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What are We Asking Patients to Do? A Critical Ethical Review of the Limits of Patient Self-Advocacy in the Oncology Setting

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Abstract

Increasing emphasis on patient self-management, including having patients advocate for their needs and priorities, is generally a good thing, but it is not always wanted or attainable by patients. The aim of this critical ethical review is to deepen the current discourse in patient self-advocacy by exposing various situations in which patients struggle to self-advocate. Using examples from oncology patient populations, we disambiguate different notions of self-advocacy and then present limits to the more demanding varieties (i.e., health-related, trust-based, and psychological); we argue that these limits create ethical dilemmas with respect to whether it is always desirable to encourage patients to self-advocate. We conclude that self-advocacy can be both under and overrated with respect to how much it benefits the patient with cancer, with many instances being indeterminate. Ultimately, providers must understand the patient's perspective relative to the challenges they are experiencing and work with them to meet their needs. While seemingly simple, this is nonetheless revolutionary in the current cancer care delivery system in which the needs and priorities of providers and systems often trump those of the patient.

Keywords

self-advocacy; ethics; self-management; patient participation; neoplasm

Background

Healthcare stakeholders strive to provide patient-centered care, promoting outcomes important to patients. While patient-centered care requires significant work from healthcare systems and providers, patients also self-advocate to ensure their needs, values, and priorities are integrated into their care. Health researchers define self-advocacy for cancer patients as a form of self-management encompassing a patient with cancer's ability to overcome challenges they experience as an individual with cancer (Thomas et al 2021).

Individuals with cancer face increased barriers to self-advocating because of the physical and mental side-effects of cancer and treatment, complex treatment regimens, long-term sequelae associated with anticancer treatment, and chronicity of many cancer treatments. As patients encounter more difficult situations, they must negotiate when and how to press

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their providers, staff, and caregivers to get their needs met. Prior research demonstrates that many patients with cancer struggle to self-advocate, especially those with limited social and financial resources, and those whose providers do not directly invite patient self-advocacy (Hagan et al 2017).

At the same time that patients with cancer are facing more impediments to self-advocacy, professional and advocacy organizations are increasingly endorsing patient self-advocacy to promote patient autonomy and benevolence. This reflects a reorientation of healthcare services and delivery to be value-driven and focused on patient engagement and quality of care (Keating et al 2021). It also exposes the practical need for patients to manage their cancer and wellbeing on their own due to limited access to high-quality cancer care (van Dongen et al 2020). In May 2021, an international group of cancer researchers and providers published a call to action advocating for improved integration of self-management support in cancer care delivery (Howell et al 2021). Their recommendations include preparing patients for increased responsibility in their care through skill-building and systems of accountability. Organizations such as the LIVESTRONG Foundation (Shapiro et al 2017), American Society of Clinical Oncology (National Coalition for Cancer Survivorship), and international organizations (McNally 1996, Errico & Rowden 2006) promote self-advocacy as a necessary part of being a cancer patient and survivor.

We support this call to action but additionally argue that this systematic shift toward patient self-management requires careful consideration. Calls to increase self-management – including self-advocacy – historically have disregarded the reasons why self-advocacy is complicated (Hagan & Medberry 2016). In fact, implicit pressure to self-advocate may expose patients to risk, expecting them to do something without equipping them with the skills necessary to do so.

In response to the recently published call to action, we argue that *on a certain reading* patient self-advocacy is generally a good way to achieve patient-centered care and self-management, but that on other readings it is potentially an unreasonable standard. Therefore, a critical ethical review of patient self-advocacy is required to identify and address the ethical concerns regarding patient self-advocacy and ultimately to improve the likelihood that all patients can engage in and benefit from it.

Disambiguating ‘Self-Advocacy’

Self-advocacy typically involves a suite of related skills related to communication, negotiation, and decision-making. While similar to concepts under the umbrella of self-management including self-efficacy and patient activation, self-advocacy differs in its focus elevating patient needs and priorities rather than the completion of tasks or engaging in health behaviors (van de Velde et al. 2019). However, there is not uniformity regarding precisely which skills are included. Early work by HIV/AIDS advocates included education, assertiveness, and purposeful nonadherence (i.e., not following clinical recommendations when they do not align with a patient’s needs) in their definition of self-advocacy (Brushers et al 1999). A full two thirds of their self-advocacy scale is devoted to questions on assertiveness and purposeful non-adherence (ibid, p. 101). Nor is this emphasis unique to

AIDS research: for example, ‘self-advocacy’ for people with disabilities is also measured largely in terms of assertiveness (Dryden et al 2014, p. 795). Despite heterogeneity in the behaviors of self-advocacy, they all align with the ethical principle of autonomy by promoting self-determination in what decisions and choices individuals make to direct their health and care.

In this early scholarship, there is a potential ambiguity regarding what is being asserted. A person can be assertive in a way that manifests control over someone or something, but they can also be assertive in a way that simply makes sure that one is heard regarding important matters such as symptom or personal value information. To provide clarity to the concept of ‘self-advocacy,’ we disambiguate two related but importantly distinct concepts:

1. *Controlling self-advocacy.* This involves assertiveness regarding treatment decisions, information gathering, and relationship management.
2. *Communicative self-advocacy.* This focuses entirely on patients’ ability to convey symptom information and value information to providers.

Communicative self-advocacy would rarely be considered inappropriate or unwarranted since patients and providers alike depend on timely, open communication regarding patients’ status and wellbeing. However, engaging in controlling self-advocacy takes time, energy, and commitment. In the remainder of this paper, we focus solely on controlling self-advocacy and the ways in which costs to instilling it run into potential ethical difficulties in many situations involving cancer treatment.

Limitations to Self-Advocacy and Operative Ethical Principles

Understanding limitations to when and how providers promote patient self-advocacy can clarify the ethical obligation to promote patient autonomy and beneficence. To streamline discussion, we assume a principlist framework of the kind found in Beauchamp & Childress (2012/1979). We focus primarily on a principlist approach for several reasons. Two lesser reasons are (1) that it is fairly common in bioethics, and (2) that it was at least designed to solve tensions between consequentialist (outcome-based) and deontological (rule-based) perspectives. (Flynn 2021, p. 14) However, the main reason we employ principlism is that it poses the most difficult challenge for our more controversial claim that we should decrease our reliance on what patients themselves have to say. Specifically, if autonomy is taken to be a fundamental principle, there is a fairly straightforward case to be made that having competent patients control their care should be close to sacrosanct. If we can establish our thesis with respect to principlism, we think it would be still more plausible under most other views. For example, if one is concerned with outcomes (as per consequentialism), then it makes all the more sense to take steps to alleviate patient discomfort and make sure they get better results. Likewise, while it can be notoriously difficult to ply prescriptions from virtue ethics, a common emphasis in healthcare on the virtue of compassion (e.g., Cohen 1994) suggests that we should do all we can to ease patient discomfort, including the sorts of discomfort that we will argue is a potential concomitant of self-advocacy. Similar points could be made about other ethical systems, such as an ethics of caring. Principlism thus stands as both a plausible system and the most difficult for us to address.

We organise our discussion into when patient self-advocacy – as it is popularly understood and researched – is overrated, underrated, and ambiguously rated, with the goal of detailing the circumstances when patient self-advocacy is helpful and harmful to patients. Because scholarship in self-advocacy has primarily focused on cancer populations, we draw upon common oncology experiences to provide contextual illustrations of our main points, though similar arguments could be made for other chronic and acute illnesses.

When Self-Advocacy is Overrated

Since much of the academic and popular literature solely focus on the virtues of self-advocacy, we begin by exploring limits to promoting self-advocacy. Employing an ethical analysis, we discuss times when the least harmful action is *not* to encourage patients to assert their needs and values.

Physical and Mental Work of Self-Advocacy.—Most saliently, there are times when patient self-advocacy would be physically and mentally burdensome on patients already stretched to the limit. Self-advocacy requires a prolonged series of potentially trying actions and abilities. For full (‘controlling’) self-advocacy, patients must work to understand their condition, their treatment options, forming a definitive preference about their preferred action, and then speak forcefully on their own behalf. At the time of diagnosis and treatment planning – when many decisions are being made – patients often feel mentally and physically overwhelmed. The added work of gathering information about the disease, its treatments, and self-management strategies to deal with symptoms and side-effects may limit the ability of patients to engage in these behaviors (Hammer et al 2015, Szamreta et al 2021). In illnesses like cancer, this is particularly troubling as the amount and depth of information related to diagnosis and treatment is staggering (Borgmann et al 2017, Lasa-Blandon et al 2019). Even physicians frequently would rather leave the actual decision-making in someone else’s hands (Ende et al 1990). All of these burdens would be difficult for a fully healthy patient, but for a patient with cancer in the midst of severe physical and psychological difficulties they could easily be psychologically (and perhaps even physically) overwhelming.

Harms of Self-Advocacy.—This brings us to the most central claim of the paper, which is that in such circumstances actively encouraging self-advocacy can be harmful, and thus doing so would be a violation of nonmaleficence. It might at first seem paradoxical that encouraging people to make a choice and speak out could harm them, but variants of this claim are commonplace in the philosophy and psychology literatures. Psychologists talk extensively about the ‘Paradox of Choice’ (dating at least to Schwartz 2004) wherein we are frequently better off the fewer options we have, and some (e.g., Gilbert & Ebert 2002) have noted that being able to make changes frequently makes people less happy and less confident in their choices. Similarly, recent critiques of the “tyranny of autonomy” have shown the ways in which deferment to self-determination without consciousness raising lacks the nuance and depth needed for value-drive care (Stammers, 2015). In short, absent reason to think that the patient would actively want to self-advocate even when it would be especially burdensome to do so, it is actively unethical to encourage them to pursue a harmful line of action.

One might argue from beneficence that patient outcomes would be better if they advocated for themselves. However, in cases such as this there is simply no reason to believe that is the case, and so the weight of benefits and harms speaks against self-advocacy. One might also worry that autonomy requires simply doing what the patient wants, which might imply a strong value on the patient expressing clearly what should happen. However, such a conception of autonomy is clearly overly simplistic. If that were the right conception of autonomy, then we would always be obligated to provide narcotics to drug-seeking patients. Instead, a more nuanced rendition of autonomy would have us respect what a patient really wants or what is valuable to them (Levy 2014), which would provide no argument in favor of encouraging self-advocacy in this case.

Employing Others to Advocate for the Patient.—The second case where self-advocacy might not be the ideal desideratum is when the patient has sufficient trust in a person that they would rather someone else be responsible for the decision and advocate *for* them in specific contexts or timepoints (e.g., when their physical health temporarily prohibits their engagement or when a decision needs significant research). While autonomy might often be cited as a reason in favor of self-advocacy, in this case it points in a different direction. If the patient wants someone else to make the decision such as a partner, provider, or trusted member of their social network, values someone else doing so, and otherwise chooses to outsource the decisional burden, it would be an imposition of the provider's values to prevent them from doing so. For example, one study participant cited the metaphor of ride-sharing, 'It's like Uber – you are in charge of where you are going, but you don't always have to drive' (Hagan et al 2017).

Individualistic versus Communitarian Cultures.—Moreover, there might be a fair degree of cultural unawareness situated largely in mainstream American individualistic providers. In many communitarian cultures (Susilo et al 2019) it would be potentially inappropriate for a patient to advocate on their own behalf without regard to what broader community members felt, and it would be culturally hubristic to assume our model is how best to engage (Obeidat, Homish, & Lally 2013). One might again think that beneficence would require that we encourage self-advocacy, but in addition to a lack of evidence that this would provide net benefit to the patient along traditional measures, we would also like to note that it potentially fails to help the patient on non-traditional measures of well-being. Well-being is not just a matter of subjective happiness, but also includes such factors as being enmeshed in a community and having a trustful relationship, both of which (along with other things) might be jeopardized if the patient is encouraged to override their fundamental trust in favor of speaking out on their own behalf.

When Self-Advocacy is Underrated

Despite the arguments in the previous section, we would not want to be interpreted as suggesting that any barrier to self-advocacy is a reason to forgo encouraging a patient to self-advocate. The simplest case is when the patient does not self-advocate because the provider will not listen anyway. One does not need a deep dive into ethical principles to realise that ignoring one's patient is ethically problematic, and thus the burden is on

the provider to reassure the patient that they will be heard rather than to discourage self-advocacy.

Self-Advocacy Impacting the Patient-Provider Relationship.—To take a slightly more nuanced example, some patients might not self-advocate because they worry this will damage the patient/provider relationship. There is no ethical foundation for enabling this fear when it is potentially within the provider's power to combat it instead. Beneficence would suggest that a patient would likely feel better when they feel that they can communicate openly with their provider (Thomas et al 2021). Veracity would suggest that providers do everything in their power to reassure patients that they should be free to speak their minds if they are so inclined, and then fidelity would require they respect what the patient has to say. We cannot think of any good justification for allowing a patient to refrain from self-advocating for fear of eroding the patient-provider relationship when it is quite typically within the provider's power to provide assurances that this will not be the case.

Providers Promoting Patient Self-Advocacy.—A slightly still more nuanced case is when the provider simply does not know how to encourage patients to self-advocate. Unless a patient is forthcoming with their needs, values, and priorities, then a provider is unlikely to know or acknowledge how the standard care could be adjusted to better align with the patient's unique circumstance. They may also be hesitant to unlock the patient-provider power dynamic to permit the patient to direct the conversation and care decisions. Again, in this case the ethical onus seems to be on the provider. First, beneficence would suggest that if saying the right thing is important then the provider has an ethical obligation to figure out what the right thing to say is. More subtly, if veracity requires telling the truth, then a potentially overlooked sub-requirement might be figuring out what the truth is *and* how best to tell it. One might worry that similar considerations to the nonmaleficence discussed above would indicate here that the provider should not burden the patient by potentially saying the wrong thing. However, unlike in the case above where the difficulties were with the psychological and/or physical states of the patient, in this case the issue is with the state of the provider. As such, the provider can alter their own state without adversely affecting the patient, negating the concern from nonmaleficence. In other words, if the concern is that the provider might say something harmful, the correct solution is not to say nothing but rather to figure out a non-harmful thing to say.

When Self-Advocacy is Ambiguously Rated

The last two limitations to self-advocacy we consider here are ones where it is not clear what to do in a particular clinical situation.

Patient Preference.—The first such scenario is when a patient is equipped to self-advocate, is not overwhelmed, but simply has a moderate preference not to be informed of what is happening. On the surface, considerations from autonomy might strongly suggest that we leave the patient be with their selection to remain quiet. However, as above this might take an overly narrow view of autonomy. In a recent piece, Wilkenfeld, Orbell, & Lingler (2021) argue that there is some ethical basis for – at a minimum – nudging patients towards receiving information when they might otherwise be hesitant.

The logic presented there is that more modern views of communication reticence to receive information might best be understood as communicative noise that should be overcome in a similar manner to a static-y signal. In some sense the patient's autonomous interests really do involve getting the information, but some exogenous factor is interfering. One quick if ultimately unsatisfying answer is that providers can attempt to understand whether a patient is refraining from self-advocacy because doing so would be genuinely burdensome or whether they are refraining based on some sort of barrier that is properly overcome. Based on the assessment, the provider can – when and *only* when appropriate – encourage self-advocacy as a means of ensuring the patient's values and needs are met and that their care revolves around their priorities.

Provider Disempowerment.—One final scenario where we maintain there is no clear answer is when the provider themselves feels disempowered. If the provider is not able to listen and respond to the patient, is it best to encourage the patient to advocate for things they cannot get or not to offer false hope? As is often the case with systemic problems, there is no clear right answer for what to do if the system itself is structured in such a way as to prevent ethical action. These are precisely the sorts of scenarios that are properly understood as lending themselves to moral distress rather than being analysed as moral dilemmas. The issue is not one of figuring out what the right action is, but of finding ways to compensate for the fact that circumstances have rendered the right action functionally impossible.

In sum, we acknowledge that this ethical review does not discuss every possible barrier to self-advocacy. Others include lack of transparency within hospital and insurance ecosystems, non-patient-centered clinic designs, and sociodemographic factors that limit access to care. However, in describing this central subset of barriers, we hope to provide a blueprint for assessing for any particular limitation whether encouraging self-advocacy is appropriate.

Surrogates: A Solution that Almost but Doesn't Quite Work

When looking at the above concerns, one might think that the solution to concerns regarding the difficulties of self-advocacy is to empower surrogates to advocate on behalf of the patient. Different from the periodic employment of others as described above, surrogates are usually in a more permanent position or professional role to advocate on behalf of patients such as patient navigators or professional advocates. While perhaps this would not technically qualify as the patient advocating for themselves, it would achieve all the virtues of patient control without the costs of patient burdens.

We do not dispute that the use of surrogates can be a valuable way to make sure patients' needs are met while reducing the burden on the patient, as this model has shown significant success in among individuals with disabilities (Peterson, Karlawish, & Largent, 2021). But as a general solution to the concerns raised above about the ethicality of encouraging self-advocacy there are shortfalls of this option. Surrogates and their interests are not identical to the patients' (Shalowitz, Garrett-Mayer, and Wendler 2006), and so there's reason to suspect they might not always be able to advocate as well. That is, advocacy by surrogates might lose many of the *benefits* of advocacy by the patient. Though in retrospect the point is

obvious, recent research (Siminoff et al 2020) has focused on the fact that surrogates are not in fact identical with patients and must be thought of as independent entities with their own needs, wants, and priorities. Indeed, there might be a dilemma here: the closer the surrogate is to the patient the more likely they are to incur the costs of self-advocacy, and the more distant they are the more likely they are not to incur the benefits.

Conclusion

This ethical investigation of patient self-advocacy provides insights that cancer providers can use when considering how to engage their patients in advocating for their needs and priorities. The solution, ‘become more involved in your care,’ ignores the complicated web of personal and interpersonal barriers to engagement. This paper argues that several ethical principles can be applied when patient- and provider-level barriers to self-advocacy impede patient self-advocacy. Ultimately, each clinical scenario requires the provider to understand the patients’ perspective relative to the challenges they are experiencing and work with them to meet their needs. While seemingly simple, this level of promoting patient self-advocacy is nonetheless revolutionary. Currently, our healthcare systems largely remain provider- and system-driven. If patient-centered care is truly the goal, then the degree to which providers and systems work with individual patients to appreciate their needs and priorities is the ultimate measure of quality care.

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