

## How do English-speaking Cancer Patients Conceptualise Personhood?

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### Abstract

**Introduction:** Understanding personhood or “what makes you, you” is pivotal to the provision of person-centred care. Yet the manner that personhood is conceived amongst patients varies significantly. This study aims to investigate conceptions of personhood in a multiracial, multicultural, multireligious setting. **Materials and Methods:** A mixed-methods study was conducted at National Cancer Centre Singapore, from January 2013 to April 2013. We used a validated questionnaire where English-speaking oncology patients rated the importance of 26 features of “personhood” on a 10-point Likert scale from 0 to 9, with 9-points being extremely important. This was followed by a semi-structured interview. Analysis of transcripts using the Grounded Theory revealed original data that inspired novel ideas about the nature of personhood, which precipitated a further study in April 2014. **Results:** Our initial study of 100 patients revealed that personhood is conceived in a unique and novel manner. To study this, we interviewed a further 40 patients using a supplemental question to our original questionnaire. Our data affirmed our initial findings and evidenced a change in conceptions of personhood. **Conclusion:** Our evidence supports the Ring Theory of Personhood, which suggests that personhood is defined by innate, individual, relational, societal elements. It also evidences that personhood is temporally and contextually sensitive allowing for better appreciation of the evolving goals of care that frequently occur at end-of-life. Most importantly, this study reminds healthcare professionals of the importance of “treating persons” and looking beyond familial interests in maintaining the interests and dignity of the patient.

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### Introduction

Understanding the way personhood or “what makes you, you” is conceptualised is pivotal to the practice of medicine.<sup>1-6</sup> Conceptions of personhood determine the moral and legal status of an individual, is central to the protection of rights and privileges and is pivotal to the maintenance of the distinctiveness of the individual at times of illness and incapacity.<sup>1-6</sup> Bishop Merrill states that, “A clearer notion of what constitutes personhood will produce better arguments for moral decisions and actions in clinical settings and in public policy. It will also shed light on issues as far-ranging as abortion, euthanasia, and quality assurance in clinical care.”<sup>6</sup>

Yet despite its vital role, personhood is poorly understood.<sup>1-6</sup> This need is particularly evident within the end-of-life setting where provision of patient-centred care, the maintenance of dignity and issues pertaining to a “good death” revolve around appropriate understanding of personhood.<sup>7-10</sup> Indeed the charge of explicating this concept has been brought into sharp focus with suggestions that a loss of personhood ought to be considered indistinguishable from biological death.<sup>11</sup> Extrapolations of LiPuma’s position could be seen to relegate many terminally ill patients who are naturally delirious or sedated as a result of their ongoing disease process or as a result of treatment, to a state devoid of personhood and akin to death.<sup>11</sup> This worrying posture

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drawn from a conception of personhood that pivots on conscious ability and social interaction explains the exigency to better explicate conceptions at the end-of-life given the repercussions to care.<sup>11-13</sup>

Such “consciousness-led” definitions of personhood are but one of many prevailing views of personhood, each with a significant impact upon end-of-life care.<sup>14-19</sup> Resonating with personalist concepts, Polkinghorne, Himma and Beckwith suggest that personhood is tied to ensoulment, whilst Nelson notes that humanist views sees personhood endowed to all by virtue of being human.<sup>14-19</sup> These concepts of innate personhood are held to be lost only with the demise of the individual.<sup>2</sup> The impact upon palliative care given this belief that personhood is preserved irrespective of the state of the patient provides little impetus to protect the dignity and values of the unconscious patient nor to ensure a “good death”.<sup>2,20</sup>

This notion of personhood however has been rejected by some philosophers who suggest instead that the crux of personhood lies in the presence of self awareness.<sup>4,21-26</sup> Fletcher’s 15 “criteria or indicators” of personhood expand upon pre-existing theories of personhood that revolve upon consciousness-dependent factors and the centrality of rational thought.<sup>26</sup> Farah and Heberlein, Fins et al and Rich on the other hand have defined personhood by one’s ability to think and appreciate one’s own existence.<sup>21-26</sup> The impact upon end-of-life care where sedation and delirium are common is inescapable.<sup>12,13</sup>

Tsai’s 2-dimensional concept of Confucian personhood, on the other hand, refutes this atomistic view.<sup>5</sup> This concept which continues to dominate local thinking holds to the view that a “person” exists within a network of social and familial interrelatedness.<sup>5</sup> The impact to end-of-life care is inescapable in the denigration of individual rights of patients in favour of the wishes and values for family.<sup>5,27-29</sup>

Influenced by growing clinical evidence and case reports of a wider concept of personhood in the form of the Ring Theory of Personhood and Hughes’s statement that our notion of the “person” must square with clinical experience, we undertook to study local conceptions of personhood to better inform our practice.<sup>7,8,9,30-33</sup> We aimed to understand how personhood is conceptualised and defined amongst cancer patients in multicultural, multireligious Singapore.

## Materials and Methods

Two mixed-methods studies were conducted at the National Cancer Centre Singapore (NCCS) from January to April 2013 (2013 study) and March to April 2014 (2014 study). Both studies were identical other than an additional question being used in the 2014 study. English-speaking patients over the age of 21 attending the centre for outpatient

chemotherapy were invited to participate in a questionnaire and semi-structured interview on personhood. They were recruited via convenient sampling on a voluntary basis. There was no predetermined sample size. The sample size was eventually determined at the end of the study when data saturation from the qualitative analysis was reached. Data saturation was attained at 90 patients in the 2013 study and 16 in the 2014 study. The subsequent 10 interviews in the 2013 and 2014 studies respectively did not add further value to the data accrued nor reveal any disconfirming data. The decision was then made by the study team to stop at 100 in the 2013 study and 40 in the 2014 study.

Thematic analysis of the data collected in the 2013 study that revealed the notion that concepts of personhood evolved with time and context provided the rationale for the 2014 study and the impetus for the design of a further question to scrutinise changes in personhood. Both study protocols were reviewed and approved by the institutional review board.

## The Questionnaire

Following informed consent, participants completed a short personhood questionnaire that is based on Sarah Bishop Merrill’s questionnaire from her study, ‘Defining Personhood’.<sup>6</sup> A list of 26 features were presented to participants who were asked to rate how important each feature was to “being a person” on a 10-point Likert scale from 0 to 9. This list of features is shown in Figure 1. No statistical software was used for the quantitative analysis of the data.

## Qualitative Interviews

Following the questionnaire, participants engaged in a face-to-face semi-structured interview based on Krishna et al’s 2013 questionnaire on personhood.<sup>7,31</sup> This began with the question: ‘What other features make you who you are as a person?’<sup>7,31</sup> Subsequent questions were based on scenarios surrounding hypothetical characters in various health states.<sup>7,31</sup> These hypothetical situations offered a less threatening method to explore sensitive subjects.<sup>10,34,35</sup> The questions and hypothetical scenarios were discussed and developed with an expert panel to minimise researcher bias. A single trained interviewer completed all interviews in each study and in both studies, our data analysis was carried out in a similar manner. In both studies the average interview length was 30 minutes, but ranged from 20 to 90 minutes. Responses were transcribed during the interview process. The interviewer was tasked to accurately transcribe verbatim all relevant comments during each interview, as the interview sessions were not audiotaped. A member of the expert panel who evaluated the design of the study tool was invited to sit in for multiple interview sessions to evaluate

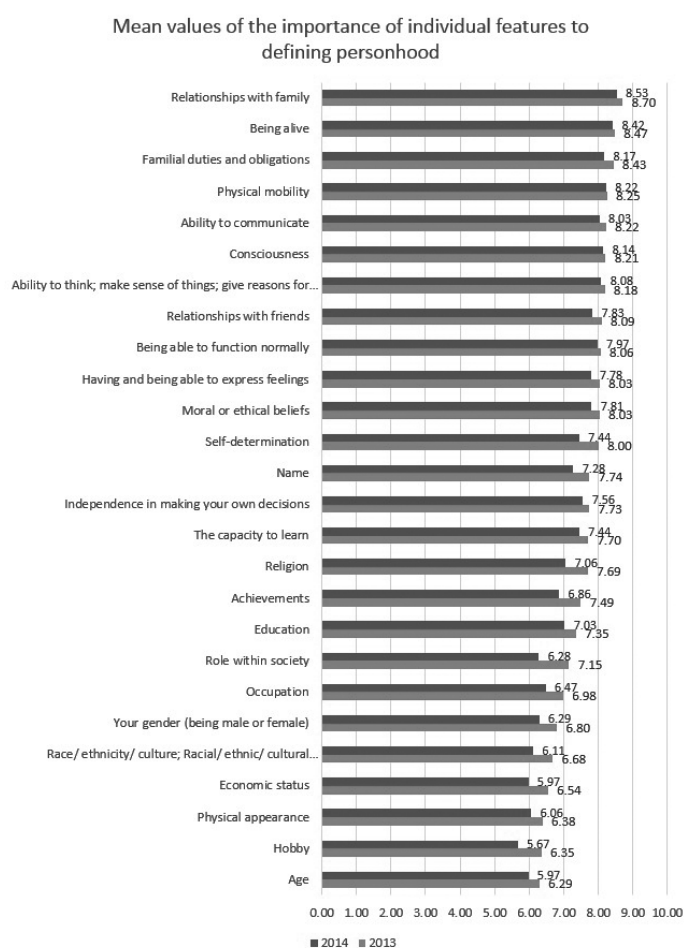


Fig. 1. Mean values of the importance of individual features to defining personhood – a comparison between data from 2013 and 2014.

the interview and transcription process. Interviewer field notes were kept throughout the data collection process.

Data analysis took place simultaneously with ongoing data collection. Transcripts were analysed using the Grounded Theory method in the following stages: 1) Open coding; initial familiarisation of the data; 2) Delineation of emergent concepts; 3) Conceptual coding; 4) Refinement of conceptual coding schemes; 5) Clustering of concepts to form analytical categories; 6) Searching for core categories; 7) Core categories led to identification of core theory; and 8) Testing of emergent theory.<sup>10</sup>

The data was constantly revisited throughout the analysis with a constant attempt to challenge developing theories. Close attention was paid to deviant cases. A minimum of 2 researchers were involved in the qualitative data analysis process at any point in time. Where there were differing codes and analyses, these were anonymously presented to external qualitative researchers to reach consensus.

The Grounded Theory method as developed by sociologists Glaser and Strauss (1967) was used as the nature of the study was broad and exploratory with aims to generate theory about “personhood” and the way it is understood, allowing these theories to be tested across a range of settings.<sup>35</sup>

Concepts that emerge from early stages of the data analysis were compared with subsequent concepts and categories emerging from the next (constant comparative method). This process of constant comparison went on until no new significant concepts emerged – ‘theoretical saturation’. The study team was constantly reminded to maintain a reflexive awareness of the research process and the researcher’s role. Apart from being open and reflexive about the methodology, theoretical assumptions and starting points were addressed by each researcher before the analysis began.

### *Design of the Question to Study Change in Conceptions of Personhood*

One emergent theme not fully captured within Krishna et al’s original 2013 questionnaire employed in our 2013 study was the issue of change in conceptions of personhood as patients progressed through their illness.<sup>7,31</sup> To study this element, a further question was to be added to Krishna et al’s questionnaire.<sup>7,31</sup>

Design of this questionnaire was inspired by a number of factors highlighted in Table 1.<sup>36</sup> We were particularly cognisant of the characteristics of the patients, their physical, emotional and practical limitations as well as the overall time constraints given our need to limit discussions to less than 30 minutes. We were also aided in our design by the data and experiences studying personhood amongst local oncological patients, a review of similar studies, our debrief notes from previous studies and refining the focus of study to the issue of change in personhood.<sup>7,31</sup> Our third question was, ‘Do you think you have changed as a person over the course of your illness?’

## **Results**

### *Participant Characteristics*

A total of 100 patients completed the questionnaire and semi-structured interviews in our 2013 study, and 40 patients participated in our 2014 study which included our new question on change of conceptions of personhood. Table 2 shows the basic demographics of participants. There was an even distribution of male (55%) and female (45%) participants in the 2013 study. In our 2014 study, 70% of our participants were males; 78% of the participants were Chinese in both studies. Representation of the other key ethnic groups in both studies closely mirrored their

Table 1. The Key Elements that Helped Guide the Design of the Question on Changes in Personhood

Debriefing	<ul style="list-style-type: none"> <li>• Prior debriefing experience in previous studies on personhood</li> <li>• Comments of students, social workers, physicians, nurses and physiotherapists</li> <li>• Relevant theories</li> <li>• Previous study findings</li> <li>• Prevailing sociocultural, philosophical and religious/spiritual views</li> <li>• Prevailing practises</li> </ul>
Psychological factors	<ul style="list-style-type: none"> <li>• Pressure</li> <li>• Stress</li> <li>• Anxiety</li> <li>• Low mood</li> </ul>
Physical considerations	<ul style="list-style-type: none"> <li>• Reduced concentration</li> <li>• Tiredness</li> <li>• Weakness</li> <li>• Lethargy</li> <li>• Sedation</li> </ul>
Participants	<ul style="list-style-type: none"> <li>• Prior knowledge</li> <li>• Knowledge built on preceding questions</li> <li>• Own experiences</li> <li>• Motivations</li> <li>• Personal characters</li> </ul>
Data-driven considerations	<ul style="list-style-type: none"> <li>• Refined key issues brought up in analysis of the initial study results</li> </ul>

respective societal representation within Singapore fairly well.<sup>36</sup> Singaporean citizens dominated both studies. The marital status and age of participants in both studies were similar (Table 2).

### General Review of the Study Results

The overall results from both our 2013 and 2014 studies were very similar (Table 3).

### Review of the 26-item Questionnaire

Participants were asked to rate the importance of each feature with respect to “being a person” on a 10-point Likert scale from 0 to 9. Zero-point was defined as not important, 1-point as minimally important and 9-points as extremely important. The mean scores for individual features for both studies are shown in Figure 1.

‘Relationships with family’ had the highest mean score. Nine features were similarly ranked within the top 10 considerations in both studies (Fig. 1). ‘Relationships with family’ and ‘familial duties and obligations’ had the lowest standard deviations in both studies—demonstrating the least variance among patients for these 2 features.

Table 2. Demographics of Respondents from the 2013 and 2014 Studies

Characteristics		n = 100 (%)	n = 40 (%)
		2013	2014
Gender	Male	55 (55%)	28 (70%)
	Female	45 (45%)	12 (30%)
Median age (range)		55 (35 – 82)	57.5 (17 – 81)
Ethnicity	Chinese	78 (78%)	31 (77.5%)
	Malay	6 (6%)	4 (10%)
	Indian	8 (8%)	2 (5%)
	Others	8 (8%)	3 (7.5%)
Religion	Christianity	32 (32%)	8 (20%)
	Buddhism	9 (9%)	14 (35%)
	Islam	11 (11%)	5 (12.5%)
	Hinduism	10 (10%)	1 (2.5%)
	Roman Catholic	9 (9%)	5 (12.5%)
	Taoism	2 (2%)	0 (0%)
	Free Thinker	27 (27%)	2 (5%)
	No Religion	0 (0%)	5 (12.5%)
Nationality	Singaporean	96 (96%)	36 (90%)
	Others	4 (4%)	4 (10%)
Marital status	Married	81 (81%)	32 (80%)
	Divorced	0 (0%)	3 (7.5%)
	Never married	19 (19%)	5 (12.5%)

The mean scores ranged from 8.7 for ‘relationships with family’ to the ‘age’ at 6.29 in our 2013 study and 8.53 for ‘relationships with family’ to the ‘hobby’ at 5.67 in our 2014 study. No statistical tests for significance were performed as mathematical calculations for *P* values were deemed to be inappropriate in the context of these studies. Instead, to further contextualise these results and investigate if the differences in mean scores between individual features were significant, we went on to analyse qualitative data from subsequent semi-structured interviews in both studies.

### The Emergent Concepts from Grounded Theory Analysis of Qualitative Data: Personhood is Represented by the Sum of Individual Features

The first emergent concept was that all 26 features in both studies were believed to contribute to personhood equally with no absolute preference for 1 feature over another in defining one’s personhood.<sup>7-9,31-33</sup> Disregarding the interviewer’s attempt to get him to rate each feature from zero to 9, Patient 44 (2013 study) stated: “The sum is greater than its parts... It is not just about having individual features on a checklist. It is the summation of all that we have—that makes us who we are”. Patient 49 (2013 study)

Table 3. Rankings and Mean Values of the Importance of Individual Features to Defining Personhood – a Comparison between Data from 2013 and 2014

Feature	2013		2014	
	Mean	Rank	Mean	Rank
Relationships with family	8.70	1	8.53	1
Being alive	8.47	2	8.42	2
Familial duties and obligations	8.43	3	8.17	4
Physical mobility	8.25	4	8.22	3
Ability to communicate	8.22	5	8.03	7
Consciousness	8.21	6	8.14	5
Ability to think; make sense of things; give reasons for what you do and don't do	8.18	7	8.08	6
Relationships with friends	8.09	8	7.83	9
Being able to function normally	8.06	9	7.97	8
Moral or ethical beliefs	8.03	10	7.81	10
Having and being able to express feelings	8.03	10	7.78	11
Self-determination	8.00	12	7.44	13
Name	7.74	13	7.28	15
Independence in making your own decisions	7.73	14	7.56	12
The capacity to learn	7.70	15	7.44	14
Religion	7.69	16	7.06	16
Achievements	7.49	17	6.86	18
Education	7.35	18	7.03	17
Role within society	7.15	19	6.28	21
Occupation	6.98	20	6.47	19
Your gender (being male or female)	6.80	21	6.29	20
Race/ethnicity/culture; Racial/ethnic/cultural characteristics	6.68	22	6.11	22
Economic status	6.54	23	5.97	24
Physical appearance	6.38	24	6.06	23
Hobby	6.35	25	5.67	26
Age	6.29	26	5.97	25

stated: “I cannot think of anything that does not make me who I am, or a person. Everything—every feature or trait I have makes me a person. Having to list features will suggest that if I lose any of these, I become less of who I am—this is not true”. This concept of personhood being the sum total of a diverse set of individual features is mirrored in both studies and is represented diagrammatically in Figure 2.

### *Innate Personhood*

A recurrent theme stressed throughout the discussion of personhood was the notion of minimal criteria sufficient for the endowment of personhood (Table 4). In both studies nearly all patients (96% in 2013 and 100% in 2014) in our study population believed that an embryo was endowed with personhood from the moment of conception. The key reasons given were that it was alive and possessed his or her distinctive physical appearance despite a lack

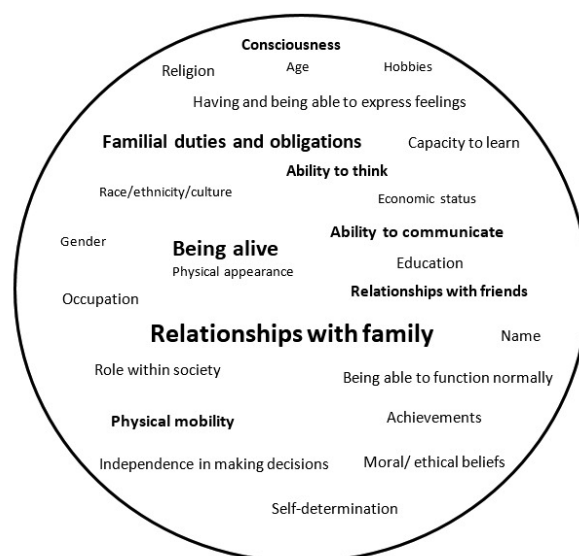


Fig. 2. Personhood is represented by the sum of present features.

Table 4. Summary of Responses to Vignettes

Vignette Questions	Response	n = 100 (%)	n = 58 (%)
		2013	2014
At the point where Jane becomes pregnant, do you consider the embryo to be a person?	Yes	96 (96%)	40 (100%)
	No	4 (4%)	0 (0%)
	No answer	0 (0%)	0 (0%)
What features make the embryo a person?*	Being alive	75 (78.12%)	16 (40%)
	Relationships with family (Acknowledgement from parents)	36 (37.5%)	7 (17.5%)
	Physical appearance	12 (12.5%)	4 (10%)
The baby is born unconscious. Is the baby a person?	Yes	97 (97%)	39 (97.5%)
	No	1 (1%)	0 (0%)
	No answer	2 (2%)	1 (2.5%)
Ben, the baby, grows up and marries Lisa. Lisa suffers a stroke and is left unconscious. Is Lisa still a person?	Yes	98 (98%)	39 (97.5%)
	No	0 (0%)	0 (0%)
	No answer	2 (2%)	1 (2.5%)
Does Lisa, being unconscious, change Ben's "person" (her husband)?	Yes	70 (70%)	25 (62.5%)
	No	28 (28%)	6 (15%)
	No answer	2 (2%)	9 (22.5%)
Does Lisa, being unconscious, change her children's "person"?	Yes	72 (72%)	27 (67.5%)
	No	26 (26%)	7 (17.5%)
	No answer	2 (2%)	6 (15%)
Lisa suffers a second stroke and is left in a permanent vegetative state. Is Lisa still a person?	Yes	97 (97%)	34 (85%)
	No	1 (1%)	6 (15%)
	No answer	2 (2%)	0 (0%)
Lisa dies. Is Lisa still a person?	Yes	47 (47%)	10 (25%)
	No	50 (50%)	30 (75%)
	No answer	3 (3%)	0 (0%)
If yes, what makes Lisa a person?*	Relationships with family	34 (72.3%)	3 (30%)
	Memories	18 (38.3%)	1 (10%)
	Religion	0 (0%)	1 (10%)
Does Lisa's death change Ben's "person"?	Yes	82 (82%)	28 (70%)
	No	15 (15%)	5 (12.5%)
	No answer	3 (3%)	7 (17.5%)

\*A single participant may have mentioned more than one response. Not all participants gave an answer. Percentages shown are with reference to only those who answered 'Yes' to the related question preceding it.

of consciousness.<sup>7-9,31-33</sup> Personhood also existed even if consciousness is never attained or is lost in various health states.<sup>7-9,31-33</sup> "It is about what is sufficient and not what is necessary" (Patient 32, 2013). In discussing the personhood of a hypothetical character, Lisa, who was in a permanent vegetative state, 97 participants in our 2013 study and 34 participants from our 2014 study reported that "she is still a person" as a result of being alive and her physical appearance. This concept of a maintained personhood by certain features despite the loss of others is represented by Figure 3.

### *Personhood Beyond its Innate Form: Individual, Relational and Societal Personhood*

Once again, the findings in both studies were similar and analysis of both sets of results revealed 3 further domains that built upon the innate elements of personhood (Fig. 3). Firstly, there are the features related to consciousness.<sup>7-9,31-33</sup> These were the basis of one's individualism or distinctness—forming an "individual personhood".<sup>7-9,31-33</sup>

The next domain revolved around one's relational links. Significant emphasis was placed on "relational personhood"

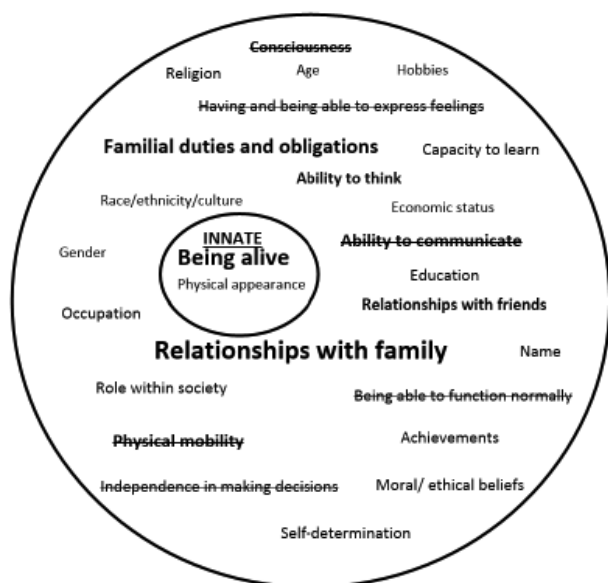


Fig. 3. Certain “innate” features form the core of personhood. The loss of certain features in various health states does not affect the overall integrity of one’s personhood.

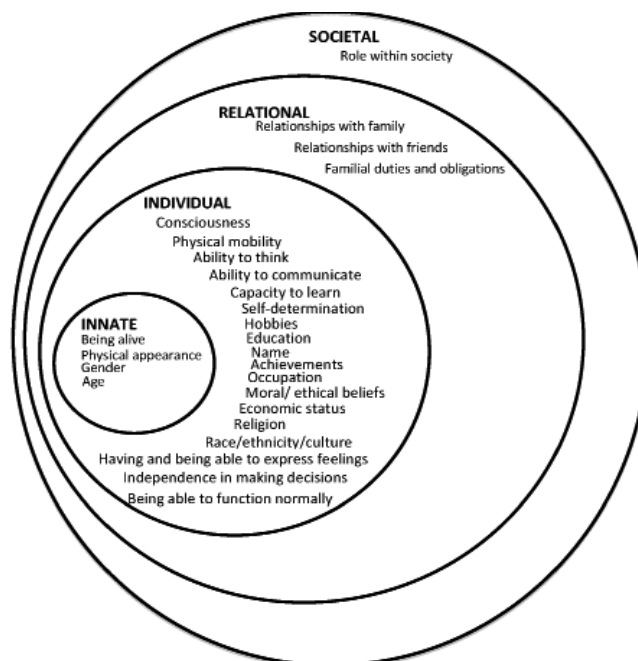


Fig. 4. Personhood beyond its innate form: the idealised forms of individual, relational and societal personhood.

which built upon “individual personhood”—personal and important relationships with loved ones.<sup>7-9,31-33</sup> These relationships included both family and close friends.<sup>7-9,31-33</sup>

Lastly, the impact of social, cultural, religious and political factors upon the practises, character, values, beliefs and interest of the patient are also acknowledged as the standards, expectations, obligations and laws they are subject to.<sup>7-9,31-33</sup> This categorised view of a developed personhood is illustrated in Figure 4.

#### *Features of Personhood are Interrelated, Interdependent, and Amenable to Change*

In the majority of interviews in both studies, the “distinct” features of personhood were found to be interrelated, interdependent and amenable to change over time.<sup>7-9,31-33</sup> Figure 5 conceptualises this aspect of personhood that in effect makes discrete domains unlikely.

Seventy-two participants in our 2013 and 30 participants in our 2014 study emphasised that relationships are dependent on the presence of conscious function. In the hypothetical scenario of a mother’s loss of consciousness, it was found that the effects upon her relationship with her husband and children affected her personhood. Participants also acknowledged that features such as culture and age also influenced the manner personhood was conceived. Patient 13 (2013 study) stated: “Lisa’s loss of consciousness may not affect her relationship with her children if they are too young to understand.”

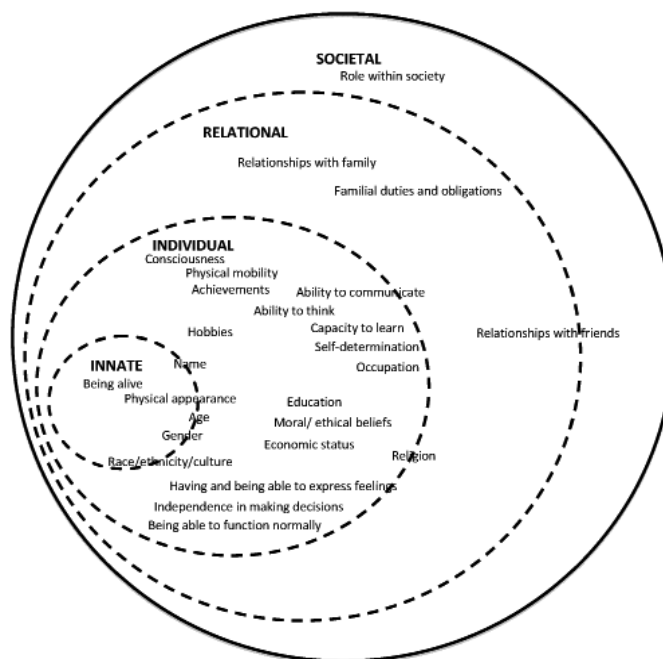


Fig. 5. Individual features overlap between domains, influence one another and are amenable to change.

In keeping with this theme of change, it emerged that personhood was perceived to be context dependent, transforming over time and with experiences particularly with illness experiences.<sup>7-9,31-33</sup> “This “list” will always change and remold and reshape the person that I am” (Patient 49, 2013 study). All 140 interviewees in both studies acknowledged this aspect of change in personhood. The idea that certain features strengthen and grow in importance while others weaken was found to recur across transcripts. There was no identifiable pattern as to how personhood changes. Rather, this was depicted as a dynamic process.<sup>7-9,31-33</sup> While some believed relational personhood to disintegrate as a result of unconsciousness, others saw it strengthening: “Lisa’s relationship with her family may paradoxically strengthen when she is sick... just like how my own experience with battling cancer has brought my family closer” (Patient 22, 2013 study).

The final theme identified builds upon the shifting features of the 4 domains highlighting the influence they have upon one another.<sup>7-9,31-33</sup> Participants in both studies noted that weakening cognitive function for instance is seen to strengthen relational ties, whilst relational ties are found to be subject to societal and cultural oversight for instance in the form of filial piety. This is overlap of rings is illustrated by the porous rings delineating each domain.<sup>7-9,31-33</sup> Indeed it was the presence of this notion of change in conceptions of personhood expressed in so many of participants in our initial study that precipitated our second study of changes in the conceptions of personhood throughout the course of a cancer sufferer’s disease journey.

### Changing Conceptions

Twenty-six (65%) (Fig. 6) of our 40 participants reported a change in personhood when asked, “Do you think you have changed as a person over the course of your illness?” (Table 5) These changes affected patient’s innate individual, relational and societal personhood as revealed in Figure 7. This represents the first empirical evidence of changes in conceptions of personhood amongst terminally ill patients. Grossly, we note that change in conceptions of personhood tends to be global, affecting more than just the patient’s innate, individual, relational and societal personhood. Second, change in conceptions of personhood does not occur in a linear fashion or at specific points. Third, change in one dimension is affected by and causes evolution in the other dimensions of personhood. Fourth, the size of the change need not be congruent with the significance attributed to it by the patient. Fifth, significance of change is determined by the patient and is influenced by contextual and temporal factors. Sixth, change of the dimension of personhood need not necessarily be seen as an involution and can in fact be an expansion of a specific element of personhood. Seventh,

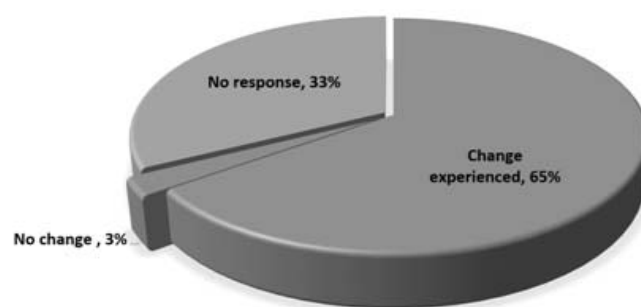


Fig. 6. Percentage of patients who experienced a change in personhood in the course of illness.

Table 5. Percentage of Respondents who Experienced Changes in the Individual, Relational and/or Societal Rings of Personhood

Any Change Experienced	Domain/Ring		
	Individual	Relational	Societal
Yes	65%	40%	17.5%
No	20%	38%	35%
Unsure/No response	15%	23%	48%

determination of the impact of change upon personhood can only be determined by a holistic review of the patient’s specific circumstances.

These findings are congruent with the conclusions drawn from our 2 studies and re-emphasise the need for patient-centred case specific holistic review.

### Discussion

Analysis of the emergent themes reveals a dynamic more holistic concept of personhood than prevailing concepts of personhood suggest.<sup>3-9,11-26, 31-37</sup> This data reveals that local conceptions of personhood do not pivot solely upon the presence of either social interactions nor conscious function negating fears that loss of either function would be tantamount to “social death”.<sup>8,9,11</sup> Critically such a finding circumnavigates suggestions that an irreversible loss of consciousness could be deemed undifferentiable to biological death.<sup>8,9,11</sup> Instead, personhood in these unconscious patients are seen to persevere through the presence of family and close relationships.<sup>7-9,31-33</sup>

However, rather than perpetuate family-centric practises that stem from a “synergistic dualist” perspective of personhood of a patient simultaneously being a distinct autonomous individual and a member of a family who must protect and advance familial interests, the data suggests an equal importance placed on preserving one’s



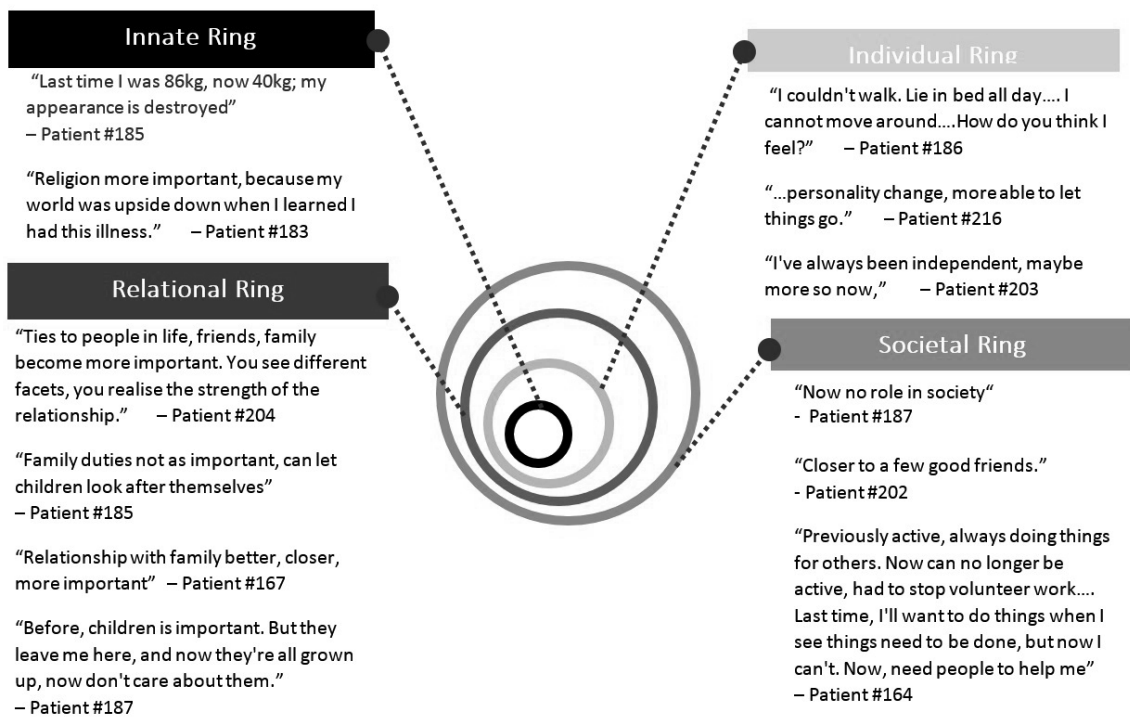


Fig. 7. Quotes from respondents on how their personhood has changed in the course of their illness.

unique identity and legacy that is not easily trumped by familial interests.<sup>7-9,31-33</sup> These findings have far reaching implications to a society that is still immersed in family-centric determinations drawn from its long embrace of Confucian beliefs that has seen the usurping of autonomous choice, overriding of previously stated wishes in a now incompetent patient and the circumnavigation of direct patient involvement in care determination.<sup>38-43</sup>

Our results validate Krishna et al's Ring Theory of Personhood (Ring Theory) that proffers a clinically relevant, culturally appropriate perspective of personhood that will better inform health care professionals of how best to provide patient-centred care within their respective clinical, cultural and social setting.<sup>7-9,31-33</sup> The Ring Theory can be seen to explain our findings as to the presence of the innate, individual, relational and societal rings (Fig. 8).

As with Krishna et al's findings, we note that our data supports the presence of an innate ring constructed on the belief that personhood is bestowed on living human beings "irrespective of their stage of development or deterioration" whilst the individual ring does represent conscious function and a continuing identity over time.<sup>8</sup> The relational ring houses "those personal relationships that the patient considers important", whilst the outermost ring, the societal ring contains "the social, professional and familial ties that are not felt to warrant a place in the relational ring by the patient" and "the societal, professional

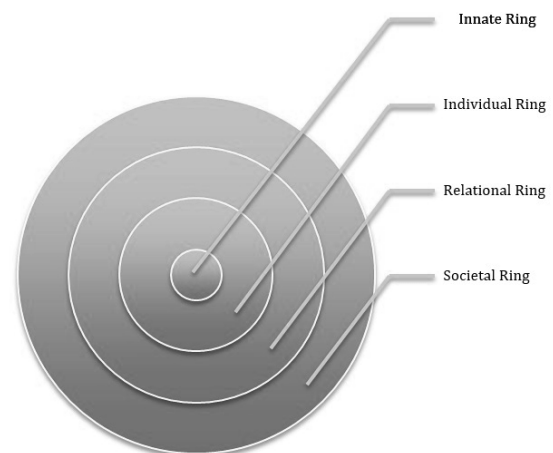


Fig. 8. The Ring Theory of Personhood

and familial expectations and standards that the patient and those within their various rings are subject to".<sup>7-9,31-33</sup> The synergistic interactions between these 4 rings are clearly focused upon maintaining the integrity of individual identity in response to changing psychosocial, clinical and contextual circumstances.<sup>7-9,31-33</sup>

Aside from affirming the Ring Theory, data from our 2014 study does provide the first insight into the manner that personhood changes throughout the course of an illness and calls for a holistic case by case review of each patient's

situation by a multi-professional team in keeping with the key practises of a palliative care approach, if patient-centred care is to be achieved.<sup>7-9,31-33,37</sup> This blueprint to patient-centred care in oncology and palliative care settings reminds us that it is only through understanding, “what makes you, you” can health care professionals hope to provide patient-centred care that is consistent with the particular interests, values and wishes of patients, regarding them as persons and protect their welfare.

## Limitations

We recognise the limitations of our study. Participants were recruited by convenient sampling and this may bias findings. This is particularly evident in the second study where there was a preponderance of males and patients who report no specific religious affiliations that could have potentially biased results. Future studies should be aimed at collecting data via varied methodologies to test the findings of this study. This includes purposive sampling to include a diversified group of participants from different ethnic, religious and language backgrounds, as well as random sampling to minimise selection or participation bias.

Our exclusion of non-English-speaking poses a particular drawback to the generalisability of these findings as does the small sample size of both studies. Future studies on the wider population particularly non-English-speaking patients are being planned as studies focused upon conceptions of personhood in various settings and stages of life.

We recognise that the results are not based on direct behavioural observations. Ethnographic studies on how patients behave and make medical decisions (with their personal values; family’s contributions etc.) may also play a role in validating the results of this study.

## Conclusion

Our studies serve to re-emphasise the necessity for careful holistic appreciation of the needs of patients particularly in times of significant psychosocial and physical distress. Our data confirms longstanding suspicions that personhood and thus individual conceptions of dignity, moral rights and patient-centred goals evolve requiring an ongoing multidisciplinary team trained in holistic care to meet the holistic needs of patients in a practical manner that complies with societal expectations, professional standards and institutional guidelines. We hope this study will usher in the advent of more patient-centric care at the end-of-life.

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