

JOHN MCMILLAN | JULIAN HUGHES | KENNETH BOYD

BACKGROUND PAPER

# OLD AGE AND MENTAL HEALTH AT THE END OF LIFE: THE ETHICAL FOUNDATIONS OF DECIDING FOR OTHERS



Religion and Medical Ethics | 11-12 December 2019, Rome

Hosted by the World Innovation Summit for Health  
and the Pontifical Academy for Life

SYMPOSIUM ORGANISERS



CONTENT PARTNER

**BMJ** Journal of  
Medical Ethics



# INTRODUCTION

Deciding for others who lack the capacity to make their own decisions is a day-to-day occurrence in medical practice throughout the world. Losing capacity can result from a variety of conditions ranging from a loss of consciousness, cognitive impairment, memory impairment, severe mental illnesses to neurological trauma. The issues that arise when deciding for others are a central concern of medical ethics.

In this pre-symposium paper, we start by presenting two paradigm cases. We will then move on to highlight some key issues that such cases reveal, then end with reflection on the underlying ethical considerations that should help to inform decision-making on behalf of those who cannot make decisions for themselves. We will also outline an approach to the nature of personhood which emphasizes the embeddedness of our individual narratives in communities where the quality of our communications is vital.

*We hope this paper will inform and prompt the discussion at the Rome summit on the key challenges at the intersection of belief-based and evidence-based approaches to care.*



**PROFESSOR JOHN  
MCMILLAN**

EDITOR-IN-CHIEF AT THE  
JOURNAL OF MEDICAL ETHICS  
AND DIRECTOR OF THE  
BIOETHICS CENTRE AT THE  
UNIVERSITY OF OTAGO, NEW  
ZEALAND



**PROFESSOR JULIAN  
HUGHES**

CLINICAL ADVISORY BOARD  
AT THE JOURNAL OF MEDICAL  
ETHICS AND PROFESSOR  
OF OLD AGE PSYCHIATRY AT  
THE UNIVERSITY OF BRISTOL,  
ENGLAND



**PROFESSOR KENNETH  
BOYD**

ASSOCIATE EDITOR AT  
THE JOURNAL OF MEDICAL  
ETHICS AND HONORARY  
VICE PRESIDENT OF THE  
INSTITUTE OF MEDICAL  
ETHICS

# CASE VIGNETTES

We start with two fictional vignettes, which are amalgams of actual clinical situations -

## Vignette 1: Mr. Al Hamad

The diagnosis of Alzheimer's disease was made five years ago when Mr Al Hamad was 79 years old. There had probably been signs of the disease before then, but his ebullient personality and sense of humour allowed him to get around any difficulties. Indeed, he resisted any form of assessment for some time, even when his family became concerned and put pressure on him to see the doctor. For instance, there had been the time when he got lost whilst driving and had only gotten home because he recognised a passer-by. Mr Al Hamad was uncharacteristically furious and alleged that the road signs had been tampered with. Subsequently, the family became more concerned about his driving and were constantly noticing his lack of assurance. His memory problems became more obvious as time went on, although his wife, Oma, frequently covered for him. It was his older daughter who finally persuaded him to go to see a doctor. He had to go through a variety of tests, all of which he hated. He said being asked questions about the date and being made to copy silly pictures was simply humiliating. After a brain scan, he was given the diagnosis. It was, for Mr Al Hamad, like being struck by a thunderbolt.

Born in 1935, Mr Al Hamad's Qatari family had flourished in parallel with the success of the oil industry in Qatar. This allowed him some privileges as he grew up. He became a successful businessman and gained an MBA in the early 1960s from the Wharton Business School at the University of Pennsylvania. He returned to Qatar in 1963 and was able to build himself a splendid home in which he enjoyed entertaining his many friends. He worked hard and no one who knew him doubted that he deserved his success. He also enjoyed being in charge, both at work and at home. Oma probably made many of the decisions without him, but she knew to run things by him so that he felt he was in control. He was always kind and fair to his children, who all felt close to him. He enjoyed debating with them and encouraged his two sons and two daughters to argue with him about a range of subjects.

Mr Al Hamad was also religious. He was not particularly demonstrative, but he prayed daily and encouraged his children to do the same. When his parents died, he accepted this was a natural part of life.

He did not, however, accept his dementia. It made him angry. Not only was he increasingly forgetful, but he gradually lost his speech and was frustratingly unable to do things for himself, for instance, he could no longer dress himself. When he started to become incontinent and Oma tried to help him he would become aggressive and it was their son, Abdul, who often had to step in to sort things out. Salama, their youngest daughter, in particular, helped her mother to look after Mr Al Hamad.

There came a point at which Mr Al Hamad took to his bed and he became completely dependent for all of his basic needs. He had been this way for about a year when Abdul became concerned that his father was not swallowing well. He was choking on food occasionally, but the frequency of these episodes was increasing. One day when Abdul visited his parents' home he was alarmed to find his father looking extremely ill and more or less unresponsive. A doctor came to see him and announced that he had a chest infection and needed to be in hospital to receive intravenous antibiotics. He was moved to the hospital, which seemed to unsettle him greatly. He became agitated and aggressive towards staff and medication was used to calm him down. Eventually he did improve, but the whole ordeal of the hospital admission had taken its toll on him and also on Oma who felt she could not go through such an ordeal again.

The doctors in the hospital, however, said that the only way to avoid a further admission would be for Mr Al Hamad to be fed by artificial means, through a percutaneous endoscopic gastrostomy (PEG) tube. They said the swallowing difficulties were now serious enough to threaten further pneumonias. The family doctor was equivocal about the need for a PEG tube and encouraged the family to pursue careful hand-feeding with the help of an elder care home nursing service. Even so, they were warned a further chest infection would seem quite likely to occur and might kill him.

Abdul said he felt his father should have a PEG tube because it was horrible to see him so ill when he had pneumonia. His daughters were more inclined to take the conservative route. During the hospital admission there had been a Do Not Attempt Resuscitation (DNAR) discussion and appropriate documentation had been signed by the doctors to record that Mr Al Hamad should not be resuscitated. Oma did not know what to think about artificial feeding. She wished neither to see her husband with a further pneumonia nor in hospital again but she did not like the idea of a tube being put through his abdominal wall into his stomach. They needed good advice.

---

## Vignette 2: Miss Jones

Miss Jones worked her whole life in the civil service, which she entered straight from school. An only child, she lived with her parents. She cared for them when they were very old whilst still doing her job in the same department. She was friendly with her colleagues but kept herself to herself.

Miss Jones was brought up a Roman Catholic. She went to Mass every Sunday but did not join in social events at her church. She was always polite when her parish priest spoke with her as she was leaving the church each week but she never proffered information about herself. She had one school friend, Geraldine, to whom she was close. When Miss Jones's parents had both died, she was aged 60. She retired and her friend Geraldine (who had also never married) moved in to live with her.

Sadly, after eleven years, Geraldine died. She had received a diagnosis of cancer two years before and Miss Jones had cared for her, as she had done for her parents. Neighbours tried to be supportive after Geraldine's death but Miss Jones became increasingly reclusive. Her immediate neighbours started to notice that she was looking uncharacteristically scruffy. When they did not see her for some time and she didn't answer the door they informed her doctor.

She had lost a good deal of weight, was withdrawn, unwilling to talk, avoiding eye contact, with no sense of warmth or rapport. She seemed to be dehydrated. The doctor admitted her to hospital where she was rehydrated by intravenous fluids. When seen by the psychiatry liaison team it was clear she was depressed. Initially, she seemed to pick up a little, but only enough to express her deep sadness, her feelings of hopelessness and her inclination that her life should be over since there was nothing to live for. Her communication subsequently declined. She was not eating and gradually her weight, which was already low on admission, started to fall further. She became frankly comatose and gave no response to anyone who saw her. This included the female Catholic chaplain who had been informed there was a Catholic on the ward by one of Miss Jones's neighbours who had visited her and knew that she attended the local Catholic church.

Some of the multidisciplinary team felt that she had just given up and that she should now be allowed to die peacefully for her life seemed empty. Others stated firmly that this was a profound depression which should be amenable to treatment, even if this meant invoking mental health legislation in order to use electroconvulsive therapy (ECT). In any event, they argued, she should be kept alive whilst a decision was made.



# DISCUSSION ON THE ETHICAL AND LEGAL ISSUES

In this section we wish to highlight some of the key issues that emerge from these cases but due to the breadth and complexity we acknowledge that it is not possible to discuss them fully; nor do we claim these are the only issues.

In both cases, the issue of **respect for autonomy** (or self-determination) arises, even though autonomy is compromised in both cases. We should note that Mr Al Hamad was used to being in control, but wished neither to engage with the diagnostic process, nor to receive care. We know less about Miss Jones, apart from her recently expressed negative cognitions about the pointlessness of her life. So how we respect the autonomy of Mr Al Hamad or Miss Jones is not straightforward. We might wish to tilt in the direction of respecting **relational autonomy**, at least in the case of Mr Al Hamad, where we should take into account the wishes of those who surround him and can reflect his own perspective.<sup>1</sup>

All of this is rather predicated on the assumption that both people lack decision-making **capacity or competence**.<sup>2</sup> Although the stories we have told suggest they lack capacity, we should remember that this must be determined before it is assumed.<sup>3</sup> If it is lacking, we should act in their **best interests**, which itself raises questions about how this is to be assessed and by whom.<sup>4</sup>

**Surrogate decision-making** might seem reasonable for Mr Al Hamad, because he has a close family. But how, in fact, do families make decisions and, whatever the law might suggest, whose views ought (ethically) to be given most weight?<sup>5</sup> **Substituted judgements**, where we try to put ourselves in the shoes of the person to decide what he or she would want, sound fine. But how do we know for sure? In the case of Miss Jones, we have very little upon which to base our judgements. The *UN Convention on the Rights of Person's with Disabilities*

commends the use of **supported decision-making**, but these are the sort of cases that test such a stance: how do you support Mr Al Hamad, whose dementia counts as a disability, to make any sort of decisions at all, let alone a complex one?<sup>6</sup> A similar point could be made about Miss Jones and the possibility of **shared decision-making**.<sup>7</sup> In the absence of valid and applicable **advance directives**, the de facto decision-makers are largely in the dark about what to do.

Meanwhile, the ethical principles of doing good (**beneficence**) and avoiding harm (**non-maleficence**) are precisely at the heart of the clinical dilemmas faced in these vignettes.<sup>8</sup> **Justice**, which might seem marginally easier to predict if we focus on a fair distribution of resources, nevertheless remains difficult in the face of clinical uncertainties.

## ETHICAL UNDERPINNINGS

The focus of decision-making for other people is the person concerned. She or he is (or should be) central to the determination that a particular decision is the correct one, even if other decisions might have done just as well. Some understanding, therefore, about what it is to be a person will be useful in, first, explaining the complexity of such decisions and, secondly, in helping us to balance different possibilities.

In short, we suggest that the ethical basis of decision-making for other people must be a broad view of the person, where he or she is seen as a situated embodied agent (the SEA view of the person).<sup>9</sup>

Whilst the relevance of agency can be questioned when it is difficult to identify agentive behaviour, the possibility of such behaviour should not be discounted. To recognise this is to recognise the essential dignity of human beings, where even

1. The idea of 'relational autonomy' and its implications were important in the report of the Nuffield Council on Bioethics, *Dementia: Ethical Issues* (London: Nuffield Council on Bioethics, 2009). See for instance paragraph 2.34: 'A key implication of these accounts [of relational or actual autonomy] is that the dependency of people as a result of their disease does not mean that their autonomy cannot be promoted, nor that promoting autonomy simply involves respecting the wishes and values they had before the onset of dementia. On the contrary, it means that people who have become dependent on others through the development of dementia may need support from those who care for them to help them retain their autonomy, and with it their sense of self.' Available via: <http://nuffieldbioethics.org/project/dementia> (last accessed 11 November 2019).
2. Of course, in the case of Mr Al Hamad it might have been possible to have had explicit conversations about decisions that might face him at an earlier stage in his dementia. Deciding when to have such conversations is always difficult. It has been argued that physicians may or may not show respect for self-determination by deciding the timing of conversations. Waiting too long may cause loss of capacity and with it loss of the ability to make the decision. See: Lindberg J, Johansson M, Broström L. Temporising and respect for patient self-determination. *J Med Ethics* 2019; 45: 161–167. Nevertheless, when and who should be involved in advance care planning discussions in dementia is not straightforward; see: Dickinson C, Bamford C, Exley C, Emmett C, Hughes J, Robinson L. Planning for tomorrow whilst living for today: the views of people with dementia and their families on advance care planning. *International Psychogeriatrics* 2013; 25(12): 2011–21.
3. Legislation about the assessment of capacity or competence will be different in different jurisdictions; indeed whether 'capacity' or 'competence' is the term used varies.
4. Complexities around the notion of best interests are many. They have been interestingly discussed in connection with the Mental Capacity Act 2005, which governs England and Wales, in: T Hope, A Slowther, J Eccles. Best interests, dementia and the Mental Capacity Act (2005). *J Med Ethics* 2009; 35: 733–738.
5. We know that family surrogate decisions are not straightforward. We know that families receive very little advice, including advice on how to approach normative decision-making. See: Emmett C, Pool M, Bond J, Hughes JC. (2014). A relative safeguard? The informal roles that families and carers play when patients with dementia are discharged from hospital into care in England and Wales. *International Journal of Law, Policy and the Family* 2014; 28: 302–320; and, Cunningham TV, Scheunemann LP, Arnold RM, et al. How do clinicians prepare family members for the role of surrogate decision-maker? *J Med Ethics* 2018; 44: 21–26.
6. The UNCRPD is not without its critics and it may well be that the full-blown supported decision-making paradigm is just not feasible in practice, but this is debated. See: Scholten M, Gather J. Adverse consequences of article 12 of the UN Convention on the Rights of Persons with Disabilities for persons with mental disabilities and an alternative way forward. *J Med Ethics* 2018; 44: 226–233.
7. The point being that, unlike Mr Al Hamad, Miss Jones does not have a disability, so the UNCRPD is not relevant. Nevertheless, if it were possible the shared decision-making model would be useful, except that even with significant modifications to the model it does not seem feasible when someone has a severe mental disorder such as Miss Jones. To consider how the model might work, see: Gillick MR. Re-engineering shared decision-making. *J Med Ethics* 2015; 41: 785–788.
8. See: Gillon R. Medical ethics: four principles plus attention to scope. *Brit Med J* 1994; 309: 184–188.
9. See: Hughes, J.C. Views of the person with dementia. *J Med Ethics* 2001; 27: 86–91. Also: Hughes, J.C. *Thinking Through Dementia*. Oxford: Oxford University Press, 2011.

slight gestures, movements, breathing, vocal noises and the like, may have meaning.<sup>10</sup> In any case, this agency is situated. The agentive quality of a movement is not decided by the movement alone, but by the movement in an embedding context, which will include knowledge of the person's previous narrative, character, likes and dislikes.

Something similar can be said about embodiment. This focuses our attention on the body in front of us: its biochemistry no less than its appearance. But, again, the body is understood in the context of its embeddedness in a history, which reflects a family, a culture, a person's religious beliefs, a particular social milieu. Moreover, the psychology of the person is itself embodied. It is made manifest through the body.

So, the central feature of a person is their situatedness; and this situatedness is multifaceted. Indeed, it cannot be circumscribed since there are always different ways in which a person can be situated. We are embedded in our life stories, in our families, friends, social groups, cultures, as well as in particular moral, legal, political, religious, aesthetic, historical outlooks, and so forth. This situatedness accounts for our rights, our values and virtues (the dispositions) that inform our judgements. It underpins our standing as interdependent, interconnected individuals in communities and the solidarity that binds us together as persons.

## PRACTICAL DECISION-MAKING

What does all this suggest in practice? Mr Al Hamad must be understood in the context of his history but his body and mind are now failing and there are biological facts that cannot be denied. It is clear that he has been frustrated and that he does not particularly like medical involvement.<sup>11</sup> His behaviour indicates his intention. We also know he is a religious man and that he accepts death as an inevitable part of life and he is surrounded by his loving family. In some sense they help to hold him in being as the person that he remains. Their lives are interconnected and their interests are entwined so they must now play a crucial role in the decisions that face him (and them). There may be differences of view within the family. These will have to be negotiated, but there are a priori grounds for thinking that enormous respect must be given to Oma's views since Mr Al Hamad's situatedness within the family was determined by his loving relationship with her. She may wish to alter her views, or not to give voice to them, or she may simply be too tired to make decisions but these are things the family must navigate, which they will do by good communication. Indeed, part of the job of the healthcare team is to facilitate the right sort of discussions and they do so within the larger context of culture and community and religious belief.<sup>12</sup>

Meanwhile, Miss Jones has no family or friends of note to help with the decisions that face her but she is now situated within the healthcare field, where she can be looked after well or poorly. In order to look after her well, doctors and nurses and others must pay close attention to her body, to her gestures, responses, vocalizations and mien. Actions will be noted. Does she push food away? Does she roll over to ignore people? Does she show any sort of reaction at all? Does anything, however subtle, evoke a response? Understanding her communications will be difficult, subject to error, but of the utmost importance.

The SEA view shows the complexity of the decisions that face Mr Al Hamad and Miss Jones and those around them. It shows how those decisions must take into account a broad array of factors, from biological to psychological and social. By attracting the focus of attention to a breadth of concerns, the SEA view helps us to balance different possibilities. No decisions should be taken about the PEG tube for Mr Al Hamad without a good deal of attention being paid to the family's (different) concerns but nor should this decision be made without looking at the evidence around PEG feeding.<sup>13</sup> The SEA view attracts our attention to the decision-making community. Thus, it's the team looking after Miss Jones that must pay attention to her narrative, as well as to her current nuanced reactions. The decision must reflect the sort of normative concerns that guide treatment in these situations: how effective is the treatment likely to be? How burdensome might it be for Miss Jones?

## CONCLUSION

It is not that the SEA view of the person that provides definitive answers but it does show us where to look; and the perspective turns out to be both wide and detailed. In a sense it is the perspective of palliative care, with its mantra of a bio-psycho-social and spiritual approach. The SEA view focuses attention on the details of embodiment and on the details of agency, but both of these are regarded in the broad context of the individual's situatedness. It is this that brings in every aspect of the person's history, from his or her attitude to medical care, to her or his attitude to religious observances. And it is this that means the team making decisions should involve everyone with relevant knowledge or experience - from the caring neighbour, to the doctor, to the pharmacist, to the chaplain or spiritual director. Decisions for others, therefore, must be made against this very broad and detailed backdrop. There may be disagreements, of course, but those who disagree are likely to share some understandings, some values, around which there can be negotiation. Nothing should be ruled out: everything (from blood tests to beliefs) is potentially relevant. In any case, if there were disagreements about the correct decision, the focus will rightly remain on the person, but on the person broadly conceived.

10. Dr Wim Dekkers developed an interesting notion of 'bodily autonomy' suggesting that bodily movements and gestures, even in severe dementia, may point towards tacit bodily knowledge, 'based on the sedimentation of life narratives' (p. 258). He went on to say, 'Although the body in severe dementia increasingly shows dysfunctions, it still remains a lived body and a body in which previous forms of autonomy have been inscribed' (p. 258). See: Dekkers W. Persons with severe dementia and the notion of bodily autonomy. In: Supportive Care of the Person with Dementia (eds. JC Hughes, M Lloyd-Williams, GA Sachs), pp. 253-261. Oxford: Oxford University Press, 2010.
11. We know that he did not want to have a diagnosis and that he has a 'do-not-attempt-resuscitation' (DNAR) order. It should be noted that having a DNAR order can often be misinterpreted by medical and nursing staff. It does not, of course, mean that the patient is refusing other forms of investigation or treatment, even if it is indicative. See: O'Brien H, Scarlett S, Brady A, et al. Do-not-attempt-resuscitation (DNAR) orders: understanding and interpretation of their use in the hospitalised patient in Ireland. A brief report. *J Med Ethics* 2018; 44: 201-203. We know that decisions about resuscitation are, in any case, difficult and especially so when made on busy medical wards. See: MacCormick FMA, Emmett C, Paes P, et al. Resuscitation decisions at the end of life: medical views and the juridification of practice *J Med Ethics* 2018; 44: 376-383.
12. The sort of dilemma facing the Al Hamad family might well be helped by the application of values-based practice (VBP), which is discussed in some detail in relation to dementia in: Hughes JC, Williamson T. *The Dementia Manifesto: Putting Values-Based Practice to Work*. Cambridge: Cambridge University Press, 2019. But VBP would also be relevant to the case of Miss Jones too.
13. Sampson EL, Candy B, Jones L. Enteral tube feeding for older people with advanced dementia (Review). *Cochrane Database of Systematic Reviews* 2009; Issue 2: Art. No.: CD007209. Available via: <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD007209.pub2/full> (last accessed 28 October 2019).

## ملخص

يعتبر اتخاذ القرار بالنيابة عن الآخرين الذين لا يملكون القدرة على اتخاذ القرارات الخاصة بهم، حدثاً يومياً يواجه الممارسات الطبية في جميع أنحاء العالم، وفقدان القدرة على اتخاذ هذه القرارات له أسباب عديدة كالغياب عنه الوعي وضعف الإدراك وفقدان الذاكرة أو ضعفها والأمراض العقلية الشديدة والصدمات العصبية، لذا تعتبر هذه القضايا التي تنشأ عن اتخاذ القرارات عن الآخرين من أهم المشاغل الرئيسية للأخلاقيات الطبية.

قدم هذا المقال حالتين نموذجيتين. أولهما عائلة السيد محمد الحمد، وهو مواطن قطري مصاب بمرض الزهايمر التدريجي منذ خمس سنوات، حيث كان من الضروري إدخال أنبوب تغذية اصطناعي، مما أثار أسئلة حول تحديد استقلاليته وقدرته على اتخاذ القرار وقضايا الموافقة الشخصية. وتحرى المقال اتخاذ القرارات عند وجود اختلاف في وجهات النظر بين أفراد الأسرة والطاقم الطبي.

عرضت الحالة الثانية القضايا المحيطة بحالة الآنسة جونز، وهي كاثوليكية رومانية مخلصه أصيبت باكتئاب شديد فلم تعد تأكل أو تشرب. ناقشت هذه الحالة التحديات التي واجهت الفريق المتعدد التخصصات في تحقيق التوازن بين الرغبات التي أعربت عنها المريضة ذات المرض العقلي المحتمل علاجه.

انتقل المؤلفون بعدها لتسليط الضوء على بعض القضايا الرئيسية التي تكشفها هذه الحالات، والتأمل في الاعتبارات الأخلاقية الأساسية التي ينبغي أن تساعد في التأثير على عملية صنع القرار نيابة عن أولئك الذين لا يستطيعون اتخاذ القرارات من تلقاء أنفسهم. في كلتا الحالتين، برزت مسألة احترام الاستقلال الذاتي (أو حق تقرير المصير) واستكشاف المؤلفون الاستقلال الذاتي العلائقي الذي يأخذ في الاعتبار رغبات من حولنا. وقالوا إن عملية استبدال القرار قد تبدو صائبة بالنسبة للسيد الحمد، لأنه لديه أسرة مقربة. كما تحروا

كذلك ما إذا كان من الصواب اتخاذ القرارات المشتركة من قبل فريق متعدد التخصصات للآنسة جونز في ظل غياب توجيهات مسبقة صالحة وقابلة للتطبيق.

ثم نظر المقال بوجه أعم في الأسس الأخلاقية لاتخاذ مثل هذه القرارات، واقترح أن الأساس الأخلاقي للقيام بذلك بالنيابة عن الغير يجب أن يبنى على نظرة واسعة للشخص، حيث ينظر إليه كعامل متجسد (أي منظور SEA للفرد). واقترح المؤلفون أن هذا المنظور للشخص لا يقدم إجابات جازمة ولكنه يبين أين ينبغي لنا النظر، حيث يتضح أن هذا المنظور واسع ومفصل. بمعنى أنه منظور الرعاية التلطيفية ذات النهج الحيوي النفسي والاجتماعي والروحي.

يركز هذا النهج على الاهتمام بتفاصيل التجسيد وتفاصيل التوكيل، لكن كلاهما يُنظر إليه في السياق الواسع لموضع الفرد. وهو ما يجمع بين كل جانب من جوانب تاريخ الشخص، من موقفه من الرعاية الطبية إلى موقفه من الشعائر الدينية. وهذا معناه أن على الفريق الذي يتخذ القرارات أن يشرك جميع من له معرفة أو خبرة ذات صلة - من الجار المتكفل بالرعاية إلى الطبيب والصيدلي والقسيس أو المرشد الديني. لذلك ينبغي اتخاذ القرارات التي تخص الآخرين في ظل هذه الخلفية الواسعة والمفصلة إلى حد كبير. قد توجد خلافات بالطبع، لكن من المحتمل أن يشارك المختلفون في الرأي بعض التفاهات أو القيم التي يمكن أن يتم التفاوض على أساسها.

نأمل أن يساعد هذا المقال في إعلام وإثارة النقاش في قمة روما حول التحديات الرئيسية عند تقاطع مناهج الرعاية القائمة على المعتقدات وتلك القائمة على الأدلة.

## SINOSSI

Decidere per coloro che non hanno la capacità di prendere le proprie decisioni è un evento quotidiano nella pratica medica in tutto il mondo. La perdita di capacità può derivare da una varietà di condizioni che vanno dalla perdita di conoscenza, al deterioramento cognitivo, alla compromissione della memoria, a gravi malattie mentali, al trauma neurologico. Le questioni che sorgono quando si decide per gli altri rappresentano una preoccupazione centrale dell'etica medica.

Questo articolo ha presentato due casi paradigmatici. Il primo, relativo alla famiglia del signor Al Hamad, un cittadino del Qatar con una storia di cinque anni di Alzheimer progressivo che ha richiesto l'inserimento di un sondino artificiale. Il caso ha sollevato domande sulla determinazione dell'autonomia, della capacità e delle questioni relative al consenso. Ha anche esplorato il processo decisionale in presenza di opinioni diverse dei membri della famiglia e del personale medico.

Il secondo ha presentato questioni riguardanti il caso della signorina Jones, una devota cattolica che ha sviluppato una grave depressione catatonica che l'ha portata a non mangiare e non bere più. Ha presentato le sfide di un team multidisciplinare nel bilanciare i desideri espressi da un paziente in presenza di una malattia mentale potenzialmente curabile.

Gli autori hanno quindi proseguito evidenziando alcune questioni chiave che tali casi rivelano, riflettendo sulle considerazioni etiche sottostanti che dovrebbero aiutare a influenzare il processo decisionale per conto di coloro che non possono prendere decisioni da soli. In entrambi i casi, è emersa la questione del rispetto dell'autonomia (o dell'autodeterminazione) e gli autori hanno esplorato l'autonomia relazionale che tiene conto dei desideri di coloro che ci circondano. Hanno discusso sul fatto che il processo decisionale sostitutivo possa sembrare ragionevole al signor Al Hamad, perché ha una famiglia unita. Hanno anche analizzato se il processo decisionale condiviso dal team multidisciplinare per la signorina Jones, in assenza di direttive pregresse valide e applicabili, fosse valido.

Il documento ha quindi esaminato in modo più ampio le fondamenta etiche di tale processo decisionale e ha suggerito che la base etica per fare questo in nome di altre persone debba partire da una visione ampia dell'individuo, dove questo viene visto come un agente personificato localizzato (la visione SEA della persona). La proposta è che questa visione della persona non fornisca risposte definitive ma ci mostri piuttosto la direzione in cui guardare; e la prospettiva risulta essere ampia e dettagliata. In un certo senso, è la prospettiva delle cure palliative, con il suo mantra di un approccio bio-psico-sociale e spirituale.

Questo approccio concentra l'attenzione sui dettagli della personificazione e sui dettagli dell'essere agente, ma entrambi sono considerati nel vasto contesto della collocazione dell'individuo. È questo che include ogni aspetto della storia della persona, dal suo atteggiamento nei confronti delle cure mediche, al suo atteggiamento nei confronti delle osservanze religiose. E questo significa che il team che prende le decisioni dovrebbe coinvolgere tutti coloro che hanno conoscenze o esperienze rilevanti - dal vicino premuroso, al medico, al farmacista, al cappellano o alla guida spirituale. Le decisioni prese per conto di altri, quindi, devono essere prese in questo contesto molto ampio e dettagliato. Ci possono essere disaccordi, ovviamente, ma è probabile che coloro che non sono d'accordo condividano alcune concezioni, alcuni valori, attorno ai quali può esserci una negoziazione.

Speriamo che questo articolo influenzi e stimoli la discussione al vertice di Roma sulle sfide chiave all'intersezione di approcci alla cura basati sulla fede e sull'evidenza.

# ABOUT THE ORGANISERS

## The World Innovation Summit for Health (WISH), an initiative of Qatar Foundation for Education, Science and Community Development (QF)

WISH is a global healthcare community dedicated to capturing and disseminating the best evidence-based ideas and practices. WISH is an initiative of QF and is under the patronage of Her Highness Sheikha Moza bint Nasser, its Chairperson.

Based in Doha, Qatar, WISH holds a biennial summit that convenes international healthcare policymakers, researchers, innovators and healthcare practitioners. Year round, WISH conducts evidence-based health research and works closely with global partners to promote its mission of "building a healthier world through global collaboration".

Through international conferences and a range of ongoing initiatives, WISH is creating a global community of leading innovators in healthcare policy, research and industry. Together, they are harnessing the power of innovation to overcome the world's most urgent healthcare challenges and inspire other stakeholders to action.

## The Pontifical Academy for Life

The Pontifical Academy for Life (Pontificia Accademia Pro Vita) is the pontifical academy of the Catholic Church that is dedicated to promoting the Church's consistent life ethic. Alongside this focus, it conducts extensive research in the fields of bioethics and moral theology.

The specific responsibility of the Academy is:

1. to study and from an interdisciplinary perspective on the problems related to the promotion and defense of human life
2. to enculture people in valuing the sanctity of life through appropriate initiatives, that are respectful of the Magisterium of the Church
3. to inform the Church leaders, in a clear and timely manner, about the various biomedical science institutions and societal health care organizations, the media, and civil society in general, about the most significant results of its own study and research

[WWW.WISH.ORG.QA](http://WWW.WISH.ORG.QA)

## SYMPOSIUM ORGANISERS



## CONTENT PARTNER

