descartes. We suggest that (1) the phenomenon of hope, as expressed in the interviews with gout and diabetes patients, is complex, even paradoxical; (2) the finesse of Descartes' descriptions of hope seems to capture the complexity of hope and makes him in that regard a valuable resource for today's debate in medical ethics; and (3) health professionals should be perhaps more aware of the plasticity of hope: hope can be an expression of self-deception but also of moral certainty, reflective uncertainty, and mental health.

3. Three Kinds of Hope

Methodological Remarks

In the thirty-six interviews conducted with stable patients suffering from gout and diabetes, we analysed how patients reacted to hypothetical participation in FIH trials using synthetic biology devices. The interview guide consisted of ten open questions; each with several sub-questions prompting patients on particular details. During the interview, the interviewer provided information about potential medical applications of synthetic biology and FIH research. Each interviewed patient was provided with the hypothetical example of the implantation of synthetically modified cells. Patients were informed that the hypothetical implanted cells would cure diabetes and gout and make other medication redundant. The average interview duration was forty-four minutes. Interviews were transcribed verbatim and quotes were translated into English. We applied a bottom-up, rather than a top-down approach: we did not use an existing theoretical framework of hope while reading the interviews. Hope emerged as one of the themes from the interview material (see Rakic et al. 2016).

This main theme was divided into three subcategories as patients referred to different kinds of hope in the medical setting[2]: hope as certainty (H1); hope as reflective uncertainty (H2); hope as self-therapy (H3). In the final phase the chosen theme, hope, including the empirically identified three sub-forms of hope—H1, H2, and H3—were analysed in the context of Descartes' moral philosophy. Finally, a recommendation was made for clinical settings: hope is not only a positive attitude towards a particular event but can even entail fear and doubt. However, hope implies an essential confidence in the ultimate outcome of events which matter to us. As such, hope should be promoted for the sake of both

[2] The paper does not claim that the kinds of hope occurring in the interviews are the only existing kinds of hope. For an overview of hope theories, see Rand and Cheavens 2009.

patients' well-being and clinical research. Details of the methods are described elsewhere (Rakic et al. 2016).

3.1 Hope as Certainty

For a number of patients, hope expresses an unshakable confidence in the effectiveness of medical treatment for themselves, and/or for future generations of patients. Hope expresses the patients' trust that clinical research will contribute to human well-being in the long run. Consider for instance patient Danielle's answer to the question of whether she has hope that the trial can be helpful: "Yes, absolutely. Yes, I have the hope that it will be of help in the future." See too the general statement from patient Yves about confidence in future therapies: "One hopes that there will be better therapies in the future to help others."

The certainty which these patients envisage is not based upon scientific research or upon complicated statistics. Neither is it the result of a long and metaphysical meditation or a blind faith in medical progress (Stempsey 2004). Rather, it is a kind of *moral certainty*, that is, a *positive evaluation* of present and future human potentialities as well as a strong faith in the overall goodness of things. In other words, hope is a conviction that things will turn out for the best. This seems to be a *spiritual resource*[3] that is available to us in adverse situations, particularly in the case of serious illnesses (Eliott 2005). The view that hope is a coping strategy, a form of medicine for the soul, is not a new idea. It was a widespread view in early modern moral philosophy, which was strongly advocated by Descartes (Levi 1964; Descartes 2015). For Descartes, spiritual fortitude does not only relate to the mental part of the human: being strong affects both mind and body. Thus, according to the Cartesian doctrine of the mind–body union, thoughts can produce improvement or deterioration of bodily health and vice-versa. Conceived as a certainty about an ultimately good outcome, hope is a medicine for the soul and for the body, as the Latin adage says *mens sana in corpore sano* (a healthy mind in a healthy body) (Scioli and Biller 2009). Ultimately, the conviction that all will be for the best, despite present pains and worries, helps protect us from interpreting our own fate and death (as well as the fate and death of other human beings) as something inherently negative.

[3] "Spiritual" is used here in its etymological meaning: of the, related to the spirit (*mens*, *anima*).

3.2 Hope as Reflective Uncertainty

Hope can also imply the awareness of uncertainty or doubt regarding the chance of recovery. As patient Chris replies to the interviewer, he would participate in the trial for the following reason: "Yes there is a chance that the treatment is efficacious. Efficacious and supportable. That there is meaning in it."

Chris states further that the reason why a paralyzed patient participates in a clinical trial is that he hopes and does not know whether he will feel better. Chris then concludes that it is an instinctive decision:

> … also if it is a paralyzed or damaged [patient], who then says: "Yes," this and that I hope, then I do not know. Then, it is a gut feeling based decision (*Bauchentscheidung*).

Patient Danielle speaks of there being "little hope":

> And therefore there can always be something, when something foreign enters the body, which causes a reaction. Of course you hope that there will be always positive reactions, but the contrary can happen as well. […] There is little hope that it [treatment] is already useful, because it is an experiment/trial.

The fact that hope can formulate uncertainty about future outcomes is not idiosyncratic to gout and diabetes patients. On the contrary, the patients interviewed tend to illustrate a recognizable pattern in human psychology. Folkman (2013) notices a similar kind of hope among cancer patients. They learn how to live well despite the fact that the outcomes are only "plausible." The French philosopher too compares hope as a speculative form of knowledge in *The Passions of the Soul* (published in 1649) and his moral correspondence. In his letter to Princess Elisabeth of Bohemia from 3 November 1645 Descartes points out this reflective dimension of hope: hope includes uncertainty, or as he writes "conjectures" and "no assurance":

> As for the state of the soul after this life, I have much less knowledge of it than M. Digby. For leaving aside what faith teaches us, I confess that, by natural reason alone, we can make many conjectures to our benefit and have some high hopes, but no assurance. (Shapiro 2007, 126)

Hope is not a blind denial of what human reason cannot control. The particularity of hope as reflective uncertainty is that it does not make us fall into despair. Hope occupies this very subtle position in our self-awareness which *compensates* for our cognitive weaknesses and *reminds* us of them.

We can now better understand the plasticity of the concept referred to earlier: hope implies both *certainty* in the sense of overall faith in the ultimate actuality of goodness and *uncertainty* in the sense of recognition of human limits. In our view, there is no necessary contradiction in stating that hope can have both meanings, since *certainty* is not on the same level as *uncertainty*. *Certainty* here relates to the moral conviction that values which matter to us (such as health and well-being) will materialize one day. *Uncertainty* relates to the awareness of lacking factual knowledge (e.g. medical knowledge). This distinction between moral certitude and reflective uncertainty, which Descartes develops in his *Principles of Philosophy*, is particularly useful here (Descartes 2006). Not only does it remind us that human life belongs to a great extent to the realm of uncertainty; it also emphasizes that metaphysic certainty—which is a divine attribute—is not a prerequisite for human lives to fare well. Hope is the awareness of lacking this absolute knowledge; it is reflective positive knowledge of one's limits. Thus hope is not an unclear concept with self-contradictory elements. On the contrary, hope has a sound self-therapeutic function when it combines both planes, that is, certainty and uncertainty.

3.3 Hope as Self-Therapy

It would be a harmful kind of hope if a terminally ill patient hoped that s/he could be cured. An example of a realistic hope would be the wish to die at home. A further justifiable form of hope is that the same terminally ill patient hoped that some treatment could be found for future patients suffering from the same incurable illness. In this hypothetical example, hope produces *consolation*. In other words, the positive emotion of hope provides comfort and therefore compensates for the grief that this patient feels when facing imminent death (Chochinov 2003; Herth 1990). A similar psychological mechanism can be observed with diabetes and gout patients, albeit with the difference that these patients are not in life-threatening conditions. A way to cope with their illness is to hope that research will cure them or future generations. The statement of patient Ines indicates how hoping can be self-therapeutic: she does not consider her illness as an immutable fate but something which can potentially create change for the better: "I always have the hope that they [scientists] will develop something that could help me someday too."

Patient Yves shares the view too that research will contribute to better health for himself or future generations. "They [patients] hope to get a better therapy with time."

The significance of hope functioning as self-therapy seems to apply for life-threatening illnesses, such as cancer (Shekarabi-Ahari et al. 2012). In his letter to Elisabeth of Bohemia from May or June 1645 Descartes emphasizes too the importance of hopeful thoughts for the sake of recovering health:

> In this regard [the curing of sadness], I judge the waters of Spa very appropriate, especially if your Highness in taking them observes what the doctors usually recommend, and clears her mind entirely of all sorts of unhappy thoughts, and even also of all sorts of serious meditations concerning the sciences. She should occupy herself by imitating those who convince themselves they think of nothing in looking at the greenery of a wood, the colors of a flower, the flight of a bird, and such things that require no attention. This is not to waste time but to employ it well. *For one can, in doing this, satisfy oneself by the hope that by this means one will recover perfect health, which is the foundation of all the other goods that one can have in this life*. (Shapiro 2007, 92; our italics)

Descartes' suggestions that Princess Elisabeth treat her depressive states by diverting her mind to pleasant activities are still valuable insights for today's range of therapies offered to cancer patients, such as music therapy (Boyde et al. 2012).

4. Conclusion

Based upon thirty-six interviews conducted with diabetes and gout patients, this paper shows the significance of hope in the context of clinical research. The findings presented and discussed are original in as much as research on hope has been focusing, until now mainly on palliative care and terminally ill patients. Our study aimed at finding out the reactions of diabetes and gout patients to hypothetical participation in FIH trials. In

their answers, the interviewees used hope in a cognitive sense: hope can imply certainty (H1) and reflective uncertainty (H2). In our view, the affirmation of H1 and H2 does not amount to a self-contradiction. On the contrary, the patients' answers showed the useful nature and plasticity of hope: as a coping strategy against uncertainty and anxiety (H1 and H2) and as self-therapy (H3). These results are positive in the sense that they confirm the therapeutic potency of hope. They also corroborate the surprising functioning of our mental resources: being ill does not make one necessarily despaired but prompts one to be hopeful for a treatment to be found. Moreover, these findings show how philosophical investigations—in particular Descartes'—explore the phenomenon of hope and provide medical research with useful resources to interpret the seemingly paradoxical nature of the empirical data on hope.

Finally it is important to stress that the three aspects of hope (H1, H2, and H3) are compatible with modern standards of bioethics in therapy and in research, in particular related to respect for patient autonomy. A traditional myth stemming from the era of medical paternalism has been that patients should not be fully informed by doctors or researchers in order to preserve hope. However, empirical studies from the past fifty years prove the contrary (see Elger 2010): these studies have shown that full and clear information is beneficial. Patients suffer psychologically the most from uncertainty and deception. Using the three aspects of hope identified both in patients' answers and reflected in the works of Descartes helps to understand why the traditional paternalistic understanding of hope is a misconception. Indeed, the combination of H1 and H2 coexists with honest information as hope is an innate certainty that is not the same as optimism following information about a good prognosis. Physicians can and should reinforce hope as self-therapy (H3) in the same way that it exists in dying patients: hope is able to cope with the worst case, the end of life. Hope in these three senses does not mean exaggerating benefits to future patients or reinforcing therapeutic misconceptions in patients participating in research and it does not mean hiding information from a dying patient.

In short, health professionals should be more aware of the great potential of hope as a coping strategy for patients. Despite its apparent contradiction, hope seems to be genuinely beneficent for patients' well-being in a therapeutic and in a research context.

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