

Part A: Understanding Grief and Loss in Children and Their Families

Discussion Guide: Understanding Sibling Grief and Loss

Learning Objectives for this Section

- 1.4** Describe common reactions and coping mechanisms of siblings with sick brothers or sisters, including:
- How children understand what it means to be sick and what causes sickness
 - How illness in a brother or sister affects well siblings
 - The child's development of the concept of death
 - How siblings can be incorporated into end-of-life care of a terminally ill brother or sister
 - How siblings grieve

Relevant Milestones: PBL2, ISC2, PROF1

Introduction

Grieving siblings of children who have died have often been described as “forgotten.” We hope the module “*Understanding Sibling Grief and Loss*” will help pediatricians to remember sibling needs when their families are struggling with overwhelming life events and help patients and families to understand these concepts.

One of the important lessons of this module is a body of knowledge about how children and teens perceive the world and how their perceptions can limit their comprehension. For example, we know that their misperceptions can interfere with understanding the implications of serious or terminal illness, or acceptance that death is an irreversible, universal event. We also share a body of knowledge about how people grieve and what factors ease or magnify the grieving process. Not surprisingly, the reactions of children and teens are not dissimilar to those of adults. In fact, how children cope with a loss is almost always a reflection of how the adults in their environment (especially their parents) are coping.

The child's or teen's understanding of life and death, causation and responsibility, guilt and burden, and hopefulness and hopelessness are similar for the ill child and for the sibling. For example, the guilt inherent in magical thinking: “I did [something] to my brother that made him sick” is not unlike “I did [something] that caused me to become sick.” Or the hopefulness of bargaining: “I promise to...if I/my sister gets better.” In fact, regression to these immature thought processes at times of crisis is almost universal, even among adults.

For residents and fellows, learning about coping with death as a common life experience can take away much of its fright, allowing you to draw your own conclusions and to act in a straightforward way, as you would if you did not wear the mantle of “doctor” or “health care provider.” That mantle often makes us think that we should act in some special “professional” way, rather than making use of our knowledge and experiences as human beings.

An important message of this module is that siblings should be included in the process of preparing to say goodbye to their dying brother or sister. That they, too, are bereaved after the death occurs is a reality that needs to be acknowledged. Of course, saying goodbye assumes that the child who dies has a time of dying, a period in which the inevitability of their death is becoming real to their loved ones. Unfortunately, no period of anticipation is possible in the case of accidental death, homicide, or suicide, the three most common causes of death among teens.

How to Use This Section

This module is presented in a series of slides that include didactic information, exercises with a case study, and four vignettes that are intended to illustrate the didactic content and stimulate interest in the topic (see **Section A.4: Slide set: Understanding Sibling Grief and Loss**). The module is intended to be used as a guide for independent study by a student, resident or fellow.

“Understanding Sibling Grief and Loss” will familiarize you with:

- how children understand health, illness, and death
- changes in family dynamics that can occur when one of the children becomes seriously and then terminally ill
- the sibling’s grieving process, both in anticipation of the child’s death (anticipatory grieving) and in bereavement
- the healing power of positive lasting memories

This module includes a number of links to websites where the words and actions of siblings, themselves, are captured. These can provide powerful experiences. A complete Resource Guide is included in the Toolkit.

Exercises

Several “exercises” have been included to focus attention on the siblings of patients, as well as promote self-reflection as a sibling. These exercises can be accomplished through individual self-reflection accompanied by essays or short stories, or by discussion within a small group of peers.

The exercises focused on *patient’s siblings* are likely to reveal how little and infrequently we know the boys and girls whose brother or sister is dying. It also highlights how little we may know about the support systems in place for these children.

The exercises focusing on the *you as a sibling* (or other family member) are not meant to be therapy sessions. Their purpose is to raise awareness. Sometimes, only the potency and immediacy of a personal experience can heighten awareness to the level necessary to help a person focus on and understand the anxiety, worry, fear, and aloneness a sibling might feel when all attention is directed elsewhere, even though the sibling is hurting, too.

By using personal experience to illustrate how a child might feel, we hope to demystify end-of-life care and bereavement. Almost every one of us has been there — for family, a friend, a treasured pet. The experience of anticipated loss, the actual loss itself, the sense of heartbreak, and then recovery and moving on are integral to the human condition. What we each feel is more the same than different from person to person.