A theological perspective on the withdrawal of care

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Decisions on the withdrawal of care are not made in abstraction. They impact on the meaning and understanding of life — the life of the individual in question as well as life in a wider communitarian sense. The web of life into which we are bound makes arbitrary decisions on the withdrawal of care suspect. Ethical perspectives must play a role in the processes leading to such a decision. At the same time, debates on the quality of life, the beginning and cessation of life and the meaning of life indicate that religious and cultural factors are part of the parameters that inform such debates. Hence the role such factors play in the ethical response cannot be underestimated.

The present structures of the medical enterprise in India — the training systems, the organisation of hospitalisation and the inbuilt attitudes regarding medical and nursing care — have emerged through a long and complex process. This includes the interaction between tradition, local practices and the impact of colonisation. The so-called 'civilising' attitudes of colonial structures of power resulted in an often crude, always problematic, interaction between the dominant forces and the reservoir of medical skills and techniques available in our own contexts. (1) The institutionalisation of medical care in comparatively recent times, and the setting up of institutions to cater to various levels of perceived medical needs, resulted not only in the emergence of clinics, hospitals and training centres, but also in the institutionalisation of an ideology of care. Generations of medical and support personnel have passed through the training institutions, either missionary-church linked or government or society-group oriented. They have imbibed, along with their training, particular ideologies of care and understandings of the meaning and nature of life. If some of the factors contributing to such an ideology were placed in the open, we might realise that even the most secular training, which disavows any connection with the Christian theological tradition or with colonial structures, has imbibed attitudes towards the body emerging from early Christian understandings of the body, and such attitudes continue to play a role in the debate on the withdrawal of care.

Here I present three cases on the approach to the body in the early Christian tradition. These raise issues on the wider debate regarding the decision to withdraw care today.

The Body of the Martyr

There is a huge literature on the deeds of martyrs in the early centuries. For our discussion, I highlight the martyrdom of a young woman, the Roman citizen Perpetua, in the amphitheatre of Carthage in about the year 203. The account of the martyrdom of Perpetua, who at the time of her death was 22 and had a nursing infant, is remarkable in the wealth of details provided. (2) The actual account of the martyrdom, which follows dramatic and moving appeals to Perpetua to respect her father's grey hair and to have pity on her mother and siblings, as well as to have consideration on her nursing infant son, is poignant and evocative. Those martyred along with Perpetua included the slave woman Felicitas, who shortly before had given birth. On the appointed day:

Perpetua went along with a shining countenance and calm step, as the beloved of the God, as a wife of Christ, putting down everyone's stare by her own intense gaze. With them also was Felicitas, glad that she had safely given birth so that now she could fight the beasts, going from one blood bath to another, from the midwife to the gladiator, ready to wash after childbirth in a second baptism.(3)

Those to be martyred were scourged by a gauntlet of gladiators because they had enraged the crowd by gesturing to the Roman procurator that though he had judged them, he would be judged by God. After having experienced this, they rejoiced because they had partaken in the suffering of their Lord. Regarding Perpetua:

For the young women, however, the Devil had prepared a mad heifer. This was an unusual animal, but it was chosen that their sex might be matched with that of the beast. So they were stripped naked, placed in nets and thus brought out into the arena. Even the crowd was horrified when they saw that one was a delicate young girl and the other was a woman fresh from childbirth with the milk still dripping from her breasts. And so they were brought back again and dressed in unbelted tunics.

First the heifer tossed Perpetua and she fell on her back. Then sitting up she pulled down the tunic that was ripped along the side so that it covered her thighs, thinking more of her modesty than of her pain. Next she asked for her pin to fasten her untidy hair: for it was not right that a martyr should die with her hair in disorder, lest she might seem to be mourning in her hour of triumph.

[Those who had survived till then were gathered in the usual spot for their throats to be cut]. *But the mob asked that their bodies be brought out into the open that their eyes might be the guilty witnesses of the sword that pierced their flesh. And so the martyrs got up and went to the spot of their own accord as the people wanted them to, and kissing one another they sealed their martyrdom with the ritual kiss of peace. The others took the sword in silence and without moving. ... Perpetua, however, had yet to taste more pain. She screamed as she was struck on the bone; then she took the trembling hand of the young gladiator and guided it to her throat. It was as though so great a woman, feared as she was by the unclean spirit, could not be dispatched unless she herself were willing.* (4)

The key words are the link between the death of the martyr and the statement that she could not be killed unless "she herself were willing." The role of the subject in determining

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her or his destiny has always played an important role down the ages. The informed choice, the open rationality, death as a spectator-event, in which the one who is to experience this reality is, up to the end, in control of the ultimate decision, are themes emerging from this episode. What about those for whom such a possibility of participating in the decision making process is no longer possible? Our story has led to the situation where the patient, about whom the decision has to be made, remains a silent participant in the processes leading up to decisions on the withdrawal of care.

The Body of the Ascetic

The extreme turns that the monastic movement took in the early centuries of the development of Christianity are illustrated with the example of the greatest of the pillar-saints, Simeon the Stylite (c. 389 – 459), who lived perched aloft pillars, including his last abode, a pillar 60 feet high, on the top of which was a small railed platform, where he spent the final 40 years of his life. (5) After a long period, undergoing extremities of asceticism and facing vicious temptations, we read:

His foot developed a gangrenous putrescent ulcer, and harsh pain came and went through all his body. And fearful pains of death seized him, but he endured them. For he did not murmur, nor was he hindered from his labour … when the affliction grew strong and acted mightily on the holy one, his flesh decayed and his foot stood exposed … And he watched his foot as it rotted and its flesh decayed. And the foot stood bare like a tree beautiful with branches. He saw that there was nothing on it but tendons and bones … The blessed man did a marvellous deed that has never been done before: he cut off his foot that he would not be hindered from his work. Who would not weep at having his foot cut off at its joint? But he looked on it as something foreign, and he was not even sad.

And as Satan was wallowing in blood and sprinkled with pus and covered in mucus, and the rocks were spattered, the just man nevertheless sang. … While a branch of his body was cut off from its tree, his face was exuding delightful dew and comely glory. (6)

Michel Foucault in his monumental history of sexuality points out that the "Christian ascetic movement of the first centuries presented itself as an extremely strong accentuation of the relations of oneself to oneself, but in the form of a disqualification of the values of private life; and when it took the form of cenobitism, it manifested an explicit rejection of any individualism that might be inherent in the practice of reclusion."(7)

This second episode focuses on an attitude of contempt for the body — a body seen as a vehicle destined for a greater good, a body marked by an almost perverse acceptance of the reality of suffering, but also marked by the fact that such suffering is necessary for the purposes of edification: "The body was fashioned anew, and with it, human order as well." (8) The ethical issue that emerges from the example of the ascetic is that of the responsibility for care of self and the reality that marks the body as a site where a greater drama is played out. The question arises: how were such extremes of asceticism to be seen by those who claimed to be edified, but were not called upon to practice such forms of asceticism in their own lives? Was it in the impossibility of compliance that non-ascetics were to be edified? Edified to do what?

The Body of the Celibate

Sexual renunciation has been and is a dominant theme in the history of the church. In the fourth century, the hermit-scholar Jerome wrote:

How often, when I was living in the desert, in the vast solitude which gives to hermits a savage dwelling place, parched by a burning sun, how often did I fancy myself among the pleasures of Rome! I used to sit alone because I was filled with bitterness … Now, although in my fear of hell I had consigned myself to this prison, where I had no companions but scorpions and wild beasts, I often found myself among bevies of girls. My face was pale with fasting, but though my limbs were chilled, yet my mind was burning with desire, and the fires of lust kept bubbling up before me when my flesh was as good as dead. Helpless, I cast myself at the feet of Jesus, I watered them with my tears, I wiped them with my hair: and then I subdued my rebellious body with weeks of abstinence.(9)

Here what is important is that the body has not been brought under control by the practice of renunciation, but that it continues to be the abode of the senses in a heightened manner: "The literal pallor and chill of a body ravaged by ascetic fasting was not matched by a cooling of desire; indeed, Jerome's libidinal imagination was producing dancing girls by the dozen."(10) A perceptive commentator notes that for Jerome, the body remained "a darkened forest, filled with the roaring of wild beasts, that could only be controlled by rigid codes of diet and by the strict avoidance of occasions for sexual attraction." (11) This insight has also been the experience of those standing within the great Indian tradition of renunciation, as, for example, Gandhi has so graphically described.

Questions on the withdrawal of care

Having examined these cases, we now need to raise and problematise the issues, which having emerged in the past, weigh upon the present.

1) The example of the body of the martyr indicates that in today's context of considering withdrawal of care, even when decisions have to be made without reference to the patient concerned, the patient's presumed rights and consent remain a problematic area. With whom does the choice lie? What about those in no position to make any kind of informed choice? How do care-givers interact with the patient's family? What is the role of economic interests in either prolonging or terminating care? Does the language of cost and benefit belong to such ethical considerations?

2) The example of the body of the ascetic seems far removed from any debate on the withdrawal of care. Nevertheless it has consequences for the present. There is a link between the withdrawal of care and the perception of suffering. Does suffering have any meaning? Is there dignity

in suffering? Does the ability, or lack of ability, to manage pain play any role in coming to an ethical decision?

3) The example of the body of the celibate may have functioned to titillate and amuse. The reality remains that the body as a site of feelings, desires and emotions leads us to the consideration of the body as something beyond the mere physical and physiological. For the terminally ill, considering those who may not be in a position to gain from the technology of medical care, decisions on the withdrawal of care raise issues of the psychosomatic nature of the human body. When confronted with the reality of a person, who even in the extremity of a near-death situation is nevertheless a human being, one needs to ask whether decisions on the withdrawal of care have sufficiently problematised the sentient nature of the human person.

You may think I am obsessed with extreme cases – the martyr, the ascetic and the celibate — that emerge from the margins. What about ordinary people, what about the life and death of such people who were not called upon to inhabit the boundaries? I suggest that extreme cases provide the basis for bringing ethical and moral judgements to bear on the lives of 'ordinary people'. Cases on the margin, and the intensity of the boundary situation, are the sources from which those who make choices draw.

Where does all this leave us today, when we have gathered to consider theological perspectives on the withdrawal of care?

I realise that I have taken refuge in examples from the past, without any theological affirmations on the withdrawal of care today. I hope that I have demonstrated that the contemporary debate would be impoverished if it did not take into account this legacy. One could benefit from a deeper analysis of how the inherited Judaeo-Christian tradition has interacted with Indian religious traditions' attitudes to the body in informing the issue in the past and even today.

I hold that, theologically, however much one may talk of life as a gift from the beyond, which nevertheless must be lived in the here-and-now, brushing aside a debate on the withdrawal of care would be irresponsible. One must remember that withdrawal of care has presumed a situation of the **intervention** of care. How was this intervention done? Why, for whom and by whom? Intervention carries with it structures of support, physical and material, human and technological. The withdrawal of care is not a withdrawal into helplessness or a descent into fatalism. It is because "death is an ambivalent event, we cannot achieve … moral certainty in order to feel comfortable in a horribly complex world of fundamental moral risks."(12) Questions on a decision's usefulness and the limits of knowing will continue to be part of the process of deciding, one which is never free from the responsibility of risk. It is the wider societal group, comprising health care professionals, ethicists, the family, and ultimately the silent patient, who are at the core of the decision on the withdrawal of care.

What does the withdrawal of care mean in relation to the body in pain and human dignity, dignity both in life and in death? The Indian Christian theologian, Stanley J. Samartha, himself suffering great pain because of cancer, poignantly asks: "Are there not moments in human life when dying with dignity is a far better option than dependence on others, humiliating struggles, and silent or audible cries of pain?" (13) Terms such as love, value and life must not be seen in monochromatic terms. The polyvalent and ambivalent nature of human reality must be seen in all its variety. A narrow appeal to a presumed 'religious' ground to persist with care functions only to obscure wider issues regarding the body and society. I hope we have the basis for a challenging and fruitful discussion.

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