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CASE REPORT

The changing face of personhood at the end of life: The ring theory of personhood

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ABSTRACT

Objective: The manner in which personhood or "what makes you who you are" is conceived is key to the provision of patient-centered care and maintenance of the dignity and quality of life of terminally ill patients. However, there is little agreement on how this pivotal concept ought to be defined. Some have argued in favor of an innate concept of personhood, while others see an individual as a reflection of their familial identity or their conscious function, and all share a common position that personhood is unchanging, and hinges upon the central theme of their respective concepts. The present paper aims to explore a more clinically influenced perspective of personhood.

Method: We report the case of a 42-year-old Malay Singaporean who had been a caregiver for her husband throughout his cancer and then became a cancer patient herself after his passing. This case explores her changing and multifaceted conceptions of personhood throughout her life and illness, and discussions about end-of-life care.

Results: The patient reports a concept of personhood that encompasses the innate, individual, relational, and societal aspects, which are interlinked and vary in terms of depth and conviction according to the various times in her life and illness.

Significance of results: Our findings support the ring theory of personhood, which provides a clinically supported model of the conception of personhood that is context dependent and encompasses the four abovementioned aspects.

KEYWORDS: Personhood, Palliative care, Ring theory of personhood, End of life

INTRODUCTION

The manner in which personhood is conceived is critical to the provision of patient-centered care and maintenance of respect for and the rights, dignity, and quality of life of terminally ill patients (Saunders, 1984; Huijer & van Leeuwen, 2000; Nelson, 2000; Douritch et al., 2001; Chochinov, 2002; Twycross, 2003; Gallagher, 2007; Ellis-Hill, 2011; Mitchell, 2012). Yet the manner that personhood is conceived continues to be contested (Nelson, 2000; Krishna, 2013; Krishna et al., 2013; LiPuma, 2013). Some authors suggest that personhood is innate, endowed to all persons by virtue of divine connection and or by being human (Chochinov, 2002). This Innate view of personhood is challenged by the Individual view of personhood, which maintains that personhood is dependent on the presence of consciousness, and by the Relational view of personhood, which posits that personhood is a facet bestowed to an individual by virtue of their belonging to a family or relational circle (Devine, 1987; Fletcher, 1979; Rich, 1997; Tsai, 1999; 2001; 2002; Farah & Heberlein, 2007; Fan Ruiping, 2007; Fins et al., 2008; Hui 2008; Ho et al., 2010; Cheng et al., 2012; Zhang, 2012). Vanlaere and Gastmans proffer a wider notion of

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personhood based on relational and divine ties drawn from a personalist approach (Selling, 1999; Vanlaere & Gastmans, 2011; Gastmans et al., 2011; Paley, 2011).

This lack of uniformity in the manner in which personhood is conceived has taken an ominous turn with LiPuma's suggestion that the unconscious terminally ill patient in whom there is little chance of recovering conscious function ought to be considered "dead" by virtue of a cessation of their social activities (LiPuma, 2013). He suggests that "social death," particularly as a result of iatrogenically induced deep sedation into unconsciousness ostensibly until death, precludes any meaningful existence and thus is differentiable from the "biological death" that eventually follows such treatment. While this suggestion was aimed at a select few patients, the repercussions of such an idea has far-reaching repercussions, particularly given that many patients at the end of life do succumb to unconsciousness as part of the natural progression of their illness. To address LiPuma is to question whether personhood is indeed solely dependent on the presence of consciousness and whether a state of unconsciousness at the end of life ought to be equated to death.

While Parfit's "bundle theory," Kitwood's and Buron's Relational and Social conception of personhood, Vanlaere and Gastmans's Personalist perspective of personhood, Tsai's Relational concepts of personhood, and Nelson's concept of Innate personhood would counter this position, in truth, none successfully capture the beliefs of patients at the end of life nor contend with inherent cultural, religious, societal, and familial differences (Parfit, 1971; Kitwood, 1997; Nelson, 2000; Tsai, 2001; Buron, 2008). We believe that the ring theory of personhood (ring theory) may fill this gap untethered to a fixed perspective (Krishna et al., 2013).

Ring theory posits a model of personhood that is multifaceted, consisting of Innate, Individual, Relational, and Societal aspects. These aspects may change in strength and breadth throughout the course of a person's lifetime, often varying with context and disease burden. Below is a case that illustrates this model.

Case Presentation

Azura (all names have been altered to protect confidentiality), a 42-year-old Malay Singaporean, first came into contact with palliative care in 2010 as a caregiver for her third husband, Ara, who had been diagnosed with rectal cancer and liver, lung, and bone metastases. Despite radiotherapy and chemotherapy, Ara's disease continued to progress, and he was referred to the palliative care team for pain control, psychological support, and financial counseling. During this time, Azura was involved in many difficult conversations with him about his end-of-care plans and conversations about "what makes me who I am."

In the years after his passing, she had to fend for herself and find a job to care for their two daughters, Safira and Nafira, who were then five and seven years old. Her only support was her sister Azlinda. She later remarried, but fewer than nine months after her marriage, Azura began to suffer from increasing back pain that necessitated a hospital admission. She was diagnosed with a primary right kidney cancer, with multiple skeletal, liver, and lung metastasis. Although she underwent chemotherapy and radiotherapy, she was aware that her prognosis was limited. When she was referred to palliative care, this time as a patient, she was already suffering significant liver capsular pain and right scapular pain. A further course of radiotherapy to her shoulder and titration of opioids, steroids, and neuropathic agents left her comfortable and ensured that she was able to start making her final care plans.

In discussing her goals of care and her end-of-life care plans, Azura explained that her conception of personhood had changed and indeed continued to evolve with time, experience, and in recognition of her changing clinical condition and life expectancy. She reported that, when she first discussed the subject of personhood with Ara as part of his end-of-life planning, she and he held differing beliefs. Ara had deeply held spiritual beliefs and strong family-centric values that he had developed following their marriage. He believed that personhood was more than an expression of his conscious physical abilities. For her, however, it was being functional and being able to communicate with family that had defined both her and Ara's personhood. Azura recalled telling Ara that she strongly believed that she was a person only for as long as she was able to function and communicate. Without conscious function at the end of life and little chance of recovery, Azura envisaged her existence as being "equivalent to being dead. All that remained is a body that looks like me but isn't me."

Azura admitted that she had not always held such a narrow "functional" view of personhood. Like many Malays in Singapore, she was raised a Muslim and had been instilled with family-centric beliefs and specific religious values, and had once subscribed to an Innate conception of personhood. However, she had seen many of Ara's friends and family members, whom he had had been close to before meeting her, abandon him when he converted to Islam to marry her, and she had started losing faith when first her second husband, Matthew, then Ara, and then subsequently Azura herself, succumbed to malignancy.

These views of personhood evolved again throughout Azura's experiences with Ara's illness and

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demise. She found that her inability to be by Ara's side all the time while he was unconscious left her concerned as to the manner in which he would be cared for. It made her "realize" that personhood, replete with its rights and privileges, must be granted to all people, particularly when patients are incapable of preserving their own rights and privileges and have no family or friends who can ensure that their personhood is maintained.

Azura noted that Ara had frequently lapsed into periods of unconsciousness and confusion as he entered the terminal phase of his illness, compromising his ability to maintain his own personhood, at times seeming like "he was somebody else." Azura had witnessed similar episodes when Ara had been given certain medications, and particularly toward the end of life, when his brain metastasis had "changed him completely. He was a different man completely. The way he thought and acted was new. The steroids woke him up, but he woke up a different person." For Azura, she chose to maintain Ara's premorbid values and goals even when he was conscious but did not exhibit psychological continuity. To Azura, the lack of Ara's psychological continuity was an indication to persist in acting in his best interests.

Her conception of personhood evolved further during the difficult time following her husband's passing. With her increased responsibilities in looking after her children, and her sister's steady support during her own illness, she came to realize that her role as a mother and sister were now as important to her functionality within her conceptions of personhood. She no longer accepted that she was defined by her physical and cogitative abilities.

"When Ara was dying and unconscious, my daughters still loved him and talked to him as though he was awake. My own feelings did not change. Maybe it was hope that he would awaken, but really it was accepting that even when he was gone, he was still my love and that wouldn't change. I understand now what he meant by being defined by my family and my roles."

Azura admitted that there were times when she found her familial duties taking precedence in her decisions, underpinned by her belief, and that at these points it was her familial role that defined who she was as a person. There were also times when it was her individuality that took precedence, particularly in determining the site and manner of her care. Azura believed that "Who I am as a person depends upon my situation."

As her disease progressed, she experienced a few episodes where she found herself too unwell to make determinations for herself. Her views on personhood evolved yet again, and Azura believed, during her periods of incapacity, that her personhood would be maintained by those she shared a "close and important relationships with." These individuals were not restricted to her family but included close friends and even her carers, with whom she had developed a strong bond. It was important to Azura to rely on those who were close and important to her, given her belief that it would ensure that she would be cared for in a manner in keeping with her personal beliefs. It was these persons who would be best able to consider her wishes and interests in situations she may not have considered.

Yet Azura also accepted that there was a basic level or standard to which her personhood would be respected, particularly when she was among "strangers and carers." Here her personhood would be determined by her demographic information and prevailing societal beliefs, clinical standards, and the laws of society. This too was important to her and addressed her earlier concerns about care for the lone and unconscious patient.

DISCUSSION

Azura's context- and role-dependent views on personhood crystallizes ring theory. Rather than attempting to refute established concepts of Innate, Individual, and Relational personhood, ring theory encapsulates them and highlights how each concept influences the other and how conceptions of personhood as a whole evolve. Azura's case highlights a further element of ring theory—the role and contextual dependence of this concept that has not yet been fully crystallized.

The Ring Theory of Personhood

The ring theory of personhood suggests that personhood is constituted by four interrelated, dynamic areas. The **Innate ring**, the innermost ring, is anchored in the notion that all humans—irrespective of clinical status, culture, creed, gender, sexual orientation, religion, or appearance—are deserving of personhood. The **Individual ring**, which encases the Innate ring, pivots on the importance of an individual's unique values, beliefs, roles, personality traits, goals, and preferences, as well as their abilities to display the various facets of consciousness. The third ring, the **Relational ring**, is defined by the individual's close and personal ties. The outermost ring, the **Societal ring**, contains relationships with societal members, estranged family members, colleagues, and acquaintances. The Societal ring is tasked with overseeing protection of an individual's rights and privileges. Taken together, these four rings make up a patient's personhood (see Figure 1).

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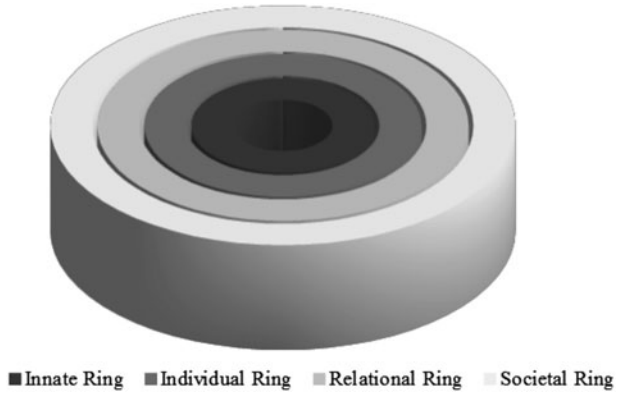

Fig. 1. Ring theory of personhood.

The Innate Ring

The Innate ring represents an individual's Innate personhood. The Innate ring revolves around the notion that all persons are a reflection of God, imbued with human dignity and rights irrespective of their stage of development or illness (Devine, 1987; Nelson, 2000). Rather than being rooted in Greco-Judeo-Christian, Confucian, Buddhist, and Hindu traditions, this position has also evolved to encapsulate Devine's nonsecular philosophical treatise of "species principle," which holds that all members of "the species *homo sapiens* are persons whereas nonhuman animals, robots, or extraterrestrial life cannot be persons." Though subject to accusations of "species-ism," this position is primed to ensure that the physical, cultural, social, and religious inequalities that still pervade some Asian societies are redressed (Goh, 2008). This Innate personhood remains constant throughout life, unaltered in the face of clinical, social, psychological, spiritual, cultural, and familial changes, or any other considerations, until all attempts to maintain biological life have ceased.

It therefore confers personhood to fetuses and patients at the end of life who are unconscious or in states of impaired capacity, ensuring that these individuals still receive the consideration and respect afforded to all persons. However, while the Innate element remains unchanging, the secondary elements—consisting of the Individual, Relational, and Societal elements—do alter with time and context.

The Individual Ring

The next ring is the Individual ring, which contains Individual personhood, which is associated with manifestations of the higher functions of consciousness, including self-awareness, self-determination, and the ability to appreciate one's self over time and in different circumstances, as well as character traits, personal values, beliefs, and goals. Of particular importance to this element is its dependence on (1) consciousness, (2) cognitive functions, and (3) psychological continuity, and (4) its association with the other elements of personhood seen on the wider canvass of a patient's specific psychosocial, spiritual, cultural, familial, clinical, and societal situation (Parfit, 1971; Mitchell, 2012).

As Individual personhood pivots on the presence of conscious function, unlike the Innate ring, a patient can lose his Individual ring while still alive through the loss of consciousness. However, this loss of Individual personhood either through a loss of consciousness or cognitive function is not seen to end personhood, due to the continued presence of other elements, but it ushers in a change in the manner in which personhood is conceived (see Figure 2).

Thus, the Individual element of personhood may be reestablished based on the extent to which it is dependent on the ability of a person to reclaim Fletcher's 15 facets of personhood (Fletcher, 1979). This includes his self-awareness, self-control, sense of time, sense of futurity, sense of the past, capacity to relate to others, concern for others, communication with others, control of existence, curiosity, change

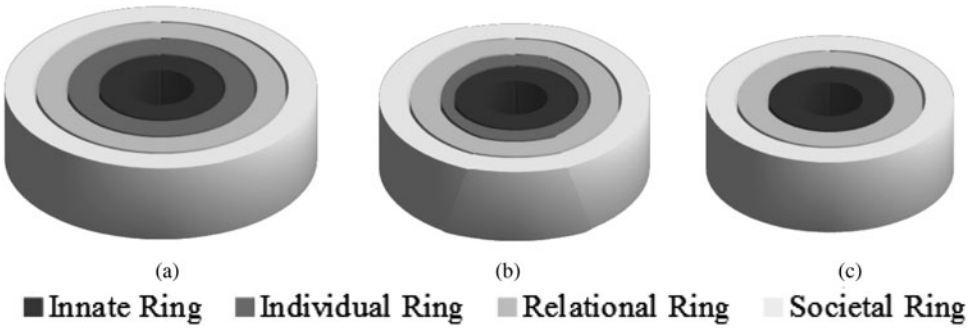

Fig. 2. Changes in ring sizes. Diagram A shows a patient fully conscious and cognizant, thus with Individual ring at full size. Diagram B shows a reduction in size of the Individual ring, due to fluctuating/reduced consciousness or cognitive ability, e.g., in delirium. Diagram C shows an Individual ring that is completely gone, e.g., due to unconsciousness, but a personhood that is still maintained by the other rings.

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and changeability, balance of rationality and feeling, idiosyncrasy, and neocortical function (Tsai, 2001). Full restoration after a period of unconsciousness entails redeeming these functions to their premorbid level and ensuring the presence of psychological continuity or "the same continuing consciousness" (Parfit, 1971; Fletcher, 1979; Mitchell, 2012).

The rings, being three-dimensional and fluid in nature, are thus defined by their size and depth. With regard to the Individual ring, its size is thus defined by the ability to manifest those features that Fletcher considered integral to Individual personhood, while depth is defined by the maturity of the various characteristics or how well developed they are, and the consistency with which these elements are held.

Consistency and maturity in manifestations of consciousness and cognitive function are particularly affected by emotional distress or such psychological states as depression, anxiety, and mania, which are common among terminally ill patients. A person with severe depression or chronic illness may experience a changing level of cognitive function similar to what a delirious or confused patient might experience, emphasizing the delicate nature of Individual personhood and the need to continuously assess an individual's condition, particularly at the end of life.

The Relational Ring

The next element is that of Relational personhood. It encircles the Individual ring, and the Relational ring is connected with the Societal, Individual, and Innate rings. It houses all close, important relationships that the individual has, and it is partly the Relational element that maintains an individual's personhood in circumstances where the Individual element is impaired. The concept of Relational personhood draws upon the feminist concept of the Relational self, the Confucian concept of persons, Personalist views, and local data, as well as regional ethnographic work (Radha Krishna, 2013).

There are two features to those relationships endowed with a place within the Relational ring. First. these relationships are both personal and deemed important by the individual themselves. Thus, it is the individual who determines membership in their respective Relational ring. Membership to this ring is not limited to family members and includes friends and carers.

The second feature of the Relational ring is that membership can change, and those no longer deemed "worthy" of a place by the patient are relegated to the Societal ring. Such consignment is at the sole discretion of the patient. Change in membership has significant repercussions for the third facet of this ring, which is the reciprocity of membership. This means that all those deemed to be part of a patient's Relational ring have within their own Relational ring a relationship with the patient. This interrelatedness feeds the local notion of shared values and entwined interests that is widely reported in Singapore and across Asia.

Like the others within ring theory, the Relational ring is defined by its size and depth at any given moment. The size of the ring is determined by the number of close, important, and interrelated relationships that the patient has, while the depth of the ring is determined by the quality of those relationships. Quality of relationships is determined by their durability and consistency, particularly when the individual is ill over a long period of time, when maintenance of the link is largely sustained by the other person.

The Societal Ring

Those relationships relegated from the Relational ring are housed within the Societal ring, which encapsulates the Relational ring. It also contains relationships with acquaintances, colleagues, family members, and friends who do not share a close or important relationship with the patient. However, rather than be subservient to the Relational ring and deemed less important than the Innate and Individual rings, the Societal ring plays a critical role in policing the other rings.

The Societal ring contains the legal, professional, cultural, and societal expectations and standards on maintaining personhood in the society of the individual, ensuring that a basic level of respect and rights are afforded all persons who are unconscious, incompetent, or incapable of preserving their own personhood. Thus, it ensures that a stranger found within a community would be afforded basic levels of respect and rights and would be cared for in a manner that would be in keeping with his ethnic, religious, and cultural background, if known. Once again, the size of the ring is dependent on the number of relationships contained within the ring, and its depth is dependent upon the strength of the oversight the Societal element has over other rings.

Applying Azura and Ara's narratives to the Innate Ring

Azura noted that, though Ara was at times unconscious and without family or friends around to care for him, a basic level of personhood was still maintained. In fact, she stated that this basic level of consideration must be afforded all patients irrespective of their clinical state and background. Azura added, "Everybody is somebody to someone. Even an abandoned newborn child is still someone to the people who find her. The child deserves respect, care, and

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love. We all do, especially when we cannot look after ourselves." This illustrates the belief in an Innate element of personhood that is always present despite circumstance.

However, Azura's belief in the Innate nature of personhood did change over the course of her lifetime and with her experiences related to changes in the strength of her spiritual beliefs. The difficulties in her and Ara's life "reduced" those beliefs, while the subsequent support by her sister and daughters, and thus restoration of her close familial relationships, helped restore them.

It is instructive to note that the reinvigoration of Azura's familial beliefs also had an impact on her Relational ring, while the change in this position also affected the Individual ring, and the conjunction of all these changes in turn affected the Secondary and Societal rings—thus emphasizing the interrelated nature of the various rings.

Applying Azura and Ara's narratives to the Individual Ring

Azura's understanding of Ara's personhood was at first heavily influenced by the Individual ring. Nearing the end of his illness, the fluctuating episodes of consciousness and cognition he suffered seemed to her to have attenuated this aspect of his personhood.

Changing levels of cognition also highlight the importance of psychological continuity. Azura chose to maintain Ara's premorbid goals, ensuring a psychological continuity between the premorbid personality and the one that emerged from unconsciousness or bouts of cognitive disruption. This illustrates the interactions between the Individual ring, and the Relational and Societal rings. The various features of consciousness and character traits that feature within the Individual ring are integral to the formation and maintenance of personal relationships and associations, and thus the Relational and Societal rings, and, in turn, the Relational and Societal rings, can help maintain the Individual ring when it is compromised. As Azura explained, while she accepted that Ara might have had a "change of heart" or even a "moment of clarity" that may have underpinned his change in behavior, Azura and the family members who knew him well maintained that the change was so stark and out of character that they felt that complying with his new requests would not be in his best interests.

Applying Azura and Ara's narratives to the Relational Ring

Both Ara and later Azura's experiences underscore the importance and changing nature of the Relational ring. In Ara's case, the maintenance of his personhood by Azura, and their daughters Safira and Nafira, illustrates the core function of the Relational ring, which is to preserve the identity and uniqueness of an individual in a manner in keeping with their premorbid personal beliefs, values, and goals, especially when the individual is unable to do so themselves. Likewise in Azura's case, she stated that there were a select few whom she would turn to when she was unable to maintain her own personhood, like when she was struggling with delirium after a severe infection earlier in her illness.

Azura noted that, while there were many friends who considered Ara a close friend, their support and presence dwindled over the course of his illness. In the end, only a few good friends were with Ara during the terminal phase—a change in the size of the ring, if not the depth.

Applying Azura and Ara's Narratives to the Societal Ring

Ara had had a difficult life and had been abused by his foster family after his mother abandoned him and his father became an alcoholic. As he lay dying, there were quarrels between his estranged mother and his wife as to the manner in which he ought to be cared for and how his remains were to be treated. It was his carers, doctors, nurses, social workers, and friends who acted to ensure that the manner of the care proposed for Ara was in keeping with his present beliefs—his Societal ring maintaining his personhood.

General Application of Ring Theory

Azura's experiences both as a carer and a patient show that conceptions of a "fixed" idea of personhood, as held presently, is improbable. Azura and Ara's conceptions of personhood evolved throughout their illnesses and changed in various settings. In both these cases, atomistic views of personhood appear to have given way to more multilayered ones.

Ring theory thus introduces a concept of personhood that is clinically based, evidenced based, and fluid, evolving with the contextual changes and personal experiences of the patient. The manner in which these changes occur within the overall conception of personhood is person specific and complex, particularly in light of the cultural, ethnic, and religious diversity of Singaporean society, reiterating the need for a holistic review of a patient's personhood.

Azura and Ara's cases also highlight that only with holistic and continuous review in tandem with ring theory can the dignity of, respect for, and rights of these patients be preserved at the end of life. It is only with appropriate comprehension of this

evolution in perception that meeting patient-centered care goals under the aegis of palliative medicine can be achieved.

Finally, Azura and Ara's narratives serve to highlight caregiver–patient variances in conceptions of personhood and their significant implications for proxy decision making and familial determinations.

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