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## Patients as persons: ethical and theological issues in the face of illness and disability

### Introduction:

In the mid 1970s, the American theologian and ethicist, Stanley Hauerwas wrote a prophetic article for the journal, *Conneticut Medicine*, with the intriguing title, '*Must a Patient Be a Person to be a Patient? Or, My Uncle Charlie Is Not Much of a Person but He Is Still My Uncle Charlie.*'<sup>1</sup> In it, Hauerwas explored the importance of 'personhood' or 'person'-status as an important concept in the then nascent, but fast-growing, field of medical ethics.

In his article, Hauerwas draws a distinction between a *protective* use of the word 'person' of the kind which he finds in the work of Paul Ramsey, where 'person' functions to protect the individual patient against the temptation to use one patient, especially in experimental medicine, for the good of others or society, and a *permissive* use, that allows the user to sidestep some of the important moral issues raised by contemporary medicine. As Hauerwas puts it, '*...if we can say with some assuredness that X, Y or Z is not a person, then our responsibility is not the same as it is to those who bear this august title.*'<sup>2</sup>

Three areas where he saw this permissive use of the word 'person' as particularly prevalent in the last quarter of the twentieth century were *abortion*, the *withdrawal of care for the dying* and the *issues surrounding the selective care of defective (sic) or deformed infants*.

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<sup>1</sup> Hauerwas, S. (1975). *Conneticut Medicine*, 39. In S.E. Lammers and A Verhay eds. *On Moral Medicine: Theological Perspectives in Medical Ethics*, Eerdmans: Grand Rapids, 1998, pp.387-390.

<sup>2</sup> *Ibid.*, p. 388.

Since Hauerwas wrote his article, the issues surrounding all three of these areas of medical and moral discourse have multiplied since advances in medical technology have posed new, and increasingly complex, conundrums for clinicians, ethicists and theologians alike not least in societies where we have seen the progressive marginalisation of care for the most disadvantaged, including those who are poor or with disabilities, especially learning disabilities, which may be multiple and profound.

In this paper, therefore, I want to map some of the developments which have arisen from the issues highlighted by Hauerwas in the light of current developments in medicine, medical ethics and theological anthropology and to suggest that a coherent theology of human personhood of the kind that Hauerwas pleads for in the title of his article, and which Paul Tournier had pioneered in the early 1940s<sup>3</sup>, can offer what I have described as theological ‘signposts’ in the medico-ethical maze.

## **Persons:**

There is much talk in the field of contemporary medical ethics about ‘persons’ – their autonomy (confidentiality, informed consent etc.), our attitudes towards them (as research subjects, as the subjects/objects of care - both in the positive sense of acting in the patients’ ‘best interests’ but also in terms of not ‘harming’ those in our care<sup>4</sup>), the issues of justice (individual or distributive) - but there is also much disagreement about who, or what, a ‘person’ actually is. What constitutes a person, when does ‘personhood’ begin or end (and whether, consequently, there are such things as human *non*-persons, as philosophers like Peter Singer or Helga Kuhse would argue), or when persons begin, or cease, to matter morally, and whether ‘personhood’ is a biological phenomenon (i.e., how human identity/personhood relates to ‘bodies’) or is some other form of construct, are all important – and increasingly pertinent – questions, not least in terms of exponential rise of those chronic conditions that are often the correlative of extended lifespan, such as dementia. Without addressing such questions, we can have no guidelines for the moral requirement of ‘respect of persons’ that underpins so much of Tournier’s writing as well as contemporary debate in medical ethics and practice, and indeed, so much of medical law. If you fail to define who, or what, a person *is*, not only do you make ‘respect’ for persons a vacuous concept, but you allow the ‘goalposts’ to be moved, virtually at will.

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<sup>3</sup> See, for example, Paul Tournier, (1940) *Médecine de la Personne*. Neuchâtel, Switzerland: Delachaux et Niestlé. Paul Tournier, (1946) *Technique et Foi*. Neuchâtel, Switzerland: Delachaux et Niestlé and Paul Tournier, (1955) *Le Personnage et la Personne*. Neuchâtel, Switzerland: Delachaux et Niestlé.

<sup>4</sup> See the Hippocratic Oath – *primum non nocere* (first, do no harm..) and other ‘protective’ codes such as Nuremberg or Geneva.

In what follows, then, I shall demonstrate how personhood remains a key concept in a medical ethics that is focussed on the recipients of medical technology rather than on the technology itself, whose use can end up being more an expression of medical ‘machismo’ than part of a duty of care to the patient. I will also suggest that any definition of ‘personhood’ or ‘person’-status which relies on biological criteria (such as sentience or neo-cortical function) alone will always be inadequate to the task. Rather, I will argue that a re-assessment of ‘personhood’, as it is used in theological discourse, to stress both the ‘other-ness’ and the ‘same-ness’ of the other, offers us a more constructive model, as it views personhood as *relational*, rather than simply *biological*. It therefore offers ethics, and wider field of medical theory and practice, a much more satisfactory frame of reference, and therefore way forward, in the medico-ethical ‘maze’.

It may be argued that in the medical context, the ‘person’ as a frame of reference, is one which was, until recently, systematically displaced, or marginalized, in an increasingly technological medical methodology since the time of the Enlightenment. This process of medicalization of healthcare, was characterised by Ivan Illich<sup>5</sup> as ‘iatrogenesis’ and by the philosopher, Michel Foucault as ‘medical tyranny’. Consequently, the re-discovery of the person has been a major task not least for a theologically orientated contribution to medico-ethical theory and praxis at this time. Certainly, philosophical notions of personhood were in a state of flux throughout this period but changes in medical practice brought about by changes in medical technology have themselves exacerbated change.

But let us return to the first element in Hauerwas’ trilogy of examples. If, as Hauerwas pointed out, it could be demonstrated that a fetus was not a ‘person’ (though clearly both ‘human’ and ‘alive’), then the rights of protection afforded by medicine to persons would not apply, and the technological skills of medicine which could be used to preserve life could also be used, both legally and morally, to destroy it. The arguments on both sides of the abortion debate, not least those which focus on notions of ‘potential’ have been well rehearsed, and it is not my intention to repeat them here.

What *is* important in this context, however, is to show how, by extension, the same arguments raised by the debate about abortion and the moral status of the fetus, came to be applied to other issues concerned with person-status, such as end of life care and the contentious issues surrounding withdrawal of treatment or assisted dying. If being of moral ‘worth’ is something that attaches to persons but not to non-persons (at least in terms of human development and ‘being’) the question remains, when is a person a ‘person’ and when are they not?

## Life before birth:

In the early stages of life, the question becomes, when does ‘personhood’ and, therefore, being regarded as of moral ‘worth’, *begin*?

From a legal perspective there is a kind of ‘sliding scale’ of ‘being’ that has developed: conception, the emergence of the primitive streak (14 days), quickening – when the fetus is first felt to move in the womb (a point identified by the medievals as the point of ‘ensoulment’), viability (which is itself so heavily dependent upon the current state of medical technology), or birth itself (when the legal rights of personhood – e.g., the right to inherit property, apply).

Trying to establish ‘personhood’ by way of a biological ‘magic moment’ seems an exercise doomed to failure, although the law will still need to continue to establish certain biological landmarks which may act as a legal watershed.

The question remains, however, whether scientific and medical discourse can of itself legitimately say anything about human identity, though it undoubtedly has a great deal to say about biological development which is necessary to the wider debate.

Of much greater value, therefore, is to see personhood as not so much in biological terms (though biology still has its part to play) but as a social construct in which relational bonds, both to the family and to humanity, posit responsibilities to the other *as ‘other’* and not simply as a physical ‘structure’. Alastair McFadyen described such a process as ‘sedimentation’, arguing that ‘personhood’ is something which is ‘sedimented’ or ‘laid down’ within the complex interplay of personal and social relationship.<sup>6</sup> Such regard for others which, in Christian terms is rooted in the concept of ‘*agape*’ – unconditional love, always sees *the other* as, to use Martin Buber’s categories, a ‘thou’ rather than an ‘it’<sup>7</sup>, or, in Kantian terms, an ‘end’ in itself. It is important to note, then, that the language of ‘personhood’ should not be seen as *substantive* (i.e., it does not have anything to say about biological development), but is rather *performative* (i.e. it says something about the recognising or *calling-into-being* of the biological entity as ‘other’)<sup>8</sup>. Thus the language of biology is qualified by different, complementary, modes of discourse offered by other disciplines, such as theology and philosophy.

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<sup>5</sup> Ivan Illich, *Limits to Medicine* (Harmondsworth: Penguin, 1976). M Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception* (London, 1973).

<sup>6</sup> A.I. McFadyen, *The Call to Personhood: A Christian Theory of the Individual in Social Relationships* (Cambridge: CUP, 1990).

<sup>7</sup> M. Buber, *Ich und du*. (Charles Scribner's Sons. 1937).

<sup>8</sup> This term was used by the philosopher, J. L. Austin who describes languages which enacts the reality of which it speaks – e.g. ‘*I baptise you...*’ as ‘performative utterances’

## **Worth after birth:**

Simply in the interests of time, I intend to conflate the second and third of Hauerwas' areas of concern: the withdrawal of care for the dying and issues which surround the selective treatment of what Hauerwas called the 'defective or deformed infant'<sup>9</sup>, not because establishing when 'life' might be said to have *ended* is any easier than deciding when such life *begins*, but for the sake of brevity and because the issues surrounding the severely damaged newborn survivor is paradigmatic of the wider debate. While once, answers to questions like '*When is a person alive and when are they dead?*' would have seemed obvious (as simple observation would usually have provided a reasonably reliable answer), within the course of the twentieth century and into the twenty-first century, a constellation of changes in the field of medicine have made such questions very different indeed.

With the advent of mechanical ventilation, the development of intensive care units in the 1960s, and the ability to measure electrical activity in the brain (and therefore to use this as a benchmark<sup>10</sup>), questions about life and death became much less simple. With the questions which increasingly surrounded the withdrawal of treatment – of ventilation, of nutrition and hydration – new ethical questions emerged. These were important not just to clinicians and lawyers, but also to ethicists, philosophers and theologians, and increasingly, not least through the intervention of the media, to the public at large.

Such issues pose some fundamental questions, anticipated by Hauerwas' article, which can be framed not only as – '*when, and under what circumstances, should treatment be withdrawn or withheld?*' but also as '*when is a person not a person?*' and '*when, if ever, do persons cease to matter morally?*'

What has underpinned much of the debate then,, for at least half a century, are two distinct but related questions: is there such a thing as a '*right to life*' (which arose primarily concerning elective abortion); and is there, consequently, a '*right to die*' (which arose in response to medical technology's increasing ability to extend biological function)? A range of cases over the last quarter of a century have highlighted these issues in the UK: Tony Bland (PVS<sup>11</sup>), and Leslie Burke (cerebella ataxia) in the UK, Terri Shiavo in the USA (PVS) and, more recently, Tony Nicklinson ('locked in' syndrome) and Paul Lamb (paraplegia), both in the UK.

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<sup>9</sup> These are not descriptive terms that would be used today but are used here because they are the terms used by Stanley Hauerwas in his article.

<sup>10</sup> The Harvard Brain Death Committee in the 1960s was set up to answer some of the questions raised by the fact that the demand for donor organs was rapidly outstripping supply and the problems of harvesting cadaveric organs.

Though I find the *life-at-all-costs* argument, which so often masquerades under the title of *respect for life*, or *sanctity of life*, but is more properly described as *vitalism* (a view that regards life, in this context, simply as continued biological function) both ethically suspect and theologically inadequate, I want, nonetheless, to affirm, both from an ethical and a theological perspective the underlying principle that life *matters*. What we *mean* by ‘life’ and whether all life is equally worth preserving are, however, different issues. Suffice to say here, that what passes for a respect for, or sanctity of life argument, often reflects an inability to come to terms with the reality of human mortality and has led people, however well-intentioned, to place what I believe are increasingly unrealistic and unwarranted expectations on contemporary medicine and medical practice.

Even where personhood, at least legally, is *not* in doubt, it is often questionable whether that the aggressive pursuit of the continuance of biological function *always* respects ‘life’, or is *always* in the best interest of the person. Does aggressive technological intervention (which may arise from fear of litigation and the need to show that what could be done, was done) serve to prolong *life* (often with little regard to its quality) or does it rather prolong the process of *dying*?

A theological perspective on the ‘person’ as *more than* mechanical and biological function, but rather as a bio-psycho-social construct (in other words, an *ontological* rather than *functional* understanding of personhood<sup>12</sup>) therefore opens up the possibility of death not as failure, but as part of our understanding of, and respect for, personhood and, indeed, life itself. Such a transformation of perspective is entirely consonant with the regard for persons advocated by Tournier, and has profound implications for the practice and goals of medicine as a moral, rather than as merely a technical and technological, undertaking. This has led in recent years to the development of initiatives in the UK such as the Liverpool Care Pathway within palliative medicine, and the NICE Quality Care Standards for End of Life Care for Adults (QS13), as well an increasing emphasis upon, and academic recognition of, the place of spiritual care in ways advocated by Paul Tournier over half a century ago.

To the human person, whether the severely premature infant or the catastrophically damaged adult, there remains then a duty of care which regards clinical obligation as forming a bond of relationship, of the kind that Paul Ramsey, and William May, describe as a *covenant* relationship of loyalty, in contrast to a more utilitarian (or, indeed, market-driven) *contractual* relationship, . Such a covenantal ethic, May argues, defines the moral life in terms of both relationship and response.<sup>13</sup>

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<sup>11</sup> Persistent Vegetative State

<sup>12</sup> See, for example, J. Fletcher, *Hastings Center Report* 4 (December, 1975), 4-7.

<sup>13</sup> W.May, *Testing the Covenant: Active Euthanasia and Healthcare Reform*, (Grand Rapids:Eerdmans, 1996), p.52.

David Thomasa similarly regards persons as possessing a sacramental character (i.e. since each person is loved by God each person is sacred). He therefore argues that love, which reinforces but moves beyond the moral norm to do no harm, is the primary reason for acting in the best interest of each person. Since it is argued that every person, of whatever age or state, reflects the image of God, every person therefore possesses an *intrinsic* worth (a de-ontological perspective).

David Atkinson in his book on *Pastoral Ethics*<sup>14</sup>, also sees *being in the image of God* as an ontological category – it is the relationship to God’s-self which God confers on us. Thus, even the impaired newborn or the patient in a Persistent Vegetative State, or the elderly patient with chronic dementia who may not be regarded by *others* as a person, is so regarded by God. The value of such persons lies, if not in *human* relationships, in being held in the divine memory, and therefore inviolably in relation to the love of God. *Agape*, therefore places upon us responsibilities of covenant fidelity to those included in God’s covenant, irrespective of biological development or functional capacity. Thus, Atkinson sees personhood much in the way that Helen Oppenheimer has described human identity – as a *‘pattern of loveability.’*<sup>15</sup> For Tournier, this would have been expressed in terms of an obligation that both recognises and respects the existence and dignity of the human person.

## **Ceasing Treatment:**

This does not mean, however, that in cases of medical futility, heroic efforts should be made to save and sustain all such lives, irrespective of cost, personal, social or financial. Under some circumstances, treatment not only *could* but *should* be withheld or, where it has begun, to be withdrawn.

A genuine respect for human life and personhood sometimes entails us, then, in the painful business of deciding when ‘ordinary’ treatment becomes unjustifiably ‘heroic’, and of letting go. As the Roman Catholic theologian, Hans Küng says, *‘the fight for health is meaningful only as long as healing is possible, but... a fight against death at any price is nonsensical: it is a help which becomes a torment.’*<sup>16</sup> Such a position in no way denies that such patients are either persons in their own right who may be known and loved for themselves alone, or that they deserve, and indeed demand, our compassionate care. It does not suggest that in them the divine image is in any way reduced or

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<sup>14</sup> D. Atkinson, *Pastoral Ethics* (Lynx Press, 1994), p.204. See also B. Whorton, *Reflective Caring: Imaginative Listening to Pastoral Experience*. (London: SPCK, 2011).

<sup>15</sup> H. Oppenheimer, ‘Handling Life: Does God Forbid?’ in G. R. Dunstone and E.A. Shinebourne eds. *Doctors’ Decisions: Ethical Conflicts in Medical Practice* (Oxford: Oxford University Press, 1989), p.207.

<sup>16</sup> *A Dignified Dying*, p. 16.

occluded on account of their condition. Indeed it may be argued that in the catastrophically damaged person, whether neonate or adult, including those with dementias, we see with particular clarity images of both incarnation and brokenness. Such people should always be regarded as full members of the human community and therefore as full recipients of the requirements of neighbour-love. Those who are beyond *cure* should never be beyond *care*, and care, as Paul Ramsey remarks, ‘cannot fall short of universal equality,’<sup>17</sup>

More recently, there has been an emergence of interest in what has been characterised as ‘*narrative medicine*’. In his book *The Wounded Storyteller: Body, Illness and Ethics*, Arthur Frank argues that ‘telling stories of illness is the attempt, instigated by the body’s disease, to give voice to an experience that medicine cannot describe.’<sup>18</sup> He therefore speaks of the body, ‘creating the person’<sup>19</sup>. Rita Charon similarly argues that ‘such movements as ‘relationship-centered care’, ‘spirituality and medicine’, and ‘the ethics of virtue’ (in other words, those that address the character of the care-giver rather than the moral validity of an action) signal deep commitment to bettering the tattered state of doctor-patient relationships and to improving the outcomes of medicine’<sup>20</sup> She writes, ‘Narrative medicine has come to understand that patients and caregivers enter whole – with their bodies, lives, families, beliefs, values, histories, hopes for the future – into sickness and healing...’<sup>21</sup> These and others have attempted to re-frame and re-establish the importance of the doctor-patient relationship by focussing on life stories which include the illness *trajectory*, and therefore shift attention away from the illness *per se* and onto the embodied self and, more importantly still, the *self-in-relationship*. Though neither of these writers make reference to the work of Tournier, his influence, and congruence with his thought, are nonetheless evident.

## Conclusion:

Thus, as Stanley Hauerwas argued, the instinct to care arises not out of abstract philosophical notions of personhood but out of the practical out-working of the moral imperatives which relational bonds lay upon us. As he writes:

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<sup>17</sup> P Ramsey, “Justice and Equal Treatment” in S E Lammers and A Verhay eds. *On Moral Medicine* (Grand Rapids: Eerdmans, 1987), p. 510. For a fuller treatment of the issues for those with cognitive disability see the work of John Swinton *et. al.*

<sup>18</sup> A. W. Frank. *The Wounded Storyteller: Body, Illness and Ethics*. (Chicago: University of Chicago Press, 1995), p.18. See also the work of Paul Ricoeur who argues in his theory of ‘narrative identity’ that the self only comes to be in the process of the life story being told, and Gabriel Marcel’s notion of being a living testimony focuses the quality of witness offered by (illness) stories and further explains how (illness) stories are not only *about* the body but *of* and *through* the body.

<sup>19</sup> *Ibid.*, p.27.

<sup>20</sup> R. Charon. *Narrative Medicine: Honoring the Stories of Illness*. (Oxford: Oxford University Press, 2006), p.ix. See also Anton Boison, who refers to bodies as ‘living human documents’.

<sup>21</sup> *Ibid.*, p.12.

*'When people are dying we seldom decide to treat or not to treat them because they have or have not yet passed some line that makes them a person or non-person. Rather we care or do not care for them because they are Uncle Charlie, or my father, or a good friend. In the same manner we do not care or cease to care for a child born defective (sic) because it (sic) is or is not a person'.<sup>22</sup>*

Whatever our view then, the damaged newborn survivor, like the unborn human and the dying patient, forms part of what Gene Outka describes as our 'moral landscape'.

Without the moral and relational perspective offered by a rigorous theology of human personhood, we are thrown back onto what I believe is a fundamentally flawed, 'life at all costs' view of medicine that Dan Callaghan has described as simply *'technological brinkmanship'*. This is why, despite, perhaps because of, the technological achievements of modern medicine, so many people are deeply frustrated by the way things turn out.

Theology offers medicine the challenge to return from its current scientifically and technologically orientated, even obsessed perspectives, to its roots as a humane art, to see the patient as 'person' and to regard their care as a form of love.<sup>23</sup> Only thus, as Tournier had hoped, will we be able to transform competent technicians into genuinely reflective practitioners.

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**Kendal 2013**

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<sup>22</sup> S Hauerwas, "Must a patient be a person to be a patient? Or, My Uncle Charlie is not much of a person but he's still my Uncle Charlie" *Connecticut Medicine*, 39 (December 1975) 280

<sup>23</sup> Recent conversations suggest that serious, evidence based research is being undertaken in the United States into 'love' as a therapeutic tool. See also work on spirituality and 'spiritual distress'.