

**Rethinking Autonomy in Advance Care Planning:
The Shift from Individualistic to Relational Autonomy**

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Introduction

The COVID-19 pandemic has brought advance care planning (ACP) to the forefront of healthcare [1]. The rise in demand for healthcare services during this trying period has resulted in increased risks of medical surges globally. ACP serves as a solution to facilitate the provision of more targeted and compassionate care for patients, especially as challenges such as lack of patient visits make it difficult to do so [1]. Addressing the goals and preferences for care services in the setting of acute, critical illness such as COVID-19 not only allows patients to live with dignity but also promotes the efficient allocation of scarce resources [1]. The former point is especially important for older patients, who are more likely to develop chronic co-morbidities and are more susceptible to COVID-19 with greater risk of having poor outcomes including mortality [2, 3]. Even without the consideration of the current pandemic, many individuals will experience health incidents requiring medical care, and these patients may not have the capacity to comprehend and make decisions regarding their own health. In fact, nearly 70% of adults aged 60 or above who need to make decisions regarding their medical treatments during their final days of life do not have the ability to do so [4]. In such situations, caregivers and family may be contacted to support decision-making for their relatives, however, evidence has shown that there may be significant inaccuracies and challenges in carrying out proxy decisions on care provision for their incapacitated relatives [5]. With the added context of rapidly ageing populations around the world, the promotion and practice of ACP remains a key priority in today's health landscape, and the elderly should be prioritised as a target population for initiating this care.

Prior to the pandemic, there was already a growing emphasis on the need to recognise ACP, to align the care provided with patients' values and goals [6]. At its core, ACP is "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care" [7]. Its main aim is "to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness" [7]. ACP is continuous and fluid in nature, and as such, patients' choices should be revisited regularly [8]. It may be associated with the development of an advanced directive, which in Hong Kong is considered to be a legally binding document detailing a patient's advance refusal of life-sustaining treatment under specific pre-defined circumstances [9].

The concept and goal of advance care planning are very much in line with the pillars of medical ethics as outlined in *Principles of Biomedical Ethics* by Beauchamp and Childress [10]. The provision of unwanted intensive treatment may cause further harm to patients through the development of adverse physical and psychosocial effects; this violates principles of non-maleficence and beneficence. With respect to justice, the equitable distribution of limited healthcare resources must be considered. In the case where resource-intensive care is provided to a patient who would prefer not to receive it, this may be considered as unjust or even inequitable as it may limit others from accessing these services. For patient autonomy, the patient's decisions regarding their own treatment or refusal thereof should always be respected, regardless of others' views. However, challenges may arise in doing so.

Discussing Challenges with the Current Approach to Autonomy

As an essential tenet to uphold in ACP, there has been extensive research and discussion on how it should be approached and sustained during this process [11, 12]. Traditionally, it is

carried out through informed consent, where patients voluntarily grant permission for certain health services to be provided in full knowledge of its purposes, risks, benefits, and alternatives [13]. Heavily corresponding to principles of the biomedical model of medicine, this approach applies an individualistic view of autonomy [12]. Patients are considered to be agents, always acting perfectly rational to serve their own interests [14]. The decisions that they make are assumed to be completely unaffected by external influences such as loved ones or even sociocultural surroundings. Notably, this aligns with Beauchamp and Childress' perspective on the concept, and they offer both positive and negative definitions [15]. The former requires that autonomy include "respectful and appropriate information exchanges and actions that foster and encourage autonomy" while the latter stipulates that it must "not be subjected to controlling constraints by others" [10].

This may have a number of consequences on the practice of ACP. Clinicians may deliver seemingly sufficient information to patients on various interventions, but these details may be de-contextualised during their presentation as healthcare providers adopt neutral positions of non-interference so as not to sway patients' decisions [16]. Family members and loved ones may be present as appropriate, but may not actually be actively involved in this process. Patients may be requested to confirm life-altering decisions on their health merely by confirming or signing off on various official documents, particularly in the case of advance directives. In the end, autonomy is viewed as a static, binary absolute, that is primarily validated by the simple formal authorisation of treatment preferences [17].

With this individualism-centric approach to autonomy, there are doubts as to whether ACP is able to meet its goal of representing patients' values and preferences for their care and wellbeing [18]. Arguments have been made that this traditional view is too restrictive and cannot capture the effects that close ones and external surroundings have on individuals [12]. In a recent study in Australia examining physicians' perspectives on this topic, one palliative care specialist shared: "I think it's a bit overly pretentious to say that a patient has full autonomy when they're dying. Because, unless others help them, it's very difficult to be

an effective agent for yourself when you're physically and mentally quite frail" [19].

Additionally, in certain cultures, faith plays an immense role in health-seeking behaviour as well as in decision-making processes regarding acceptance of Western medical interventions. In other communities, traditional family structures and their values may affect the degree of autonomy that one perceives that they have in addition to their potential responses to treatments [20]. For example, in Chinese culture, the idea of self is often viewed in relation to the family; there is a significant focus on filial piety and "harmonious interdependence" in family relations [21]. Decisions are not made through the conventional interpretation of self-determination, rather they are crafted by "family- determination" [22]. Individualistic autonomy may reject these notions, since they may be viewed as the patient not actually making an independent choice for themselves, when in fact, it is these very external factors that shape who the patient is as an individual.

Ultimately, an individual's preferences for care cannot simply be considered in isolation of their social roles and relations or even wider societal beliefs and expectations.

Considering Relational Autonomy

In light of the challenges associated with the current individualistic strategy, a relational approach to autonomy may better align with the principles of ACP. Relational autonomy can be viewed as "a cluster of approaches to autonomy that emphasize the socially embedded nature of agents whose identities are shaped by their relationships with others" [23].

Originating from feminist movements and ideologies, this perspective emphasises individuals' unique contexts in terms of their social identities, locations, and relationships [16]. It also looks at their lived experiences as well as the socioeconomic and political circumstances that influence their identity, viewpoints, and decision-making processes [16]. In this way, self-determination is viewed and undertaken in a social context, where an individual establishes their own identity in order to express autonomy [24].

With respect to how this can support ACP processes, it may encourage more individuals to initiate these conversations to learn about themselves as well as the influences of their social surroundings. This may encourage them to make more mindful and well-rounded decisions regarding their own care. For those accompanying their loved ones who navigate challenging routes of illness and make life-changing choices that affect their health and wellbeing, they may feel more comforted by the fact that they can be considered in these important discussions. This is due to the recognition that choices on end-of-life care impact and are impacted by patients' close ones [11, 16, 25, 26]; as such, the decision-making process should be "in consultation with" and "in consideration of" others [27]. By integrating the notion that social contexts are ever-changing into the application of autonomy, we can address the challenge of "conceptualising [patients'] past, present, and future selves to ensure that care is goal-concordant" [28]. Since ACP concerns choices are made on future aspects of care, it can be difficult for patients to even begin to think about what their later wishes may be. Even if they are able to specify these, their decisions may change with time. For example, in a recent study interviewing breast cancer patients, Shih et al noted that as patients progressed through their various treatments, they were able to reflect on their experiences and gain a deeper understand of the range of medical interventions available [29]. This, in turn, strengthened their self-confidence in making and expressing decisions regarding their care [29]. Applying relational autonomy encourages a more nuanced consideration of their lived experiences, and in turn, patients may be more inclined and willing to share any changes in their decisions with clinicians.

Employing the approach of relational ethics in ACP also allows for greater cultural sensitivity for the local setting. As it stands, the individualistic interpretation of autonomy is strongly linked to Western bioethics and cultural principles [16]. This may not be appropriate for application in different contexts featuring distinct values, such as community or family harmony. In a world today where we are becoming more and more connected with each other, there is an immense need to ensure that the way in which we practice autonomy is in line with our pluralistic society [16, 30, 31].

Operationalising Relational Autonomy with Narrative Medicine

This begs the question: how do we exercise relational autonomy in the practice of ACP? Narrative-based medicine (NBM) may be a sensible answer, and this refers to “a fundamental tool to acquire, comprehend, and integrate the different points of view of all the participants having a role in the illness experience” [32]. According to Professor Rita Charon who originated this field, the essence of NBM lies in narrative competence, or “the ability to acknowledge, absorb, interpret, and act on the stories and plights of others” [33].

NBM encourages patients to reflect on their own lived experiences and to share this with healthcare professionals, in order to better facilitate ACP. This is in direct alignment with relational autonomy, where the emphasis is on patients’ self-determination as explored by their social contexts [34]. By bringing the focus to the patient’s stories and circumstances, such as what makes them who they are or how surrounding environments shape their decision-making processes, this allows ACP practitioners to be more mindful of the web of social structures shaping patients’ decision-making [35]. In doing so, this will support more proactive initiation and engagement of conversations on individuals’ values and motivations, which may then lead to greater cognizance on their preferences for future care. Even if such decisions are not fully expressed at the consultation, having this awareness can support more accurate extrapolation of patients’ identities and worldviews to their goals for future care and services.

As NBM encourages active listening of individual narratives, it certainly builds rapport between patients and providers [35]. This is especially important as ACP is a continuous and iterative process with the aim of reflecting the progression of a patient’s journey throughout life [8]. Fundamentally, the utilisation of NBM, as a way to achieve relational autonomy, is key in promoting awareness of patients’ complex principles and goals towards care in ACP.

Conclusion

Our current individualistic approach to autonomy is greatly limited as a “characteristic of decisions rather than a characteristic of persons” [16]. In consideration of ACP, autonomy must be practiced through dynamic interactions that reflect the complexities of individuals’ social contexts over time. As such, a relational approach, which may be achieved with the practice of narrative-based medicine, is needed to promote autonomy in ACP.

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