

MAINTAINING THE INTEGRITY OF PERSONHOOD IN PALLIATIVE CARE

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ABSTRACT: The integrity of personhood refers to the wholeness or intactness of the self in all its diverse aspects. Life threatening illness can compromise the intactness of the self in many ways, four of which are examined here ; the resultant suffering can be understood as spiritual pain, since spirituality and the integration of the self are closely connected. The needs of persons faced with the threat of dis-integration of the self are examined, and it is suggested that such needs may be best met by carers in four ways :- by Seeing, Listening, Loving , Respecting the Mystery. To do this requires not so much professional expertise as a way of being, a quality of presence which depends upon who we really are, as persons.

Key Words: Palliative Care, Personhood, Hope, Spiritual Care, Suffering, Transcendence

Introduction

‘Palliative Care is concerned with the whole person—a person’s body, mind, emotions, social and family context, and spiritual values. The interplay among all the components of the human condition is fully recognised in palliative care.’ (Palliative Cancer Care Guidelines 1994)

Palliative care aspires to be total care, care which is holistic in its focus on the physical, psychological, social and spiritual aspects of the person living with life threatening illness. It seeks, as far as possible, to maintain the integrity of the person in all these aspects, and to address the challenge of what Cicely Saunders called ‘total pain.’(Saunders 1967)

In the following article I attempt to describe certain ways in which serious illness can threaten the intactness, the integrity of the person. I then go on to say something about the needs of persons, and how carers might address these needs. I am conscious throughout of how closely intertwined the concepts of personhood, spirituality and hope are, in the context of palliative care.

Let me begin by quoting from a poem by G.Hughes, entitled ‘Old Man’:

*Until the end of sunset, the great chestnut tree
clutched a ray of light to its heart
and the old man sat under it, as if he felt
that holding a light within the surrounding dark
was a symbol of the proper way to depart*

I find this a moving image, and one which is relevant to the theme of maintaining the integrity of personhood. Integrity in this context has to do with wholeness, unbrokenness, entirety. Here is someone who senses on all sides that encroaching darkness which symbolises the ending of his life. And yet, still he holds a little bit of light, round about him and inside him. The anonymity of the darkness has not claimed him yet. He is himself, and he is holding on to the wholeness of himself for as long as he can.

What is a person?

Campbell (1972) cites Boethius’ definition of personhood as ‘ the individual substance of a rational nature ’, and describes it as the locus classicus of an approach which stresses the uniqueness of the individual. Persons are unique. Persons are also rational. Personhood implies the capacity to think, decide, choose, reason, understand,act, exercise autonomy. Persons are said to have intentions and purposes, to make choices, to solve problems.(Pettifer 1987). Persons have rights, duties, moral responsibility. And it may be that personhood in its fulness only emerges through our ongoing relationships. So I am

not a person, perhaps, not fully, but I have the potential to *be* a person. I may be becoming a person, or there may be aspects of my living which in fact impede my progress toward personhood.

I intend in the above merely to indicate some of the sheer richness, the many facets, suggested by the terms 'person' and 'personhood'. No one definition will do. For the purpose of what follows, however, I should like to concentrate on four of what seem to me to be four important aspects of personhood, especially in the context of a discussion on maintaining the integrity of personhood in palliative care.

- Persons are unique individuals
- Personhood is nurtured in relationship
- Persons have potentiality to grow in personhood
- Personhood is essentially a mystery

Suffering of persons

Persons are who we are; ourselves in all our complexity. And when we suffer, we suffer as persons. In other words, our suffering is complex. The concept of total pain recognises this.....pain physical, psychological, emotional, spiritual, social...suffering which can seem to threaten the disintegration of all that I am, all that I have been, or will be, or could be.

Life threatening illness can cause persons to suffer loss of personhood in all four of the aspects listed above.

Persons are unique individuals

'Had I to carve an inscription on my grave, I would ask for none other than The Individual' (Kierkegaard 1847)

'We have many things in common, and we are also completely individual and particular' (Ruddock 1972)

Nicoll (1992) expresses powerfully the threat posed by serious illness to the uniqueness of the individual, the 'me-ness of me'.

'It's the living on as something other than, less than, I'd rather be. A me-minus. It's about losing dignity. It's about having to face a slow disintegration...it's also about a fear of dying in an impersonal bed, in a

hospital full of caring staff who still cannot give me what I really need...a personal and private place in which to die. For me, that has to be in my own little boat out at sea. In other words, it's all about the individual staying the individual he would rather face the world as, and leaving it that way.'

The fantasy of dying in a little boat out at sea is part of Nicoll's personhood. No doubt we all have in our minds an 'ideal' setting in which we would like to die if we had the choice. Such things are so personal to each of us. Our tastes, our talents, our habits, our culture, our secret lives, our unspoken fears..all, all of them form part of our uniqueness as persons.

But suddenly to become a patient! To become a case, a set of symptoms, the object of medical curiosity, or a challenge, perhaps to medical science which can seem from the sufferer's point of view to focus on disease and not on illness, not on the suffering which may not be physical pain, but something else entirely, something hard to express, unscientific, intensely personal.. What then? Surrounded by well meaning carers, I may still feel as if my personhood is being compromised, even violated. I am an object. I am a problem which may or may not be solved. I am one of many, so many.

Personhood is nurtured in relationship

'A person makes his appearance by entering into relation with other persons'(Buber 1937)

But serious illness has brought with it such devastating changes in my relationships! I no longer feel that I can be an equal partner in any exchange. Am I worth relating to now, diminished as I feel myself to be? Am I still a worthwhile partner, parent, friend? Do they smother me in solicitude, or avoid me, resent me, lie to me? Do they blame me? Am I an embarrassment? What social role do I play now? Am I able to express somehow, to someone, what I really feel? Is anyone willing to enter this sudden and terrible aloneness? And what of my relationship with God?

Persons have the potential to grow in personhood

'The human journey is a continuous act of transfiguration' (O'Donohue 1997)

‘a person is a fluid process, a flowing river of change, a continually changing constellation’ (Rogers 1961)

However significantly they may diverge in their understanding of its exact nature and purpose, the voices of christian spirituality and of psychotherapy are united in the conviction that personhood implies potentiality for growth, through relationship, through experience, through humour, courage, imagination, and all that we bring to our understanding of the business of living and dying.

Potential to grow, but also to diminish? What can I become now,

except less than I was, a me-minus? So much is diminished: strength, control, independence, attractiveness. How can I grow, when I can see little real hope or future, and when everything is girt about with fear, a fear which saps the strength and resilience which I thought I possessed?

How can I grow, when humour, courage, imagination seem so overwhelmed by circumstance?

Personhood is essentially a mystery

O’Donohue (1997) contemplates writing a story about a world in which you would only approach one person in the course of your life. He writes ‘You would have to practise years of silence before the mystery of presence in the Other; then you could begin to approach.’

But I have lost touch with the mystery of me. I am no mystery now. I am a set of problems to be addressed by sundry experts in physical, social, psychological, spiritual malaise. I have been scanned, invaded, cut, sown, irradiated. Who I am now is encompassed within a set of casenotes. My identity is to be found somewhere along the line of the differential diagnosis. There is strangeness everywhere, around me, inside me, but no mystery to stir my spirit.

The anguish expressed above is essentially about the threat of disintegration.

‘Suffering is the state of severe distress associated with events that *threaten the intactness of the person*. Its manifestations include sadness, anger, loneliness, depression, grief, unhappiness, melancholy, rage, withdrawal and yearning’. (Cassell 1991) And all this, sometimes, with barely a word spoken.

‘Only one dreamer going back
to how he felt when he was well,
Weeps under the pillows at his lack
But cannot tell, but cannot tell.’ (Jennings 1985)

Personhood and spirituality

Like personhood itself, the term spirituality is not easy to define. Twycross (1991) describes the spiritual dimension as the integrating component, holding together the physical, psychological and social dimensions of the person. Many definitions of spirituality suggest that it concerns three areas :- integration, relatedness and a transcendent context (ie something greater, more enduring than the self.)

‘The spiritual dimension *transcends* and *holds together* the physical, psychological and social dimensions. The spiritual *integrates* the other three into an ‘I’, an individual who is more than the sum of his parts.’ (Interdenominational working party 1992)

The suffering, then, of those whose illness threatens dis-integration, isolation and meaninglessness could be described as spiritual suffering, and maintaining the integrity of personhood could be counted as part of the task of spiritual care.

The needs of persons

What do persons need? Cassell (1991) lists three things

Support ; Meaning ; Transcendence.

He defines support as a process of borrowing and being sustained by the personhood of others when our own personhood is threatened by suffering. Meaning concerns all those awful questions which arise when serious illness comes. Is it my fault? What did I do? Why me? As persons, we need to set our suffering into some context of meaning, if we are not to be overwhelmed entirely by it. Not that the terrible ‘why?’ questions *can* be answered at the deepest level. Why suffering at all? Who dare answer that? And yet, we construct meanings that we can live with, and we do that within the context of a relationship in which the questions can be asked and pondered, if not answered.

And what of transcendence, the third on Cassell’s list? The person located in a larger landscape than that of the self, perhaps? I am not alone in my suf-

fering. I am not isolated. Perhaps through this experience I can somehow reach out beyond my small self and feel more keenly my bonds with others, or my connectedness with creation, in which everything grows and decays and is renewed, or my connectedness with God, with whom I struggle, but who receives my anguish and my questions. Again, persons do not engage in this process alone. We do it from the security of relationships in which we know that we will be kept and held and affirmed, no matter what. Cassell's categories of support, meaning and transcendence are through and through relational.

Kitwood,(1997) although writing specifically about persons with dementia, lists needs which surely have a wider relevance in the context of life threatening illness. He mentions comfort, identity, attachment, occupation and inclusion. Comfort is the warmth and strength which might enable persons to remain in one piece when they are in danger of falling apart. Attachment and inclusion are about being held in relationship. Occupation has to do with meaningful activity and creative outlets. Identity is that sense of self, which can be enhanced or diminished by the validation which we receive from others. Kitwood sets out all five like the petals of a flower, and at the centre, holding them all together, he places love.

How do we maintain the integrity of personhood in palliative care?

It should be obvious by now that it is impossible to reduce the answer to a set of do's and don'ts. We are very far from being in the realms of checklists here. So much of our effectiveness, as carers, in this area, depends not so much on what we have learned from books or gained degrees and diplomas in, as on who and what we are, as persons. 'Where is the wisdom we have lost in knowledge?'(Eliot 1969). The importance of knowledge in palliative care cannot of course be underestimated. Those involved in this field need a sound and up to date scientific base for what they do, and the skills to do it well. And yet, perhaps especially in palliative care, attending as it does to the needs of the whole person, all that knowledge of ours is in fact placed at the service of something else. The science of medicine is the servant of the art of medicine. Knowledge is placed in the service of wisdom. The application of scientific medical knowledge, in the absence of the warmth and balance, the solicitude and compassion of wis-

dom, might indicate that something less than healing was going on. The suffering of the person might even be increased.

It seems to me that if we are to maintain the integrity of personhood in palliative care, then we need to have, need to convey a certain quality of presence. We must be willing to risk stepping out from behind the protection of role or uniform or claim to expertise, and to meet a fellow human being on the ground of shared humanity.

How do we convey that quality of presence ? I would suggest that we convey it in four ways :-

by seeing
by listening
by loving
by respecting the mystery

Seeing

'truly to be noticed is to be allowed space in which to unfold and blossom as a person.'(Wright 1996)

To see is such a rare gift, and yet most of us, most of the time, look with a superficiality which robs all creation of its wonder. Dennis Potter described to Melvyn Bragg the sight of a plum tree in blossom outside his window. His seeing is made acute by the fact that he knows he will not live to see another spring.

'...looking at it, instead of saying..oh, that's nice blossom..looking at it I see it is the whitest, frothiest, blossomest blossom that there ever could be, and I can see it.'(Potter 1994)

This intense quality of seeing is a kind of seeing in depth, a kind of insight through which hidden truth comes to light. I believe that inside all of us there is a yearning to see and to be seen with that concentration of attention, that intensity of focus, which reveals the truth. See me for who I truly am. See me in my uniqueness, my specialness, my one-offness. See me in my suffering. Don't just look at the tubes, the x rays, the scans (employing what Foucault (1963) described as 'the anatomo-clinical gaze') Byock (1996) talks about the clinician who, having assessed symptoms, pain, functional status and so forth, leans forward, establishes a direct gaze with the patient and asks 'And how are you in yourself?'

The asking of that question is therapeutic in itself, because it conveys a willingness to *see*.

Listening

‘To be human is to speak. And to be abundantly human is to speak freely and fully. The converse of this is a profound truth also; that the good listener is the best physician for those who are ill in thought and in feeling.’(Johnston 1956)

There is more to me than a case history. I have a past which makes me who I am, for good or ill. I use language, metaphor in my own way, creating my own meaning. I have anxieties which I find it hard to frame in words and so...I need you to listen, even to the unsaid, the unsayable.

Newshan(1998) focussing on the contribution of the nurse, has this to say : ‘When listening sincerely, the nurse shows sthat the human spirit is something sacred, to be respected and honoured.’

and again, in the words of Wilcock(1996) :

. ‘When we listen, we can be a bridge, a touching place, a way back into spiritual connectedness for the one who is torn apart by grief or by fear. Often, such listening is all that is required to give the patient confidence to re-establish their own spirituality, to find, amid the fragments of life as it was, at least a small spring of grace, a hope of meaning.’

Loving

‘If you can love what you do, then you will do it beautifully’(O’Donohue 1997)

There are skills of observation, of listening, which can be studied and taught, practised and honed. And yet, in the words of John Ruskin, ‘where love and skill combine, expect a masterpiece’. Cassidy(1994) expresses something similar when she speaks of having shed her professional facade, knowing that what patients really respect is ‘that heady mixture, competence and compassion.’ If we are to be true healers of persons, then our seeing, our listening, and every other skill we possess will be employed with what might be called the imagination of love.

‘Ultimately, what we have to offer is not technical expertise, but ordinary faculties raised to a higher level : our power to feel, to give, to stand in the shoes, or sit in the chair of another, through the use

of our imagination. At times, we may even offer love.’(Kitwood 1993)

Respecting the mystery

‘The person fully explained could easily be the person lost.’(Campbell 1986)

Respecting the mystery of persons has to do with recognising that even when we share most deeply at the human level with another person, there are always things left unsaid, unexpressed, unresolved, and necessarily so. ‘Individuals are unknowable in their entirety.’(Cassell 1991) and care which aspires to tend to the whole person must be mindful and respectful of this. Unless we want to reduce mystery to a set of problems, then this must be so. To respect the mystery is also to convey an awareness of that transcendent dimension, and to be sensitive to the fact that a real healing encounter between two persons nourishes the personhood of both, and sets it in a context which is somehow greater than both. And if we respect the mystery of persons, we will not harbour any delusions that we are able somehow, or should be able, to eliminate the suffering of those for whom we care. We cannot always do that. We can sense the woundedness of persons, acknowledge it, but refrain from too intrusive an effort to mend, to resolve. Perhaps there is a level of suffering which is inevitable, given our strange and question filled life in this world, and which can often best be acknowledged in a shared silence.

Conclusion

O’Donohue(1997) reflects that although the human body is born complete in one moment, the human heart is never completely born. ‘It is being birthed in every experience of your life.’ In this striking image he describes what we spoke of earlier as the potentiality for growth in personhood. It is possible for the heart to be birthed, for personhood to develop, through the experience even of life-threatening illness; even, according to de Hennezel(1997) of death itself.

‘Death can cause a human being to become what he or she was called to become; it can be, in the fullest sense of the word, an *accomplishment*.’

In our efforts to maintain the integrity of personhood in palliative care, we are involved in a mode of caring which makes possible the birthing of the human

heart, and through which persons can be helped to hold to the light around and within them, for as long as they have life.

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