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Medicine's collision with false hope: The False Hope Harms (FHH) argument

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Abstract

The goal of this paper is to introduce the false hope harms (FHH) argument, as a new concept in healthcare. The FHH argument embodies a conglomerate of specific harms that have not convinced providers to stop endorsing false hope. In this paper, it is submitted that the healthcare profession has an obligation to avoid collaborating or participating in, propagating or augmenting false hope in medicine. Although hope serves important functions—it can be 'therapeutic' and important for patients' 'self-identity as active agents'— the presentation of false hope along the hope continuum entails a misconstrued balancing act. By not speaking up against unrealistic patient and family requests—including some requests for rights to try, resuscitative efforts in terminally ill patients, or other demands for non-beneficial treatments—healthcare providers precipitate harms, i.e., the FHH. These harms arise on both individual and communal levels and cannot be ignored. The goal of this paper is not to offer a definition of false hope, because the phenomenon of false hope is too complex for any simple definition. Instead, this paper seeks to make four points while outlining the FHH argument: consumer medicine and false hope are connected; providers and patients are very vulnerable in the system of consumer medicine; providers have a responsibility to stand up against false hope; and how the FHH argument could perhaps offer a footing to resist giving in to false hope.

KEYWORDS

bioethics, clinical ethics, consumer medicine, false hope, harms

1 | INTRODUCTION

False hope challenges modern medicine, especially where hope and false hope are presented as mere ends on a spectrum. Hope is advertised widely, extending to miracle advancements, cures, and substantial quality of life improvements. Promises of consumer medicine exacerbate this optimism. New and complex applications of medicine are presented in rapid succession to promote wellbeing. Interventions previously unheard of generate consumers who are chasing medical dreams. For instance, head and penis transplants promise quality of life improvements. Stem cell clinics offer cures for diseases that do not have a treatment in 'evidence based medicine'. Public cases illustrate these hopes. Experimental interventions were offered to Charlie Gard, born in the UK with an incurable and rare degenerative disorder, which had never been tried before.[1] Charlie's parents resolutely pursued these interventions for a future of hope, which many providers and courts deemed hopeless. Interventions were offered to keep hope alive in the case of Jahi McMath, a US-based young lady. She was declared brain dead by physicians and court rulings. However, Jahi was kept on artificial nutrition, hydration and a ventilator,[2] while her family hoped that she would recover from brain death.

The false hope phenomenon has been approved of as a side effect of hope's benefits. Hope serves important functions. It would be 'therapeutic' and central for patients to 'self-identify as active agents'.[3] Referencing hope's positives mitigates the harms of false hope. Endorsements of false hope together with complacency toward its costs and harms are easy to find.[4] In 2018, Jennifer Blumenthal-Barby et al. argued for 'permissiveness' in cases of suspected denial/self-deception/unrealistic optimism in the medical arena.[5] In a 2008 JAMA piece on brain death, Artur Applbaum equally endorsed false hope, suggesting that 'it is decent for physicians to accommodate some false medical beliefs of living patients'.[6] He justified this by referencing diversity and compassionate futility.

The goal of this paper is to introduce the false hope harms (FHH) argument. This concept seeks to counter the emergence of false hope, especially as consumer medicine exacerbates the risk of FHH. It suggests that hope and false hope are not of the same magnitude, and that equating them entails a misconstrued balancing act. False hope encompasses a myriad of harms, which cannot be mitigated by the positives of hope. The argument suggests that giving in to patients' requests for interventions is problematic, if these interventions are consumer-driven rather than medically appropriate. According to this argument, providers have a duty to avoid FHH. The FHH argument demands being mindful of a reduction in welfare and a set-back of individual and societal interests, and for major harms, including the undermining of trust in medicine. By not speaking up against unrealistic patient demands and requests, healthcare providers (hereafter 'providers') precipitate FHH.

To outline the FHH argument, I will start by offering a working description of false hope. I will not offer a definition of false hope, because this phenomenon is too complex for a simple definition.[7] Then I will make four points to present my argument and outline the scope of FHH. First, I seek to establish intricate connections between false hope and consumer medicine. Next, I will describe how consumer medicine creates excessive vulnerabilities for patients and providers. Then I lay out the FHH argument in more detail. I describe the harms and what the responsibility entails. Before concluding I submit that the argument offers grounds to resist giving in to false hope.

2 | A WORKING DESCRIPTION: DEFINING FALSE HOPE IS CHALLENGING

Defining false hope is difficult, which is highlighted by consumer medicine phenomena. Advertisements and science communications illustrate its complexities. Headlines such as 'Dying organs restored to life in novel experiments' exude hope, but show the intricacy in distinguishing it from false hope. The headline seems to reveal a sudden and unexpected 'fighting chance'[8] for a young baby that could not always have been expected to happen. So what does it mean that a hope is false, and how can we ever know what can happen? Epistemological challenges and postmodern thinking about limitations of our knowledge lead to the question: What are the ends of knowledge? Can hope be false, and when is it really false?[9]

Some instances of false hope are easy to describe. These are hopes 'for an outcome that cannot happen'.[10] Two examples from the public domain illustrate this well. Charlie Gard was born in the UK with a rare mitochondrial degenerative neurological disease that had no cure, according to his doctors. His parents connected with a US-based provider who offered an experimental procedure. Fighting to pursue this intervention, their request captured the world. The court stopped Charlie's parents from pursuing this avenue, however, as many providers believed this intervention was doomed to fail. The courts held that the intervention would not be in Charlie's best interests. They halted false hope interventions and reinforced the standard of care in palliative measures.

Jahi McMath's case was another example of false hope driving requests for treatment. Jahi had been declared brain dead by several institutions after a complicated tonsillectomy in 2013. Despite the diagnosis of brain death, confirmed by several doctors and court rulings, she continued to receive medical interventions. Her parents hoped that the doctors were wrong, and that Jahi would 'recover from death'. Their hope was kept alive, until an operation for liver failure and bleeding in 2018. Only then did her mother accept Jahi's failing state, halting needs for further interventions. Standard procedures for brain dead individuals had

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[1] Wilkinson, D., & Savulescu, J. (2018). Hard lessons: Learning from the Charlie Gard case. *Journal of Medical Ethics*, *44*(7), 438–442.

[2] Aviv, R. (2018, February 5). What does it mean to die? *The New Yorker*. 2(1).

[3] Petersen, A., Seear, K., & Munsie, M. (2014). Therapeutic journeys: The hopeful travels of stem cell tourists. *Sociology of Health & Illness*, *36*(5), 670–685.

[4] Simpson, C. (2004). When hope makes us vulnerable: A discussion of patient-healthcare provider interactions in the context of hope. *Bioethics*, *18*(5), 428–447.

[5] Blumenthal-Barby, J. S., & Ubel, P. (2018). In defense of 'denial': Difficulty knowing when beliefs are unrealistic and whether unrealistic beliefs are bad. *American Journal of Bioethics*, *18*(5), 4–15.

[6] Applbaum, A. I., Tilburt, J. C., Collins, M. T., & Wendler, D. (2008). A family's request for complementary medicine after patient brain death. *JAMA*, *299*(18), 2188–2193.

[7] The complexity of defining hope and false hope vicariously has been recognized in many fields. See, for example, Kube, T., Blease, S., Ballou, S., & Kaptchuk, T. (2019). Hope in medicine: Applying multidisciplinary insights. *Perspectives in Biology and Medicine*, *62*(4), 591–616.

[8] Kolata, G. (2018). Dying organs restored to life in novel experiments. *New York Times*. Retrieved from https://www.nytimes.com/2018/07/10/health/mitochondria-transplant-heart-attack.html

[9] Musschenga, A. W. (2016). Valse hoop. *Filosofie & Praktijk*, *37*(1), 4-2.

[10] McMillan, J., Walker, S., & Hope, T. (2014). Valuing hope. *Monash Bioethics Review*, *32*(1–2), 33–42.

been postponed, in Jahi's case, and extraordinary measures had continued for five years.

Other instances make false hope more difficult to capture, especially in the 'grey area' of medicine. Here the likelihood of success of interventions is less clear, as experts disagree on what is possible. The area of 'longshot treatments', [11]for example, involves last-ditch interventions of which the safety and efficacy has not yet been proven, but which are based on reasonable scientific rationales. Other examples might involve appeals to the limits of western evidence-based medicine, where evidence seems to fall short of what can or cannot happen.

As a working description then, the remit of false hope and our FHH argument is determined by five components: (1) A desire for a certain future oriented outcome; (2) This outcome is appraised by most stakeholders, including the patient or family, as possible though uncertain; (3) This outcome would be judged as highly unlikely to scientifically impossible by the vast majority of providers, who would regard it as mostly delusional or unreasonable to expect; (4) The hope results in an action, such as a request for an intervention, a therapy, a journey, or a purchase; (5) Requests for these healthcare interventions lead providers to deviate unreasonably from the 'standard of care'.

This description of false does not exclude uncertainty in the 'grey area'. It does not offer certainty about possibilities outside of western evidence-based medicine either. The key to our demarcation lies in the requirement that interventions are 'based on medical expertise', 'medically reasonable' and not-entailing a shift in the 'standard of care'. Sometimes innovative treatments entail a shift in the standard of care, and this can be acceptable as long as they are medically reasonable, per a reasonable provider community and have a sound scientific rationale. Interventions in the grey area would be assessed on a case-by-case basis.

The scope of the FHH argument entails that interventions should not be offered as a result of incentives from consumer medicine, without sound foundation. Such demarcation, I submit, could be approached by the 'universalizability' criterion, which is illustrated by an example of Wilkson.[12] To establish an intervention's reasonableness, he asks if it would be ethically acceptable to offer it to thousands of people in case of an epidemic, for months, to achieve improvement. If the answer is a clear and unambiguous 'no', without other scientific reasons underpinning the request, the intervention is really offered to satisfy patient demands and likely generates false hope. This distinguishes situations of greater agreement about something not being possible from those of genuine disagreement amongst experts.

An example on the fringes of false hope offers the case of Bobby, a hypothetical but common clinical scenario. Bobby, a middle-aged woman, is admitted to the hospital for nausea, abdominal pain and vomiting. She has a history of obstructed bowel syndrome, decreased kidney function, wasting syndrome, AIDS, anorexia, cancer, depression, and pressure ulcers. Bobby used to live in a nursing home but needed assistance with all daily tasks. In the hospital she refuses to get out of bed, to participate in activities, but states that she wants to live for her children. None of the children visit her in the hospital, nor did they visit her at home. Bobby has decision-making capacity and wishes to be resuscitated. No discussion about the state of her disease, the implications of resuscitation and the 'impossibility' of success changes her opinion.

Bobby's providers do not wish to start resuscitation, but they do not want to start a conflict either. Resuscitation is not medically indicated as the providers agree that Bobby would not survive resuscitative efforts. However, providers deem it important for Bobby's wishes to be heard and to be hopeful. When her heart fails, the providers resuscitate Bobby for 40 minutes, when her death is declared. Providers shifted the standard of care because of Bobby's wish. While one may question if providers endorsed false hope, the FHH argument would suggest it did. Even if it was not absolutely certain that Bobby's heart would not continue to beat after the 40 minutes, or even start functioning again on its own, the intervention did not meet the standard of care, the universalizability criterion, and was purely based on Bobby's request.

3 | CONNECTIONS BETWEEN FALSE HOPE AND CONSUMER MEDICINE

False hope and consumer medicine are connected. Consumer medicine stands for medicine where products, services, and the provider-patient relationship are mediated through market mechanisms, as opposed to being settled by physicians.[13] In this system, '[t]he use of advertising, educational material and different forms of media, such as the internet … play an increasingly important role in its development'.[14]

Connections between false hope and consumer medicine are historical and continue to the present. Snake oil, for example, is characteristic of a lengthy history of fraudulent products, advertisements, and sales based on false hopes. The beauty industry is a more modern example, where consumers purchase hopes to be more attractive, more successful, and to overcome the aging process.[15] The expansion of consumer medicine has exacerbated the prevalence of false hope. The internet allows for worldwide advertising of fancy complex medical procedures, broadening the territory of hope and false hope. Medical information trickles through to patients via the media, without expert filters qualifying information. In a global economy, vast areas of modern medicine have been identified as hotbeds of false hope, as shown by table 1.

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[11] Weiss, E. M., & Fiester, A. (2018). From 'longshot' to 'fantasy': Obligations to pediatric patients and families when last-ditch medical efforts fail. *American Journal of Bioethics*, *18*(1), 3–11.

[12] Wilkinson, D. (2017). Beyond resources: denying parental requests for futile treatment. *The Lancet*, *10082*(389), 1866–1867.

[13] Tupasela, A. (2010). Introduction: Consumer medicine from passive patients to active consumers. In A. Tupasela, *Consumer medicine* (pp. 13–24). Norden: ThemaNord.

[14] Ibid: 15.

[15] MacInnis, D. J., & Chun, H. E. (2007). Understanding hope and its implications for consumer behavior: I hope, therefore I consume. *Foundations and Trends® in Marketing*, *1*(2):97–189.

Features of false hope exist beyond consumer medicine and can arise in any system of medicine. False hope is not necessarily cognitively based, originating in a lack of knowledge of misunderstanding due to advertisements, but can exist as coping mechanisms for patients or compassionate providers in every healthcare system. False hope can stem from emotional reasons. Individuals might pursue interventions to be assured that everything has been done. Yet as the pursuit and exploitation of hope is facilitated by the ability to pay for treatment and to demand choice in healthcare, the risk of false hope is multiplied in a system of consumer medicine.

4 | CONSUMER MEDICINE AND VULNERABILITIES TO FALSE HOPE

Various innate features of consumer medicine create a breeding ground for false hope. First, advertisements of rare interventions can easily generate false hope due to misinformation and ignorance. Promising to slow disease progression, clinics exploit searches for stem cell treatments to alleviate pain, to improve quality of life, or to cure many diseases. In reality, however, clinical indications for stem cell treatments are very limited.[16] Second, misperceptions about the chances of success of treatments give rise to false hope. Quick fix interventions to overcome social and medical infertility, for example, readily appeal to patients.[17] Overselling the chances of success, private clinics cannot offer higher fertility rates compared to publicly funded clinics. Clinics 'know' that they cannot deliver the total of what their advertisements are promising. Yet selling the dream of having children, these clinics thrive on misperceptions, commercialize expensive hopes and pocket the profits. Similarly, rapid advancements in medical technologies create confusion and distrust. Reliance on technology creates false hope that technology can do anything and causes a lack of trust in the reliability of humans. Individuals ask for continuing interventions on their loved ones, based on beliefs that doctors might be inadequate in diagnosing brain death or beliefs that providers falsely hold brain death irreversible.[18] Table 1 highlights that selling hope is rewarding. Initially people will not feel harmed by buying into the possibility of hope.

Patient and provider stakeholders face extra vulnerabilities to false hope as a result of consumer medicine. The vulnerabilities of 'patient consumers' can be illustrated, for example, by referencing access to healthcare in the US. Traditionally, access in this country is money-driven, not being formulated as a right but as a privilege. Individuals 'choose' to pay for access, positioning them as consumers. Someone who opts to pay for insurance will want to have a voice in the purchase of a product. As medications for common illnesses are advertised on national television, the system creates proactive customers. Paying a high price for healthcare, patient consumers feel entitled to purchase what they hope for and what they think is best. This easily influences the standard of care.[19] But consumer medicine is not limited to the US. Germany, too, is notorious for offering extraordinary miracle cancer treatments in the private healthcare sector, attracting international patient consumers.[20] The problem is not limited to private medicine but includes public medicine as well. False hope thus entails stakeholder vulnerabilities and potential harms in both sectors, and while our FHH argument exceeds the system of consumer medicine, it will have particular value in this context.

Providers are increasingly vulnerable to offering (false) hope in this consumer-based system. Afraid of losing patient-customers thanks to dissatisfied clients, providers may avoid denying patients their desired treatment, afraid of bad reviews, lawsuits, and loss of clients. Time constraints and reimbursement structures already limit their ability to care for patients, and any reason to address contrary views is unwelcome and unrewarding. The placement of providers in the system of satisfaction-driven healthcare, dominated by surveys, generates disincentives to avoid FHH. Indeed, catering to false hopes is profitable for providers in consumer-based systems, whereas addressing potential FHH is not incentivized. In places where medicine is run like a business and organized around treating patients to generate income, providers are rewarded for prescribing treatments instead of having difficult discussions.[21] At the same time, legitimacy to limit access to hope is missing for providers. Restricting access to a desired product requires proper justification when consumers are willing to pay a price for medical products. Especially as calls that patients should not be treated as consumers are sounding more loudly,[22] it may be hard for providers to act against all these forces without a solid footing.

Providers' reasons for endorsing false hope may lie beyond consumer medicine. They might be victims of false hope themselves, based on misbelief or the affiliative dimensions of hope, or believing that compassion requires giving patients what they want. Despairing about their patients' trust in them, providers may comply with the

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[16] Boseley, S. (2017). Charlatans threaten stem cell research with unproven cures, say experts. Retrieved from: https://www.theguardian.com/science/2017/oct/04/charlatans-threaten-stem-cell-research-with-unproven-cures-say-experts (last accessed 8 August 2018).

[17] Social infertility refers to individuals who have difficulty conceiving due to their age, sexual orientation and other social or cultural reasons, instead of biological or health reasons.

[18] Tsou, A., & Caplan, A. (2010). Cheating death and the dangers of false hope. *The Lancet*, *(9723)*:1337–1338.

[19] Sumpradit, N., Bagozzi, R. P., & Ascione, F. J. (2015). 'Give me happiness' or 'take away my pain': Explaining consumer responses to prescription drug advertising. *Cogent Business & Management*, *2*(1).

[20] Gorski, D. The deadly false hope of German alternative cancer clinics. Retrieved from: https://sciencebasedmedicine.org/the-deadly-false-hope-of-german-cancer-clinics/ (last accessed 26 March 2018). Science Based Medicine.org

[21] Vos, M. S., & De Haes, J. C. (2007). Denial in cancer patients, an explorative review. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, *16*(1),12–25.

[22] Gusmano, M., Maschke, K. J., & Solomon, M. Z. (2019). Patient-centered care, yes; patients as consumers, no. *Health Affairs*, *38*(3), 368–373; Tilburt, J., & Cassel, C. K. (2013). Why the ethics of parsimonious medicine is not the ethics of rationing. *JAMA*, *309*(8),773–774.

patient.[23] Providers might be convinced that softer and more hopeful messages reflect trustworthiness, compassion, and higher quality of care.[24]

Yet the incentives for the provision of services on demand make consumer medicine a large contributor to false hope and to generating vulnerabilities. Hope is well known as a successful marketing strategy.[25] Commercial incentives of providers' practice might lead providers to ignore or dismiss the FHH. Indifference about the use of resources, or even the financial profit for providers' own practices might steer compliance with patients' requests. Commercial interests may be involved in accommodating false hope at the systems level.

5 | THE FALSE HOPE HARMS (FHH) ARGUMENT

Under the False Hope Harms (FHH) argument, providers have a responsibility to avoid harms stemming from false hope. This responsibility demands that providers are concerned about the conglomerate of harms that arise under the support of false hope. Before outlining the details regarding responsibility, details of the premise and arguments need further description.

Under the argument, the harms cannot be compartmentalized, contrasted and compared with the benefits of hope, on a 1:1 level, even if the harms can be distinguished. The argument implies that the individual benefits of hope cannot nullify the benefits of false hope, either on an individual, or on a systems level. Under the FHH premise, false hope is not the flipside of hope. It stands for the idea that false hope undermines the profession and the healthcare system as a shared resource, beyond its impact on the individual level. As stated above, consumer medicine easily produces false hope, but FHH befalls all systems of medicine. The argument goes beyond the consumer context.

Laying out the FHH argument is challenging. Referencing the benefits of hope, suggestions about harms are often mitigated. Especially on an individual level, hope's benefits have been well described and empirically supported. Hope creates a sense of meaningfulness and agency. Hope has been described as a driving force in medicine, which fits cultural ideals such as the perfectibility of humankind, the heroic techno medicine ethos, the love of miracles, and the dislike of leaving people behind, particularly in the US.[26] Convinced of hope's benefits, physicians tend to support patients' false hopes,[27] and refraining from dismantling false hopes is seen as benefiting the therapeutic relationship.

False hope itself would also carry several benefits. Endorsing false hope allows physicians to 'keep people happy' and to increase 'satisfaction rates'.[28] Its endorsement is also relatively simple; extending empirical evidence of hope's benefits, even if false, is easier than proving the contrary.[29] Moreover, false hope has also been endorsed as a matter of respect for diversity of views on scientific truths and values. Detailing some of the FHH below, however, shows their vastness. The following paragraphs detail how the simple benefits of hope and false hope cannot be weighted on the scale that measures the conglomerate of FHH.

5.1 | Harms under the FHH

Evidencing the harms under the FHH is challenging. Aside from the problem around the subjectivity or 'greyness' of viewing harms, the harms are mostly indirect, delayed, and difficult to validate. Financial costs, such as hospital bills, arrive mostly retrospectively and, while contributing to enormous debts in the US healthcare system, these are nearly invisible.[30] Financial toxicity, or the impact of costs on the next of kin, might not be of immediate concern to a provider as they arise outside the patient-physician relationship. Furthermore, predicting how people will respond to the emotional costs of failed hope will differ between individuals. Some will be devastated while others respond with acceptance. Shame and grief after pursing a futile task are mostly only visible later, once the hope is dissipated and the patient is home or being taken care of by a new physician.

At the same time, FHH are not easy to demonstrate, especially because private money and willing participants might make harms difficult to appreciate as being ethically problematic. Jahi's and Charlie's parents asked for interventions. Bobby asked for resuscitation. Could we state that they were harmed if their requests were informed? Surely, significant money was spent in all three cases without clear benefits. Yet these implications would not necessarily be harming the individual, as money would come from the public system and not their own funds. Medicaid funds at least partially took care of Jahi's case, and GoFundMe campaigns raised the money necessary for Charlie's. Accordingly, stating these as harms may be equivocal.

In balancing hope's benefits with the harms, many of the FHH are not accounted for. They concern system level harms, which may be ignored for being too remote and invisible or difficult to quantify. Below, I will first delve into systems level harms, i.e.,

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[23] It needs to be acknowledged that providers might also (perceive to) be harmed as a result of false hope. For example as a result of patients' reduced trust in them. However, careful discussion of these harms falls outside the scope of this paper.

[24] Winner, M., Wilson, A., Ronnekleiv-Kelly, S., Smith, T. J., & Pawlik, T. M. (2017). A singular hope: How the discussion around cancer surgery sometimes fails. *Annals of Surgical Oncology*, *24*(1), 31–37.

[25] Kemp, E., Bui, M., Krishen, A., Homer, P. M., & LaTour, M. S. (2017). Understanding the power of hope and empathy in healthcare marketing. *Journal of Consumer Marketing*, *34*(2), 85–95.

[26] Del Vecchio Good, M .J., Good, B. J., Schaffer, C., & Lind, S. E. (1990). American oncology and the discourse on hope. *Culture, Medicine and Psychiatry*, *14*(1), 59–79.

[27] Ruddick, W. (1999). Hope and deception. *Bioethics*, 13(3–4), 343–357.

[28] Blendon, R. J., Benson, J. M., & Hero, J. O. (2014). Public trust in physicians—US medicine in international perspective. *New England Journal of Medicine*, *371*(17), 1570–1572.

[29] Coughlin, S. S. (2006). Hope, ethics, and public health, *Journal of Epidemiology & Community Health*, 60, 826–827.

[30] Picton-James, R. (2018). Please stop merchandising mental illness. Retrieved from: https://www.nytimes.com/2018/07/28/style/anxiety-necklace.html?rref=collection%2Fsectioncollection%2Fhealth (last accessed 8 August 2018).

financial harms and invisible harms, like undermining trust and access. Then I will engage with the individual level harms, which are often sliced up into small pieces and dismissed under references of hope.

5.1.1 | FHH on systems level

False hope can undermine professional know-how and cause mistrust in medicine. Even if satisfaction increases, patients merely getting what they want for non-medical reasons undermines expertise. In turn, resulting mistrust disadvantages individual patients and patient cohorts; without trust patients would not come forward, even in cases of infectious diseases. Without trust, problems for individual patients are unavoidable. Distrust of medical professionals is associated with lower healthcare engagement, less participation in research, and decreased medication adherence, all contributing to worsened health outcomes.[31] Additionally, mistrust has been connected to decreased health access issues in preventive services, adherence, and continued enrolment. Mistrust harms the basis of the fiduciary relationship. Unwarranted higher costs in medicine are the result.

False hope interventions can entail further harms, because they bring more complexity of care and threaten the accessibility of healthcare. Providers will be overwhelmed with more interventions that are medically inappropriate. Their own shortage of time results in less attention to other patients and thus fewer possibilities to access good quality care.

False hope inevitably leads to more expensive healthcare, because of continued or new interventions without goal-congruent benefits. In healthcare systems where a right to health care exists, such expensive care could violate a right to quality care that is reasonable as well. Similarly, where medical schools are publicly funded, taxpayers can demand that their money should be put to good use; their duty to contribute to reasonable healthcare correlates to a right to be treated by reasonable physicians. But even in systems without such rights, offering unreasonable interventions seems a harmful set-back of interests. For example, an individual's interest in access to care could be violated in various ways.

Financial toxicity, associated with unnecessary interventions, for example, threatens access to medicine. Similarly, non-parsimonious medicine, which generates excessive costs associated with false hope treatments, would really only be accessible by the financial elite. Excessive healthcare without substantial benefit, beyond purely psychological benefit, does not satisfy valid interests. Psychological benefits can be addressed by means other than expensive interventions.

Financial harms arise on the dividing line between system and individual level harms. For individuals, even if the direct costs of care are not on their charge, the financial costs of travel and other expenses are often sky high. Then, medicaid reimbursements, as in Jahi's case, have financial implications for the healthcare system, even if not visible on an individual level. Maintaining Jahi in the brain dead state resulted in bed and caregiver scarcity, even in the private setting. Accommodating patients returning from experimental treatments abroad, like Charlie would have been, similarly involves draining significant public resources. Caring for patients after botched experimental stem cell injections, for example, strains the public system, even if such treatments were, initially, privately funded. Furthermore, actions of Bobby's providers burned the system with resource intense procedures that had no chance of success and diverted potentially beneficial procedures away from other users.

5.1.2 | FHH on an individual level

Aside from the systemic harms, FHH may arise on the individual level. These extend to financial, physical, psychological harms and harms of excessive treatment. Such harms may be obvious, somewhat hidden, insidious, and covered up by patients' hope or appeasement, particularly after patients have got what they want. Harms might involve large sums of money or small gestures. They may be hidden behind a cover of 'compassionate providers',[32] and may be direct and indirect. For example, providers might directly infringe on Charlie's bodily integrity, and might be paying less attention to the quality of Charlie's death. At the same time, they might be paying less attention to other patients who have strong claims to more effective medical care.

The FHH arise as violations of individuals' interests and rights. False hope violates individuals' interest not to be treated as a means to an end, including an intrinsic interest not to be exploited and a non-commodification interest. Mutually advantageous exploitation occurs in situations where neither party is overtly harmed and there are no consent problems, but the relationship or transaction is unfair or inequitable to one of the parties.[33] Patients who offer money without goal-congruent returns are vulnerable to this harm in false hope scenarios. While providers or systems earn a profit by the intervention, the intervention is futile for a patient's goal.

Major FHH concerns are stated as issues of autonomy. These include harms relating to cognitive understanding and infringing rights of self-determination. Deborah MacInnis explains that in the comforts of hope, patients are vulnerable to biased processing and ignoring information. These impacts can be harmful.[34]

In segmenting the harms, not everyone agrees that infringements on autonomy and cognitive understanding are convincing and actionable harms. Blumenthal-Barby dismisses many concerns in favour of the benefits of (false) hope, illustrated in table 2. She argues that informed consent is the only relevant justification

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[31] Bickell, N. A., Weidmann, J., Fei, K., Lin, J. J., & Leventhal, H. (2009). Underuse of breast cancer adjuvant treatment: Patient knowledge, beliefs, and medical mistrust. *Journal of Clinical Oncology*, *27*(31), 5160.

[32] Applbaum, op. cit., note 7.

[33] Wertheimer, A. (1999). *Exploitation*. Princeton, NJ: Princeton University Press.

[34] Macnnis, op. cit., note 16, p.33.

for interventions, provided they are based on adequate information, and regardless of understanding being clouded by false hope. Sceptics like her dismiss the intrinsic harms of false hope and dismiss medicine as a social profession. They solely consider obligations to individual patients and substitute a medical scientific rationale for a satisfaction rationale. Because an intervention makes a patient happy, the intervention should be offered, while the absence of medical indications is a secondary concern. This narrow view compartmentalizes harms and discounts many of the FHH. It overlooks the fact that even patients with narrow interests at the end of life can be harmed due to unnecessary procedures, complications, and distracted providers.

The harms outlined above may be identified individually, but under the FHH they cannot be considered in isolation. The FHH are an aggregate that risks hollowing out medical expertise and the medical profession. This aggregate entails a responsibility under the FHH argument.

6 | RESPONSIBILITY UNDER THE FHH ARGUMENT

Responsibility under the FHH paradigm relies on three components. First, it requires establishing the framework of false hope, and then two further parameters to determine its falseness. False hope, in our understanding, is not necessarily a cognitively incorrect belief, i.e., where the likelihood of a treatment's success is misunderstood, misperceived, or misjudged. It can include conative components. The two parameters then, include assessment of the parameter regarding the probability of the hope and likelihood of success, and on the parameter of the hope's reasonableness and compatibility with the goals of medicine. This responsibility falls on the individual provider, but by relying on professional standards this burden is not solely theirs, as explained below. There are many areas in which these assessments are not black and white. For this greyness, the individual provider will have to resort to standards of care and invoke the FHH argument as a tool to counter their own vulnerability.

The first parameter involves assessment of probability and possibility, and includes consideration of harms. As the question of what is possible can be challenged, providers should not easily give in to such challenges; absolute certainty is merely a linguistic term rather than a scientific-philosophical concept. In the language of hope, nothing seems impossible. Providers knew that Jahi would not recover from brain death. Yet continuing interventions unremittingly to overcome uncertainty around brain death seemed impossible given the harms. Reasonable providers knew that Charlie's interventions were to no medical avail beyond a psychological and hope-fulfilling benefit. Surely, while innovative treatments are important and can be reasonable in some cases, the attending physician (and the broader medical community) had nothing innovative to offer apart from speculative interventions that were not realistic possibilities in this case. Accordingly, a provider's responsibility is not to rely solely on patient preferences in this assessment, even if patient preferences are important, but also to respect widely endorsed standards of care. A provider's role extends to stewarding the patient's medical interest, based on a scientific and medical rationale, and not just serving psychological needs by affirming unrealistic possibilities. Providers are justified arbiters of which hope medicine can cater to, and which hopes are false and could lead to harms.

The role of the providers under this argument is to judge, secondly, the reasonableness of these hopes. In this assessment they are to consider statistical, logical and responsible action, with the action reaching a standard endorsed by peers. The goals of medicine should be part of this assessment. In Bobby's example, if her goal for resuscitation is to be reunited with her children, this could be judged as unreasonable given medicine's goals and statistical capabilities. Providers' reflection about these issues and resources is part of their stewardship duties. Medical professional judgment seeks to determine the likelihood of success of an intervention, as well as goal-congruency, referencing standards of care and expertise. False hope does not always imply a theoretical impossibility.

In exercising this responsibility, providers are not sole decision makers. Providers rely on guidance from professional bodies and their assessment of the standard of care. Providers' expertise and accountabilities imply concern for reasonableness and medical possibility. At the same time, they should avoid conflicts of interests. Providers should balance out the individual patient activist. Where democratic deliberation of future possible treatments is needed, these contributions would have to happen on the meso- and macro-levels, and not on the micro-level. Even if harms on this level are probably much smaller, this cannot be part of the equation. Questions about patient-provider power differentials should not be concerning when providers exercise the FHH argument, as they should (ethically) rely on the standard of care.

Providers' duty according to this argument is not to take away hope, but to address false hope. Like hope, false hope can be dissected into cognitive and conative components, including affective, and affiliative hopes.[35] The FHH argument means that providers should examine and address these variations. Bobby's demand for resuscitation, as above, could be based in various (false) hopes. She could hope for her resuscitation to succeed, to be recognized as a virtuous person who holds the sanctity of life principle, or to reconnect with her children before she dies. She could hope to live for decades on life support. Yet providers should not necessarily accommodate these hopes, but maintain the standard of care, being arbiters of hope-based requests for treatment. They are legitimate gatekeepers regarding questions about false hope and how to assess harms. As stewards of trust and gatekeepers of reasonable medicine, they have a duty to guard against and avoid FHH.

The responsibility under the FHH argument involves avoiding harms and redirecting the patient's hopes to, what some have

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[35] Musschenga, op. cit., note 10.

proposed, more mundane hopes or to concrete and achievable ones. Instead of offering false hope, providers should downshift hopes to simple, general, ‘vital or survival hopes’.[36] The FHH argument does not imply a duty to force the truth upon a patient. The responsibility is not focused on restoring a ‘sense of autonomy’.[37] Instead it involves, for example, avoiding FHH by shifting to a hope for a feasible outcome, rather than to leave it intact as the hope for a cure.

Providers' responsibility thus includes not surrendering to activist calls enabling medicine to become an endless lobbying competition. Patients have claims to be heard and claims to a reasonable patient-physician relationship based on dialogue, communication and shared decision making in so far as it is possible. Providers should, however, not become hostages to the system of consumer medicine and ignore FHH.

7 | RESISTING THE ARGUMENT'S CHALLENGES

Although the responsibility to reduce FHH may be counterproductive from some physicians' perspective, it is an important part of the medical profession. Unravelling false hope, if done carefully, is painful, time consuming and complicated. Physicians are hardly reimbursed for difficult conversations, while offering interventions can be perceived as being beneficial. Yet providers cannot hide behind a veil of complicatedness, or behind an excuse that they have not been trained in ‘difficult decisions’. They should avoid harms, and the FHH argument will facilitate this mission.

Respect for diversity, inclusion, and compassionate futility cannot discharge the responsibility to avoid FHH. Of course providers acknowledge individual variation in how to accommodate hope and to acknowledge other types of knowledge, such as traditional, indigenous, or religious knowledge. Yet this duty does not extend to accommodating false hope. False hope is not a solution to ensure that all stakes and interests are represented and taken seriously. Calls for diversity appeal to a false set of values about inclusion, and respect for diversity does not require providers to treat hope and false hope in the same way.

Concerns about unjustifiable paternalism via false medical expertise cannot either set aside the responsibility to avoid FHH. Easily accessible online resources or ubiquitous marketing might make patients believe in their own expertise, as sketched by the Dunning-Kruger effect. Yet access to information does not create patient experts. Decentralization of information to patients does not actually stand for a diminished level of expertise. Anti-paternalism concerns alter the nature of a physician-patient relationship, but those concerns do not remove the patients' or system's vulnerability.

Democratization of knowledge does not make false hope beneficial or legitimate.[38] Proponents of ‘flat earth’ beliefs are scientifically ignorant; they are not just expressing a diverse scientific perspective. Diversity in views on scientific truths, evidence or values requires a discussion by professional bodies through policy. It

TABLE 1 Areas of false hope

Area	Illustration
Autologous stem cell transplants for a variety of diseases	‘What they're really selling is false hope’, states Timothy Caulfield, a health law professor at the University of Alberta. ‘It's science-polation.’[39]
Reproductive attempts	‘Data on the safety, efficacy, cost-effectiveness, and emotional risks of elective oocyte cryopreservation are insufficient to recommend elective oocyte cryopreservation. Marketing this technology for the purpose of deferring childbearing may give women false hope and encourage women to delay childbearing.’[40]
Brain death	‘Grouping brain death together with vegetative and minimally conscious states falsely implies that a patient might one day improve from brain death. Gupta is offering false hope to a potentially large audience.’[41]
Experimental treatments for children	‘Words matter. In pediatrics, a number of organizations such as the Children's Miracle Network and the Make-A Wish Foundation use fantastical language in a way that fosters hope.’[42]
Obesity treatment	‘Many therapists may be contributing to this psychological damage by giving their patients false hope for success and by failing to recognize that seeking treatment for obesity may be triggered by psychological problems that are not addressed in obesity treatment.’[43]

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[36] Garrard, E., & Wrigley, A. (2009). Hope and terminal illness: False hope versus absolute hope. *Clinical Ethics*. *4*(1), 38–43. See also McMillan, op. cit., note 11, p. 33, and Winner, op. cit., note 25, p. 34.

[37] McMillan, op. cit., note 11.

[38] Democratization of knowledge is often a matter of populist epistemic incoherence. One source of apparent legitimacy for that phenomenon is the frequent enough fact that physicians ignore or discount some patient experience that is a critical clue to their real medical problem. But the correct way to describe this phenomenon is to attribute it to physician inexperience, guideline hypnosis, or perhaps even carelessness, not to patient knowledge. Patients generally have no way of integrating their narrative into a meaningful and correct diagnosis (Email exchange: L. Fleck).

[39] McGinley, L., & William, W. (2019). Miracle cures or modern quackery? Stem cell clinics multiply, with heartbreaking results for some patients. Retrieved from: https://www.washingtonpost.com/national/health-science/miracle-cures-or-modern-quackery-stem-cell-clinics-multiply-with-heartbreaking-results-for-some-patients/2018/04/29/80cbcee8-26e1-11e8-874b-d517e912f125_story.html?utm_term=.9b981b78fdb5 (last accessed 8 August 2018).

[40] Practice Committee of the American Society for Reproductive Medicine, and Practice Committee of the Society for Assisted Reproductive Technology (2013). Mature oocyte cryopreservation: a guideline. *Fertil Steril*, *99*(1), 37–43.

[41] Tsou, op. cit., note 19, p.1337.

[42] Chen, D., Epstein. E., Almarode, S., Winter, J., & Marshall, M.F. (2018). What the ‘F’? *American Journal of Bioethics 18*(1), 16–18.

[43] Wooley, S. C., & Garner, D. M. (1991). Obesity treatment: The high cost of false hope. *Journal of the American Dietetic Association*, *91*(10), 1248–1251.

TABLE 2 Why false hope is not a problem, as derived from Blumenthal-Barby[44]

Arguments against false hope	Why this argument is not valid[a]
Violates: informed consent	False hope does not always mean a lack of knowledge: Patients can choose to believe information and choose not to be informed False hope through self-deception does not undermine accuracy of decisions
Violates: truth-preparedness	False hope creates happy feelings that may outweigh harms, while consequential claims of being less prepared for the truth do not have empirical evidence to support it
Violates: opportunities	False hope does not create as many opportunity costs as critics contend, and the argument around sacrificing opportunities is an empirical claim that cannot be substantiated False hope can lead to increasing opportunities by pleasant experiences motivating actions (e.g., by not believing your husband has an affair, you stay married to your husband)
Violates: instrumental value of truth	False hope can be practically rational and does not always amount to epistemic irrationality–False hope can make you happy and there's nothing wrong with being happy

[a] According to Blumenthal-Barby.

requires a discussion about justice and scarce resources. These issues cannot be solved by individual providers.

Altogether, 'reasonable diversity' does need to be recognized with respect to false hope, but this recognition does not require all hopes to be treated in the same way. We noted earlier authentic 'grey areas' with regard to identifying false hopes. These grey areas are the domain of informed consent. The legitimacy of the boundaries here would be determined by collective medical judgment (to preserve trust), but also by social understandings regarding the scope of individual preferences that make claims on social resources (to preserve justice). In contrast, 'unreasonable diversity' requires empathy but also clarity as to it being out of bounds. Challenges as to establishing the scope of false hope should not generate false hope or FHH. The FHH argument may offer providers a rhetorical tool to shield them in their vulnerability, and to avoid providers falling victim to approving interventions in the gap between diversity and false hope.

8 | CONCLUSION

The FHH argument should be recognized as encompassing many harms that cannot be dissected or compartmentalized. The argument proposes that false hope is more than the antithesis of hope, a phenomenon that is exploited in consumer medicine. It suggests that FHH threaten medicine as a valuable shared resource because individuals' pursuits of false hope drain the healthcare system.

By not speaking up against unrealistic patient demands and requests, providers precipitate FHH. As stewards of patient vulnerability, but also of medical scientific expertise and resources, providers should heed the significance of FHH. Regardless of informed consent, false hopes allow for exploitation and for negating medicine as a social profession where trust and expertise serve individual and communal interests.

To ultimately serve patients, providers, and the system, we should recognize and address the reality of the harms of false hope in the medical field and recognize the FHH argument. The concept stands for the idea that these interests need to be considered under a broad argument and cannot be brushed aside by focusing on compartmentalized benefits. Although not all instances of false hope entail an equal amount of harm, false hopes should not be given any leeway or ethical honour. The argument not only functions for serious false harms, but also for those harms that are not as 'expensive'. Embracing the FHH argument, providers will have a device to counter patient consumers and a tool to address consumer medicine. The argument encompasses acknowledgment for patient and provider vulnerability, proper stewardship of resources, and implies being mindful of the integrity of the system which has social, communal, and financial implications. The FHH argument affirms healthcare as a shared resource.

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[44] Blumenthal-Barby, op. cit., note 6.