Applying futility in psychiatry: a concept whose time has come

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ABSTRACT

Since its introduction in the 1980s, futility as a concept has held contested meaning and applications throughout medicine. There has been little discussion within the psychiatric literature about the use of futility in the care of individuals experiencing severe and persistent mental illness (SPMI), despite some tacit acceptance that futility may apply in certain cases of psychiatric illness. In this paper, we explore the literature surrounding futility and argue that its connotation within medicine is to describe situations where patients (or their substitute decision-makers) believe that interventions will almost certainly provide no meaningful benefit. We then provide two arguments in support of the use of futility within the care of individuals experiencing SPMI: that some SPMI can be considered a terminal illness, and that the risk-benefit ratio is a dynamic entity such that futility can help describe what Gillett calls the 'risk of unacceptable badness' when it comes to considering how an intervention might impact a patient's quality of life. We posit that capacity should not pose an obstacle to declaring futility when caring for individuals experiencing SPMI and explain how futility is not antithetical to recovery in mental health. Finally, we describe how using futility within psychiatric practice can allow for a reorientation of care by signalling the need to shift to a palliative approach.

INTRODUCTION

The debate around the concept of futility emerged in the 1980s as life-sustaining interventions became increasingly commonplace and sophisticated. Questions were raised about when to continue treatments of uncertain benefit that were coupled with potential harm.[1] Futility remains controversial because of a lack of consensus on the definition of futility, the primacy of individual autonomy in Western contexts, uncertainty in prognostication and varied understandings of quality of life. Moreover, futility is a moving target. Advances in technology and medical expertise, not to mention the setting in which care occurs, influence the potential for clinical improvement in any illness.

Though futility has an extensive literature within multiple medical disciplines, rarely has it been discussed within psychiatry. This absence is notable given a recent survey of psychiatrists: over 50% of respondents deemed further treatment futile across case examples of treatment refractory psychiatric illnesses.[2] However, the current orientation of psychiatric care—which includes promoting recovery, distinguishing between physical and mental illness, and making findings of incapacity to compel treatment—challenges the legitimacy of naming futility in clinical decision making.

Particularly controversial is how futility might apply to patients[i] living with severe and persistent mental illness (SPMI), a term that most commonly refers to individuals diagnosed with chronic schizophrenia or affective illnesses. The National Institute of Mental Health defines serious mental illness (SMI) as '(a) mental, behavioural, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities'.[3] The Substance Abuse and Mental Health Services Administration further clarifies that SMI is distinct from SPMI in that not only are SPMI conditions serious, but also 'chronic and always disabling'.[4] Unlike recent arguments against futility in psychiatry,[5] we argue that the time has come to apply futility within psychiatric practice specifically in the care of individuals living with SPMI. Futility is helpful in delineating the limits of psychiatric intervention. Once determined, futility may lead to conversations about the realities of ongoing treatments that are not evidence based and potentially harmful. Naming futility acts as a signal that our approach to care must change.

In this paper, we clarify important concepts that have emerged in the futility literature, giving particular attention to ideas relevant to the application of futility to psychiatric practice. We present two arguments in support of the use of futility in psychiatry. First, that some SPMI can be considered a terminal illness and second, that risk–benefit ratios are dynamic entities. We address capacity in treatment decision making as a challenge to applying futility in the care of individuals experiencing SPMI, and we highlight some ethical imperatives that render capacity of lesser significance. This paper will not address medical assistance in dying for psychiatric patients.[ii] We highlight how the concept of futility may resonate with emerging models of care, such as palliative psychiatry with its comfort-based orientation to care.

REVIEW OF FUTILITY

Three dominant understandings of futility are present in the literature. Physiological futility refers to interventions as being futile if they cannot achieve their physiological goals.[1] Physiological futility values physiological homeostasis as the most

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[i] We recognise the contested nature of this term and that there is no consensus about language within psychiatry. We chose it over alternatives to reference the traditional ethical obligations doctors are thought to have towards those who entrust them to provide care.

[ii] Medical assistance in dying for psychiatric illness has been discussed elsewhere in the literature.[17 27 28]

important outcome of a treatment. Prioritising a physiological definition of futility is consistent with a biomedical approach to disease. In psychiatry, it is more difficult to apply this concept given the incomplete nature of neurobiological explanations of mental illness and, therefore, uncertainty in what constitutes a homeostatic state.

Quantitative futility involves judgements about when it is justifiable to attempt a particular treatment on the basis of a high probability of a successful outcome. A physician may declare quantitative futility when the proposed intervention has 'failed' in the past one hundred cases of physician experience or in case descriptions in the literature.[1] There is no clear theoretical or empirical basis that this rate of failure is the definitive marker of futility, making it difficult to evaluate the ethics of adhering to this logic. Rates of success or failure can be difficult to determine given the variety of clinical scenarios and the particulars of any given situation.

Qualitative futility centres on quality of life judgements.[1] As with any quality of life consideration, the decision-making process hinges on who is party to the discussion, and of those involved whose voice or voices are privileged or silenced. Stigma, discrimination, social structural factors and ableist ideologies have all contributed to the historical exclusion of individuals experiencing SPMI from participating in their own healthcare decision making. Consideration of who is allowed participation in quality of life discussions is particularly salient when considering futility within the care of people living with SPMI given their heightened risk of marginalisation within society and the healthcare system.

Some authors argue that futility is determined by the likelihood of achieving a target state, or by the initial condition of the patient, as interventions are considered.[6 7] In this understanding, physicians hold the balance of power in futility determinations given their status as medical content experts who provide probabilities on the basis of that knowledge. In contrast, definitions of futility that emphasise determinations on the basis of the worth of possible treatment outcomes gives authority to the patient in as much as the physician permits her to collaborate in the decision-making process. Discussions of futility in clinical settings can be nullified if the patient decides that value lies in the act of intervention itself.[7] In light of this dilemma, some authors have argued that futility should not be used in specific clinical situations. Instead, futility is a more useful concept in higher-order medical decision making (eg, policy making). It is an idea that allows physicians to assert their own values against the pressure to privilege patient autonomy above all other considerations in the practice of care.[8]

A unifying ethical principle in all of these proposed definitions is the edict to 'do no harm'.[9] Mohindra highlights that futility should only be considered in situations where interventions carry equal probability of benefit or harm. If there is an imbalance, physician ethical obligations are clear: harmful interventions should not be provided and beneficial interventions should be recommended.[7] The vast literature on futility suggests that clinicians invoke this concept in scenarios beyond those rare instances of 'neutral' interventions where the likelihood of benefit and harm is balanced. Futility is an idea that is most often raised when tensions exist with respect to next steps in dire clinical situations. Pope proposes 'potentially inappropriate treatment' as an alternative to futility.[10] He argues that only physiological futility is a valid definition and potentially inappropriate treatment is an illuminating concept in situations where clinicians think that treatments may have an impact on the body, but no benefit to the person. The concepts of qualitative and quantitative futility provide explanatory models as to why treatments are inappropriate.[10] While conceptual clarity would be ideal, what is evident from the literature is that 'futility,' however understood, has a familial resemblance; it may look different across clinical contexts and philosophical orientations, but there is a shared use in its implication that there exists a situation in which the intervention will almost certainly have no benefit—clinical or psychosocial.[11]

FUTILITY IN PSYCHIATRY

Futility has seldom been discussed in the psychiatric literature. Anorexia nervosa is one of the only psychiatric illnesses in which futility has been raised.[2 12] More recently, there has been discussion of futility within the nascent field of palliative psychiatry for SPMI.[13] There remains an absence of a conceptual understanding of futility in psychiatric care and when it may be appropriately applied.

One might argue that futility, though not explicitly named, is often referenced in psychiatric practice through the use of the terms 'treatment resistant' or 'non-responder'.[14] There is little formal guidance in treating patients once the course of their illnesses has reached beyond the limits of clinical guidelines and evidence. In these situations, a formal, accepted understanding of futility becomes relevant and useful to help determine future directions of care. A challenge in translating futility from other medical disciplines to psychiatry is that, despite a chronic lack of clinical improvement, individuals living with SPMI are rarely considered to have a terminal illness. Calling on futility seems most accepted in scenarios involving end-of-life or illnesses that are easily perceived as physiologically fatal.[9] In the rare instances in which futility has been discussed in the psychiatric literature, psychiatrists have argued that there is a difference between end-stage illnesses and severely treatment refractory ones and that without categorising disease as 'end-stage' futility determinations are unwarranted.[5]

SPMI AS TERMINAL ILLNESS

There may be tacit acceptance among psychiatrists that there is a terminal quality to some SPMI. For example, 94.5% of respondents to a recent survey of Swiss psychiatrists thought that SPMI could be considered a terminal illness.[2] Yet, it is uncommon for mental illness to be formally labelled as terminal illness which has been an obstacle to introducing discussions of futility within the field. Moreover, there is a lack of clarity around 'terminal illness' as a conceptual entity within the entirety of medicine. However, unifying themes can be found. One study describes that the presence of a progressive and irreversible disease with a limited prognosis (without a shared defined time frame) is a common condition in the varying uses of 'terminal illness'.[15] With this conceptual distinction, one can see how the term 'terminal illness' may not apply solely to end-of-life. This condition is in keeping with our understanding of individuals experiencing SPMI having a chronic course and permanent disability. In both psychotic and affective disorders, repeated unsuccessful treatment trials and longer symptomatic periods suggest an increasing risk of illness episodes and a decreasing likelihood of symptom remission. Epidemiological research demonstrates that individuals with SPMI have higher mortality rates than those without.[16] Taken together, this literature suggests that SPMI can be progressive and have potentially refractory symptoms, resulting in a limited prognosis.

An examination of the differences between the concepts of 'fatal' and 'terminal' illness strengthens this assertion. Fatal can be understood as a natural kind term that can be applied to all instances of a given illness. It applies to those diseases for which we can draw a causal link between disease process and death, and thus cannot easily describe SPMI. In contrast, terminal illnesses are socially mediated; were it not for certain choices that patients make, or environmental and social structural contributors to SPMI, the illness may not result in death.[17] SPMI can certainly be considered a terminal condition, despite the fact that its neurobiology does not necessarily render it fatal. At the extreme, suicidal behaviours might make a disorder terminal. More commonly, the very medications used to treat SPMI may contribute to a terminal state given their consequent physical risk (eg, kidney disease resulting from chronic lithium use) that would not be present were it not for the underlying psychiatric condition. We are not arguing that individuals experiencing SPMI are at end-of-life. Terminal illness in psychiatry can be understood as a condition in which ongoing interventions do not produce meaningful change in symptoms such that a patient deems their quality of life as unacceptable. The concept of terminal illness can be applied to SPMI, fulfilling the implicit assumption that futility might only be discussed and applied in terminal illness.[17]

THE DYNAMIC RISK–BENEFIT RATIO

Ironically, clinicians' reticence to introduce futility in psychiatry and collaborate in shifting the focus of care increases the likelihood that SPMI may become terminal illness. There are few guidelines that address the needs of patients who lack treatment response. Once an illness is categorised as treatment-resistant, some physicians resort to interventions that have no evidence base and unclear risk–benefit ratios.[17 18] As illness becomes treatment refractory, part of the decision making should focus on reducing the non-trivial iatrogenic harms associated with treatments. For example, cardiac disease is the leading cause of death in individuals with SPMI and can be correlated with pharmacologic intervention.[19] As the risk–benefit ratio shifts through the course of illness, futility can help express the 'risk of unacceptable badness'—a present or future state of living that the patient would themselves consider unacceptable—which can guide clinicians and patients to alternate pathways of care.[20]

There is evidence for diminishing returns with each subsequent intervention in both affective and psychotic disorders, the two diagnostic categories that compose the largest proportion of SPMIs.[2 17] The risk–benefit ratio is a dynamic entity when proposing treatments, especially with the use of pharmacology, given the declining probability of therapeutic success with each treatment trial. The shifting nature of the risk–benefit ratio is often ignored in favour of the attitude that repeated and tireless treatment attempts are of greater integrity than declaring futility.[21] Patients and substitute decision-makers often feel pressure to accept ongoing treatment attempts given hopes for eradication of disease and stigma surrounding psychiatric symptoms. The result is that individuals experiencing SPMI are at risk of receiving overly aggressive interventions,[9 22 23] care that can create more negative than positive outcomes. Futility determinations, identified on a shared understanding of the patient's priorities, can be used as a clinical tool. If futility were to be applied within psychiatric care, it may be of benefit to individuals living with SPMI who would otherwise be subjected to ongoing harms of interventions that may not be in keeping with their own wishes and values.

The argument for the application of futility in psychiatry on the basis of a dynamic risk–benefit ratio most closely aligns with understanding futility as connoting 'potentially inappropriate treatment' on the basis of qualitative considerations. Staging models, similar to those used in cancer or cardiac diagnoses, might provide guidance with respect to goals of treatment as illness progresses.[18 23] Side effects can play a larger role in futility judgements in psychiatric illness because the illnesses are not immediately life-threatening.[17] Some individuals with SPMI may conclude that the treatments available to them are futile, not necessarily because there is no clinical benefit at all, but rather based on their own lived experience the treatment does not contribute enough to quality of life to outweigh the downsides of the particular intervention, pharmacologic or otherwise.[17] This reasoning further justifies some cases of SPMI as terminal conditions. While some patients may consider their quality of life as intolerable due to internalised oppressive attitudes towards people experiencing SPMI, to promote personal recovery values such as empowerment and self-determination should be prioritised in care,[24] thus supporting the need for safe clinical spaces in which patients can voice their questions and concerns. Physicians should work collaboratively with patients to determine the basis for the individual's experience of poor quality of life and proceed with appropriate management (which might include withdrawal of treatment).

INSIGHT AND CAPACITY

The issue of patient capacity has been raised as a barrier to the application of futility in specific instances of SPMI (namely, in the care of individuals with anorexia nervosa). Opponents have claimed that the illness itself interferes with patients' insight into their symptoms and therefore with their ability to engage with treatment services.[5] This pattern typically leads to delays in treatment initiation, and therefore a longer symptomatic period which itself can worsen treatment outcomes. Without insight into illness it is unlikely that patients will have the ability to consent to treatment or maintain a treatment plan once initiated. Making a finding of incapacity, and executing a plan of forced treatment, is based on the assumption that treatment might restore insight thus increasing the long-term likelihood of efficacy with intervention.

These arguments promoting a position of beneficent paternalism are troublesome. First, those who are found incapable to consent to treatment are more likely to get aggressive treatment.[9] Given the nontrivial harms associated with pharmacological interventions, using capacity as a barrier to futility declarations may lead to a significant reduction in both quality and duration of life for individuals experiencing SPMI. This group is also at risk of aggressive treatment in the form of repeated involuntary hospitalisations and progressive loss of rights over finances and treatment decisions. This type of care is difficult to justify once the severity and persistence of the patient's illness has declared itself and there is little novel intervention to offer. The utility of making an incapacity finding itself is called into question due to the shifting risk–benefit ratio of any treatment that might be forced once a determination of incapacity is established. As psychiatric illness progresses, a finding of incapacity (itself an intervention) may lead to little benefit, or, stated in stronger terms, become futile.

The argument that incapacity secondary to diminished insight precludes the applicability of futility appears to unjustifiably differentiate illness processes in mental disorders compared with physical ones. SPMI — like pain, fatigue and other forms of suffering — can interfere with patients' decision-making processes. Given the nature of these illnesses, impaired decision making has a similar quality to any other characteristic of illness that affects the probability of treatment efficacy. In any futility calculation, clinicians and patients alike are considering a specific intervention within the context of a specific instance of a disease course. Just as a certain threshold of renal dysfunction might limit the efficacy of intervention in kidney disease, a persistent 'lack of insight' might indicate that similar threshold of severity in mental illnesses.

People living with SPMI are between a rock and a hard place: the majority of these individuals are too far from end-of-life to be considered terminal and therefore eligible for futility discussions, yet because of their longevity the harmful side effects of treatment interventions might have a bigger impact on futility considerations. They continue to be exposed to psychiatric interventions with potentially minimal clinical benefit and high risk of harms because futility is not thought to apply. Futility has been argued to be forever an inappropriate determination because patients' incapacity interferes with intervention efficacy. Again, these patients are at risk of harm to their bodies and identities without an alternate conceptualisation of how they might be supported. An acknowledgement of futility in these cases may be validating for patients and clinicians alike, offering a recognition of the life altering quality of these illnesses and the associated suffering. Futility might offer a bridge to alternate care models in which patients are not abandoned, recovery is promoted, and there is no undue interference with health and agency.

FUTILITY AND RECOVERY

While futility initially seems like a challenge to recovery-oriented care, holding the two philosophies in opposition is a false dichotomy. Recovery refers to both clinical and personal recovery. Clinical recovery is achieved by either cure or illness management (ie, symptom control). In contrast, personal recovery refers to reaching a point where one is functioning at one's best, despite ongoing symptoms, and is defined by the individual. It encapsulates the idea that illness does not define the person.[25] As we describe it, futility both recognises clinical recovery in the form of being oriented to illness management while acknowledging that intervention itself can interfere with personal recovery. Futility can advance personal recovery by creating space for collaboration between clinician and patient, such that there is a realignment of care to fit with a patient's priorities as his or her illness progresses. This approach to care is consistent with the stance espoused by many advocates that 'clinical recovery is subordinate to personal recovery'.[24]

CONCLUSION

There is a growing call for alternative care pathways for individuals experiencing SPMI, including the recent introduction of palliative care models specific for mental disorders.[2 13] Though we hope for breakthrough treatments to come, some patients have symptoms that resist modification with intervention, as is true for all chronic illness, and discussing futility becomes important. We have contributed our voices to the argument that futility has a role within the care of individuals experiencing SPMI. These patients can be considered to have a terminal illness, meeting the implicit criteria that appears to underlie futility determinations. The dynamic risk–benefit ratio becomes important due to the connotation of futility within the literature. More harm is done in avoiding futility determinations altogether instead of applying it in appropriate circumstances as a framework for more compassionate patient-centred care that might involve less 'traditional' psychiatric intervention. We have argued for removing the issue of capacity as a barrier to the use of futility within psychiatric care given that findings of incapacity may, in some situations, provide little benefit to patients and place them in the path of greater harm.

The suspicion of futility is a signpost that we should think deeply about what we are doing, and consider changing our approach.[8 26] Futility's place in psychiatry may be to signal engaging in a more palliative mode of care. Our model of futility in psychiatry is not solely applied to pharmacology. As such, futility determinations will require input from the entire interprofessional health team. We argue for a broad concept of futility that considers the social determinants of health and institutions within which patients are situated. Futility is not a concept that should be used to justify abandonment of care, but rather a reorientation of it such that the patient is best served in their current stage of illness. Healthcare professionals must include patients' experiential knowledge in planning care provision at individual and systemic levels. Understanding patient perspectives on futility in mental healthcare should remain an active area of research. We hope that future research will also elucidate the specifics of when it is clinically appropriate to invoke futility, and most importantly, how it might result in more compassionate patient-centred care.

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