

Living and Dying with Cancer

Living and Dying with Cancer is a powerful and moving account of the experiences of those affected by one of the most common causes of death in the Western world. Through a series of individual narratives based on extensive interviews carried out by the author, the book explores the impact that being diagnosed with cancer has on those with the disease and the people around them. It follows the different trajectories of the disease from the very first symptoms, through treatment to death and shows how the experience of the disease and even the way it develops is affected by the social context of the people involved, as well as their own physical and psychological characteristics. This book will be an invaluable resource not only for social scientists and health professionals but also for those coming to terms with the impact of cancer on their own lives.

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This book is dedicated
with love to my father, Ronnie Armstrong, who
taught me so much
and to
all the individuals who participated in the research,
many of whom you will meet in the pages of this
book.

Death is no enemy of life; it restores our sense of the value of living. Illness restores the sense of proportion that is lost when we take life for granted. To learn about value and proportion, we need to honor illness, and ultimately to honor death.

Arthur W. Frank, *At the Will of the Body* (1991: 120)

. . . my *life* counts; its termination, its being-no-more, my *death*, is no more a senseless, absurd, unjustifiable occurrence: not that sinking into the emptiness of non-existence it once was – that vanishing which changes nothing in the world. Through making myself for-the-other, I make myself for-myself, I pour meaning into my being-in-the world. I refuse the world the licence to disdain and dismiss my presence; I force the world to note, and to dread in advance my passing away, and to bewail it when it comes. [his italics]

Zygmunt Bauman, *Mortality, Immortality
and Other Life Strategies* (1992: 202)

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Preface: Opening the silence

Dying is a period of life, fraught with complex issues which can occasion a depth of feeling impossible to quantify. This, in part, may be why details about the actual minutiae of dying, a devastating experience, are not usually made public knowledge. The actuality of serving what is left of a life, of continuing to survive in what to many becomes an enforced and unspeakable existence, is not often aired before the public. The pain is quite simply too much to be transmitted (Frank, 1995). Consequently, there is a dearth of valid, truthful experiential accounts of dying which warrants immediate attention. My respondents allowed me a brief glimpse into that most awful of experiences.

To give these previously silent voices a space in which they may be heard, to open up this silence, I decided that this book would be narrative driven. I was aware of the value of the stories and the responsibility of presenting the information ethically. Having grasped something of their pain and appreciated the urgent need for these stories to be made public, my objective was to act as transmitter of what I heard. This book is primarily concerned with presenting and analysing the respondents' view, the stories which they told me. It makes no claim to be generalisable. It quite simply attempts to present a series of accounts from individuals of what it was like for them to be dying from cancer. As with all individuals, their reactions were based on their interpretations (Hammersley and Atkinson, 1996) of their experiences, so it would be foolish to claim that any one reaction held validity over another or that anyone else, given the same variables, would act in the same way.

My problem was that the data required was, even by the standards of those not dying, of an exceptionally sensitive nature. I needed a tool that could respond effectively and appropriately. Indeed, I was aware that some of the issues arising during the interviews could focus directly on thoughts which some may have had difficulty countenancing even when in good health. This difficulty was compounded by the fact that I knew I would be retrieving it from individuals who would probably be at their most vulnerable, both physically and psychologically.

Having weighed the prospective difficulties of longitudinal interviewing against the potential benefits and, in spite of knowing that it would add years to this study, I specifically chose to do just that, as it would allow me to monitor the physical and social changes which occurred to the respondents as their dying journeys progressed.

This decision was greatly influenced by the knowledge that working with vulnerable people would call for trust, which could only be earned over a period of time. The interviews began, continued and, as I hoped, our relationships matured sufficiently to foster the disclosure of the more sensitive 'private' accounts (Cornwell, 1984).

The decision of whether to participate in the research was left to the respondents, who received the information sheets and consent forms, approved by the relevant Research Ethics committees, from their medical staff. At no stage did I actively recruit any particular respondent or refuse any individual who volunteered themselves.

Although I am in no way medically trained, I have had previous experience of working as a volunteer in hospices. I was pleased then, when two hospices, including one where I had previously worked, were kind enough to allow me to carry out my observations there.

At the beginning of each initial interview, every respondent was given and read what I refer to as Pre-interview Information. This explained to them, amongst other facts, that I would endeavour to ensure that they would receive anonymity and complete confidentiality at all times, that they might terminate their inclusion in the research whenever they wished and that I was not a counsellor nor medically trained but a social science researcher. All of these interviews, which were taped, were open; the content and issues under discussion being determined by the respondents with minimal intrusion or prompts by me and then only in an attempt to facilitate a more coherent articulation of the subject under discussion.

When I arranged the initial interviews, I left it up to the individuals concerned whether we would be alone or have a supporter present. Some, like Clive, I saw alone; others like Gita's family, I saw as a complete unit. I also interviewed several professionals and this proved invaluable in educating me on the substantive detail that has informed the background to this work.

All the respondents were given different names, allocated after some reflection, with consideration to names that might have been popular around the time and place where they were born. I have also altered some minor details of their lives, to protect their anonymity further.

The main participants in this study fell into three groups: respondents who had cancer, supporters of these respondents and individuals who had been recently bereaved. To allow development of their stories, I have

used extensive quotations and examples from a small subset of these respondents but my comments and analysis apply equally to many more.

During the study I encountered several unexpected and difficult problems. Amongst other factors, these concerned respondents who did not conform to their anticipated trajectory, either by fortunately outliving their prognosis or by, regrettably, dying prematurely. I found the problem of premature death especially demanding to deal with. It was difficult to recruit respondents for the study, as I was seeking volunteers who were facing very real physical and psychological issues. When a respondent agreed to be interviewed, I had to establish contact speedily as the very reason I was interested in them, their status of being terminally ill, might in itself preclude them from taking part.

It is difficult to determine which part of the fieldwork I found most challenging; however, having to learn to temper, and at times quell, my natural inclination to ‘cheer people up’ by presenting an alternative perspective to a problem they felt was insurmountable, was very demanding.

The prolonged periods spent in my ‘volunteer’ observer role within the hospices were difficult, too. As it is emotionally draining work, regular volunteers there usually work one shift every two weeks. My need for this research was to observe the evolving dying trajectories of several patients, so I needed to spend concentrated periods of duty there. This inevitably led to my relationships with the patients and their families becoming closer, which introduced its own problems. I clearly remember my shock when, on reporting for duty on the Care Floor one evening, I asked after one young patient, who had been vigorously alive just the evening before, and was casually told ‘Oh, he’s just been taken to have his eyes removed’. He had, of course, died before becoming a donor! That same difficult evening two patients asked me to help speed their dying.

Counter to the reaction of many others to people who are dying, I always perceived my respondents to be very much alive, possibly because, in our interviews there was frequently more laughter than tears. In understanding that this laughter probably functioned as a valve to release heightened emotions, I feel strongly that dying does not diminish a sense of humour but rather serves to stress the vital side of life so that all its aspects are appreciated.

Acknowledgements

A few moments before she died, a hospice patient explained to me that in giving a person your time you were really giving them a part of your life. It is important therefore that I acknowledge the contributions and support given by my friends and colleagues during the composition of this book. I am especially indebted to Joan Busfield who gave generously and unstintingly of her time supervising much of my PhD, which has formed the nucleus of the text. The support I received from the sociology staff at the University of Essex was remarkable; my special thanks go to Elizabeth Francis (now at LSE), Jeff Geiger, Ken Plummer, Colin Samson and John Scott. My thanks also to Ian Craib, who gave me the freedom to pursue my research but who has since, sadly, died.

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