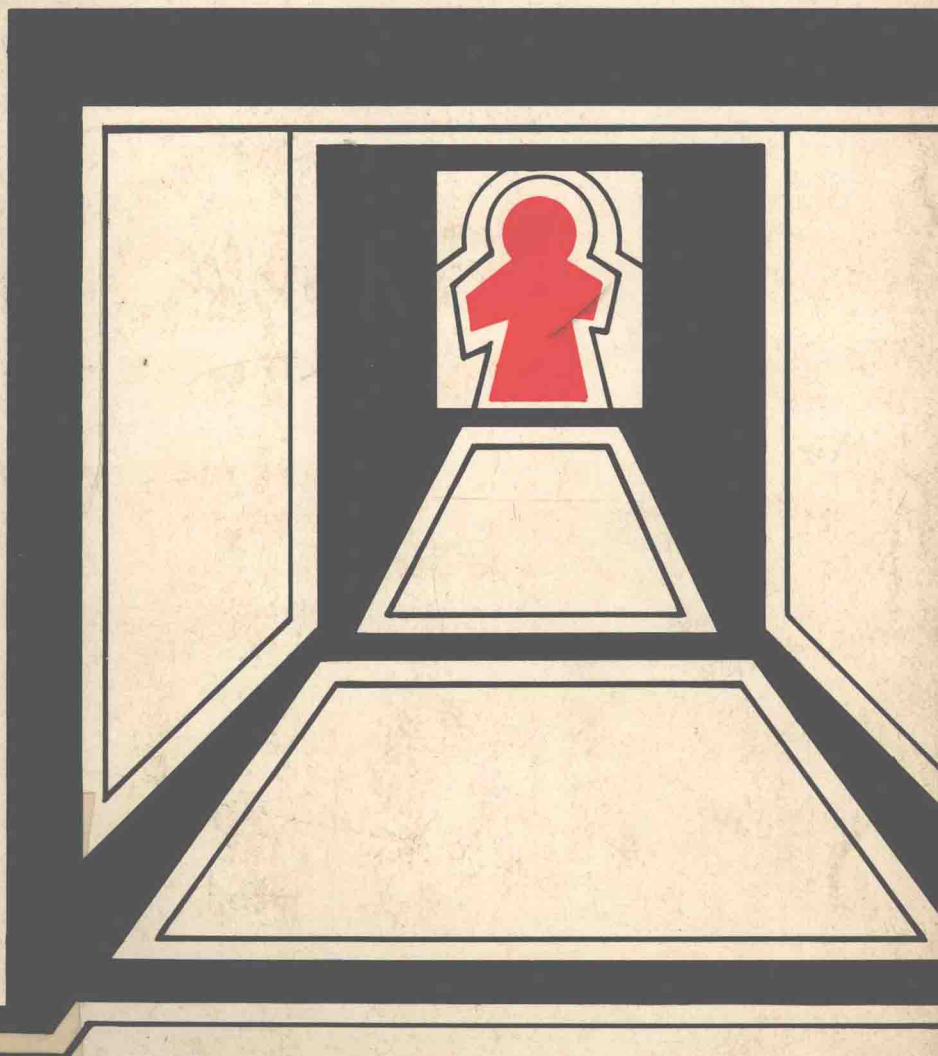


THE CHILD AND DEATH

Edited by OLLE JANE Z. SAHLER



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THE CHILD AND DEATH

It was a brisk, sharp January, just nine years ago.
I was six years old, but not too young to know
what piece of my life had been torn from the whole
by this tragedy which would torment my soul.
Still, I giggled when first told the news;
It had to be a trick, a thoughtless ruse!
But in a few lonely days I learned to lose.
It had happened—and that was how life had to be,
Yet I cried for days, for I believed that he
had died not of illness, but of me.

JORDAN WASSERTHEIL SMOLLER

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PREFACE

In mid-September, 1977, many of us represented by this book gathered at the University of Rochester Medical Center for a 2½ day symposium: "The Child and Death." For all those hours we, and more than a hundred others from many places and representing many disciplines, discussed, debated, challenged, and supported one another as we attempted to sort out data, clinical impressions, and personal experiences. As we struggled with our own feelings as caregivers—and some as parents—of the fatally ill child, we learned that, just as important, we are also the comforters and teachers of those who are the siblings or children or friends of someone who has died.

This compendium covers more than we could possibly have dealt with in that relatively short period of time, for it also contains the thoughts and feelings of some who could not join us then, but who agreed to add their considerations and deliberations to ours in the context of this book.

The unique thing about this book is the tremendous amount of personal sharing that many of the authors have included in their presentations, as well as the critical review to which they have subjected their particular biases. The overall impression is that there are, fortunately or unfortunately, no absolutes; instead, each individual must learn to understand the child and his family, to resolve personal issues, and to continuously support himself and those around him as each strives to find his or her own most comfortable place within the framework of coping with death.

My thanks to the contributors are incalculable.

In addition, I am indebted to Dr. David H. Smith, Chairman of the Department of Pediatrics, who eagerly provided sponsorship for the symposium and encouragement in editing this collection.

I am grateful, too, to Lyn Neary, who always maintained incredible equanimity despite all the rigors and frustrations of manuscript preparation.

To acknowledge my own family seemed almost superfluous until I realized that too often I do not actually and publicly express the thanks that I feel. And so, to Chip, who listened patiently, advised, and sup-

ported; to Brian, who taught me that toddlers can be very wise; and to Catherine, who was an integral part of me throughout the preparation of this book, arriving almost simultaneously with the galley proofs: thank you.

OLLE JANE Z. SAHLER

INTRODUCTION

OLLE JANE Z. SAHLER

One of the most profound and far-reaching changes to occur in our society in recent years has been the tremendous increase in our ability to postpone, almost indefinitely in some cases, the cessation of life. What has come out of this awesome power is a new awareness of death.

It has not been to the particular credit of modern medicine that death education, the concept of death with dignity, and Right to Die legislation have, for the most part, arisen only in response to the openly and repeatedly stated needs and desires of the lay public. However, there is some consolation in the fact that, once challenged, medicine has been able to respond, meaningfully and self-critically, to the demands of those who seek better answers to the many questions that surround death. It is also understandable that the fields of nursing, social work, education, religion, ethics, economics, and law, among others, have had to join medicine in attempting to provide reasoned answers.

Despite this new openness about death in our culture, children, as a group, are precluded from expressing themselves in an organized fashion. Thus, their needs become known only by inference and only to those who go to particular trouble to discover what those needs are, for almost never are they explicit.

One of the fascinating things about children is the naive, simplistic way in which they approach the unknown. Yet it is this very naiveté that makes their questions the most difficult to answer. They usually have no prior experience on which to base their reactions, and so their earliest grief and mourning is unique to each of them, often outside the confines of socially dictated rituals of which they are ignorant. Their grief, instead, centers around the familiar: themselves, their families and friends, their daily routines. They seek comfort and acknowledgment of their own intrinsic worth.

Despite all the research that has been done on the child's concept of death, we still do not have an adequate understanding of the responses of children under 4. This shortcoming reflects the research tools that have thus far been devised, almost all of which depend heavily on verbal ex-

pression or picture drawing—impossible tasks for the infant and toddler. Behavioral observations, more appropriate to this age group, on the other hand, cannot be as carefully controlled or as easily quantitated and systematized. Yet there is great need to look more carefully at the dynamics of the very young and their families to gain better insight and by it, offer more substantial direction and consolation to the child, the family, and ourselves. Marion Barnes' careful observations in Chapter 16 offer a first step in interpreting the behavior of these children, and we learn that children under 4 are more aware and more affected by bereavement than we have speculated, although abstraction, on which we formulate norms, is not within their repertoire.

Sister Berger's comprehensive bibliography, which includes a number of books that are suitable for even the very young, offers another possible vehicle for work with children in the late toddler to early preschool age range, although here again, there is heavy reliance on verbal expression and understanding. As a general statement, however, I would like to underline one of her major tenets: the reader, even if a young child, should be allowed great flexibility in choice of books, even if, at first glance, the parent or teacher feels that the content may not be suitable. Thus is realized the intent of bibliotherapy: a working out of an emotional response to a situation, ideally in conjunction with support, guidance, and explanation from a trusted adult.

Rather than thinking, however, that the reactions of children are specific only to them, I venture that their questionings and misconceptions and feelings of guilt and magical omnipotence are pervasive throughout all ages. The major difference between a child and an adult is that the adult can usually subjugate these feelings to some higher order of thought or relegate them to the unconscious until some loss, devastating in its impact on the individual and his defenses, loosens the tight bonds that hold these forces at bay. A prime example of this adult regression to early childhood thinking is the "if only . . ." phenomenon seen, for instance, among the parents of a fatally ill child. Even when all that is rational argues emphatically that there is no, and never could have been any, "if only . . .," this rationality gains no foothold with the parent, just as it is a fruitless argument with the child. Distance in time for the parent—perhaps—and greater maturity for the child—usually—are the only paths to eventual resolution.

Thus, the principles that apply to understanding the child's developing concept of death, managing his acute or chronic grief, helping his family, and recognizing the role of formal and informal education about death are not restricted only to the child or adolescent. Rather, they transcend all age groups, even the very old.

Throughout the following writings, some have noted the caregiver's or teacher's need to come to some realization about his own immortality before effective work with the dying can take place. My own bias probably most closely parallels that of Hal Lipton in Chapter 4, who states that this has been, for him, an impossible task. Rather, his obligation to his clients, as he sees it, is to help them sort out their feelings about dying by being an available, responsive, but nondirective sounding board for their individual deliberations. This seems to me to be the most realistic goal of any caregiver.

However, from another vantage, I am personally also a member of the team that has struggled long hours to save a life. I have experienced the exhilaration of success and the despair of failure—the most agonizing part of which is facing the family and admitting defeat. There is, undeniably, a feeling of self-incompetence, most jarring because it is usually so well hidden by complacency. I am reassured by the reflections of Peter Viles (Chapter 12) that I am not alone, and perhaps we are both reassured by John Schowalter and Bruce Axelrod (Chapters 10 and 11), who tell us that not only are we not alone, but there are many in our cohort.

Members of many different disciplines—nursing, social work, the ministry—emphasize repeatedly that work among the fatally ill is a lonely experience, sometimes very rewarding but sometimes not. When it is rewarding, we derive our support and incentive to continue from the gratitude of those we have helped. Unfortunately, that kind of gratitude is not often forthcoming when we are most vulnerable, when we perceive ourselves as having failed.

It should be noted that occasionally we rely too heavily on patients and their families to provide incentive for continued caregiving without really understanding or accepting their needs as paramount to our own. For example, we may be “turned off” by the adolescent who does not and will not share his or her deepest feelings with us, even though we accept intellectually that he or she may not need to do so because of a particular personality style or because of the presence of another support system for this kind of ventilation. We are sometimes provoked to anger when a patient becomes angry or noncompliant, morose, thankless, or withdrawn. We are personally affronted—a natural response—rather than understanding when individuals or families have no more to give, when their grief is so overwhelming that social niceties and facades are no longer tenable. Yet for the caregiver who feels deeply and who has seen himself as an emotionally supportive partner, such withdrawal is perceived as a rejection rather than as a reminder of the tremendously forceful egocentrism of profound grief: the cry, “Leave me alone. How can you possibly know my pain?”

Where do we turn? Most say that we do not turn to our peers, because admitting the need for reassurance too precisely delineates our fallibilities among the very group with which we are in constant explicit or implicit competition. We go instead to someone who is enough removed from our battles to maintain an undercurrent of admiration for us and our work no matter what the specific crisis or perceived shortcoming: to a spouse who, whether in the same field or not, can give love and understanding by virtue of the nature of the marital bond; to a professional of another discipline who “could never do the wonderful things you do”; to a confidante, a confessor, a teacher.

Lest the reader walk away with the sense that those who work with the dying or who teach or counsel about death revel in their own masochism, let me point out that the rewards are many and they are real. From those children and families whom we help, we derive a tremendous sense of fulfillment. From those innovative changes that we are able to make in the health care and educational systems that benefit society at large, we derive great personal satisfaction and public respect. From those delvings into our own minds, those struggles to comprehend what may, in effect, be incomprehensible, and from those wounds that are eventually healed, we derive a sense of ourselves, perhaps in a slightly larger context than we might otherwise have achieved.

Despite all of this, however, the battle is never completely over. It goes on through other deaths where, although the reactions of the dying and the survivors might be predictable, they are still heart-rending in their initial intensity and persistently throbbing in their chronicity. Just as no death is ever entirely erased from the memory of the caregiver who struggled to forestall it, so it is remembered all the more by the family and friends who remain, bereaved, for the rest of their lives. To “get over” a death means to be able to function adequately and appropriately despite its having happened; it does not mean to forget.

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