

# Fostering relational autonomy in end-of-life care: a procedural approach and three-dimensional decision-making model

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## ABSTRACT

Respect for patient autonomy is paramount in resolving ethical tensions in end-of-life care. The concept of relational autonomy has contributed to this debate; however, scholars often use this concept in a fragmented manner. This leads to partial answers on ascertaining patients' true wishes, meaningfully engaging patients' significant others, balancing interests among patients and significant others, and determining clinicians' obligations to change patients' unconventional convictions to enhance patient autonomy. A satisfactory solution based on relational autonomy must incorporate patients' competence (apart from decisional capacity), authenticity (their true desires or beliefs) and the involvement level of their significant others. To that end, we argue that John Christman's procedural approach to relational autonomy provides critical insights, such as the diachronic or socio-historical personhood, sustained critical reflection and his recent explication of the nature of asymmetrical relationships and helpful interlocutors. This study reviews Christman's account, proposes minor modifications and advocates for an integrated three-dimensional model for medical decision-making. Clarifying the relationship among the three elements promotes an ethical framework with a coherent understanding of relational autonomy. This model not only provides a descriptive and normative framework for end-of-life care practice but also reconsiders the nature of the clinician–patient relationship and its normative implications. We further present a case study to illustrate the merits of our proposed model. Altogether, our proposal will help navigate complex medical decision-making, foster trust and negotiate shared values between patients and their significant others, particularly in end-of-life care.

## INTRODUCTION

In end-of-life care, intricate decisions on whether to undergo invasive interventions or withhold or withdraw life-sustaining treatment involve not only great uncertainty but also tension between the patient's self-determination and the interest of third parties. Respect for autonomy is widely asserted as a key arbiter, operationalised through assessing patients' decision-making capacities and fulfilling their treatment preferences.<sup>1</sup> However, this principle's role as an ideal ethical panacea is increasingly being challenged, particularly from the perspective of relational autonomy (RA).

Originally proposed in political and social philosophy, RA criticises the mainstream individualistic interpretation of autonomy for its omission of social connectedness as the quintessence of human

existence and external forces on one's autonomy.<sup>2–4</sup> RA has been increasingly adopted to resolve end-of-life issues,<sup>5–9</sup> and its proponents recognise that the clinician–patient relationship has important ramifications in fostering patient autonomy.<sup>10</sup> Three ethical recommendations are commonly highlighted for clinicians: (1) merely securing patients' informed consent is insufficient to respect their autonomy; (2) consulting or involving patients' significant others in the decision-making process is desirable and; (3) one must sensitively deal with relevant historical, religious, cultural and social contexts that influence patient autonomy.

Despite these laudable recommendations, clinicians struggle with knotty dilemmas: how to ascertain the true beliefs of their patients, how to meaningfully engage with various parties,<sup>11</sup> and the potential disagreements among them.<sup>12 13</sup> Further, given a patient who firmly endorses a rather unconventional cultural stance or personal conviction, should a dissenting clinician attempt to proactively change the patient's perspective?<sup>14</sup>

Scholars generally endorse *competence* and *authenticity* as two essential conditions of autonomy, subject to specification by each theory.<sup>15</sup> As a specific theory of autonomy, RA purports that individuals must possess some necessary competence apart from ordinary decision-making capacities and act according to their true desires or authentic selves.<sup>3</sup> Some scholars propose an interdependent decision-making model that justifies different modes of *involving others*, depending on the patient's capacity or competence.<sup>11</sup> However, this model fails to incorporate the patient's authenticity and thus does not completely align with RA. Contrary to some early critics,<sup>16 17</sup> authenticity has gained considerable traction in bioethical discourse.<sup>18–21</sup> Incorporating the authenticity condition of autonomy may produce a thorough, coherent RA solution to the above-mentioned dilemmas. To the best of our knowledge, only one study<sup>8</sup> has attempted to balance all three essential elements (ie, patients' competence, authenticity, and the involvement level of others) by using Mackenzie's multidimensional theory of RA,<sup>22</sup> however, without contemplating any potential alterations to the nature of the clinician–patient relationship.

In this study, we refer to a largely undervalued resource as a better theoretical construct: John Christman's theory of RA. Christman's theory of RA has recently received considerable attention from bioethicists in terms of ethical issues involving deep brain stimulation,<sup>23</sup> psychiatric disorders,<sup>24</sup> cognitive enhancement,<sup>25</sup> genetic counselling,<sup>26</sup>



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biobanking,<sup>27</sup> advanced directives for dementia patients,<sup>28–29</sup> shared decision-making (SDM)<sup>30</sup> and organ donation.<sup>31</sup> Nevertheless, these studies often use Christman's theory in fractions, primarily based on his famous explication of the authenticity condition of autonomy. This may be because of the publication lag between Christman's contributions and his sequential minor revisions, making it difficult for bioethicists to track his account. Nevertheless, his recent view of the nature of asymmetrical relationships holds great potential for reconciling ethical conflicts in end-of-life care, lending a critical lens to reflect on clinicians' roles in actual clinical encounters.

We believe Christman's theory could contribute to two veins. First, with two minor modifications to his theory, we propose a three-dimensional decision-making model that fully agrees with RA. This integrated model provides a descriptive and normative basis for end-of-life care. Second, this theory could explain the nature of the clinician–patient relationship by emphasising that clinicians should respect and foster patient autonomy. In this context, this study uses an illustrative case to demonstrate how clinicians can facilitate meaningful interactions with various parties to enhance patient autonomy during clinical encounters.

### REVISITING JOHN CHRISTMAN'S ACCOUNT

Some understanding regarding the categorisation of RA is necessary here. There are two types of relational autonomists: proceduralists and substantivists. Proceduralists commit to 'content-neutrality' and do not provide a normative standard to determine the 'rightness' of the agent's choice, while substantivists place certain normative constraints on the contents of agents' preferences.<sup>3</sup> In this study, we commit to justifying an ethical solution in a procedural sense by pacing Christman's stance. This section first lays out Christman's original position and then proposes modifications that lead to a distinctive ethical approach to end-of-life care decision-making.

Christman's *diachronic* or *socio-historical conception of self* maintains that everyone has a unique trajectory of growth, consciously or not, explicitly or implicitly accepting or rejecting numerous social norms across their lifespan. Although individuals might encounter countless ambivalences about their true beliefs or possible tensions between beliefs, or they could never elucidate the formation of certain beliefs, Christman encourages us to embrace such a human reality: an individual who can always clearly identify their beliefs with wholehearted endorsement is virtually non-existent.<sup>32–34</sup> Hence, this theory rejects the Frankfurtian and Dworkinian hierarchical model of desire (ie, identification and endorsement). Moreover, it contrasts with the time-slice or ahistorical conception of self, which devoids individuals from their intimate experiences, viewing their living history as irrelevant to selfhood.<sup>34–36</sup>

Perceiving selfhood in a diachronic way thus affirms that one's authentic beliefs cannot settle on the functioning of faculties at a given time but hinges on subjective approval of personal history. The same traits can be reflected over time and under different circumstances to produce a coherent autobiography or an appropriate narrative. Christman calls this reflective process '*sustained critical reflection*' (SCR), which ensures that certain traits can endure through an ever-growing personal history, better reflecting one's true self<sup>34(p152)</sup>. Christman is not proposing 'any *actual* reflection take place on the characteristic in question; nor does it demand that wholesale self-evaluation from a disembodied standpoint take place,' instead, he claims that occasional, tokenistic '*hypothetical and piecemeal*' reflection 'in light of the history of the factor's development to take

place, [one] would not feel deeply *alienated* from the characteristic in question'<sup>34(p145, emphasis added in italics)</sup>.

Accompanied by the SCR, Christman used a *non-alienation* test to determine whether certain traits were counted as authentic. Being alienated involves not only one's cognitive judgement but also one's salient emotional arousal, strong disapproval and intense resistance towards certain traits. Christman viewed subjective non-alienation as a good basis for instantiating one's '*diachronic practical identity*'<sup>34(p151)</sup>. Borrowing Christine Korsgaard's theory of practical identity, Christman asserts that a well-consolidated, non-alienated practical identity not only provides motivation for agents to act authentically but also elicits their '*reflexive self-affirmation*' upon their identity, promoting their self-regarding attitudes (ie, self-trust and self-confidence)<sup>37(p222)</sup>. Acknowledging that individuals are hardly detached from their social roles, Christman expands SCR to include publicly available categories, allowing one to examine whether a description of certain social roles (ie, mother, teacher) could reflexively pass the non-alienation test, apart from solely focusing on the private category of personal desire or motivation<sup>37(p219–220)</sup>.

To reckon as a competent agent, Christman maintains that one only needs minimal social, bodily, affective and cognitive competence to engage in SCR; the lack of self-regarding attitudes is not necessarily a prior precluding factor<sup>34(p182)</sup>. However, the reflective process might also need to be free from constraining factors, such as 'in an uncontrollable rage, or while on heavy doses of hallucinogenic drugs, or having been denied minimal education and exposure to alternatives'<sup>34(p147)</sup>. Since this depiction does not impose sophisticated or complex requirements, it is firmly in accord with Christman's commitment to broadest inclusivity in political and social circles; it reaffirms his long-standing stance as a proponent of anti-perfectionism by rejecting to preclude people's political and social participation only based on specific moral standards external to their convictions.<sup>38</sup>

More recently, Christman has acknowledged that third parties or interlocutors could aid in forming practical identities by proposing a joint deliberation model that presses a more relational approach to RA.<sup>37–39–40</sup> Christman has revised his theory to consider 'asymmetrical relationships,' reconciling potential paternalist charges on RA. While paternalism might be difficult to eliminate in this context, the advantaged actor might decide whether the best advice or intervention is to restore the vulnerable person's sense of autonomy depending on the latter's evolving practical identity<sup>39(p379)</sup>. In some cases, Christman suggests the advantaged, such as social workers, not only ought to assess the vulnerable's autonomy—a requirement to respect their autonomy—but also bear an obligation to value their autonomy and facilitate their sense of autonomy<sup>39(p373, p379)</sup>. Further, Christman also underlines that the advantaged must avoid performing anti-social attitudes towards the vulnerable, which could posit a detrimental effect on the latter's autonomy<sup>39(p381)</sup>. To maintain the proceduralist 'content-neutrality' commitment, Christman suggests that, while the vulnerable might feel alienated from their previous autobiographies or entirely change their perspective after accepting advice or intervention, they need to provide at least a '*process-independent reason*,' indicating that the change of mind has nothing to do with the intervention itself, to avoid potential undue influence from the powerful actor.<sup>40</sup>

### AN INTEGRATED DECISION-MAKING MODEL OF RA

Terminally ill patients often encounter deep uncanniness; they experience profound life-transformative events, such as

unfamiliarity with their currently ill bodies, first-time experience living in wards, inexperienced communication with medical teams and duelling with family members' loaded emotions. This uncanniness not only frustrates them but ultimately undermines their RA. Focusing solely on one's decisional capacity or treatment preferences at the decision-making point cannot effectively discharge the ethical duty of respecting patient autonomy.

To that end, operationalising Christman's RA theory, this section integrates an individual's competence, authenticity and involvement level of significant others into a unified, three-dimensional framework. Our proposal raises the need to reinvigorate the need to maintain good clinician–patient communication and is not intended to promote a direct, hands-on to resolving ethical dilemmas. As noted by Entwisle *et al.*, '[r]elational account will not generate simple action lists for clinicians that guarantee protection for patients' autonomy'<sup>10(p744)</sup>; clinicians must attend to the context-specific nature of each encounter and patients' characteristics. We elaborate on the relationships among the key elements and discuss a minor modification to Christman's original account: relaxing the competence condition to allow a broader spectrum of patients to engage in SCR.

### Competence and authenticity

A comprehensive theory of RA must define a clear relationship between competence and authenticity. According to Christman's theory of RA, stake detachment between a patient's current episodes and past historical narratives undoubtedly interrupts socio-historical selfhood. To better capture the traits that truly reflect a patient's autobiography after experiencing drastic events, clinicians can first invite the patient to engage in SCR and use the non-alienation test. An appropriately constructed autobiography could, in turn, serve as an essential reference for medical decision-making and determining the treatments that align with a patient's authentic wishes. In addition, clinicians can help patients rethink their expectations of their multiple social roles, enhancing reflexive self-affirmation.

Regarding the competence condition, patients' fluctuating conditions and possible acute situations may seem too demanding to engage in SCR. As stated above, Christman maintains that only minimal social, bodily, affective and cognitive competence are required to engage in SCR. Patients with mental capacity or consciousness impairment (eg, dementia, brain injury, frailty or delirium due to deteriorating illness), temporary emotional distress (eg, anxiety or depression), psychiatric disorders (eg, schizophrenia or bipolar disorder) and learning disabilities (eg, people who are illiterate or have little or no speech) might have increased disadvantaged of being precluded the chance to express their preferences or wishes.<sup>41</sup>

Christman's competence requirement reminds clinicians to resist the temptation to forgo engagement with patients unwarrantedly based solely on their disease category. A person with one of the health conditions stated above does not necessarily lack the capacity to make a specific decision and engage in SCR, unless evidence proves that this is not possible by any means.<sup>42</sup> One may lack the capacity to make some decisions (eg, to decide on complex financial issues) but can still make other decisions (eg, to decide what items to buy at the local shop). Hence, not only clinicians ought to engage with their patients substantially and creatively, but future research must also be encouraged to develop feasible communicative tools and techniques for clinicians to meaningfully engage with patients with special needs. Granted, when individuals are concerned, patients in a persistent vegetative state, irreversible coma and certain severe psychiatric and learning disability conditions might be deemed unsuitable to

engage in SCR. Clinicians and significant others may determine these patients' authentic wishes, which will be addressed in the following discussion.

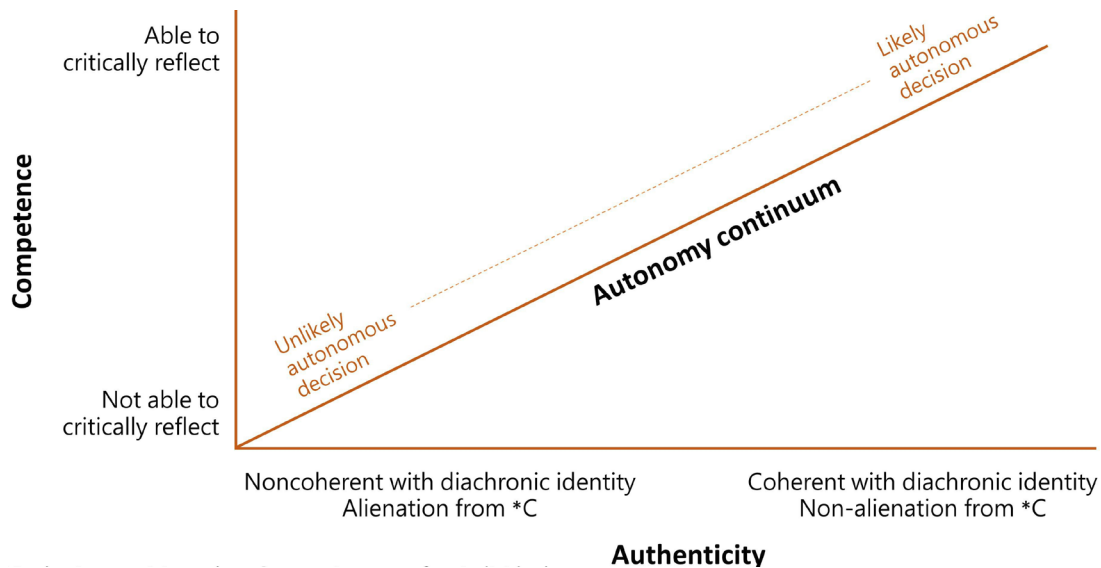
However, we contend that a subpart of Christman's competence requirement—one must be free from the constraining factors—must be relaxed to maintain his ambit and include a broader range of individuals in healthcare settings. Particularly, Christman's original position precludes people 'having been denied minimal education and exposure to alternatives' from engaging in SCR. This condition must be dropped in the end-of-life realm, as it might deny their opportunity for critical reflection and result in the unilateral exclusion of certain groups or people, impeding Christman's anti-perfectionist stance. By recognising that some patients might be too deprived to form their authentic wishes, clinicians and the interdisciplinary treatment team must always allocate sufficient time to continuously engage with and consult patients to understand their perspectives to the greatest extent. Moreover, clinicians could invite significant others' input to construct possible contours of patients' autobiographies. However, if clinicians' prudence deems patients susceptible to familial malfunctioning or interpersonal dominance, they should consider limiting the perpetrators from speaking on patients' behalf. Given the best efforts to draw possible historical profiles of patients, and they are comfortable with, or at least not opposed to this narrative, we contend that it is sufficient to locate patients' non-alienation. We believe this does not oppose Christman's SCR requirement that the patient has engaged in 'hypothetical and piecemeal' reflection, and overdoing patients might not be beneficial to building trust towards clinicians. Additionally, appealing to substituted judgement standards straight away might further strip patients of autonomy.

In [figure 1](#), the two extremes of the continuum reflect the probability of performing autonomous decision-making: 'likely autonomous decision' and 'unlikely autonomous decision'. The former implies that an individual can engage in SCR and is not alienated from their basic organising values and commitment in light of historical processes. The latter implies that an individual cannot engage in SCR and that their decision cannot be explained by their socio-historical understanding. Between these extremes, a plausible autonomous decision could coincide with changes in an individual's critical reflection ability, and it must be assessed whether this decision aligns with or deviates from the individual's fundamental life-long values and goals.

### Competence and involvement level of significant others

Largent *et al* have elaborated on the relationship between an individual's capacity and the involvement level of significant others in medical decision-making.<sup>11</sup> Their interdependence model proposes a continuum between 'total independence,' where patients with full capacity can decide for themselves, and 'total dependence', where patients without capacity would need a surrogate to speak on their behalf. Between these extremes, the individual's capacity level and various combinations of significant others involved in the decision-making process exemplify the interdependent nature of the decision-making continuum (eg, in the form of supported decision-making and permission plus partial involvement).

We adapted Largent *et al's* model and applied Christman's conceptual understanding of 'competence' to propose a revised model as seen in [figure 2](#). Building on the proposed changes in Christman's condition of competence, this model values one's ability to perform SCR as well as the involvement of others during the decision-making process. Patients without a bare minimum of competence cannot decide for themselves (lower-left corner



**Figure 1** Competence and authenticity. \*C= basic organizing values & commitments of an individual.

of figure 2) and should be considered rare in real clinical settings. Moreover, even if patients possess full competence, they could voluntarily delegate their decision-making authority to others (lower-right corner of figure 2).

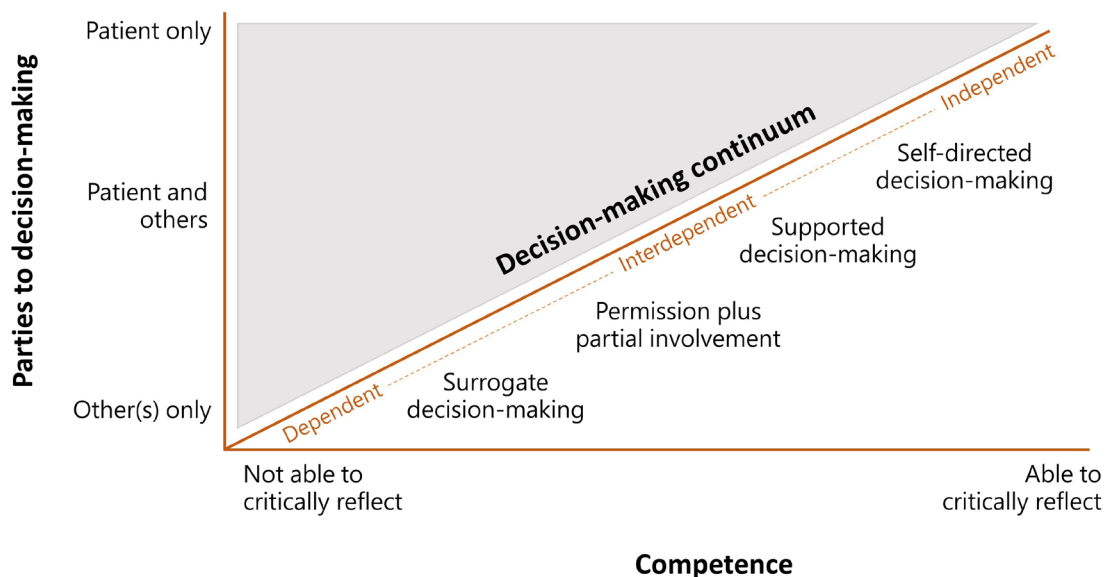
Apart from patients’ significant others and surrogates, health-care providers can use their expertise to partially alleviate barriers for patients to enable them to exercise competence, such as by restoring appropriate cognitive or physical functions and reducing physical and/or psychotic distress. As illuminated by Christman, clinicians ordinarily in a superior position could use communicative skills to improve patients’ self-regarding attitudes and avoid anti-social attitudes towards them. Certain communicative and social conceptions, such as cultural competency,<sup>43</sup> structural competency,<sup>44</sup> and epistemic justice,<sup>45</sup> must be imbued into clinical conversations. Tackling clinicians’ unconscious, implicit biases towards certain patient traits<sup>46 47</sup> and raising awareness about disempowering daily language could better equip clinicians to empower their patients.<sup>48</sup> Without such prior readiness, clinicians might not detect anything extraordinary in

their patients and be unable to resolve ethical dilemmas sensitively by considering each patient’s uniqueness.

Moreover, when medicine cannot restore a patient’s competence (eg, permanently incapacitated), clinicians could determine which decision-making standards should be applied in collaboration with patients’ significant others or surrogates. We agree with Scheunemann *et al* that if the surrogates hold sufficient information to make decisions that accord with the patients’ authenticity, this standard should prevail over the best interest standard.<sup>19</sup> Hence, clinicians need to robustly and sensitively engage with surrogates, especially those experiencing psychological distress and grief.

**Authenticity and involvement level of significant others**

According to Christman’s theory of RA, once individuals’ decisions are not alienated from their life values and commitment after exploring their historical experience and self-identity, certain competence conditions are satisfied. We further echo Christman’s characterisation of helpful interlocutors, showing



**Figure 2** Competence and involvement level of significant others.



that clinicians, and not physicians alone, play an equally paramount role as significant others in coconstructing a patient's autobiography.<sup>11 19</sup>

In our approach, desirableness includes patients' significant others in decision-making; however, we elucidate what clinicians might contribute. Some proponents of SDM have highlighted its nature as an 'existential journey,' viewing patients from a whole-person perspective rather than mere patients.<sup>49 50</sup> As Gulbrandsen *et al* highlighted, patients' dependency on medicine and health professionals could invariably be seen as putting trust in this asymmetrical relationship. Taking a relational view of patients' selfhood, while good *cure* strives to accommodate patients' physical or bodily related vulnerabilities, good patient-centred *care* would need to take their delicate relationalities and social needs onboard, particularly their inevitably interrupted sense of selfhood. As a 'curator', the clinician needs to tailor appropriate strategies for conducting SDM for each patient, adjusting the content of the daily clinician–patient conversation, and working jointly with the patient to rebuild their new sense of selfhood and existential meaning for consecutive life.<sup>49(p1508)</sup>

Moreover, numerous practical techniques, such as the 'life review' approach and lifeline interview, have also been developed to guide clinicians in working with patients and constructing treatment preferences based on their socio-historical backgrounds.<sup>51 52</sup> These trends have coincided with Christman's ethos. As mentioned above, clinicians must be equipped with certain communicative skills and mindsets to better engage with patients and their significant others. Recently, a group of clinician scholars have shown the feasibility of the 'lifeline interview' method for advanced lung cancer patients.<sup>52</sup> In this study, these Japanese patients are asked to draw a consecutive line on a formatted graphic to describe the magnitude of the ups and downs of certain life events. This process is accompanied by a semistructured interview guide conducted by the research team to better elicit the reason why patients put a certain magnitude towards each life event and record whom the patient would want to engage in the SDM or advanced care planning process. The authors claim their work is feasible mainly to help patients 'to rediscover their values and strengths' even in a country that usually sees talk of death as taboo.<sup>52(pE142)</sup>

### Clarification and implications

We have proposed a three-axis model of RA in end-of-life decision-making, enabling more contextual medical decision-making practices. Therefore, we have shown that integrating the three elements (competence, authenticity, and involvement level of significant others) for end-of-life care decision-making is theoretically possible within the ambit of RA and largely explains the core insight of current end-of-life care practices.

We do not prescribe any concrete marker(s) to indicate potential signals of the patient's alienation or what milestone(s) should be achieved in the clinical encounters. Although we encourage the development of practical tools and educational curricula, we urge clinicians to exert their practical wisdom to unearth delicate details in each conversation session and act responsively. Busy clinicians might be relying on the prescribed marker(s), thus creating a perverse incentive for them to disregard potential signals from their patients and undermining their ethical sensitivity in the long run.

This study's model has two implications. First, it might appear that the SCR and non-alienation test are not different from other mechanical procedures, such as decision-making capacity assessment. By contrast, while the latter might be executed without robust bidirectional engagement between clinicians and

patients, the former urges clinicians to exemplify their professional competence by diligently working with various parties to co-construct an autobiography that best fits the patient's authenticity. Hence, a proceduralist does not necessarily adopt a non-interfering formalistic stance but is open to meaningful humane interaction and healthcare within the ambit of the RA. Second, this model urges clinicians to play an active role in constructing patients' autobiographies, underlining an interdisciplinary approach to end-of-life care. Although physicians and nurses bear the primary responsibility for the care plan, the involvement of pain management, bereavement, holistic care and spiritual care share differential weights depending on the situation.

### THE CLINICIAN–PATIENT RELATIONSHIP AND RELEVANT OBLIGATIONS

To better characterise the obligations borne by clinicians and patients, we must rethink the asymmetrical clinician–patient relationship. We agree with Entwisle *et al* that clinicians have a general duty to support patient autonomy but maintain that it is supererogatory to restore patients' self-regarding attitudes in every instance.<sup>10</sup> Although one needs to possess some social skills to develop and exercise autonomy, it is distinct to state that clinicians must instil or foster these skills in patients. A proceduralist only needs to adopt an 'interpretive model' of the clinician–patient relationship to 'reconstruct the patient's goal and aspirations, commitments and character.'<sup>53(p2222)</sup>

Building on the classic procedural-substantive RA debate, the substantivist might worry that patients' elicited beliefs might be influenced by 'adaptive preferences', hence undermining their capabilities for developing and exercising RA.<sup>3</sup> When Mackenzie presents a female patient whose practical identity 'is governed by the norms of traditional femininity', she decries the procedural account of RA even operationalises with the non-alienation test. The patient might be so oppressed that she could not feel alienated from her belief<sup>14(p518, 521)</sup>. She further charges clinicians an obligation to proactively shift patients' adaptive preferences to enable them to discover alternatives<sup>14(p528)</sup>.

Against this backdrop, we err on Christman's assertion that even if one is genuinely influenced by adaptive preference, it does not automatically preclude them from exercising RA on a particular decision, including medical decision-making.<sup>34 37</sup> It seems inappropriate to value patients' *global autonomy*<sup>1</sup>, and this overarching goal may overextend the mission of medicine, especially in the end-of-life realm. Recently, prominent substantivists also admit that '[h]ealthcare professionals cannot be expected to secure the global autonomy of healthcare recipients'<sup>4(p80)</sup>. As shown above, clinicians should work jointly with their patients and significant others to produce a coherent autobiography. Patients' dependence on clinicians is best explained as they put an equivocal trust in their power, clinicians not only to relieve their physical illness but also seeking to build a new sense of selfhood for them.<sup>49</sup> If we are correct that the procedural approach of RA is best to adopt an interpretive model of the clinician–patient relationship, attempting to proactively change patients' unconventional convictions would obscure the opportunity to uncover their true beliefs and hence violate their autonomy, not to mention that patient would lose trust to their

<sup>1</sup>While 'local autonomy' refers to one's exercise of autonomy on a particular decision, proponents of 'global autonomy' go further to claim broader oppressive social structure hinders one's genuine autonomy.<sup>3</sup>

clinicians momentarily if clinicians persistently challenge their basic life commitments.

Additionally, even leaving aside whether there is a universal understanding of ‘adaptive preference’, it is unwise to label all unconventional beliefs under this category. As Quill Kukla (writing as Rebecca Kukla) shows, given that clinicians use their authority positively to enable patients to ‘critical engagement with their own healthcare practices’, it is justified to ascribe patients who fully delegate their decisional authority to clinicians as autonomous<sup>54(p40)</sup>. Some might argue that such patients could be motivated to lower their cognitive dissonance during decision-making or to please their clinicians. However, this objection does not present a unique problem given that the conclusion is reached through robust conversations with clinicians and that their competence and authenticity do reflect that.

Under this clinician–patient relationship model, we largely agree with Lewis, contending that these parties are engaging in a bidirectional, mutual-recognition relationship and each must be answerable to the other, enabling the co-production of medical decision-making<sup>30(p125–126)</sup>. For clinicians, proceduralists confirm numerous established obligations (eg, privacy and confidentiality) and impose additional obligations. Although clinicians are permissible to incorporate third parties’ opinions or convictions in decision-making, they cannot coerce or manipulate patients’ decision-making by arbitrarily limiting the scope of information flow and treatment options. Furthermore, clinicians are obliged to assess whether patients’ wills and choices contradict medical norms, even when patients exercise proper competence and authenticity.

Patients, in turn, are obligated to provide ‘appropriate reasons’ for their choices, inform those who will be influenced by the decision (ie, clinicians, family members, and significant others), and consider the latter’s views in their deliberations<sup>30(p130)</sup>. Then, combining Christman’s theory, must patients provide ‘process-independent reason’ when changing their minds? Notwithstanding this legitimate coercive concern, we believe this should not be the case. In contrast to Christman’s example as a social worker, the end-of-life dialogue might be the only channel for patients to engage in reflection, perhaps the only one in their lifetime. As medicine might not be intended to promote patients’ global autonomy, requiring patients to provide a process-independent reason could overburden patients facing life-threatening conditions. It may necessitate disclosing excessive personal information to justify a changing stance, disproportionately bleaching their privacy. Additionally, the worry of ‘adaptive preference’ must not divert attention to hold the medical enterprise to a higher bar and take serious care of each patient by constructing their unique autobiographies.

A reiterative reflective framework is essential for procedural accounts of RA that are not prescribed positively. This framework can become integral to clinical practice, particularly in the context of end-of-life care. In the remainder of this paper, we use an illustrative case study to demonstrate how our three-dimensional RA model contributes to real-life end-of-life care decision-making.

## A CASE STUDY

Consider the following scenario:<sup>ii</sup>

*Shu-Fen is a 63-year-old woman who has terminal bone cancer. She is being cared for by her daughter, a single mother with two young children. Shu-Fen has decided to refuse all*

*life-sustaining treatments to reduce physical suffering and avoid becoming a burden on her daughter and society. The healthcare team concludes that she possesses full decision-making capacity.*

*Recently, Shu-Fen underwent a below-the-knee amputation and is having to come to terms with the prospect of permanent disability. Her illness left her feeling guilty towards her daughter and questioning her own self-worth. Shu-Fen expressed her wish to the healthcare team to cease any further treatment and let nature take its course if the cancer spreads to other parts of her body.*

*However, at times, when Shu-Fen experiences pain from cancer, she longs for the healthcare team to save her or at least allow her to spend more time with her daughter and grandchildren after talking and being with them.*

*Seeking to understand the daughter’s perspective, the healthcare team discusses with her. They observe that Shu-Fen is a self-abnegating woman who always puts family needs before her own and is used to sacrificing herself for others. Her daughter explains that her mother has experienced hardship since childhood and is not used to being dependent on others. However, she has willingly taken on the responsibility of caring for her mother and pleads with the healthcare team to do everything possible to save her.*

*Recognising the importance of understanding Shu-Fen’s desires and ensuring that she makes informed decisions, the healthcare team approaches her to explore her thoughts. However, she declines to express her views directly, indicating her preference to leave the decision-making authority to her daughter. Privately, though, she frequently hints that she believes her life has been fulfilling enough and does not want to burden others further.*

*The healthcare team finds itself in a difficult situation, as it has been unable to make substantial progress in direct communication with Shu-Fen. They are left with no choice but to discuss with her daughter, which raises concerns about whether this approach fully respects and honours Shu-Fen’s autonomy and wishes.*

Shu-Fen’s case exemplifies a common scenario in clinical settings, especially in Asian contexts. This case demonstrates various complexities: (1) Shu-Fen has expressed seemingly conflicting feelings, expectations and preferences regarding her illness and death; (2) Shu-Fen and her daughter disagree; (3) Shu-Fen delegates decision-making authority to her daughter but occasionally expresses her preferences, making it challenging for others to follow. Some patients may be hesitant or reluctant to make decisions for themselves, lack a sense of autonomy, or be unfamiliar with their rights in healthcare decisions. They may not even consider themselves to have the authority to make decisions. In such cases, healthcare teams often communicate with patients’ family members and act on their decisions. While this approach may be well intentioned and ease the decision-making process, it can result in disregarding the patient’s agency and autonomy in healthcare.

First, patients often have oscillating preferences rather than clear-cut or consistent. As noted by Ohnsorge *et al*, the coexistence of opposing wishes can be authentic, multilayered experiences and moral understandings at the end of life.<sup>55</sup> Recognising that patients’ seemingly contradictory thoughts and requests can be part of the process of meaning-making and negotiating normative claims on a personal level and through interactions with others, healthcare professionals can adopt a more nuanced approach<sup>55(p630)</sup>. Through the lens of a diachronic socio-historical account of selfhood, the patient’s self is an ongoing, transforming process. By engaging in open and empathetic discussions with Shu-Fen, the healthcare team can evaluate the extent of her competence in reflecting on her fundamental values,

<sup>ii</sup>This case is inspired by the clinical experience of the authors CPL and YCC with cancer patient care.

desires, and beliefs, as well as her expectations of her social roles as a mother and grandmother. It is vital to facilitate a decision that is not alienated from her diachronic practical identity. In the terminal phase, patients approach death with each passing moment. Self-understanding may be more important than consistent decision-making. Exploring the patient's authentic self and collaboratively composing an autobiography and narrative that embraces evolving perspectives may be the proper way to honour RA in end-of-life care.

Furthermore, the development of RA transcends mere individual contemplation—a procedure of internal critical reflection—and transforms into an intersubjective, interactional accomplishment that unfolds within the fabric of communicative practices. In particular, one's narrative may become more explicit through joint reflection and support from others. As argued in the previous section, healthcare teams, instead of being detached from the whole process, are obligated to provide support, such as offering medical information, alleviating symptoms, and enhancing patient confidence and self-esteem, to reduce the barriers to patients' reflection and decision-making and to take an active part in the co-construction of patients' autobiographies. In this case, we propose that clinicians should not limit their role to merely assessing Shu-Fen's decisional capacity and freedom of choice; instead, they should try to engage both Shu-Fen and her daughter in a meaningful dialogue to exercise Shu-Fen's RA. When clinicians actively support patients in exploring and reflecting on their authentic wishes, it builds trust and strengthens the healing relationship.<sup>56</sup>

Our proposed model also considers the broader socio-cultural and healthcare contexts and the interpersonal and social dynamics within which one is situated. Therefore, when supporting the decision-making process of terminally ill patients, it is essential to be mindful of how their past experiences and social and structural backgrounds interact and how these relationships can shape their identities and, in turn, either enhance or hinder their autonomy. In Shu-Fen's case, her upbringing and social norms shape her perspective. As a woman and mother, she may have become habituated to self-sacrifice, prioritising the well-being of her family over her own. Nevertheless, pulled in different directions by her intersecting relationships with her daughter and the clinicians, she remains uncertain about her true preferences.

Closer examination revealed that Shu-Fen's perspective evolved as she interacted with her family. Initially, Shu-Fen perceived herself as a burden and thought that the best way to benefit her daughter was to die earlier. In this case, the healthcare team should regard Shu-Fen's refusal of treatment as an opportunity to create an open space for meaningful dialogue. This would allow the patient to express her reasons for refusal and negotiate treatment choices that may deviate from standard medical advice. Additionally, it provides an occasion to communicate with her daughter and clarify her understanding, considering what these relations mean to her identity and, hence, her decisions. Through these open and supportive dialogues and interactions, the family members can foster mutual understanding and realise that the daughter also depends on Shu-Fen, values her company and desires her to live longer, revealing the interdependence of their relationship. These relationships facilitated Shu-Fen in developing a stronger sense of self-worth and self-trust, improved her articulation skills, fostered self-reflection over time and enabled better integration of her practical identity and social values during the decision-making process.

How should we approach the role of Shu-Fen's daughter? Engaging significant family members in communication and decision-making is crucial when patients prefer family-led care.

This involvement should neither be perceived as hindering or impeding the patient's autonomy nor should it suggest substituting for the patient's decision. By integrating these three interrelated dimensions into the decision-making process for end-of-life care, the healthcare team seeks to foster Shu-Fen's competence and authenticity in a 'cooperative deliberation' process with others.<sup>40</sup> Respecting Shu-Fen's RA in a procedural sense does not compromise her choices in clinical practice. It is important to note that we should avoid endorsing East/West cultural stereotypes and perpetuating the false dichotomy between Eastern and Western principles of autonomy.<sup>57 58</sup>

## CONCLUSION

This study enriched the application of RA in end-of-life care medical decision-making. Our primary contribution lies in modifying John Christman's theory, illuminating the nuanced interplay between competence, authenticity, and relational dynamics. We proposed relaxing Christman's competence condition of autonomy to include the broadest range of patients engaged in SCR. Additionally, we suggested that terminal patients should not be obligated to provide 'process-independent reason' when changing their treatment preferences.

Adopting a procedural approach to RA is justified in end-of-life care where strong substantive conditions are inappropriate for terminal patients who should not be compelled to undergo significant changes in beliefs and values unless overt manipulation or oppression is evident. The case of Shu-Fen exemplifies how factors such as illness and oppressive socialisation can affect decision-making, prompting a shift in focus from liberating patients from external influences to promoting their competence and authenticity in autonomous decision-making.

Moreover, our integrated three-dimensional decision-making model for RA refines Christman's socio-historical account and offers descriptive and normative insights into end-of-life care. This model emphasises the dynamic and evolving nature of the authentic self and recognises the fundamental roots of autonomy in intersubjective and dialogical processes, thus providing a more contextual framework for medical decision-making. In the ongoing pursuit of advancing RA in end-of-life care, future studies should build on our model and provide concrete suggestions for enhancing clinicians' competencies through professional development.

Importantly, advocating for a procedural approach to RA does not imply an endorsement of a 'thin' or 'minimalist' conception of autonomy. In the terminal phase, patients undergoing a stressful ordeal due to life-threatening illnesses make decisions concerning and depending on clinicians and other professionals. Our theory of RA contributes a meaningful explication to the nature of the clinician–patient relationship, emphasising the ethical responsibility of healthcare teams in responding to patients' needs and expectations and fostering their autonomy. It provides a practical framework for navigating complex decision-making scenarios, fostering trust and negotiating shared values between patients and their families. By embracing a relational perspective and considering the dynamic nature of authenticity, we hope to pave the way for healthcare professionals to engage in meaningful and supportive interactions with patients. This approach ensures that autonomy is respected and actively fostered throughout the challenging journey of end-of-life care.

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