When Part of the Self Is Lost

Helping Clients Heal After Sexual and Reproductive Losses

Constance Hoenk Shapiro

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PREFACE

"I think I'm going crazy." "My family says I should get on with my life, but I just can't." "I feel as if I've lost a part of myself." These are some of the sentiments expressed by my clients in response to the intense grief caused by their sexual and reproductive losses. Are these clients unusual? Are their presenting problems unique? Not at all. The clients I see are people with AIDS, infertility problems, spinal cord injuries, and chronic illnesses; victims of sexual assault; cancer patients; couples who have suffered pregnancy losses; and people whose sexuality has been affected by the course of normal aging. All these conditions have grief and sexual loss as a common denominator.

Many books have been written on these two topics separately, but this is the first book to address their interrelationship. Grief and sexuality were prominent themes in my recent book *Infertility and Pregnancy Loss: A Guide for Helping Professionals* (1988), and in many ways that book served as an impetus to expand my attention to those themes. The reader may note that I have drawn some material from my earlier book, notably on the topics of infertility, pregnancy loss, and stillbirth, and have used this material to enrich the content of *When Part of the Self Is Lost.*

A major purpose of this book is to present sexual and reproductive losses in a bio-psycho-social perspective; such an

approach is crucial for professionals who may be working as members of a team in an effort to coordinate services for a client or a patient. Second, by providing case vignettes throughout the book, I have tried to move the professional beyond the *facts* of the client's condition to the *feelings* of loss and grief associated with the conditions discussed. Finally, the book provides detailed information about the counseling and therapeutic skills necessary for work with clients who are grieving a loss.

Despite its emphasis on the intensely private areas of grief and sexuality, this book is not intended to be morose or depressing. The reader is encouraged to think of griefwork as an opportunity to help clients heal and reclaim their lives. The attention to sexual losses is balanced by an emphasis on how to help clients redefine their sexual needs and find joy in new or expanded forms of sexual expression. And, most important, since many clients feel extremely isolated when they are grieving their sexual losses, this book is written to help the professional empathize with the client's emotional pain, develop systems of support, and find creative ways to help clients work through their grief and empower themselves in spite of the losses they have endured.

Who Should Read This Book?

Many different helping professionals can offer emotional support to people experiencing sexual and reproductive losses. Social workers, psychologists, psychiatrists, oncologists, gynecologists, obstetricians, nurses, midwives, family counselors, other medical professionals, and rehabilitation providers such as speech, occupational, and physical therapists are likely to be consulted as men and women from many walks of life experience a sexual loss, mourn for what has been lost, contemplate the implications of the loss, and confront the ongoing life decisions that they must make. Clergy of all faiths are in a special position to offer support and solace when parishioners turn to them in times of despair, loss of faith, and anger that their prayers are not being heard.

The following professionals, paraprofessionals, and volunteers in a variety of facilities and agencies may also find this book helpful: staff in women's clinics and counseling programs, crisis intervention programs, nursing homes, hospice programs, AIDS clinics, convalescent hospitals, retirement communities, and programs that offer support and self-help groups. As an educator of students in social work and the human services, I believe that this book is also appropriate for students preparing for careers as helping professionals.

Professionals reading this book need to be aware of the importance of working in tandem with other professionals involved in the client's recovery from loss. A fragmented delivery of medical and emotional interventions undermines a person's courage as he or she undertakes the difficult griefwork precipitated by a sexual or reproductive loss.

Overview of the Contents

The book is organized into three parts. The first part (Chapters One and Two) provides an overview of theoretical material that the professional can use as a guide when organizing interventions with clients. These chapters provide information on attachment and loss in the context of sexuality, including in-depth attention to the dynamics of grief and coping.

Chapter One offers a framework for conceptualizing certain sexual and reproductive life events as losses, thereby sensitizing both client and professional to the griefwork that will become an important part of the recovery process.

Chapter Two presents several theoretical models of the mourning process and emphasizes a range of coping strategies that clients can be encouraged to use as they resolve their losses and reconstruct their lives.

Part Two (Chapters Three through Ten) provides information on the sexual and reproductive dimensions of specific injuries, medical conditions, and the process of normal aging.

Chapter Three illustrates the various sexual losses experienced by clients who have had hysterectomies and enterostomies and clients with diabetes, endometriosis, and paraplegia.

Chapter Four presents concrete information on cancer and AIDS and discusses the emotional needs of the client who alternates between feelings of despair over the diagnosis and the wish to maximize periods of good health and remission. This chapter concentrates on cancer of sexual and reproductive body parts: the breast, prostate, uterus, ovary, and testis. Special attention is given to feelings and attitudes of professionals who work with terminally ill people.

Chapter Five emphasizes the attachment formed by an infertile couple to a fantasy baby, as yet unconceived, and details the disruptions caused by the diagnostic workup and treatment efforts. This chapter also notes the common themes of loss that occur in the infertility struggle and suggests specific ways in which the professional can help couples to cope.

Chapter Six examines the concept of symbolic attachment and the ways in which it becomes an integral part of the mourning process following an elective abortion, miscarriage, or ectopic pregnancy. Although the woman often bears a unique burden in reproductive losses because of her incapacity to give birth to a healthy child, this chapter also emphasizes her partner's response to their shared loss.

Chapter Seven addresses the emotional anguish felt by couples whose baby is born dead. This chapter pays attention to the immediate needs of the couple while the woman is still in the hospital, as well as the ongoing emotional needs once the woman is discharged to return home with empty arms.

Chapter Eight emphasizes the needs of the sexually abused young person within the context of the family. Using the clinical perspective of posttraumatic stress disorders and referring to the phases of the rape trauma syndrome, the author familiarizes the reader with the expectable reactions of children and adolescents who have been sexually abused. The reader is reminded that other professionals probably will be working with the child and the family (child protective services and legal and medical personnel); consequently, each professional must be clear about the boundaries of his or her role so

that the child does not feel confused, betrayed, or further traumatized.

Chapter Nine uses the framework of rape trauma syndrome to conceptualize the adult's response to rape. Whether the assault was by a stranger, an acquaintance, or a spouse, the survivor will have a series of losses to acknowledge and work through. This chapter highlights the therapeutic implications of the losses experienced by adult males and females who have survived a sexual assault.

Chapter Ten explores the concerns of older persons as they come to terms with many losses, some of which tend to eclipse their sexual needs. This chapter encourages the professional to explore with older clients *all* of the losses, including the sexual ones, that cause them regret or distress in their later years.

Part Three (Chapters Eleven through Thirteen) contains chapters that examine the role of the professional beyond therapeutic efforts with clients.

Chapter Eleven uses a developmental perspective to remind the reader of sexual and reproductive issues at each stage of the life cycle. The chapter encourages the professional to consider the client's needs from a broad bio-psycho-social framework rather than adhering too narrowly to any one professional area of expertise.

Chapter Twelve challenges the professional to look beyond individual circumstances to the community in which clients must maintain their coping strategies. The chapter raises questions about organizational barriers that professionals must surmount in their roles as educators, advocates, and change agents.

Chapter Thirteen discusses the need for professionals to maximize their therapeutic helpfulness by continually improving their knowledge base, increasing their intervention skills, and gaining personal replenishment. This chapter emphasizes self-awareness, assessment of one's own areas of resilience and vulnerability, and the importance of developing support net-

works so that psychological energy can be replenished on an ongoing basis.

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A number of people have been very helpful and supportive as I have written this book. I am especially indebted to Karen Dashiff Gilovich, Heidi Dana Lipson, Wendy Robertson, M.D., Sue Rochman, and Bonnie Shelley for their willingness to share professional literature with me and, later, to make incisive comments on the first drafts of specific chapters. I also appreciate the precision with which Seana Rolland helped me with the many references contained in this book.

Since all my clients are struggling with sexual or reproductive losses, I have learned an immense amount from them as they courageously mourn their losses and seek new ways of coping with altered life hopes.

And, of course, I owe a special thanks to my family: to my husband, Stuart, who offered constant encouragement; to my children, Adrienne and Daniel, who were accommodating in juggling our use of the family computer; and to Glenna Vangeli, who provided loving care to my children while I was immersed in the research that has culminated in this book.

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THE AUTHOR

Constance Hoenk Shapiro is chair of the Department of Human Service Studies in the New York State College of Human Ecology at Cornell University, where she is also professor. She received her B.A. degree (1969) in sociology from Wellesley College, her M.S. degree with distinction (1971) from the Columbia University School of Social Work, and her Ph.D. degree (1978) in education from Cornell University.

Shapiro's main research activities have been in the area of human sexuality, with particular focus on adolescent pregnancy, infertility, and pregnancy loss. She has received numerous teaching awards and has published extensively in professional journals. She is the author of two books: *Adolescent Pregnancy Prevention: School-Community Cooperation* (1981) and *Infertility and Pregnancy Loss: A Guide for Helping Professionals* (1988). In 1989, she was coeditor of her most recent book, *Adolescent Sexuality: New Challenges for Social Work* (with P. Allen-Meares).

Shapiro has been on the faculty at Cornell University since 1974, serving as the director of its social work program from 1986 to 1992. She is on the board of directors of the Ferre Institute in Utica, New York, and was a founding member of the Central New York Chapter of RESOLVE, Inc. She also serves as a consultant to federal, state, and local organizations on issues relating to human sexuality. In addition to teaching, consulting, and research, Shapiro maintains a private practice for infertile individuals and couples.

CONTENTS

PART 1

Loss and Grief

1

Attachment and Loss in the Context of Sexuality

Coming to grips with losses in American society is a challenging task for several reasons. First, Americans tend to value the stoic image of the person who "bears his loss well." People who have experienced a loss are said to be "making a good recovery" if they resume their normal activities shortly after the loss, make few and unemotional references to the loss, and do not disconcert others by their efforts to adjust to the loss.

Second, our increasingly mobile society disrupts our ties with families and stable neighborhood networks, traditionally sources of solace for persons coming to grips with a loss. The sacrifice of physical closeness with loved ones who have given comfort during periods of childhood loss, adolescent change, and adult transition is significant. Comfort now must be gleaned through long-distance telephone calls or truncated visits in the midst of a crisis; also sacrificed are the day-to-day comfortings that can cushion the pain of loss: child care, a healthy casserole, transportation, a dinner invitation, a lingering cup of coffee. The cycle of reciprocity that encourages families in close contact to comfort one another over life's losses is broken for many families today.

A third challenge that we face in coping with loss is to *define* a variety of life events as representing losses. The early literature on loss tended to focus almost exclusively on the death of a loved one. Later, notably in the work of Elisabeth

Kübler-Ross, that definition was extended to include one's *own* impending death as a loss to be mourned. More recently, loss has been broadened to include symbolic losses, life transitions, and the loss of physical functioning. However, even mental health professionals do not agree about what should be viewed as a loss or how it should be treated. Largely because of the seminal work of Erich Lindemann (1944), who studied people's responses to the deaths of loved ones in a Boston nightclub fire, counselors now recognize that a catastrophic loss can precipitate certain emotional reactions. However, the literature on crisis intervention, which had its roots in Lindemann's research, tends to ignore the individual's need to confront grief and loss and favors instead the goal of returning the person to normal functioning.

In this book, loss is defined as the disruption of an attachment—an attachment to other people, to body parts, to inanimate objects, to fantasies, to habits, and to life-styles. Perhaps Peter Marris (1974) conveys the broadest meaning when he reminds us that we feel immediately threatened if our basic assumptions and emotional attachments are challenged. Parkes and Weiss (1983) observe that persons threatened with loss typically intensify, rather than give up, attachment behaviors.

Peretz (1970) groups the concept of loss into four major categories: the loss of a significant or valued person, the loss of a part of the self, the loss of external objects, and developmental loss. Let us explore these losses in the context of life events concerned with sexuality and reproduction.

Loss of a Significant Person

The early work on responses to loss focuses on loss of significant others, with a concomitant emphasis on grieving the loss. Although death is often cited as the most final kind of loss, other life events disrupt relationships enough to cause a profound feeling of loss. Examples include physical separation from a loved one (caused by hospitalization, a jail term, family members leaving home, a geographical move to a new home);

dissolution of a relationship (a broken engagement, placing a child for adoption or foster care, divorce); loss of a symbolic attachment (pregnancy loss, infertility); and dramatic personality changes that sever the original attachment (changes resulting from psychiatric illness, an accident, or the aging process). The loss of the loved one may be total or partial, permanent or temporary. There may also be a loss of some special aspect of the person, even though the person is still physically present.

Sarah, an eighty- year-old woman, speaks of her life after she placed her ill husband in a skilled nursing facility:

> While he was home, I kept so busy just taking care of him. But my doctor finally told me that I would kill myself if I kept it up, so I arranged to put him in a nursing home. Do you think I did the right thing? I keep thinking of our wedding vows and the words "In sickness and in health till death do you part." So now I putter around doing nothing all day. My daughter takes me to see him once or twice a week, but we have no privacy, and all I can do is give him a kiss hello and a kiss good-bye. I wear his pajamas to bed at night to help me remember what it was like to snuggle up with him in the night.

When we think of ways in which the loss of a significant person bears on one's sexuality, we tend to think of a lover or a spouse. But the emotional response of grieving a loss almost always affects one's capacity for sexual intimacy (Orfirer, 1970; Simos, 1979; Shapiro, 1988). Thus, professionals need to be aware that changes in sexual practices and preferences are common when a client is mourning *any* loss, not only the loss of a sexual partner.

Loss of a Part of the Self

Our sense of identity, which encompasses our beliefs about our physical attributes and our worth as human beings, is shaped over a lifetime of interactions and personal growth. Many events occur that change our perception of ourselves, and we are often prepared for these changes by associations with others who have handed down folk wisdom and educational infor-