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Decision-making in the shadow of death

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Introduction

It is often assumed that decision-making is a completely rational process. In reality, of course, numerous heuristics and biases influence the way we think and the decisions we make in clinical, research and policy contexts. While Blumenthal-Barby elegantly describes various types of heuristics and biases, and the effect that they may have on one's autonomy,ⁱ we suggest that there is insufficient attention given to the heuristics that may be most determinative in medical contexts – *hope*, and its attendant emotion, *fear*. Our insights are drawn from an empirical study of the legal and ethical 'limits' of consent in the setting of decision-making around a high risk medical interventions (bone marrow transplantation - BMT) which revealed that *every* formal element of consent is shaped or transmogrified by a patient's 'hope for a future'.ⁱⁱ In this qualitative study we examined the accounts of patients with haematological malignancies, their loved ones and the health care professionals caring for them regarding the decision to offer, and go through with, BMT - where BMT provided the possibility of 'cure' but carried a high risk of death (particularly in the first year post-BMT) and long-term morbidity. While the heuristics described by Blumenthal-Barby were evident in the narratives of all of the participants in this study and undoubtedly impacted upon understanding, intentionality and effective autonomy,

what was most striking was the degree to which *hope*, and its attendant emotion, *fear*, impacted upon decision-making and overwhelmed all other considerations that may have been relevant to the decision to proceed to BMT.

While there is limited, if any, evidence that hope (an expectation of achieving a particular goal), or a 'positive approach', can influence biological processes or the trajectory of serious illness in any meaningful way, it is broadly accepted that retaining hope and maintaining a positive attitude may encourage treatment adherence and assist people to cope with their illness.ⁱⁱⁱ All of the participants in our study recognized the positive contribution that hope could make in the context of BMT – but they also spoke achingly about its *fragility* – particularly in situations where people faced a threat to everything that they knew or held dear and felt defenceless or vulnerable. For the patients in our study this meant distancing themselves from doctors who insensitively destroyed their hope and seeking instead the security that came from being surrounded by healthcare professionals who, at the very least, shared a belief/hope that a positive outcome for this individual was achievable.^{iv} In other words, they needed to feel that their transplant team both respected their need to have hope, and shared the notion that this hope was credible and not unrealistic. Transplant physicians, perhaps surprisingly, also recognised the need to instil and maintain hope in their patients – using a number of different techniques to achieve this, including; acknowledging that the patients were experiencing a frightening time in their lives, being open and honest in all their discussions with patients and their significant others, promising patients that they will remain 'present' throughout BMT – irrespective of what may occur, and providing reassurance that they had extensive experience dealing with the many uncertainties and risks associated with BMT. At the same time, however, physicians spoke of the fine line they trod between ensuring that the patient and their family were fully aware of the risks they were about to face, while also assisting them to remain positive and hopeful about the chances of remission or survival.^v What they offered, therefore, was *measured hope* where outcomes were genuinely uncertain and profoundly divergent. For the most part, this appeared sufficient for patients, as it provided at least the possibility of a future – a future in which they existed.

Patients undergoing BMT were therefore driven not only by hope that they may return to the life they knew following transplant but by a fear that they may cease to exist and that the world that they knew would continue on without them.

That patients undergoing BMT should fear the possibility of dying should not surprise us as it is universally accepted that many, if not all of us, fear death (even though it is arguably irrational to fear something that is unavoidable and comes to us all). Across time and straddling cultures much has been made of the anxiety that people feel about dying and death. The Roman philosopher Lucretius talked of the fear of death as an 'abject terror' - an imagination of the horrors that could befall us, while Thomas Hobbes noted that simply being aware of one's own mortality created in man a state of constant anxiety. But irrespective of whether one regards a fear of death as a normal or pathological human emotion (as Freud would claim) there is little doubt that it permeates the clinic and inscribes decision-making where life itself is at stake.

For the people about to undergo BMT interviewed in our study the possibility that they may die was intolerable both because it spelt the end of their own lives but also because they could envisage the profound impact that it would have on those who depended upon them. This is consistent with the writings of Victor Florian^{vi} who described the subjective construction of one's own mortality and the meanings people attach to death as an inherent part of the meanings they attach to their own life. Florian described how different people may fear death for very different reasons, with people who put strong emphasis on the pursuit of *intrapersonal* goals related to achievement, power, personal success, as being particularly afraid of death due to its consequences to self-realization and the accomplishment of one's projects, while those who placed more emphasis on the pursuit of *interpersonal* goals throughout life fearing death because of the impact that this would have on their social identity and network and the welfare of their family and friends.

None of the patients in this study imaged that they would not one day die – they just did not want to die *now*. Not while they were so young, not while they had things to do, goals to meet, and activities in which to participate. Not while they still had a future and, most importantly, not while there was something *that they could do* – BMT - to secure that future. In this regard, the fears that patients expressed resonated with the work of Gadamer who wrote of death being a severing of the 'conversations' that define life – leaving questions hanging, unsatisfactorily unanswered. But it also seemed much more than this – a more profound, existential anxiety that was both deeply felt and impossible to fully articulate.

Patients with life-threatening illness did not, therefore, rationally consider the risks and benefits of BMT in deciding whether they should undergo it. Rather, their decision-making was, even before they entered the clinic, even before they spoke with their transplant physician, entirely shaped by a desperate hope for a future and a fear that death may come too early. They believed they had *no choice* but to undergo BMT. In this regard every element of consent – freedom, voluntariness, capacity, understanding and authorisation – was transformed by the lived reality of illness. Haematological disease had created the situation that they were in, shaped their choices (or lack of them), reduced, or at least limited their capacity, constrained their understanding and stripped them of agency.

This is not to say that the consent provided by patients when their life is under threat is invalid. Rather, it reminds us that abstracted constructions of consent in law and ethics provide simply a framework for understanding what consent means and how it can be assessed. And as with the work done by Blumenthal-Barby, it points to the need to see autonomy as relational and interdependent (rather than as atomistic) and decision-making as shaped as much by vulnerability and need as by capacity and rationality.

ⁱ J Blumenthal-Barby, "Biases and Heuristics in Decision-Making and Their Impact on Autonomy," *AJOB UAJB*-2014-0514.R1(2016).

ⁱⁱ Camilla Louise Scanlan, "The Legal and Ethical Limits of Consent in High Risk Medical Interventions: An Empirical Study" (University of Sydney, 2015). <http://hdl.handle.net/2123/14180>

ⁱⁱⁱ Norbert Grulke et al., "Patients Confronted with a Life-Threatening Situation: The Importance of Defense Mechanisms in Patients Facing Bone Marrow Transplantation. An Empirical Approach," in *Advances in Psychology*, ed. Uwe Hentschel, et al. (North-Holland, 2004).; Jochanan Benbassat and Reuben Bauml, "What Is Empathy, and How Can It Be Promoted During Clinical Clerkships?," *Academic Medicine* 79, no. 9 (2004).

^{iv} Mary-Jo Del Vecchio Good et al., "American Oncology and the Discourse on Hope," *Culture, medicine and psychiatry* 14, no. 1 (1990).

^v Roberta Ann Shechter, "The Psychodynamics of a Clinician's Hope: A Delicate Balance," *Clinical Social Work Journal* 27, no. 4 (1999).

^{vi} Victor Florian and M. Mikulincer, "Terror Management in Childhood: Does Death Conceptualization Moderate the Effects of Mortality Salience on Acceptance of Similar and Different Others?," *Personality and Social Psychology Bulletin*, 24(1998).; Mario Mikulincer, Victor Florian, and Rami Tolmacz, "Attachment Styles and Fear of Personal Death: A Case Study of Affect Regulation," *Journal of Personality and Social Psychology* 58, no. 2 (1990)..; Florian, V., Kravetz, S., & Frankel, J. (1984). Aspects of fear of personal death, levels of awareness, and religious commitment. *Journal of Research in Personality*, 18, 289-304.; Florian, V., & Mikulincer, M. (1998a). Symbolic immortality and the management of the terror of death -- The moderating role of attachment style. *Journal of Personality and Social Psychology*, 74, 725-734