

The Patient's Ordeal

William F. May
Indiana University Press, Bloomington
and Indianapolis, 1991, 218pp

This book is a pearl, formed over many years of personal experience, study, collaboration, reflection and meditation. May redresses a bias in medical ethics, by focusing on the "patient's ordeals" rather than the "professional's quandaries". This perspective may be seen as part of a broader movement among researchers and philosophers from a variety of disciplines. In order to advance understanding of human development and behaviour, we need to allow the stories of those people themselves to be heard. In addressing the ordeals of patients May also addresses a considerable gap in the traditional literature in medical ethics which largely focuses on the solution of moral dilemmas. In this book, he looks at problems which persist, that "must be faced rather than solved", problems faced by patients (and often their families) which "confront us with someone to be. They assault our identity".

The book is organised around a series of studies of specific human experiences which demand continuing ethical responses from the individual, his/her family, and society. The first six chapters examine extreme experiences or ordeals which nevertheless raise many issues common to us all eg parenting, and illuminate common questions and approaches within traditional medical ethics.

In Chapter One "The Burned", May provides a penetrating description and analysis of the moral issues facing the patient suffering from severe burns. Within this chapter he identifies particular limitations of our simplistic use of "life vs quality-of-life" positions, and denounces the inappropriateness of the two extreme positions of "professional paternalism" and "patient choice". This particular case-study pays overdue tribute to the heroism of the patient:

... without consent to transformation the patient cannot move from saying "please let me die" to "I am glad to be alive". That heroic movement does not vindicate his

doctors, because the deeper decision must be his, and only as it is his do we see in him not simply a patient encased and obscured by the surgeon's art but the uncanny radiance of a man (p35).

In the second chapter, "The Retarded", May uses the issues involved in parenting a child with mental retardation to illuminate both the extreme demands of such parenting and also the general moral issues in all parenting. As such, this chapter provides an insightful perspective, but it is mistitled in that it fails to discuss the ordeals/moral dilemmas faced by people who are mentally retarded themselves. By choosing this chapter title, May's failure to note the difference highlights the very ordeals which "the retarded" experience - their lives are interpreted largely through the "ordeals" they impose on their families or service providers. They are seldom perceived as having lives on which they have their own valued perspectives and interpretations. Notwithstanding these comments, this chapter contains much wisdom and highlights one of the recurrent themes of the book, namely the naivete and inappropriateness of "marketplace" and utilitarian philosophies in solving healthcare resourcing dilemmas. This book should be required reading for all politicians and policymakers in health and disability support services.

The next chapter on "The Retarded Institutionalised" also suffers from May's lack of personal experience with people who are retarded and with recent advances in education and service provision. Contrasting experiences in ordinary families and community settings would have led to different viewpoints on the experience reported here of one visit to an institution. This chapter therefore provides extended description but limited analysis or reflection apart from identification of some very relevant moral dilemmas in treatment programmes for people with profound disabilities.

Chapter Four, "the Gestated and Sold" provides a basis for further developments of May's condemnation of a "marketplace" paradigm for the delivery of medical services. Concepts

derived from manufacturing which separate process from product are seen as wrong and dangerous in areas such as birth. May extends his discussion to include all of us who are parents and warns us of the danger of yielding to the temptation to treat children as products, by vicariously living our own lives through the performance of our children. As he points out:

Parents may need to recognise that marriage and parenting resemble dirt-farming more than engineering ... In the changing seasons of married and family life, one turns the soil, broadcasts a little seed, prays for a little sun and rain, and hopes for the best. (p78)

Chapters five and Six deal with the ordeals suffered by those who experience violence to the person - the ongoing pain resulting from physical and sexual abuse - "The Battered" and "The Molested". May's discussion highlights how

..... ethicists underestimate the ordeal that people face in the moral life when they euphemistically refer to 'trade-offs', as though people in trouble need only spread out, like accountants, a balance sheet (p85).

He also re-examines his own basic model of ordeal - "death/perilous passage/rebirth" - and points out its limitations in oversimplifying the ordeals experienced by victims of violence, by restricting this "death" ordeal to the original trauma. "Rehabilitation also menaces and confronts the victim as a death" (p119).

May's exposition on "The Aged: Their virtues and vices" in Chapter 7 speaks to us all - no one can be exempt. In this chapter he discusses both our attitudes to the aged and their own moral responsibilities. This chapter shows how relevant moral considerations are to the practical issues of service design and provision for elderly persons. The study of ethics is not just for ministers of religion and academics. For those of us who are (or will soon be) aged ourselves, May's discussion of the "ethics of care-receivers" is compulsory reading. To respond to the moral issues posed by aging, May argues that we need "virtues or strength of character", which include (among others) courage, humility, and patience. This chapter

illustrates again May's thesis that "our reduction of ethics to purely pragmatic issues of problem-solving" has resulted in a serious neglect of other moral issues which require us to *be*, not just *do*.

In Chapter Eight, "Afflicting the Afflicted: Total Institutions", May examines our health care institutions as symbols of death. His historical and philosophical analyses of institutions and their practices are enlightening, but I feel that he fails to adequately justify his own conclusions that institutions are necessary. Indeed, some of our "health care" institutions for people with chronic disabilities have failed miserably in their provision of good health care and have merely provided "care" - and often very poor care at that. His own thesis of our neglect of dependent people as moral persons in their own right, deserves greater attention in this chapter.

The final two chapters deal with "The Afflicted assisting the Afflicted",

through study of Alcoholics Anonymous (as an example of a lay support system), and the issue of organ donations for transplants. May brings a unique contribution from his own Christian background to issues of organ donations, in addition to relevant experiences of recent examinations of these issues.

In the Postscript May presents his personal analysis as a Christian theologian of the themes discussed in this book. Each reader will identify with this in different ways, depending on his or her own spiritual and ethical life.

This wonderful book provides a unique contribution to the field of ethics. In medical ethics, it redresses an imbalance in favour of "quandary ethics" by focusing on the neglected but more extensive field of "virtue ethics". For policy makers in health, it has important messages about the inappropriateness and danger of marketplace and

manufacturing models and concepts, and the relative neglect of rehabilitation and on-going care and support vs acute care. The writing is a great pleasure to read, drawing on May's extensive literary, religious, ethical, and personal knowledge. It is a book which is written for a wide audience and is accessible to such an audience. Every person faces ordeals in his or her life that require a moral response in identity and living. We may be spared the extreme ordeals discussed in this book, but our responses to the ordinary experiences of living are also illuminated. As May says in his Introduction:

..... the events of courting and love, birth, generational conflict, sickness, and death present us with something to do; but more important, they also confront us with someone to be. They assault our identity (p4).

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