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7. Indigenous Values and Practices in Health

Rites of Passage Expanding the Boundaries of Health Care

Brian F. McCoy S.J., La Trobe University, Melbourne

Introduction

[1] A few years ago in the east Kimberley region of Western Australia there was a vehicle roll-over. A number of Aboriginal people were seriously injured. One died at the scene and another was taken unconscious to the regional hospital. He was then air-lifted by the Royal Flying Doctor Service to a major emergency hospital in Perth, some thousands of kilometers south. After some days, and with no signs of him regaining consciousness, the city hospital contacted the regional hospital that had been in regular contact with the young man's wife. She had been inquiring about the health of her husband and whether she could come and see him. The city hospital encouraged her to come. They added that it was likely a decision would have to be made whether his life support would have to be turned off. The nurse at the regional hospital then rang the community clinic and spoke to the Aboriginal health worker to arrange transport for the patient's wife to go to Perth.

[2] After hearing that the young man in Perth was still unconscious, the health worker said to the nurse that *under no conditions* was the wife of the patient to go to Perth. She was not the appropriate person to decide when this man's life support should be terminated. It was culturally inappropriate. There were others who should make these decisions. The nurse responded quite strongly and criticized the health worker for her attitude. Clearly, from the nurse's perspective, the health worker was not thinking either of the good of the patient or his wife. The health worker then became quite upset. In her understanding those who *did* have responsibility to make decisions in this situation were not being recognized and respected.

[3] This paper examines some of the complexities around decision making and care when people are undergoing serious changes in their health. Cultural differences can be revealed, differences that can become intensified and inflammatory even when caregivers act with the best of intentions. Health changes not only affect the individual but also affect other family members such as partners, children, and close friends. It can also affect those who have the responsibility to advise and provide the most appropriate medical and pastoral care at these critically important times. The exercise of power becomes even more fraught when situated, as in this case, within historical contexts and conflicts of culture and race. With an increase in life expectancy occurring within countries throughout the world (Kinsella and Phillips), along with the likelihood that some cohorts of aging populations within western countries are showing signs of increasing disability (Seeman et al.), the contexts of decision-making and care within health fields deserve careful attention and scrutiny.

[4] The example that begins this paper also adds a further dimension of complexity. Most cultures have their own ways of dealing with death and what they believe about a person's transition from life into a next, or other world. In some cultures there are also very strong traditions that allow people to express their grief at this time, that is, before death. In providing very public expressions of grief, they allow people to communicate to the family and those most closely related to the dying, that they have played no part in that person's final and terminal condition. It is not surprising, then, that there are cultural contexts where the rituals associated with a person before they die link closely with those immediately after death. This is the case with a number of Australian Aboriginal peoples. As I describe these understandings further in this paper, I note that such approaches to the dying may not be shared or understood by non-Aboriginal health care professionals. They are likely to be more focused on their own culturally appropriate and immediate responses, and less aware of other possible responses, at such critically important times for the dying person and their family.

Extending Life Expectancy

[5] Since the early 20th century many nations have increased life expectancy by reducing their infant, childhood, and maternal mortality levels (Kinsella and Phillips). The increase in aging populations also brings particular economic challenges to those medical interventions aimed at helping people live longer (Wright and Weinstein). There is more at stake for people as they age than simply becoming "grey nomads," as Australians often refer to their active, travelling, retirees. Medical breakthroughs and new technology can now help people overcome infectious diseases or delay chronic conditions that previously would have killed

them at a younger age and more quickly (Kinsella and Phillips). Older people can live with cancer, heart disease, and kidney disease in ways that could not be imagined a generation ago. We have discovered many ways to extend and improve the quality of life using a wide range of medical interventions, medications, and physical therapies (Crimmins).

[6] At the same time, aging populations are also learning that they might live longer but not necessarily with the same quality in which they have become accustomed. End Stage Renal Disease (ESRD) and dialysis is a good example. It often extends life by some years but it can come at a very high price. It offers its own particular form of life-style restriction; some experience it as a form of periodic detention. The patient needs to report to a centre on a regular basis and have waste from their blood removed. This can go on, a number of times a week, week by week, often for some years. It brings a major change to a person's life, particularly for indigenous people who live in remote communities and must move to urban centers for treatment. They, and other family members who accompany them, have to relocate from their traditional homelands, and from the support offered by extended family members and communities, if they wish to access dialysis. They are provided an extension of life but at a great personal and social cost.

Health Pathways

[7] What we witness at such a time in a person's life as a health change is significant personally and socially as well. Like the major rites of human passage, such as from childhood into adulthood, from single to married life, and even from life to death, such changes involve the letting go of a previously experienced and familiar way of life. They also invite society to accept that the person has changed and has now a new status. This process often generates a period of liminality, an "in-between" space, where a person is neither in their old human condition or the new one (Van Gennep). In the case we have already mentioned, liminality can describe that time when the young man was unconscious, neither conscious nor dead, neither totally with or apart from his kin. A machine kept him breathing, but his family was unable to have any verbal communication with him. During such rites of passage, there is often the expressed hope that despite change (sometimes named and experienced as "letting go" – a metaphorical if not literal act of "dying"), another form of "living" might emerge.

[8] Rites of passage are ones of change. While they include, in various degrees, some experience of loss, letting go, and grieving, they offer possibilities of human growth, transformation, and gain. They are processes that can be potentially generative, not necessarily always the dangerous, depressing, and discouraging events they can be perceived or experienced to be.

[9] Rites of passage have been described and understood as comprising three distinct movements or stages: *separation*, *transition,* and *incorporation* (Van Gennep). A person is taken from a place or space they are familiar with, and from a specific status in relationships, e.g. a young person living at home. They undergo change through a liminal phase, e.g. applying for studies at a University, leaving home, and beginning studies. In time, they subsequently transition into a new status and set of relationships as they settle into College and University life. They become recognized as "members," entering more fully into the relationships, culture, and activities of their group. They are the "new" group. In such social passages,

people can experience themselves being transformed: emotionally, socially, and spiritually. However, not all rites of passage work seamlessly or perfectly every time. Interference to any one stage can influence the process and final result, particularly during the liminal stage when the person is particularly vulnerable, neither in the "place" they were before nor completely in the new one.

Separation, Transition, Incorporation

[10] In order to explore how we might better engage these ritual pathways in the realm of health rather than ones involving strictly social status, I have chosen as an example a particular rite of passage: the rite of male initiation in western desert Aboriginal communities within Australia. It is a ceremony that I am quite familiar with and it continues to be celebrated across many Australian Aboriginal communities, with some variations across different groups (McCoy; Myers; Tonkinson). The rite can help illuminate the three stages of human movement: *separation*, *transition,* and *incorporation*. In describing this rite I need to emphasize that I am not commenting on anything secret within these ceremonies, but rather public aspects of them that are open for all, young and old, male and female, Aboriginal and non-Aboriginal, to witness. I wish to respect that boundary of knowledge that desert people seek to maintain around their own ceremonial space and hence say nothing about what happens privately within these ceremonies. I will also use some Kukatja words to describe aspects of this rite, some of which are common to other Aboriginal desert languages within Australia.

Separation

[11] When young teenage Australian Aboriginal boys are taken for their first initiation ceremony into adulthood, they do so within a community context. As the sun sets on a chosen day, the members of that particular desert community gather in a public place. The women sit to one side with their young children and the men stand or sit apart. The young boy, often a young teenager, who has been chosen by his family and relations to enter into this ceremony, is sitting on the ground with his mother, the other women, and their young children.

[12] At the designated time this young man is gently picked up by the wrist by a group of older male relations. He is taken into the company of the other men for the duration of ceremonies that will later occur in the "bush," i.e., to sacred and gender-specific ceremonial places or arenas, a short distance away from the community. At that moment he is taken, the boy's mother, and other women, particularly his kinship mothers and aunties, begin to cry. The separation that begins the ritual is public and clearly evident. The wailing invites the recognition and mourning of something important that is being lost. The young man is now leaving behind his boyhood. No longer does he come under their care and responsibility as a child.

Transition

[13] This movement of the young man away from the women and children is the beginning of a liminal phase. While no longer a boy, he is also not yet a man. The significance of this transition is that the young men who enter an initiation ceremony at the same time are given a shared name, *yarlpurru*. It is the name they then call one another, and will continue to do so,

for the rest of their lives. It is a special and close relationship. As they enter this exciting, uncertain, and even frightening new space as initiates, they are watched over by older men (*wati*) and their older brothers (*kurta*) and cousins (*pangku*), who ensure that they are protected, fed, and watched over during this significant ritual journey into male adulthood.

[14] Those who help the young men most at this time are slightly older than them and who have personally experienced the same ceremony. They explain and accompany the initiates through the various stages of it. These are their blood and kinship male brothers and cousins. At the same time, the older men also watch over them. They protect the whole gathering physically, emotionally, and spiritually by the ways they carefully attend to the serious performing of the various stages of the ritual. They are aware that these are important ceremonies and believe that people can be hurt or become sick if they are not performed correctly.

Incorporation

[15] After the initiation ceremony is completed, away from the sight of women and children, and several days later, the young man is formally brought back into the community once again. It is late in the day, just before sunset. He comes from being secluded in the "bush" and walks towards the assembled group of men, women, and children. They are sitting on the ground, the men separated from the women with children. As he comes to the group, he turns around and sits on the back of one of his kinship brothers-in-law (*panytji*), who has gone down onto his knees to form a table for him to sit on. He now has his back to the women and children. His mother and his other kinship mothers and aunties stand up and come to him. They wipe his back with leaves and cry once again. Similar to the sweeping of the land with leaves, and the wiping away of a person's footprints after their death, here they mourn the loss of this young man's boyhood. The man, while still young, is now recognized as an adult and able to continue his public journey with other men into adulthood. In this process, he will begin to learn more of those spiritual and cultural meanings that link him with his ancestors, the land, and with others.

[16] The process of *separation, transition,* and *incorporation* formally allows a young person time and support to undergo change. It is personal, relational, and embodied change. It brings the initiated back into the community with public recognition that *he has changed* and *their relationship with him* has also changed. He now faces a new pathway in life but one in the company of adults and with new and trusted male relations. He enjoys a new social status and, along with that new status, important social relationships and responsibilities.

[17] The ability of this young man to understand and embrace this important change in his life depends in large part on how well he was supported and accompanied through the various three stages. The presence of older people, their wisdom and care, provides a social context where he feels safe and protected while experiencing vulnerability and uncertainty. The company of other young men, those who have been on a similar journey in previous years, provides a relational context where he can feel supported and confident for the future. He is not stepping out alone as an adult.

[18] This process, whereby a young man enters a new personal and social pathway, can offer insight into the ways we might approach and support other significant changes in people's

lives. Health changes are increasingly becoming part of the experiences and choices of some people as they age in western societies. Over the past three decades, for example, the number of people with major and multiple diseases has increased in the U.S. older population (Crimmins 2001).

Encountering the Unconscious Patient

[19] As human beings, our most critically important health and personal changes are associated with birth and death, when we enter and leave this world. While we do not have much personal control or consciousness over the former, we do have some control over the latter. However, when we lose our autonomy, as in the earlier story of the unconscious young man, understanding how people make decisions and care for people at or near death is not always so clearly obvious or simple. What are the rights, roles, and responsibilities that are appropriate for people within their culture at these times?

[20] As a result of that fractious communication between the nurse and the Aboriginal health worker, a protocol for similar events was drawn up by the health worker, her colleagues, and myself. This was later incorporated into a painting (following traditional ways in which Aboriginal people have used art to record, teach, and pass on knowledge) and a publication (Baadjo et al.). That painting now hangs on the wall of the Wirrimanu health clinic (Figure 1). It details a number of steps after someone is seriously injured (beginning in the bottom left corner): 1. There is an accident. 2. The injured person is taken to the hospital where they are attended to by health workers, nurses, and doctors. 3. The family (*yirrkapirri*, partners, and parents) sit and wait outside. 4. The hospital social or liaison worker, or health worker, talks to the family about the injured patient; if serious they send for the *tilitja*. *Tilitja* are *not* a patient's partners, parents, uncles, aunties, or children. They are their blood and kinship *brothers, sisters,* and *cousins* (Koning et al.). Those who are closest by blood to the person are considered the *tilitja* with greater responsibility and authority at that time. 5. The *tilitja* meet with the patient. 6. They consult the hospital staff; they make any decisions affecting the end-of-life treatment of the patient. 7. If the person dies, the *tilitja* gather. 8. The *tilitja* take responsibility for the mortuary and funeral rites (Baadjo et al.).

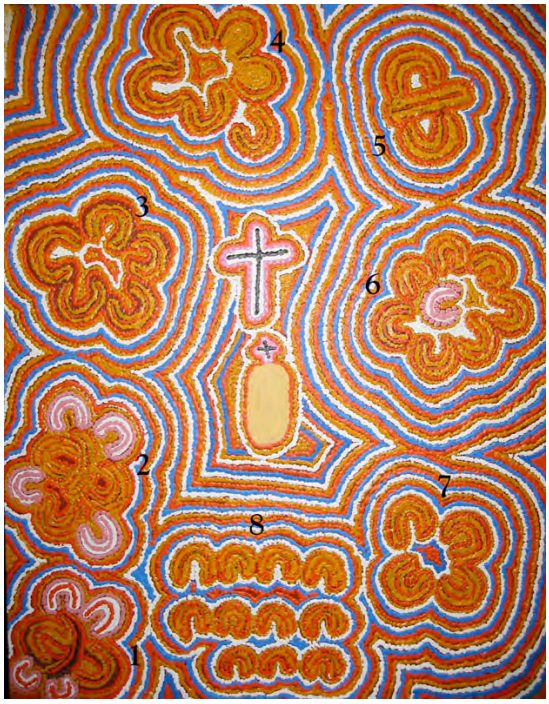


Figure 1. Communication Protocol

[21] What the painting and publication explain is a social and cultural pathway where decisions involving health care are made for a person who is unable to make a decision for themselves. This process holds together a tension between the importance of care for the most vulnerable and those whose worry and grief make them also very vulnerable at this

time. It expresses one particular cultural way of doing this. It outlines people's rights, roles and various responsibilities and, unlike some western cultural emphases, removes the burden of care and decision making from the patient's grieving spouse and parents.

Activists and Mourners

[22] Robert Tonkinson, in his work with the Martu Aboriginal people in Western Australia, has described the division of the living at the time of a death as either *mourners* or *activists* (Tonkinson). Mourners are allowed to grieve. They wear white ochre, fast from meat, and are embraced by others who visit them. The activists arrange and prepare the ceremonies associated with the death. Not only do all people know whether they are (by blood or kinship relationship) mourners or activists when a particular person dies, but they also know who are the key people who need to take responsibility for what has to be done. To return to the earlier example of the unconscious patient, the activists are the *tilitja*. Others, such as the partners, parents, and uncles are the *mourners*.

Other Health Pathways

[23] This example of the unconscious patient shows how, in a particular culture, the roles of decision-making and grieving can be separated. Both groups of people care deeply for the wellbeing of the person, and wish others to share that care. However, one group knows that it has the responsibility to make the important decisions, allowing the other group to remain in their grief. In this case, for those who cannot or are unable to speak for themselves, there are clearly identified people who have defined rights and responsibilities at this time.

[24] Death has always been an important ingredient of human life. What of those other significant health changes where the person is neither dying nor near death? With the advent and development of medical science some of our significant health changes can occur when people are teenagers or young adults. They may be in the position to legally make their own decisions and engage a new health pathway. However, these can be important life-changing moments. They can be experienced as lonely and difficult, if not well understood and carefully supported by health practitioners, family, and close friends.

[25] People can experience health changes as burdens. They can find it difficult to sustain the regularity of medication, the change of lifestyle, and the isolation from friends and family. I have already mentioned ERSD and the burden of kidney dialysis. For some Aboriginal people in Australia there can be additional burdens. In order to access treatment, people from remote communities have to move to a larger urban centre (where English, which is not their first language, is spoken), away from traditional homelands, family, and community. As with other health changes in a person's life, the energy involved in regular self-care can remain difficult to maintain and treatment can become discouraging and depressing. How might it be possible to support people at this time? What does the wisdom of *separation*, *transition,* and *incorporation* teach us? Can important religious, healing, and spiritual values within cultures support these significant health changes?

[26] *Separation*. Any new and significant change to a person's health pathway begins with some form of separation from what they have previously experienced. This is often initiated when a person moves to a hospital or begins therapy or treatment. However, the moment of separation can begin well before that time. Ceremonies that involve change also involve loss.

When a young man is initiated, it is not just the women who cry. The fathers and uncles also cry. They assume the role of *mourners*, acknowledging the pain associated with loss, and also the fears and risks that come to someone leaving an old status and entering a new one. At such times of separation, Aboriginal people will allow those who are most affected by separation to publicly grieve. They will also look to the company of others to assist the person in need at this time.

[27] When experiencing serious health changes, it can be helpful to identify those who wish to offer sympathy and share grief, as well as those who come to support, advise, and help with decision-making. *Mourners* and *activists* are both needed.

[28] *Transition*. It would be inconceivable in Australian Aboriginal society that a person could enter a new and important health status by themselves. Each person needs the company, support, and advice of others to make it a safe, and also hopefully, a successful and transformative transition. Like the example of Aboriginal male initiation, health transitions are strengthened when different people, skills, and resources are identified to support the person during that time.

[29] Ideally, in such a process, a person is supported by those who have the role, relationship, and knowledge that gives them some authority them at this time. In some situations, they will be people of knowledge and expertise, in other situations they will be those who have already made that transition and understand what is involved. The person who is undergoing a serious health change needs time to adjust and to accommodate a new way of "being." It is here that the role of chaplains, traditional healers, and counselors are important. They help the person find meaning in their new health experience. They allow people to find hope as they experience serious health transitions.

[30] *Incorporation*. The ritual whereby a young man comes out of his first initiation ceremony is solemn. It celebrates the reality that any incorporation involves leaving the past (the initiated faces away from the women), beginning a new journey with others (he is formally welcomed back into the community), and being in a place where people promise to be his support and company for the path ahead (he sits on the "back" of his brother-in-law). Incorporation means that a person's status has changed and that person has become a new member within the group.

[31] In the context of health, a person's "embodiment," the relationship between themselves and their body, has also changed. Formal recognition of these changes is needed. In some cases, people will find it difficult to fully accept their new health role and the social space it occupies. They will resist and struggle with a personal transformation not of their own desire or expectation. Others may also find it difficult to accept their new status. However, there are ways in which incorporation can be supported and achieved. As people formally enter into new ways of living with disease, disability, and illness, they invite health professionals, family, and friends to find ways of sharing and recognizing their new journey.

Getting on the Right Health Pathway

[32] Modern medical science is demonstrating that we can now live with diseases and infections, not simply die from them. If we wish to assist people in their important health changes we might view these changes (and even ritualize them) as valuable rites of passage.

We might ask: What is the nature of the separation? Who are the people involved in it and where is the grieving and support that occurs when one enters the liminal stage? What is the transition? Who helps name and deepen the person's experience of change? How is this socially, rather than just medically, actualized? How is this change valued and affirmed for the person and their wider family and relations? Finally, what does it mean to be incorporated into a new way of being in society? What is the new social status? What is the nature of this new form of embodiment (i.e. physically, emotionally, and spiritually)? Who shares and supports the person through and into a new phase of their life-cycle?

Conclusion

[33] As I have tried to explore in this paper, those who care for people who are experiencing important health changes are not always the same across different cultures. Hospital or public health protocols that refer simply to a person's "next of kin," their "partner," or "close family members," can too easily overlook the various ways in which different cultures mark and emphasize inter- and intra-generational relationships of care, and how it applies to decisions about those most in need. Western cultures can also exclude extra legal and ritual relations, such as partners, adopted family members, and significant friends. So, too, some cultures can emphasize autonomy and individual consent to the exclusion of decision making within a family or group. They can establish very fixed and narrow models around decision making and care.

[34] Secondly, those who care for people when they are near death are likely to be different from those who care for them when they are younger and face long-term illness, treatment or, disability, such as ESRD. End-of-life illnesses can be viewed culturally as a distinct phase of a person's life cycle. Care for people near death will tend to focus on their passing from this life to the next and their journey into another way of being. It will be aware of, and attentive to, rituals around final farewells, and mortuary and funeral practice. These rituals will bring into public awareness the naming and celebration of important religious and cultural values. There will be particular ways in which the person is shown final respect by close and grieving family members. However, there will be other decisions where long-term planning is needed, such as with various interventions, treatments, procedures, and operations. These decisions can link to inter-generational and wider family support structures, beyond those provided by a small nuclear family. Being relatively recent in western health care, particularly for some older people, these evolving stages of health care can become ambiguous and undefined. Considering them as rites of passages provides models both of and for society. They can provide a clear understanding with distinct statuses for experiences that involve change and liminality. They outline and reinforce the various rights, roles, and responsibilities people share during such times.

[35] Thirdly, with medical science helping to increase life expectancy, the skills of health providers and practitioners (including social workers, chaplains, counselors, and therapists) will need further refinement in assisting people through the different health processes they will continue to encounter in the future. With increasing medical specialization and professionalization the culturally specific and proper role of kin can be put in jeopardy, as with our opening example. We can learn much from the process of rites of passage in exploring how we might better facilitate health processes and change in our societies and be

respectful of other societies and their cultural practices. Apart from offering attention to the needs of the highly vulnerable, we can also become more attentive to the wider group of family, relations, and friends, and their various supporting roles.

[36] Finally, and most importantly, when we better understand these pathways of human health change and we allow them to support those in need, we avoid confusing *those who are* from *those who should be* making decisions at these times (as with the opening example). It is important to know who share responsibility to care for others, but it is also important to recognize the importance of offering care. Caring relationships, particularly when people are in that liminal or that "in-between" space of change, hold families and communities together. Rites of passage benefit whole communities, not just individuals. We also need to see the roles and positions of designated decision-makers as negotiable and developing rather than fixed essences.

[37] As indigenous and other cultural groups interact with the health culture of western medicine they can engage quite different approaches to decision-making and care when people are critically sick or dying. This is not to assume that western approaches can be more or less caring than others at such times. However, whatever the relative benefits of different cultural approaches, a conflict of values can result, particularly where there is a history of one particular and dominant form of expression. For example, one on my Aboriginal friends, who lives in a large urban city in the north-east of Australia, has reflected with me how all her family funerals tend to become moments of great tension and argument. Perhaps, she has suggested, one of the reasons is simply that there are different and conflicting models of funeral practice being implemented. One comes from a memory of earlier Aboriginal practice, the other a more recent western and Christian one. Another Aboriginal friend, who lives on the other side of the country in the south-west, has also told me about the funeral for his young daughter some years ago. According to western practice he was expected to take responsibility for the funeral, a responsibility he found difficult to cope with. He fulfilled the role but later, on reflection, realized that he wished (using the categories we have already described) to have been a *mourner* rather than an *activist* at that time.

[38] When we understand those who have responsibility for others during the significant health changes in their lives, we can provide better contexts for decision-making and care. Health care is not simply medical. It is also social and relational. We need to allow and invite personal transformation to occur, both to the person receiving care but also to the medical and social groups offering it.

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