The Dying Process: Patients' Experiences of Palliative Care

By Julia Lawton. Routledge, London, 2000.
£14.99, 229pp. ISBN 0-415-22679-1

Julia Lawton is a research fellow at Newnham College, Cambridge, although the biographical information does not inform the reader what her subject is. No matter, after reading this volume it is clear she is a sociologist, a social scientist with a strong ethnographic interest. It is also clear that she has fundamental disagreements with some of the tenets of the hospice movement, disagreements which are not spelled out in full, to the disadvantage of the argument she is trying to make. Her volume attempts to describe itself – particularly in its subtitle – as a study of patients' experiences of palliative care. Yet, though Lawton sat and observed in two hospice or hospice-type institutions over a period in this research, the amount of true, unedited experience recorded here is limited. We read of patients whose bodies literally disintegrate, of foul smells and stinks, of pain relief that does not reach psychic pain, of isolation and pointlessness. However, we read it – in part – through Lawton's eyes and nose. Her first pronounced impression of hospice is the smell, and she never gets used to it.

That disgust – for such it is, experienced by many of the patients and their families as much as by Lawton – brings her to question whether palliative care is the only, the true, way of approaching death. One feels her arguing with a hospice movement whose younger practitioners are less doctrinaire than its founders; Dame Cicely Saunders is undoubtedly deeply opposed to euthanasia, as are most palliative care and pain specialists. However, ask some of the younger ones how they feel about suicide, as long as they are not asked to assist, and you might be surprised at the response. In my experience, few of those who work in hospices believe that they have all the answers, and even fewer feel that they can support adequately those who are in despair at their physical disintegration that makes them

disgusting to themselves. However, Julia Lawton misses the point. The question is the alternatives, and – despite the title – she does not ask the patients. Would euthanasia have been preferable? Why did they not commit suicide? What about faith, expectation, the legitimacy of suffering?

I would have liked to have heard more from the patients here, and less sociological theory. I would have liked fewer references to literature (often American, and largely irrelevant in a UK hospice setting), and more display of the diversity of patients' feelings. She claims ethnicity and culture were minor in a Judeo-Christian framework. Yet Judaism and Christianity attach very different significance to pain and suffering, and the last vestiges of life on this earth are perhaps even more precious to Jews than to Christians, for theological reasons. Yet that is unremarked, and she makes no effort to observe a hospice where diversity is commonplace, such as the interfaith hospice in north London. Diversity matters because attitudes to death, suffering and body image vary so considerably, and attitudes to psycho-social support matter too, or spiritual care.

One ends up feeling that Lawton's own views colour her observations too strongly, and that she remains unconvinced by hospice care. However, because the volume is such a mixture of academic treatise, with countless studies mentioned, and personal, unrandomized, observations, it is hard to follow the argument other than to register her doubts and distress. Two other works are waiting in the interstices of this volume. One is a real study of patient and family views, as randomized and diverse as possible, which would be fascinating. That could build on the important work of Lesley Cullen and Michael Young (not quoted by Lawton) in examining attitudes to grief and bereavement in east London. If done well, it could throw considerable light on patient and family expectations of palliative care. However, the other work is what one senses Lawton wishes to write, a brave – or foolhardy – polemic about our societal desire to believe hospice cures all because it cures physical pain.

Lawton wants to challenge us into re-thinking our attitudes to death with dignity, and she is right to do so. However, this volume is not the right book for that. Its complicated sociological verbiage only obscures, rather than clarifies, her

honest doubts and heartfelt, and nose-sniffed, criticisms.

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