

Rough Crossings: Family Caregivers' Odysseys through the Health Care System



**United
Hospital Fund**

Shaping New York's Health Care.
Information. Philanthropy. Policy.

OFFICERS

Howard Smith

Chairman

James R. Tallon, Jr.

President

Mrs. Edward H. Gerry

Mary Hanlan Hess

Mrs. Lewis Schachne

Vice Chairmen

Paul J. Brignola

Treasurer

David A. Gould

Sally J. Rogers

Senior Vice Presidents

Rene Frayman

Vice President and Chief

Financial Officer

J. David Seay

*Vice President, Secretary,
and Counsel*

DIRECTORS

Luis Alvarez

Mrs. George M. Billings

Rev. John E. Carrington

Derrick D. Cephas

William L. Cobb, Jr.

Ernest J. Collazo

J. Barclay Collins II

William M. Evarts, Jr.

Timothy C. Forbes

Livingston S. Francis

Mrs. Edward H. Gerry

Mrs. Bruce A. Gimbel

Michael R. Golding, M.D.

Mary Hanlan Hess

Mrs. Robert A. Levinson

Walter N. Rothschild

Mrs. Lewis Schachne

Howard Smith

Frank S. Streeter

Most Rev. Joseph M. Sullivan

James R. Tallon, Jr.

Allan Weissglass

HONORARY DIRECTORS

Donald M. Elliman

Douglas T. Yates

Honorary Chairmen

Herbert C. Bernard

Mrs. H. Lawrence Bogert

John K. Castle

Mrs. Herbert Greenberg

United Hospital Fund of New York

The United Hospital Fund is a health services research and philanthropic organization addressing critical issues affecting hospitals and health care. The Fund constantly seeks to enhance its traditional role as the nation's oldest federated charity by helping to improve the delivery and shape the financing of patient care in today's changing environment. It does so by organizing and consolidating philanthropic activities; by initiating and conducting research, demonstration projects, educational programs, and health policy development; and by bringing together professionals and volunteers.

Rough Crossings: Family Caregivers' Odysseys through the Health Care System

Carol Levine
Director, Families and Health Care Project

United Hospital Fund of New York

Copyright 1998 by the United Hospital Fund of New York.

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording, or otherwise (brief quotations used in magazine or newspaper reviews excepted), without prior written permission of the publisher. The Outlines that appear in Section V and the Guiding Principles that appear in Appendix B may be copied and used without permission, but may not be republished without prior written permission of the publisher. Printed in the United States of America.

Library of Congress Cataloging-in-Publication Data

Levine, Carol.

Rough crossings : Family caregivers' odysseys through the health care system / Carol Levine.

p. cm. — (A special report)

Includes bibliographical references.

ISBN 1-881277-43-7

1. Medical personnel-caregiver relationships. 2. Caregivers—Services for—Planning. I. Title. II. Series:

Special report (United Hospital Fund of New York)

R727.47.L49 1998

362.1'042—dc21

98-38769

CIP

For information, write, Publications Program, United Hospital Fund of New York, Empire State Building, 350 Fifth Avenue, 23rd Floor, New York, NY 10118.

"The Ship Pounding," from WITHOUT by Donald Hall. Copyright (c) 1998 by Donald Hall. Reprinted by permission of Houghton Mifflin Company. All rights reserved.

The Ship Pounding

Each morning I made my way
among gangways, elevators,
and nurses' pods to Jane's room
to interrogate grave helpers
who had tended her all night
like the ship's massive engines
kept its propellers turning.
Week after week, I sat by her bed
with black coffee and the *Globe*.
The passengers on this voyage
wore masks or cannulae
or dangled devices that dripped
chemicals into their wrists,
but I believed that the ship
travelled to a harbor
of breakfast, work, and love.
I wrote: "When the infusions

are infused entirely, bone
marrow restored and lymphoblasts
remitted, I will take my wife,
as bald as Michael Jordan,
home to our dog and day."
Months later these words turn up
among papers on my desk at home,
as I listen to hear Jane call
for help, or speak in delirium,
waiting to make the agitated
drive to Emergency again,
for re-admission to the huge
vessel that heaves water month
after month, without leaving
port, without moving a knot,
without arrival or destination,
its great engines pounding.

—Donald Hall

Executive Summary

Each year more than 60 million Americans are admitted to or discharged from health care facilities. For institutions, these entries and departures are routine processes; for patients and their families, they are often fraught with anxiety and fear. This special report explores these transitions from the unique perspectives of family caregivers—the unpaid relatives, partners, or close friends who either provide direct care and emotional support to, or manage the health care of, those who are chronically ill or disabled. Its purpose is to contribute to the development of responsible and reasonable ways to respect, understand, and help all families coping with serious illness and the major transitions that mark that journey.

SOURCES OF INFORMATION FOR THE REPORT

- Section I. Academic literature on transitions in illness and family caregiving.
- Section II. Six focus groups of family caregivers which the United Hospital Fund's Families and Health Care Project convened in New York City in September 1997.
- Section III. Planning grant applications submitted by 28 New York City hospitals in April 1998 to the United Hospital Fund's Family Caregiving Grant Initiative, established to help New York City hospitals develop and test programs to respond to caregivers' unmet needs.

SECTION I. ILLNESS, CAREGIVING, AND TRANSITIONS

- Caregiving transitions occur in the context of the progression of a disease. While clinicians treat and classify the stages of disease, patients and families experience the symptoms, suffering, and changes brought about by illness.
- Caregiving can be considered to be a "career," replete with myriad stages, transitions, and stresses, which place caregivers in a state of constant flux.
- Caregiving can be seen in the context of a family's life cycle. A serious illness interrupts common transitions such as births, launching young adults, marriage, and retirement, and requires that families adjust to the anticipation of further disability and untimely death.

- Any transition from one health care setting to another, therefore, adds a complex layer of adjustment to the transitions already underway in a caregiver's family and his or her experience of illness.

SECTION II. CAREGIVERS' VOICES

The focus groups produced remarkably consistent themes, especially in terms of caregivers' feeling unprepared for caregiving tasks. The conversations provide insights into caregivers' individual experiences, and have direct implications for improving the health care system and for creating smoother transitions between care settings.

Family Ties

- Caregivers were usually thrust into their role by necessity, although most wanted to provide care because the ill person was significant in their lives.
- Caregivers whose family members and friends shared the burden of caregiving fared better than those who provided care alone.
- Caregivers' emotional attachment to their loved one was a powerful motive for providing care, but also led to anxiety and fear about the patient's welfare.

Caregivers' Reactions to Changes in Illness and Care Settings

- Transitions can be traumatic because they are often times when caregivers first become aware of changes or deterioration in the patient's condition. Many times they feel a heightened, even overwhelming, sense of personal responsibility for the patient's health and well-being.
- Many caregivers spoke of their sadness and the loss or change in their relationship with the care recipient.

Going Home

- Caregivers experienced discharge from the hospital as an abrupt, upsetting event because hospital staff failed to prepare them technically and emotionally for changes in the patient's condition. Many felt abandoned at a critical time.

Admission to a Hospital or Nursing Home

- Although most of the discussion centered on transitions from institution to home, the reverse—transition from home to hospital or nursing home—also presented problems.

- Many caregivers fear that their loved one will be neglected in hospitals and nursing homes. A transition to an institution means extra vigilance for the caregiver.
- In general, participants reported that hospital staff failed to acknowledge their emotional needs. None of the participants said that health care professionals had referred them to community-based agencies for emotional or other kinds of support.
- Many caregivers believe that older people are not treated sensitively in hospitals.
- Caregivers want compassion and understanding from institutional staff, and they want to be able to communicate with health care professionals about their loved one's condition.

Culture, Family Structure, and Religion

- Caregivers reported that cultural differences created special care needs, and sometimes led to problems with health care professionals whose backgrounds differed from those of the family.
- Some caregivers who are not immediate family members, or who do not fit into the traditional definition of "family," reported having difficulties obtaining information from, and being acknowledged by, hospital staff.
- Although some participants sought a religious explanation for their situation, no one mentioned organized religious institutions or clergy as a source of solace or assistance.

Financial Factors

- In most groups, discussion centered more on the emotional aspects of caregiving transitions, and less on financial concerns.
- When discussion did turn to financial issues, participants criticized the health care system's focus on costs, and spoke of needing more resources to provide care.

Death and Dying

- Bereaved caregivers did not have markedly different caregiving experiences from current caregivers, but they experienced the additional stress of what they felt was inappropriate care at the end of their family member's life.
- Most bereaved caregivers were either unaware of hospice or felt that it was an inappropriate choice for their family member.

SECTION III. HOSPITALS' PERSPECTIVES

The applications submitted by 28 New York City hospitals to the Family Caregiving Grant Initiative demonstrate that hospitals are beginning to recognize the tremendous burdens upon family caregivers. Their comments both confirm and amplify many of the themes articulated in the focus groups.

General Themes

- The health care system fails to adequately support and train caregivers.
- Fragmented communication leaves caregivers confused and uninformed.
- Discharge planning, as currently practiced, often fails to create smooth transitions.
- The health care system does not sufficiently recognize the role of family caregivers.
- Patients from diverse backgrounds have different needs and circumstances.

Barriers to Serving Family Caregivers

- Hospitals lack the time and financial resources necessary to address caregivers' needs.
- In their focus on the patient's clinical condition, health care providers often overlook the caregiver.
- Information systems fail to collect and share facts about the social and emotional aspects of care.
- Language, cultural, and educational differences can create challenges when families and health care professionals come from different backgrounds.
- Families' emotional responses to illness can make it challenging for hospital staff to provide support in a meaningful way.

These applications suggest that, at least at some administrative and clinical levels, professionals want to do better, and recognize the substantial barriers to improvement that they face.

SECTION IV. RECOMMENDATIONS FOR CHANGE

The following recommendations for change are a beginning. They are not so grandiose that they depend on vast changes in the American political or economic system nor so trivial that they accomplish little more than a token bow to family caregivers. These recommendations, in conjunction with the Guiding Principles for Effective Partnerships between Family Caregivers and the Health Care System (see Appendix B), can make a difference and should be implemented

Recommendation 1: Health professionals, government agencies, and managed care organizations should recognize explicitly, in policy and practice, that family caregivers who assume significant care responsibilities are a valuable but vulnerable resource.

Recommendation 2: This recognition of the critical role of family caregivers must be built into medical, nursing, and social work training and continuing education.

Recommendation 3: More research is urgently needed to understand the impact on family caregivers of changes in the health care system and on interventions that families need and want.

Recommendation 4: Health care providers must make discharge planning, and transitions from one care setting to another, a process rather than a single event. The outlines entitled “Covering the Basics for Family Caregivers” (Section V) provide a good start toward creating smoother transitions. They are designed for use by both health care professionals and family caregivers, and should be adapted to fit individual circumstances.

Recommendation 5: Hospitals and other health care institutions should develop model programs that offer innovative ways of involving and meeting the needs of family caregivers.

Recommendation 6: Public and private insurance plans and managed care organizations should evaluate benefits and service plans to reflect the importance of training, supporting, and communicating with family caregivers.

Contents

Foreword	xiii
<i>James R. Tallon, Jr.</i>	
Acknowledgments	xv
Introduction	xvii
I. Illness, Caregiving, and Transitions	1
II. Caregivers' Voices	7
III. Hospitals' Perspectives	23
IV. Recommendations for Change	29
V. Covering the Basics for Family Caregivers Outlines	33
The Inpatient Stay	
Discharge to Home	
Working with Home Care Agencies and Vendors	
When the Patient Has a Terminal Illness	
Appendix A	39
Families and Health Care Project National Advisory Committee 1997-1998	
Appendix B	41
Guiding Principles for Effective Partnerships between Family Caregivers and the Health Care System	
Appendix C	47
Focus Group Methodology	
Table 1. Demographics of 56 Focus Group Participants	
Table 2. Demographics of 56 Care Recipients	
Appendix D	51
Focus Group Moderator's Guide	

Appendix E	55
Focus Group Recruitment Screener for Current and Bereaved Caregivers	
<hr/>	
Appendix F	61
Excerpts from the United Hospital Fund Family Caregiving Grant Initiative Planning Grant Application	
<hr/>	
Appendix G	65
Hospitals Awarded First-Phase Planning Grants under the Family Caregiving Grant Initiative	

Foreword

This report marks the beginning of an important new dialogue in American health care. For years, while we have examined how the sweeping changes in health care delivery and finance affect institutions and the patients they serve, we have overlooked the needs of those upon whom the health care system greatly depends—the relatives, spouses, partners, friends, and loved ones who provide ongoing care at home to seriously ill and disabled patients.

More than 25 million Americans provide such care, and they face enormous, unprecedented burdens that jeopardize their well-being and threaten their ability to fulfill the duties they willingly take on. Several factors have converged to create these new circumstances: Cost containment and medical advances have trimmed hospital stays and moved daunting and complex care into the home. These advances are saving lives, but as a result, many more people suffer from long-term, chronic illnesses. An aging population requires more care than ever, and women, the traditional caregivers, have moved into the workplace and are less able to provide full-time care.

The United Hospital Fund's Families and Health Care Project has been working since 1996 to advance public understanding of the crucial role of family caregivers, and to stimulate the development of sound practices that support their needs. To capture the issue quantitatively, Carol Levine, the project's director, and Peter Arno, a health care economist and researcher, conducted a study to assess the economic value of family caregiving. Their study found that if these more than 25 million individuals were compensated on the open market for the care they provide, the cost would amount to nearly \$200 billion per year, the equivalent of 20 percent of national health care expenditures. This figure dwarfs annual home health and nursing home care expenditures—\$30 billion and \$79 billion, respectively—making family caregivers the largest provider of long-term care.

The Families and Health Care Project conducted focus groups of family caregivers last year to capture the issue qualitatively as well. The caregivers who participated in the groups spoke about how the health care system often fails to provide them with the technical, practical, and emotional support they need to fulfill their caregiving responsibilities. Not long afterwards, the Fund established a \$1.3 million grantmaking initiative to support New York City hospitals in developing and testing programs to respond to caregivers' unmet needs. Independently, the health care professionals who submitted applications to our grant initiative made many of the same observations as the focus group participants.

True to the mission of the Families and Health Care Project, this report highlights what the *family caregivers* had to say. Their stories provide rare insights into the direct and powerful consequences that the vast changes in the health care system are having on this vulnerable population. We also present reports from health care professionals who submitted applications to the grant initiative, and we offer recommendations to encourage the development of supportive, respectful relationships between family caregivers and professionals.

This publication is only a starting point. It introduces a largely unacknowledged but very timely issue into the broader discussion of health care. We hope that it creates understanding of the issues family caregivers face, and inspires health care institutions to more sensitively respond to the needs of those who care for the sickest and most fragile among us.

JAMES R. TALLON, JR.
President
United Hospital Fund of New York

Acknowledgments

This special report is the result of a collaborative process involving many individuals and organizations. Several staff members at the United Hospital Fund helped shape the report and the activities on which it is based. David A. Gould and Deborah E. Halper expertly guide the Families and Health Care Project. Sally Rogers creatively manages all aspects of communication. Dillan Siegler participated in many essential activities; her diligent coordination of the focus groups was especially important to their success. Alexis Kuerbis contributed to the final version in many ways. Barbara Kreling, a researcher at the George Washington University Medical Center, developed the focus group screener and moderator's guide and facilitated the focus groups with tact and sensitivity. The Fund's Communications Division brought special insights and flair to the production of the report. Phyllis Brooks, Ray Rigoglioso, and Liza Buffaloe were especially crucial to this process.

The Families and Health Care Project owes a special debt of gratitude to the funders who have made the project possible. They are the Altman Foundation, The JM Foundation, The Nathan Cummings Foundation, The New York Community Trust, The Prudential Foundation, and The William Stamps Farish Fund. The Family Caregiving Grant Initiative is partially supported by funds from the United Way of New York City.

The Project's National Advisory Committee (see Appendix A) provided invaluable assistance in defining the issues family caregivers face and reviewing preliminary information from the focus groups.

Finally, this volume would not have been possible without the candid and heartfelt contributions of the focus group members whose experiences make up the core of this report. We are grateful for their willingness to describe their often painful and always meaningful stories.

Introduction

Each year more than 60 million Americans are admitted to or discharged from health care facilities. For institutions, these entries and departures are routine processes; for patients and their families, they are often fraught with anxiety and fear. In many cases these transitions signify not just a medical determination that a patient is sick enough to be hospitalized or well enough to go home, they represent a change in the course of an illness and in the family's caregiving roles and responsibilities.

This special report explores transitions in health care settings from the unique perspective of family caregivers—the unpaid relatives, partners, or close friends who either provide direct care and emotional support to, or manage the health care of, those who are ill or disabled. Family caregivers, often called “informal caregivers,” have complex relationships with “formal” caregivers, who are health care professionals. Formal caregivers include physicians, nurses, and social workers; representatives of hospitals, nursing homes, and rehabilitation centers; employees of managed care organizations, private insurers, and government programs; home care agency staff; equipment and supply vendors; transportation contractors; and other employees or providers in the health care system. The transition process includes a move not just from one place to another but from one care system to another. In the case of a discharged patient receiving home care, it involves encounters with several uncoordinated and fragmented systems.

The report is intended for several audiences:

- **Clinicians:** they rely on family caregivers to provide or manage significant levels of patient care at home and encounter family caregivers in inpatient settings.
- **Administrators:** they establish policies and regulations in institutions that affect family caregivers as well as patients.
- **Legislators and policymakers:** they set a public policy agenda and determine eligibility and reimbursement rates in publicly funded programs for patient and family caregiver services.
- **Insurers and decision makers in managed care organizations:** they determine benefits and services for privately insured patients and caregivers.
- **Representatives of patient/caregiver advocacy and service organizations:** they offer community-based services for caregivers and organize advocacy efforts on behalf of their constituencies.
- **Family caregivers:** they are often so isolated from one another that they fail to realize they are not alone and that others have responsibilities toward them, just as they accept responsibilities toward their loved ones.

GENESIS AND ORGANIZATION OF THE REPORT

This report grew out of several activities of the United Hospital Fund's Families and Health Care Project (FHCP), which was created in October 1996 to analyze the impact of the changing health care financing and delivery system on family caregivers. One important initial goal was to develop principles on which to build constructive partnerships between family caregivers and health care professionals (see "Guiding Principles for Effective Partnerships between Family Caregivers and the Health Care System" in Appendix B). As the project developed these principles, through literature reviews, discussions with providers and caregivers, and meetings of the project's national advisory committee, it became very apparent that family caregivers experience particularly serious difficulties when their loved ones move from one care setting to another. Any discussion of how the health care system affects family caregivers, therefore, must include attention to these transitions.

The first section of this report summarizes some of the literature on transitions in illness and family caregiving. It explores the role that underlying family dynamics play in caregivers' experiences, and provides insight into how the illness of a loved one places family caregivers in a constant state of transition. This discussion establishes an important context for understanding how the problems associated with a loved one's *physical* transitions between care settings, explored in Section II, intensify the stress on caregivers.

The second section of the report presents information gathered from a series of six focus groups convened by the project in September 1997 in New York City. The information obtained in these focus groups serves as the primary source for this report. The focus groups engaged 56 individuals who provide, or who have provided, significant levels of care at home to elderly, chronically or terminally ill, or disabled family members and friends, and who have experienced several transitions in care settings. Four of the groups included current caregivers, and two consisted of family members whose loved one had died within the past two years. The groups included individuals of diverse ages, genders, ethnicities, religions, socioeconomic status, and educational backgrounds.

Focus groups are a qualitative research method especially well suited to eliciting detailed and sensitive information. The dynamics of a group interview have two advantages. First, group members stir each other's memories and emotions as they relate their experiences. Second, groups of participants who perceive each other as similar to themselves are generally more open than they would be with an interviewer who is not perceived as having shared their experience. Focus groups are limited in terms of developing quantitative data, but they provide nuances and narratives that are hard to capture in more structured methodologies.

The accompanying vignettes of caregivers' stories, gleaned from the focus groups, offer glimpses of the caregiving experience at critical times in patients' and families' lives. They hint at the intricate web of family relationships that exists apart from, but also as

part of, the experience of illness. Little research exists that provides complex, ethnographic descriptions of caregiving. Case histories usually have a pathological focus, and media accounts typically portray only the exceptional circumstances—either the heroic or the abusive family stories. These vignettes suggest that future research should attempt to capture a broader range of caregivers' experiences.

The third section presents a secondary source of information obtained from planning grant applications submitted by New York City hospitals in April 1998 to the Fund's Family Caregiving Grant Initiative. Because the Fund established this major grantmaking initiative a few months after the focus groups were held, but before the results of the focus groups were analyzed, there was an unplanned opportunity to informally compare hospital perspectives with those of family caregivers. Twenty-eight New York City hospitals responded to the Fund's Request for Proposals (RFP) for Phase I of the Family Caregiving Grant Initiative. In May 1998, 16 hospitals were awarded \$20,000 each to gather and analyze data about family caregivers' unmet needs and to explore the possibilities of collaboration with community-based partners such as nursing homes, home care agencies, or patient/family advocacy and support groups. The RFP stressed the importance of listening to family caregivers and of developing a multidisciplinary team. Part of the RFP asked applicants to describe the circumstances and environment family caregivers face in their hospital, and to identify barriers to creating services for them. In Phase II of the Initiative, which will begin in February 1999, six hospitals will be awarded two-year grants of \$150,000 to \$200,000 to implement the most promising program designs.

The two sources are not directly comparable. The focus group information was gathered from extended conversations with a diverse group of nonprofessional caregivers. The hospital applications were written by professionals seeking funding; applicants were not asked specifically to answer questions about transitions. Nevertheless, both the focus group participants and the hospital applicants identified remarkably similar problem areas. That nonprofessional and professional caregivers, who are at times at odds with each other, should independently arrive at the same conclusions, indicates the magnitude of the issue and clearly points to the need for change.

These sources offer, from both the family caregivers' and hospital professionals' perspectives, insights into the day-to-day experience of transitions. The final section of the report offers several recommendations for improvement. Transitions may be problematic, but they are also opportunities for intervention.

I. Illness, Caregiving, and Transitions

The chronically ill often are like those trapped at a frontier, wandering, confused in a poorly known border area, waiting desperately to return to their native land....This image should also alert us to the...entrance and exit formalities, the visas, the different languages and etiquettes, the guards and functionaries and hucksters at the border crossing points, and especially the relatives and friends who press their faces against windows to wave a sad goodbye, who carry sometimes the heaviest baggage, who sit in the same waiting rooms, and who even travel through the same land of limbo, experiencing similar worry, hurt, uncertainty, and loss. Social movement for the chronically ill is back and forth through rituals of separation, transition, and reincorporation.¹

Illness disrupts expected transitions and creates unplanned ones.

From birth to death, transitions are part of the pattern of an individual's and a family's life. Illness disrupts expected transitions and creates unplanned ones. Sometimes illness-related transitions are dramatic and sharply defined. A stroke or traumatic brain injury brings immediate change to patient and family. Sometimes transitions are apparent only after long periods of subtle accommodations to the changes wrought by Alzheimer's disease. In some cases the period of transition from wellness to death is short and precipitous; in others, there is a dizzying roller coaster of remission and recurrence.

Whatever the disease or injury and its medical course, typically the patient and family at some points encounter the institutionally based health care system through admissions to and discharges from a hospital, rehabilitation center, nursing home, or other facility. In addition to signaling changes in medical condition and prognosis, these are literal transitions—moves from one place where care is provided to another. These transitions involve all the “entrance and exit formalities, visas, and different languages and etiquette” Kleinman invokes in his image of chronic illness as a border area for patient and family. For family caregivers—the unpaid relatives, partners, or close friends who either provide direct care and emotional support to, or manage the health care of, those who are chronically ill or disabled—often the “heaviest baggage” they carry relates not to the specific tasks, but to the altered relationships and new roles that illness imposes.

Theorists have developed several different ways to view caregiving transitions: as part of the process of disease progression; as a “career” path for the family caregiver; and as part of the family life cycle.

Disease progression. Clinicians diagnose and “stage” diseases; that is, they examine test results, symptoms, and clinical signs to determine what disease category encompasses this set of findings and whether the disease is in an early, middle, or late phase. This analysis helps determine recommendations for curative or palliative treatment, and is an important factor in prognosis. Patients and families, however, experience illness rather than disease. As Kleinman distinguishes the two states, illness is “the innately human experience of symptoms and suffering.”² The stage of disease, a technical determination, may or may not correspond to the stage of illness, the subjective response of patient and family, and the level of adaptation.³

Medalie stresses that “[E]ach phase [of the clinical time-cycle] has its *own demands and tasks which require different attitudes and solutions*....Some patients and families adjust well to all the phases, some do not adjust at all, while the majority probably do well most of the time but have difficulties with some phases or parts of phases” [italics in original].⁴ His schematic description of the chronic illness cycle begins with the crisis of symptomatic prediagnosis, diagnosis, and initial treatment phases, during which the patient and family experience acute stress. Chronic stress dominates the “long-haul” phase, involving post-treatment adjustment and chronic maintenance, with the possibility of acute stress recurring with repeat crises or emergencies. Acute stress usually occurs when the patient enters a terminal phase of the disease, and when the patient dies. The final period of mourning and adjusting to loss brings another “long haul.”

Family caregivers whose loved ones are hospitalized with the same diagnosis or for the same procedure react very differently depending on the stage of the disease and their experience with illness. They may be adjusting to the diagnosis, still hopeful of a cure, or fearing that the end is near. Similarly, the transition from hospital to home differs for those who have been through the experience many times and for those who are new caregivers.

Caregiving as a “career.” “Career” may seem an unlikely term to apply to people who are often thrust into the role by circumstances, are not paid and receive no work-place benefits, and have no opportunities for advancement. Nevertheless, the term does suggest that the experience of caregiving is dynamic. Pearlin identifies three transitions in a caregiving career: residential (home) care, institutional placement, and bereavement.⁵ Within the context of these transitions, Aneshensel, Pearlin, and colleagues describe career stages: role acquisition, role enactment, and role disengagement.⁶ A stage, they note, is not necessarily a period of stability, and within each stage, there is great diversity. Furthermore, the timing and sequencing of transitions vary. These authors emphasize that “the caregiver role is likely to have emerged after other roles have been in place long enough to have been accommodated into the flow of daily life. Caregiving is the new kid on the block. Once it emerges, furthermore, it does not simply take on a stable presence....More typically, the caregiver role keeps expanding in its demands so that even

Alone, Angry, and Worried

Evelyn's story*

I take care of my 79-year-old grandmother who has breast cancer. She was diagnosed last summer and had a mastectomy. After the surgery the doctors told me she was all better, but the cancer eventually spread and she had to go back into the hospital.

My grandmother lives with me, and I do everything for her. I cook and take her back and forth to the hospital for chemotherapy. She has a part-time home attendant, but she doesn't like strangers doing anything for her. She comes from a very clannish background.

For me, personally, I've had a lot of death. My nephew was killed before my eyes. I lost my husband in the hospital. My cousin was robbed and killed, and my mother died. When my grandmother got sick, I was hating God. I said, "What are you doing God?"

I have no one to talk to, either. I tried talking to some of my friends, but you mention the "C" word and they run. The few who keep in touch just tiptoe around the subject. And here I am trying to cheer up my grandmother when she knows she's dying. I feel tremendously angry and resentful. How can I give care to this person when I can't handle it myself, and when there's no one to help me cope? It's terrible.

I was also very angry when my grandmother had to be readmitted to the hospital when her cancer returned. The doctors told me about the recurrence in a very, very cold manner. If one person had sat down and taken my hand, it would have helped. No one did that. They run like you have a disease.

What's most difficult about taking care of my grandmother isn't the physical part, it's the worry. If I turn my back I wonder what's going to happen. I work part-time and I worry about what's going on. It's constant—is she going to get better or get worse?

If I had any say in how things are run, I would have social workers redefine their profession. If they've studied sociology and social work, they should deal better with people, they should be compassionate. But they essentially said to me, "We don't care." They just talked about the bills and discharge. They should give you information about support groups and assistance, like someone to bring food, for instance. Someone should tell them how difficult it is to be a caregiver.

* Names and identifying characteristics have been changed to preserve the family's privacy.

with adjustments in other areas, it keeps a steady pressure on the boundaries of other roles in the constellation.”⁷

Caregivers, in other words, are in a more or less constant state of transition.

Caregiving creates stress by itself but also adds stress to the other areas of the caregiver’s life, such as employment, friendships, responsibilities to other family members, financial

Caregivers are more or less in a constant state of transition.

affairs, and leisure or community activities. While caregiving responsibilities may place stress on a caregiver’s job, satisfaction with employment can buffer the negative stress that results from caregiving. One study found that women employed full-time derived more benefit than part-time workers because they spent more time away from caregiving

and received greater financial, psychological, and social rewards.⁸

Building on Pearlin’s work, Seltzer and Li examine the period during which family members provide direct care. They note that the transition to caregiving usually grows out of existing patterns of support and assistance, unlike transitions such as parenthood or widowhood, which are marked by distinct dates.⁹ In cases of acute disease or trauma, of course, the point of transition is easy to identify. And even when the patient’s disease develops slowly, caregivers can usually remember when they began to provide substantial assistance. Nevertheless, it is very difficult, as Pearlin and Aneshensel note, to pinpoint when people start thinking of themselves as “caregivers.”¹⁰ The transition from “daughter” or “husband” to “caregiver” profoundly affects one’s identity, expectations, and

It is very difficult to pinpoint when people start thinking of themselves as “caregivers.”

actions. Additionally, people might avoid acknowledging themselves as caregivers until a very late stage of disease to preserve or maximize their loved one’s identity.¹¹ Unfortunately, there are no well-defined role definitions or boundaries, and no rituals to accompany this major life transition. The first time a family member may be confronted with this new identity is when the hospital discharge planner presents a care plan that is based on the expectation that the family member will provide whatever “informal” care is needed.

Recognizing the complex and variable nature of caregiving careers, Seltzer and Li suggest that each person’s career can be characterized by three indicators: type of disease onset (abrupt or gradual); duration of care (short- or long-term); and stage of caregiving (early, middle, or late). They also point out that the experience of caregiving is conditioned by variations in the kinship relationship (the differences between wives and daughters, for example), and in residential patterns (such as whether the caregiver lives with the care recipient). Caregivers’ own perceptions of the stage of caregiving and their response to it may be quite different from an independent observer’s evaluation of the situation.¹²

Family life cycle. Illness-created transitions affect families differently depending on their stage of the life cycle. All life cycle models include several key transitions: births, launching young adults, marriage, divorce, retirement, and death.¹³ At such moments it is common to think about life and death, separation and loss. Rolland says, “The diagnosis

of a serious illness superimposes the illness life cycle onto that of the individual and the family. One of the family's primary developmental tasks then becomes accommodating to the anticipation of further disability and possibly untimely death."

Young parents building careers, homes, and families who face a life-threatening disease experience enormous losses of a sense of future; they may become isolated from peers who are seemingly invulnerable. A teenage boy striving to build an identity separate from his parents may be unable to go away to college because of the financial drain caused by a parent's or sibling's illness. A middle-aged woman looking forward to the end of raising her children may face a new and less rewarding role as caregiver for a debilitated parent.

While certain stages of the family life cycle are typically associated with certain roles, the more fluid family structures seen today may not conform to traditional expectations. A "blended" family with children from previous marriages may function reasonably well until illness disrupts the equilibrium. Adult children from a former marriage may resent their parent's caregiving for a new spouse, or may resent the new spouse who becomes a caregiver and apparently displaces them in their parent's affection or takes over decision making. Illness may bring together—or force further apart—biological and families of choice, such as gay partners.¹⁴

In brief, a disease is much more than a medical event. For the family caregivers of chronically ill or disabled individuals, it imposes a constant state of stress and flux. Any transition from one health care setting to another, therefore, adds a complex layer of adjustment to the transitions already underway in a caregiver's family and his or her experience of illness.

Notes

1. Kleinman, A. 1988. *The illness narratives: Suffering, healing & the human condition*. New York: Basic Books, p. 183.
2. *Ibid.*, pp. 3-6.
3. Shaul, MP. 1997. Transitions in chronic illness: Rheumatoid arthritis in women. *Rehabilitation Nursing* 22(4):199-205.
4. Medalie, JH. 1997. The patient and family adjustment to chronic disease in the home. *Disability and Rehabilitation* 19(4):165.
5. Pearlin, LI. 1992. The careers of caregivers. *The Gerontologist* 32:647.
6. Aneshensel, CS, Pearlin, LI, Muillan, JT, Zarit, SH, Whitlatch, CJ. 1995. *Profiles in caregiving: The unexpected career*. San Diego: Academic Press.
7. *Ibid.*, p. 37.
8. Martire, LM, Parris Stephens, MA, Atienza, AA. 1997. The interplay of work and caregiving: Relationships between role satisfaction, role involvement, and caregivers' well-being. *Journal of Gerontology* 52B(5): S279-S289.

9. Seltzer, MM, Li, LW. 1996. The transitions of caregiving: Subjective and objective definitions. *The Gerontologist* 36(5):614-626.
10. Pearlin, LI, Aneshensel, CS. 1994. Caregiving: The unexpected career. *Social Justice Research* 7:373-390.
11. Reynolds, NR, Alonzo, AA. 1998. HIV informal caregiving: Emergent conflict and growth. *Research in Nursing and Health* 21:251-260.
12. See note 9.
13. Rolland, J. 1994. *Families, illness, and disability: An integrative treatment model*. New York: Basic Books, p. 187
14. Brown, MA, Powell-Cope, GM. 1991. AIDS family caregiving: Transitions through uncertainty. *Nursing Research* 40(6):338-345.

II. Caregivers' Voices

The six focus groups held by the United Hospital Fund in September 1997 in New York City produced remarkably consistent reports of caregivers' experiences, especially in terms of their feeling unprepared for caregiving tasks. Often when a participant stated a problem, others throughout the groups followed with nods or other signs of assent. This held true despite the diversity of caregivers who participated. Caregivers represented a wide range of ages, and came from diverse ethnic, religious, socioeconomic, and educational backgrounds. Both women—the traditional providers of care—and men participated. Four groups consisted of current caregivers, and two were made up of bereaved family members. (For information about the focus group methodology employed, and for more details about participant and care recipient demographics, see Appendix C.)

Conversations in the focus groups covered many aspects of caregiving. Some provide insights into caregivers' individual experiences, bringing to life the theoretical discussion of transitions in Section I. Others have direct implications for improving the health care system and the physical transitions from one care setting to another. The themes that emerged from these discussions follow below.

FAMILY TIES

Caregivers were usually thrust into their role by necessity, although most wanted to provide care because the ill person was significant in their lives. By design of the focus groups, the participants were providing or had provided significant physical care and emotional support to patients with serious, debilitating conditions. Caregivers usually found themselves thrust into their role by necessity, although most wanted to provide care because the patient was a loved one. Participants said they hardly discussed the issue of choice in the matter; they simply approached the task, they explained, because "She's my mom," or "He needed me."

In many cases, the patient was a "favorite" relative or one with whom the caregiver had a strong bond. Caregivers were not just children or spouses of the patient, as might be expected, but grandchildren, nieces, and siblings. Only two participants reluctantly assumed caregiving responsibilities; in both cases the recipient was a mother-in-law, and the caregiver a woman. Their husbands, supported by other family members, felt their wives should provide the care but remained largely uninvolved themselves.

One of these women reported that she had gone through early menopause, had developed a thyroid condition, and was in the process of getting divorced as a result of

The Five Most Difficult Things

By Jacqueline, who lost her father-in-law to cancer*

- 1. The constant tug-of-war with family members over where he should live, even though he obviously chose to come to our home to die.**
- 2. The emotional effects on my children—trying to explain the whole situation to them.**
- 3. My employer not understanding my role as a caregiver and not affording me flexible hours so I could run home or go to the hospital if I had to.**
- 4. The constant friction with my spouse as to whose turn it was to do what.**
- 5. The overwhelming sadness at the loss of a loved one at the end. I couldn't believe that this person I loved had left me.**

* Names and identifying characteristics have been changed to preserve the family's privacy.

the stress of taking care of her mother-in-law, who was abusive toward her and required total care. "I couldn't take it any more," she said. "You slut," she called me. We finally put her in a nursing home, but it destroyed my husband. She was either going to burn the house down, get lost, I was going to kill myself, or she was going to kill me."

Caregivers whose family members and friends shared the burden of caregiving fared better than those who provided care alone. Major decisions were especially difficult for caregivers providing care without assistance from family, friends, or professionals. From the reports of caregivers in these groups, the variable that seems to be critical is whether or not the caregiver has others sharing the responsibility. Adult only children and caregiving spouses seem to have the most difficult and overwhelming experiences because they are most often alone.

Additionally, very few caregivers felt that their friends and family members acknowledged their stress and frustrations. In fact, one man said he thought that, as a caregiver, he was "invisible" to everybody else. No one asked how he was. He said friends called at night after he had been at work all day and then at the hospital until late in the evening. He said they just asked about his wife and they only wanted to hear good news. He began resenting the calls. One woman, who has several very close friends, was so worn out answering her mother's questions and dealing with doctors and therapists that by the end of the day, she said, "I literally couldn't speak to [those who called] because I had no saliva left in my mouth."

Even those in large families reported that they sometimes found themselves alone in providing care. One woman from a large, Mediterranean family whose father was brain-

damaged said sadly, "When my father was in a coma, our house was full of friends and family. As soon as he came out of it, and everyone realized he could barely speak, they stopped coming. I don't understand why they can't just stop by to say 'hello.'"

Caregivers who are part of families who cooperate easily and share responsibilities became aware in the focus groups that in spite of their feelings of burden, their situation was actually much easier than that of other participants. They said they did not know how they would provide care alone.

Caregivers' emotional attachment to their loved one was a powerful motive for providing care, but also led to anxiety and fear about the patient's welfare. While the closeness of the relationship provides meaning and emotional reward for the caregiver, it also adds a psychological burden to the physical burden of caregiving. Some caregivers worried that their emotions might make them more prone to errors. One woman said, "When you're a professional and detached, it's one thing. When you're emotionally involved, it's easier to make mistakes with the practical things." Another said of her sister, "The physical care is emotional because of who I'm doing it for."

Several caregivers spoke of their distress at seeing their loved one in constant pain and being helpless to do anything for them. Responsible for the administration of pain medications at home, they felt they had to wait until the designated time to administer the prescribed dose because "that's what the doctor ordered."

CAREGIVERS' REACTIONS TO CHANGES IN ILLNESS AND CARE SETTINGS

Transitions can be traumatic because they are often times when caregivers first become aware of changes or deterioration in the patient's condition. Caregivers often feel surprise and sometimes shock at changes in their loved one. Finding out that a patient returning home from the hospital is incontinent; having to care for a demented patient who is more confused after returning home after major surgery; realizing that a stroke victim will never walk or talk—all these events are traumatic for the caregiver. The less prepared the caregiver is for the patient's condition or the kind of care he or she will have to provide, the more upsetting the transition will be.

One woman talked of her husband's transition from a rehabilitation center to their home after a stroke. She was more technically prepared than many other participants because she had attended all her husband's rehabilitation sessions. "When we went home, I didn't have any help or support," she said. "He couldn't do anything! I felt very isolated and became terribly depressed."

The husband of a woman with multiple sclerosis who underwent surgery for a leg infection said that when she was discharged he expected her to be "well enough to go home" or "as good as she had been before." He did not know that she was incontinent and that her bandages would need changing. During the first night home, he realized the

Fending for Myself, Defending My Partner

Bill's story*

I take care of my boyfriend who has AIDS. He takes up to 45 pills a day, and I make sure he sticks to the right schedule, which is very regimented in terms of taking pills with and without food, and at certain times of the day. I do most of the food shopping and household chores. When his viral load is high it is hard for him to get around, so I help him walk and take a shower.

He's only been in the hospital three times, mostly because he's stubborn and doesn't like being there. When I visit him in the hospital, the staff doesn't even acknowledge me. I usually run into problems seeing him outside of visiting hours, so I arrive within those times and tell them I'm bringing him dinner. When I get to his room I don't leave. I usually stay the night and sleep in a chair. Because I'm not technically a "family member," I'm not supposed to stay. But I *am* his family, and I'm the only family he has in the area.

At first the nurses are brusque and rude and don't help, but after a night, they see I'm not there to cause a scene. I get extra pillows or ice or whatever he needs because it takes them too long. They're not helpful or communicative. When I ask, "When is the spinal tap going to take place?" the nurses won't tell me. Because I'm not his "spouse," maybe they're not legally permitted to communicate with me.

The biggest problem with going to the hospital is that no one acknowledges that I am important to the health care of the patient. I feel as though I'm fending for myself and defending my partner. I sneak around to get what he needs. And with experience, I'm getting better at knowing what to demand right away and what to wait for.

It's ironic because the last time my boyfriend was in the hospital, the doctors depended on me to know what was going on. Every new staff person who came into the room—the neurologist, the internist, the psychiatrist, and the nurses—all asked questions trying to find out what was going on, but never spoke with each other. The transition to the hospital made me extremely anxious. Coordination became *my* job, but I didn't have any authority. And he was only having tests done. I can't imagine what it would have been like had he required immediate care.

* Names and identifying characteristics have been changed to preserve the family's privacy.

bed was wet and the bandages were oozing. "I didn't know what to do, who to call, or who to get angry at," he recalled. "Nobody said to me, 'This is how your life is going to change.'" One young woman who had difficulty speaking about her predicament to the group explained haltingly, "My grandmother had her legs amputated. I was afraid and didn't know what to expect. Before she went to the hospital she was able to get around. Then when she came home, she had no legs. I was pretty young then and it was hard for me to deal with."

Many caregivers spoke of their sadness and the loss or change in their relationship with the care recipient. Even if the patient is still alive, some caregivers feel they have lost the family member, since the patient is not the person he or she used to be. Caregivers also feel they lose part of their lives in having to provide care, and they suffer when they see their loved one deteriorate to the point where he or she becomes a stranger. One woman taking care of her grandmother who is demented and has cancer said, "It is very sad because she cared for us as children and now she doesn't even remember us." One daughter said, "I think of Mom as dead now because she's not the Mom I knew."

The wife of a stroke patient said, "You see someone you love deteriorating and it breaks your heart." The daughter of a father who suffered brain damage while in the hospital remarked, "It's very hard to see somebody who was so strong end up this way. When I take care of him, there is such sadness in his face." Caregivers also spoke of patients' unexpected moods, such as hostility, and how difficult they are to experience. Participants also shared that they often feel reluctant to express their emotions around their family member. One woman, whose sister died of cancer, said, "It was heartbreaking to see her like that. I tried not to show my emotions around her."

GOING HOME

Caregivers experienced discharge from the hospital as an abrupt, upsetting event because hospital staff failed to prepare them technically and emotionally for changes in the patient's condition. In many cases, participants reported, the patient after discharge required nursing skills or equipment they did not possess and had little time to acquire. Many caregivers felt they were expected to do things for which they were not trained. One daughter, whose mother died of cancer, said she was shocked to learn that her mother would be bedridden and would need a catheter when she came home. She said, "I was afraid. I'm not a nurse. We weren't trained. We didn't even get a piece of paper about how to bathe her or anything."

Another woman, whose husband returned from the hospital after a stroke, had difficulty monitoring a feeding tube, which had confusing computer settings. She had seen it in the hospital but received little training in how to use it at home. "I was terrified of it," she said, "It's broken twice. When we left the hospital they showed me 1,2,3 and that's it."

They said, 'Don't worry, you'll learn it.'" The same woman talked about being unprepared for her husband's moods. She said, "He was full of anger and insults. It was part of the illness but I didn't know it." When another woman commented, "You have to be understanding," the wife retorted, "How can you be understanding when you don't understand?"

Caregivers also find it stressful to be responsible for administering pain medications and often do not feel they have the training they need. One woman said the doctor did not explain to her the medication regimen her critically ill father would require. When she asked, the doctor told her, "Use your instincts."

Several participants suggested that hospitals provide caregivers with more information to ease the transition. "There should be an 800 number to call up after discharge to

"When you buy a pet at a pet store, you are given written instructions about how to take care of it, but you get nothing when you take a parent home from the hospital."

find out if something is normal," several stated. As one participant said, "The doctors don't get back to you. They should give you a pamphlet or something." One woman said she calls the pharmacist for medical advice because she can always reach him. One young woman critiqued the lack of information available on how to care for seriously ill patients at home. "When you buy a pet at the pet store, you are given written instructions about how to take care of it, which things to look for, and what to do about them," she said. "There are books about how to take care of babies: when to call

the doctor; what is normal; and what is not. But you get nothing when you take a parent home from the hospital. And these are ordinary diseases—things that happen every day."

When a patient leaves the hospital and returns home, the increased burdens of caregiving and the new kinds of care required often frighten and overwhelm the caregiver. A young woman said that when her grandmother, who has dementia and had a mastectomy, returned home from the hospital, "I felt incompetent. They said she might try to take the stitches out. I watched her constantly. I don't think I slept for a week." At the same time, her grandmother lost her ability to walk but was too heavy to lift. Eventually, after this young woman developed back problems, she reluctantly hired an aide to help her lift her grandmother. But the time immediately after discharge was very difficult because she felt she ought to be able manage by herself.

ADMISSION TO A HOSPITAL OR NURSING HOME

Although most of the discussion centered on transitions from institution to home, the reverse—transition from home to hospital or nursing home—also presented problems. Many caregivers gave several reasons why they do not experience the expected relief when their loved one is admitted to a hospital or nursing home. First, because many lack confidence about the quality of care in the institution, they feel responsible for supervis-

ing care and protecting the patient. They often feel exhausted from being at the hospital every day, all day, in addition to their other responsibilities. They worry about the condition of their loved one and fear that he or she may never return home. Many caregivers indicated that the unfamiliar surroundings of an institution sometimes make a patient extremely anxious and disoriented. Caregivers also talked about the difficulty of getting information in the hospital. As one man said, "They give you instructions about how to use the telephone and the television, but not how to get medical questions answered."

Many caregivers fear that their loved one will be neglected in hospitals and nursing homes. A transition to an institution means extra vigilance for the caregiver. Caregivers' worries ranged from doubt that the patient was getting enough attention to fear that the patient might actually be harmed. Several caregivers spoke of having to be vigilant so that their family member did not get bedsores. The wife of a stroke victim said she "paid

"I paid an attendant to wipe my husband. Patients get a little more attention if you pay."

someone to wipe him. They [the patients] get a little more attention if you pay." Others agreed, saying, "You give them a few extra dollars and they get better care." Another person said, "We had to slip an attendant a few dollars to [have my mother be treated] like a human being." Another said he felt the staff considered his father "just another bed."

Caregivers said they sometimes provided direct care for the patient in the hospital. This was either met with resistance or welcomed by the nursing staff. One woman said her mother "lost her ability to speak so I felt I needed to be there [in the hospital] all the time. I became part of her care team and no one resented me. They showed me where the linen closet was and let me change her bedding." When her mother was moved to a nursing home, which she and her family had chosen after exhaustive research, she began to feel doubtful about the quality of care when she observed the lack of caring on the part of staff toward other residents. "I knew I couldn't turn my back on my mother for one minute," she said. "They tried to get me to go home. When I wouldn't leave, they called a security guard and forced me out." She said her mother had been in the hospital for four months, but the three weeks she was in the nursing home were "the worst weeks of my life." When her mother's condition necessitated readmission to the hospital, she said, "No one from the nursing home called to find out how she was doing. I just got a call about paying her bill."

One man caring for his partner with AIDS said he feels the hospital staff does not acknowledge him as someone close to the patient at all. As a result, he said he feels that he is "fending for myself and defending my partner. I sneak around to get what he needs. And with experience, I'm getting better at knowing what to demand right away and what to wait for." He said no one recognizes that the caregiver is important to what is going on. "No one acknowledges that I am important to the health care of the patient."

The Isolated Caregiver

Sarah's story*

My mother is 79 and lives with me. In the past four years she's had surgery three times, and has difficulty walking. I do the shopping, cooking, and cleaning. I give her medicine and help her take a bath. I have no brothers or sisters, and my mother won't let anyone else near her. My mother is a Holocaust survivor. She thinks her medical problems are caused by spells people in Austria put on her.

The last time my mother had surgery they discharged her into a nursing home for two weeks. It was the hardest time of my life. She was convinced she would not return home, and I had to reassure her every day. When she was in the hospital I could sometimes take a day off from being with her, but when she was in the nursing home I had to be there every day, from seven in the morning until eight at night. When I brought her home she still needed physical therapy, but she didn't want the therapist or the visiting nurses coming in.

Fortunately, I have some exceptionally close friends, but even they became a burden. When my mother came home from the hospital, over and over I had to talk to the therapist, the pharmacist, and the doctor. When my friends called at the end of the day I literally couldn't speak to them because I had no saliva left in my mouth. I started resenting their calls, and finally told them there is no point in reiterating what she does every day because it doesn't change. I became angry. I was angry with God, too. I took care of my father through three strokes, wasn't that enough? Why did we have to be Holocaust survivors?

During that period I could have used some help so I could have had some time to myself. But she doesn't trust other people. She has no friends, not since her entire family was killed. She believes there is no God. When I light Sabbath candles, she looks at me like I'm an idiot, as if I haven't found out yet that there is no God.

Looking back, it would have helped if the doctors had talked to me about what it was going to be like for me as a caregiver. They could have also started preparing my mother about her condition before she left the hospital. I think it comes better from a professional.

* Names and identifying characteristics have been changed to preserve the family's privacy.

He also talked about the lack of coordination between health care professionals at the hospital. "Every new staff person who came into the room—the neurologist, the internist, the psychiatrist, and the nurses," he explained, "all asked questions trying to find out what was going on, but never spoke with each other. The transition to the hospital made me extremely anxious. Coordination became *my* job, but I didn't have any authority."

There were only a few reports of consistently good care. The good experiences seemed to reflect institutional, rather than individual provider, attitudes and behavior. Most of the time caregivers reported having had positive institutional experiences when their loved one had been in a specialized facility or unit.

In general, participants reported that hospital staff failed to acknowledge their emotional needs. None of the participants said that health care professionals had referred them to community-based agencies for emotional or other kinds of support. One woman said she spoke with her husband's doctor about her depression, and the doctor said, "You don't need medication. Just make up your mind that this is how it's going to be."

A granddaughter of a woman who had breast cancer said she thought the cancer was "all better" but was told the cancer had returned and her grandmother would have to go back in the hospital. The granddaughter felt angry, she said, because the doctor told her in a very "cold" manner. "How can I give care to this person when I can't handle it myself?" she asked. "If one person had sat down and taken my hand, it would have helped." She also stressed that the physical part of providing care isn't that bad, "it's the worry."

While participants reported that they had not received any referrals for emotional or other kinds of support, it is possible that hospital staff may have made such referrals at times when caregivers were too overwhelmed to absorb or act on the information.

Many caregivers believe that older people are not treated sensitively in hospitals. One woman said that hospital staff members "don't take the time with older people." Another woman described her experience when she took her mother to a nursing home for an interview. She said the social worker did not explain the purpose of her questions and began the interview by asking her mother very loudly, "Do you know where you are?" Her mother, who had no cognitive impairments, replied, "Yes, don't you?" When it became obvious that her mother was not cognitively impaired, the social worker nevertheless continued, "Do you know who the President is?" The mother snapped back, "You mean you don't know that either?" That ended the interview.

Another participant echoed this same sentiment. "Hospital personnel don't care about the elderly," she said. "My father had a colostomy and they didn't want to help. I had to change it. I had to be there all the time and it was embarrassing for him." Another woman complained that nurses shouted at her father. The daughter said they had placed

a sign over his hospital bed with his age written in large numerals. She said when the nurses saw “80” on the sign, they assumed he was deaf.

Caregivers want compassion and understanding from institutional staff. Family caregivers and professionals seem to develop better relationships when professionals acknowledge that caregivers are important to the patient’s well-being, and that they are also going through a difficult time themselves. As one woman said, “Professional staff should recognize that families are upset and acknowledge that it’s a difficult time and that the hospital team is there to help.”

In several cases, individual nurses were perceived as compassionate. As one woman said, though, “They’re either great or they’re rotten.” When nurses are good at communicating compassion, caregivers are very grateful. One woman said that she kissed the nurse

When nurses are good at communicating compassion, caregivers are very grateful.

when her mother went home, because the nurse had been so good to the family. Others said that hospital staff needed courses in being sensitive and sympathetic. One participant went so far as to say, “Sometimes the cleaning people are nicer [than the professional staff].” One woman said that there is a line between being professionally distant and overly involved, and that most professionals are on the wrong side of it.

Participants criticized social workers the most. Typically the social worker’s only interaction with the family focused on discharge plans and paying the hospital bills. No one reported that a social worker had spoken with them about caregiving needs after discharge.

No one reported that a social worker had spoken with them about caregiving needs after discharge.

One woman said, “Social workers need to redefine their profession. If they’ve studied sociology and social work, they should deal better with people.” Social workers were reported as being helpful in two cases, however. One woman’s grandmother is 102 years old and lives with her 70-year-old daughter who is legally blind. A social worker visits once a week and arranged for the grandmother to go to hospice for respite care for a short period every other month.

Another woman’s aunt, who lived with her, underwent surgery for a colostomy. Nursing staff assumed the niece would change the colostomy bag, and on the day of discharge tried to show her how to do it. The niece almost fainted when she realized it involved direct contact with an open intestinal lesion and approached the hospital social worker in tears. The social worker arranged for the aunt to go to a nursing home until the colostomy was reversed as planned. This nursing home option, which was available under Medicare, was not presented to the niece until she became upset and refused to take her aunt home. This was the only instance in the focus groups in which a participant reported refusing to provide a particular kind of care.

CULTURE, FAMILY STRUCTURE, AND RELIGION

Caregivers reported that cultural differences created special care needs, and sometimes led to problems with health care professionals whose backgrounds differed from those of the family. Several caregivers attributed their parents' reluctance to receiving home care from strangers to their cultural backgrounds, even though these care recipients' racial and ethnic backgrounds differed from each other. One African-American woman explained that her mother is "clannish" and does not like strangers coming to her home. Three other women from varying cultural backgrounds who were in the same group also said their parents were suspicious of strangers and want their daughters to "do everything for them." One caregiver stated, "If I'm not in the plan, she won't have anything to do with it." A daughter reported that her foreign-born mother, who does not speak any English, will not let any physical therapists or other professionals in the house.

Another caregiver recounted her family history, which included surviving the Holocaust. Her mother now thinks her medical problems are caused by "spells people in Austria put on her." The result is that she is afraid to be left alone in the hospital and will not have strangers in the house.

Cultural differences emerged as being important in other ways. A woman from a large Hispanic family said that when her mother was dying many family members came to the hospital. "There were too many doctors doing too many things. They gave us all different stories. My sister doesn't speak English but she was the one authorized to sign the papers because she is the oldest." She said that because there were so many family members, the staff got tired of them. When they had to make a decision about ending care, the doctor told them, "There is no hope. You don't want her to be a vegetable. Let her go." She said, "We had no choice. We could have used more help in understanding this decision."

Some caregivers who are not immediate family members, or who do not fit into the traditional definition of "family," reported having difficulties obtaining information from, and being acknowledged by, hospital staff. Some participants reported feeling unacknowledged or encountered difficulty in obtaining information in the hospital because they fall outside traditional family roles. This was especially true of the man who is the caregiver for his partner with AIDS and the only person emotionally close to him in the area. He says he is ignored in the hospital, does not get information, and has a hard time seeing his partner outside visiting hours. The niece who cares for her aunt says she does not get information because "they only want to talk to the next-of-kin." One young woman caring for her grandmother said, "The nurses patronize me because I'm so young. But I'm willing to learn."

Although some participants sought a religious explanation for their situation, no one mentioned organized religious institutions or clergy as a source of solace or assistance. A middle-aged woman who cares for her grandmother said caregiving was particularly hard because she had already experienced so many deaths. Her cousin and nephew had been killed, and her husband had recently died. When her grandmother became ill with cancer, this woman said, "I was hating God. I said, 'What are you doing, God?' I didn't have anyone to talk to. I tried to talk to some of my friends, but you mention the 'C' word and they run." The woman whose family survived the Holocaust said, "I was angry with God. I had taken care of my father through three strokes, wasn't that enough? Why did they both have to be in this condition? Why did we have to be Holocaust survivors?" Despite her anger, she continues to observe religious rituals, which her mother disparages. "My mother believes that there is no God. I light Sabbath candles and she looks at me like I'm an idiot—as if I haven't found out yet that there is no God." Another woman who cares for her rapidly deteriorating father said, "God will decide when it's his time to go, but I have to take care of him every day, and I need more help."

None of these or other individuals reported obtaining guidance or assistance from a religious leader, church or temple, or other religious organization. When specifically asked about hospital chaplains, one woman, whose mother had died in a hospital, said that a chaplain had spoken to her family and that it was "helpful."

FINANCIAL FACTORS

In most groups, discussion centered more on the emotional aspects of caregiving transitions, and less on financial concerns. While the ability to pay for help at home and to maintain other important family goals is certainly a factor in a family's capacity to provide ongoing care, the caregivers in these focus groups did not emphasize the financial aspects of care. They were much more concerned with describing the emotional and physical drain of caregiving. The only direct conversation about money and costs pertained to paying extra for better care in the hospital or nursing home. There was no discussion of the cost of medical care or about the illness being a financial burden on the family. However, several women said that they had quit their jobs to provide care. Many others were juggling jobs and caregiving, and reported that even when hospitals did provide some support groups to caregivers, they were held during the day when caregivers were at work.

When discussion did turn to financial issues, participants criticized the health care system's focus on costs, and spoke of needing more resources to provide care. Many caregivers expressed the opinion that hospitals are "only interested in the money," and that care decisions are made on an economic basis. Several participants critiqued managed care organizations for discharging their family members from hospitals before they were

Unprepared for the Task

Arthur's story*

My wife is 71 years old. She has multiple sclerosis and is wheelchair-bound. She can't feed herself, lacks motor control, and is incontinent. She goes in and out of dementia as well. Sometimes she's passive and pleasant, other times she is very irritable, angry, and acts out. You never know which person you're going to be talking to.

Earlier this year I took her to a local hospital where she received physical therapy twice a week. But Medicare stopped paying for it because they said it was only maintaining her health, not improving it, even though it helped her.

Not long ago, she was hospitalized for 40 days after developing a life-threatening infection, which required aggressive surgery. All that time I would go to work, drive 25 miles to the hospital after work, stay with her, talk to the nurses, have supper in the cafeteria, visit with her some more, and go home to return 40 phone calls. I was exhausted by the time I got home, and I began to resent the calls. People were well-intentioned, but it was very tough on me personally.

When she came home from the hospital she seemed fine. I put her to bed, and went to bed myself. During the middle of the night I woke up to find the bed wet and her bandage oozing. My first thought was, "Why did they discharge her? She's not ready, she's not perfectly well." No one told me she was incontinent, and that her bandages would need changing. They just said to come back in three days to see the doctor. At that moment I asked myself, "How am I going to wait three days to see the doctor?" I didn't know what to do, who to call, or who to get angry at. Nobody said to me, "This is how your life is going to change." I had to discover that myself.

It would have helped if I could have spoken to a counselor in the hospital—and I don't mean the social worker. All she talked about was discharge. I also wish someone had informed me about support groups for caregivers of people with multiple sclerosis. I eventually learned about one, and it has been a great comfort. My friends and family members ask how my wife is, but they don't really want to know. They only want to hear me say she's okay. But when I talk to someone else whose husband or wife has MS, they really understand.

* Names and identifying characteristics have been changed to preserve the family's privacy.

ready to come home, or for limiting the time spent in a rehabilitation center. One woman said her father was denied further rehabilitation because, "They said it would be a waste, since he'll never get better." Some caregivers cited the need for more home care assistance than their insurance would pay for. A few participants said they had looked into hiring private duty nurses from the hospital where their loved one had received care, but could not afford the rates. None of them considered pursuing any lesser level of care, such as a home health aide, however.

DEATH AND DYING

Bereaved caregivers did not have markedly different caregiving experiences from current caregivers, but they experienced the additional stress of what they felt was inappropriate care at the end of their family member's life. Since several participants were both current and bereaved caregivers, there was overlap in the groups. One participant currently caring for her cousin had taken care of both of her parents, who died in hospitals. She expressed regret for having brought her parents to the hospital because she believed their treatment

"It would have helped if someone could have assisted me in making end-of-life decisions since I am an only child."

was inappropriate and painful. Her mother received cardiopulmonary resuscitation, even though she did not want it. Her father was operated on even though he was near death. She said, "It was traumatic because no one told me what was going on. It would have helped if someone could have assisted me in making decisions since I am an only child—someone who could give real facts and probabilities. I read a book about a good death, but I didn't know how to do it—how to keep them home. I just went along with sending them to the hospital."

Most bereaved caregivers were either unaware of hospice or felt that it was an inappropriate choice for their family member. Only one or two of the participants reported that they had used hospice. A few said they had heard about it but had not explored it any further. Those who were familiar with hospice said it was not appropriate in their situations because the care recipient was not close to death. One woman, who had already experienced one death, asked, "When do I call them, the week before?" A daughter who does not like the hospice philosophy said, "We didn't want to buy into the idea that this meant [my mother] 'had six months to live.'" One man whose father died in a hospice unit said he had received helpful information about his father's impending death, but complained about the facility's dreary appearance. "The atmosphere was awful and scary," he said. "It would have been nice for him to have been in a beautiful room or at home."

SUMMARY OF THEMES FROM THE FOCUS GROUPS

Caregivers want recognition that they are a part of what is happening to the patient, both the distress and the care. They want information and training to prepare them for what is going to happen and to allow them to feel confident in their own ability to provide care. They want access to professional advice during transitions and they want support from other caregivers who are having similar experiences. When the patient is in a hospital or nursing home, caregivers want to be able to communicate with health care professionals about their loved one's condition, and they want to be able to trust that the patient will be given good care and treated compassionately.

Transitions are difficult for the caregiver because they are times of discontinuity and uncertainty. During transitions, caregivers often feel a heightened, even overwhelming, sense of personal responsibility for the patient's health and well-being. The more fluid family structures that exist today mean that these caregivers might not be immediate family members or the next-of-kin. Focus group participants stressed the need for professionals to identify the primary caregiver, and to recognize that some are alone and without support. Finally, a greater sensitivity on the part of hospital staff to the needs and perspectives of caregivers will lessen caregivers' anxiety and may promote cooperation with health care professionals.

In brief, caregivers felt unprepared, both technically and emotionally, for the responsibilities they willingly undertook. Many felt abandoned at a critical time.

III. Hospitals' Perspectives

The previous section describes, from individual perspectives, the pressures that family caregivers face on many fronts. Their circumstances are by no means isolated incidents, however. They demonstrate the impact of broad changes that are occurring in health care delivery and financing systems. As hospital stays become shorter, patients are discharged with more complex medical needs. At the same time, pressures on staff to discharge patients quickly mean they have less time to prepare family caregivers, both technically and emotionally. As nonprofessionals, family caregivers often find the increasingly complex medical technology moving into the home to be intimidating. As a result, they feel overwhelmed and frightened by their new responsibilities. Their loving attachment to the patient complicates the learning process because they fear they will make mistakes.

The applications submitted by 28 New York City hospitals to the United Hospital Fund's Family Caregiving Grant Initiative demonstrate that hospitals are beginning to recognize this impact on family caregivers. As professionals, of course, hospital staff approach these problems from a different perspective. Some applications address the general hospital population, while others focus on specific patient populations, such as those with Alzheimer's disease, traumatic brain injury, AIDS, and chronic pain. While hospital staff wrote these applications with a different purpose (to obtain funding), and addressed somewhat different issues, their comments both confirm and amplify many of the themes articulated in the focus groups. (See Appendix F for excerpts from the Family Caregiving Grant Initiative planning grant application.)

GENERAL THEMES

The following themes sum up the observations of the health care professionals who submitted grant applications about the circumstances family caregivers face.

The health care system fails to adequately support and train caregivers. All the applications describe hospitals' concern about family caregivers and outline activities they currently provide to serve them, including some very active programs. Nevertheless, the applications in general acknowledge that whatever efforts do exist are largely unsystematic and inadequate to meet the enormous need. One application states candidly: "[T]here are few hospital resources that have been devoted to family caregivers. Caregivers are an invisible and unrecognized resource, except as a means to reduce direct costs of care. Professionals give little, if any, thought to the havoc that results when a family member

Living with an Accident's Aftermath

A Case Study from Jamaica Hospital Medical Center, Brady Institute for Traumatic Brain Injury*

Robert and Theresa Smith heard a knock on the door one warm summer evening, alerting them to their worst nightmare: their 18-year-old daughter Jill, who had been crossing a neighborhood street, had been struck by a speeding delivery van. Running to the scene, they arrived just before the ambulance doors closed, and accompanied their bleeding, unconscious daughter to the hospital. She remained in a coma for two weeks.

Jill's prognosis was not promising, but her parents held out hope. They befriended the staff hoping to glean bits of information about her condition. They waited at the cognitive therapy rooms to speak with the neuropsychologist in the traumatic brain injury unit. With more than 20 patients at a time, he could sometimes offer only a few sympathetic words.

During the third week Jill opened her eyes, but could not speak or control her limbs, bladder, or bowels. She needed to be fed a thick liquid so she wouldn't choke. Her diapers required frequent changing. She was strapped into bed so she wouldn't try to get up and injure herself.

When the insurance for inpatient care ran out after two months, Robert and Theresa had to decide whether to place Jill in a long-term care facility or care for her at home. After much agonizing, they brought her home and began a grueling schedule of seemingly endless caregiving.

Thus also began a continual campaign for services—in-home physical, occupational, and speech therapy, nursing care, and equipment. The Smiths advocated for home health aides to care for Jill so they could both return to work. They developed a workable, but tense, strategy: Mrs. Smith cut her job to part-time so she could spend the balance of the day taking care of Jill's affairs—interviewing home attendants, few of whom lasted more than a week, contacting health providers, and negotiating and scheduling services.

Robert received little attention from his wife. During evening meals, which were usually take-out, she would engage him in decisions about Jill's care, and conflicts often erupted. After a long day at the office he didn't want to think about or second-guess his wife's preferences. Tension grew between them until they seldom spoke. They stopped going out alone together. Their intimate life ended.

This was only the first chapter in the Smith's ongoing struggle. After two years of caring for Jill at home, they faced the arduous task of getting her on Medicaid. And for the rest of her life, Jill will remain seriously disabled and will require ongoing, intensive rehabilitation.

* Names and identifying characteristics have been changed to preserve the family's privacy.

“Caregivers are an unrecognized resource, except as a means to reduce direct costs of care. Professionals give little, if any, thought to the havoc that results when a family member assumes caregiving duties.”

assumes caregiving duties.” One hospital describes the problem this way: “While family care can be emotionally supportive, it is also inherently unstable....[F]amily members are not always trained to provide the care that is needed. While well-meaning, they may not understand the medications, treatment regimens, or physical care that is needed to properly care for the patient.”

One application focusing on patients with difficult pain management problems reports, “Caregivers play a key role in pain management. This role may involve administering the analgesic medication prescribed by the physician; using non-drug pain relief methods; obtaining, filling, and refilling prescriptions; assessing pain; making decisions about dosages; communicating with the health care team; reminding or encouraging the patient to take medications; keeping records; and controlling technical aspects of patient controlled analgesic pumps. Sleep deprivation and exhaustion from dealing with pharmacies and insurance companies have also been reported over the course of a long-term illness.” Despite the crucial role family caregivers play, and their vulnerability due to exhaustion, the hospital offers them little training and support.

A hospital that provides substantial services to its family caregivers who care for patients with disabling head injuries nevertheless feels that, “Our impression is that these services only begin to address the substantial needs of this population. [Family members] frequently complain about the enormous impact and extent of their burden, and the dearth of services in the community. They desperately but unsuccessfully seek day programs and...unable to find them, complain of *their own* increasing imprisonment in the home.”

Fragmented communication leaves caregivers confused and uninformed. Echoing the focus group participants' complaints about poor communication, one application notes that, “Communication with health care providers is often fragmented, leaving caregivers uninformed or confused. Ongoing communication with the caregiver is essential to effective planning and outcomes and remains a significant challenge. For example, frequently neither caregivers nor patients have the opportunity to discuss issues such as advance directives prior to a critical event.” This application states that because many caregivers are employed full-time, it is extremely difficult for them to be available during daytime hours, which hinders effective communication between professionals and family caregivers and can compromise quality of care.

Discharge planning, as currently practiced, often fails to create smooth transitions. One hospital explains, “Theoretically, discharge planning should make the hospital-to-home transition a smooth one. Significantly, the voice of the caregiver is not heard nor is it solicited; patients are asked to sign off on plans already made, disempowering the patient

“Compounding difficulties around discharge planning, our hospital lacks educational and training materials to educate clinicians and caregivers about the challenges that confront family caregivers.”

and more importantly the family caregiver.” Compounding difficulties in discharge planning, another hospital states, “is our lack of educational and training materials to educate clinicians and caregivers about the challenges that confront family caregivers....There has been relatively little in-depth training of clinicians in negotiating and understanding the acute care-community interface. Furthermore, tools that are currently used by clinicians to assess how well ‘caregivers’ understand their emotional and technical responsibilities do not distinguish individuals who provide short-term assistance following a loved one’s acute illness or injury from those who provide ongoing care and decision making for their loved one’s chronic or terminal condition.”

The health care system does not sufficiently recognize the role of family caregivers. One application says: “In mainstream American medical care, the family has never been truly integrated into the system of caregiving in the hospital, a situation that presents extraor-

“In mainstream American medical care, the family has never been truly integrated into the system of caregiving in the hospital.”

inary difficulties for families of dementia patients. Unfortunately, [these families] often actually feel unwelcome and unsupported in their efforts to ensure the best care for the patient....Family caregivers who feel that hospital staff do not properly attend to the special needs of the patient with dementia may become angry and lose trust in the institution’s ability to provide care without their constant vigilance.” The expertise that these families develop regarding the patient’s unique needs and personality often remains unutilized and unacknowledged by health care professionals.

Patients from diverse backgrounds have different needs and circumstances. Several applications mention the ethnic and cultural backgrounds of their family caregivers. In describing African-American family caregivers, one application states: “In addition to the burden placed on female black adult children, many times the prime caregiver is a sibling, elderly himself/herself. Often doubling up and living together, the well elderly sibling is asked to assume caregiving responsibilities beyond his/her capability. The desire to keep the loved one at home and out of a nursing home prompts these elderly siblings to take on these caregiving responsibilities.” Another hospital, with a predominantly Hispanic population, says, “Due to the extended family structure, Hispanic and other minority families are frequently opposed to long-term placement of loved ones. The impact of managed care regulations, shortened length of stay, and reduction of formalized home care assistance, are imposing stronger demands [which notably affect these] families....Most [of these] family caregivers have no outlet for respite to maintain their health and well-being.”

BARRIERS TO SERVING FAMILY CAREGIVERS

The RFP asked applicants to describe the most significant barriers to involving family caregivers and meeting their needs. Applicants identified the following:

- **Lack of time and financial resources.** This was by far the most common response. One application sums up the problem: “The major barrier within our hospital and extended care facilities to improving services to family caregivers currently comes down to a lack of funds to address these important and newly recognized needs. In the current Medicare and Medicaid environment, we are anticipating further cuts rather than additional funds to address these issues.” One hospital places economic constraints as the primary barrier, but also notes a second barrier: “The limited time that social work staff can devote to counseling and developing an in-depth understanding of family needs.”
- **Overlooking the caregiver.** One application notes that health care providers—both clinicians and staff—generally focus on the patient’s clinical condition and, in doing so, often overlook the needs of the caregiver. “This may be due to a variety of causes,” it states, “including: the power health care providers have over others; personal values; an unwillingness to admit that they do not have all the answers; concerns about patient confidentiality; and a reluctance to deviate from procedures to accommodate the varied situations of families.”
- **Inadequate information systems.** “Information systems focus on sharing clinical information,” an application notes, “while no infrastructure exists to collect and share the social and emotional aspects of care.”
- **Language, cultural, and educational differences.** Problems can arise, one hospital states, when families and health care professionals come from different cultural backgrounds, and when they speak different languages. Educational differences can also create barriers to communication and understanding between families and the medical establishment.
- **Families’ emotional responses to illness.** A loved one’s illness can prompt a range of emotional reactions for caregivers, including guilt, fear, and anxiety. “It is especially challenging for strangers [i.e., hospital staff],” one application says, “to [provide] emotional [support] in a meaningful way....There are no clear prescriptions for help.”

These frank and thoughtful applications suggest that, at least at some administrative and clinical levels, professionals are aware of the increasing burden on family caregivers.

They want to do better, and recognize the substantial barriers they face. This is the beginning of what will inevitably be a long process. The failure to recognize and support family caregivers did not begin with managed care; it has been intrinsic to the American health care system. The changes in health care delivery and financing in the past several years, and the advances of technology, have brought the issues to a new level of concern. No single action or program will be a solution. Building long-term partnerships of mutual trust and respect takes time. The following recommendations outline some key steps.

IV. Recommendations for Change

The following recommendations for change are a beginning. They are not so grandiose that they depend on vast changes in the American political or economic system nor so trivial that they accomplish little more than a token bow to family caregivers. These recommendations, in conjunction with the Guiding Principles for Effective Partnerships between Family Caregivers and the Health Care System (see Appendix B), can make a difference and should be implemented. The first three recommendations are general in nature; the last three address transitions specifically.

GENERAL RECOMMENDATIONS

Recommendation 1: Health professionals, government agencies, and managed care organizations should recognize explicitly, in policy and practice, that family caregivers who assume significant care responsibilities are a valuable but vulnerable resource.

Recognizing that family caregivers can no longer be taken for granted is the first step in meeting their needs. Family caregiving is sometimes conveniently seen as only the simple and ordinary assistance provided to elderly people. Yet, at the most intensive end of the caregiving spectrum, family caregiving is often total care and management of seriously ill or cognitively impaired family members, and often lasts for many years. While all family caregivers can benefit from assistance and support, those with the most demanding or long-term responsibilities are particularly vulnerable to physical and emotional problems. A new awareness of the potentially devastating impact of increased responsibilities on family caregivers, and on family functioning and stability, must shape program and policy development.

Recommendation 2: This recognition of the critical role of family caregivers must be built into medical, nursing, and social work training and continuing education. New efforts are underway to bring training in home care, including working with family caregivers, into the medical school curriculum. These efforts should be supported and expanded. All health care providers whose patients are cared for at home should learn and experience the challenges of providing quality care in an environment designed for family intimacy. A home is not a hospital.

Recommendation 3: More research is urgently needed to understand the impact on family caregivers of changes in the health care system and on interventions that families need and want. Although there is a vast literature on family caregivers, most of it focuses on a health care system that no longer exists, on the needs of the frail elderly, and on conventional family structures. Much more research is needed. Some examples are: the establishment of a common research definition for caregiving and disability so that studies can be more easily compared; the elements of successful respite programs; and cross-cultural studies of family caregivers in the new health care environment.

SPECIFIC RECOMMENDATIONS ABOUT TRANSITIONS

Recommendation 4: Health care providers must make discharge planning, and transitions from one care setting to another, a process rather than a single event. Health care organizations must identify better and earlier ways to organize transitions so that family caregivers are given targeted and ongoing training, support, and follow-up. Links to community-based sources of support—religious organizations, patient/family advocacy and support organizations, civic organizations, and others—should be developed and maintained for appropriate referrals. The outlines in Section V, entitled “Covering the Basics for Family Caregivers,” provide a good start toward creating smoother transitions. They are designed for use by both health care professionals and family caregivers, and should be adapted to fit individual circumstances.

Recommendation 5: Hospitals and other health care institutions should develop model programs that offer innovative ways of involving and meeting the needs of family caregivers. While most family caregiving is provided at home, hospitals and other health care institutions (home care agencies, rehabilitation centers, community-based agencies, nursing homes) play an important part in the patient’s and family’s life. Because they are often leverage points in arranging services in the community, they can be leaders in involving family caregivers in creatively developing model programs, for example, in meeting the needs of culturally diverse populations, or for caregivers with family members with a specific medical condition.

Recommendation 6: Public and private insurance plans and managed care organizations should evaluate benefits and service plans to reflect the importance of training, supporting, and communicating with family caregivers. As more responsibilities and direct costs are shifted to patients and family caregivers, there is a potential for adding new costs to the health care system: re-hospitalizations or additional treatments for complications caused by the family’s inability to cope or understand how to provide adequate care; the added health care costs when a caregiver develops illnesses from the physical, emotional, and social strain of caregiving; and the subsequent need to substitute for that caregiver.

Additional, modest paid help for training or respite at critical points in the course of the patient's care may reduce these undesirable consequences. Family advisory councils should be created or given enhanced roles in managed care organizations and public and private insurance plans to provide feedback on benefits and service plans, proposed policies, and other issues.

The implementation of these recommendations must involve the people who provide most of the nation's health care (family caregivers) and focus on the setting in which most care is actually provided (the home). These recommendations go beyond helping families cope with common ailments, the miseries of the flu, the inconvenience of a broken wrist, or the emergency of an appendectomy. They are designed to help those who are often the lifelines for the cognitively impaired elderly, the seriously ill, the severely handicapped, and those who need continuous intervention to survive and flourish. While it is understandable that heroic families are praised, public policy should not be based on an expectation of martyrdom.

This report and its recommendations are intended to contribute to the development of responsible and reasonable ways to respect, understand, and help all families coping with serious illness and the major transitions that mark that journey.

V. Covering the Basics for Family Caregivers Outlines

- **THE INPATIENT STAY**
- **DISCHARGE TO HOME**
- **WORKING WITH HOME CARE AGENCIES AND VENDORS**
- **WHEN THE PATIENT HAS A TERMINAL ILLNESS**

The following outlines are intended to suggest some concrete ways to create smoother transitions, as mentioned in Recommendation 4. Because a change in a patient's health status and/or a move to a different care setting provide opportunities to review and reevaluate the family caregiver's situation, the outlines are organized around these common transition points. They can be used by health care professionals and family caregivers in these instances, and others as well, such as when changes in a family caregiver's health, responsibilities, or financial circumstances occur. They should be adapted or expanded to meet specific family needs.

From Levine, C. 1998. *Rough crossings: Family caregivers' odysseys through the health care system*. New York City: United Hospital Fund of New York. Outlines may be copied and used without permission, but may not be republished without prior written permission of the publisher.

COVERING THE BASICS FOR FAMILY CAREGIVERS

The Inpatient Stay

For patients admitted to hospitals, nursing homes, rehabilitation centers, and other health care facilities.

FIRST STEPS

Identify the primary family caregiver(s).

Name(s) _____

Relationship to the patient _____

Identify the one or two health care team members (physician, nurse, social worker, physician assistant, etc.) who are responsible for communicating information about the patient to the primary family caregiver(s):

Name(s) _____

Phone number(s) _____

DISCUSSION DURING THE PATIENT'S STAY

With consent of the patient, health care professionals, family caregivers, and patients should discuss the following:

Patient Status/Continuing Care

1. The patient's condition in clear, lay-language terms.
2. Treatment options in terms of risks, benefits, financial coverage, and likely outcome.
3. Estimated date of discharge.
4. Any likely changes in the patient's condition after discharge.
5. The family's caregiving capacity and needs.
6. If this is a readmission, a reassessment of the family's caregiving capacity and needs.
7. Options for placement after discharge.
8. The institution's policies and expectations of family participation in care.
9. Advance directives, designation of health care proxy.

Support Services

Health care professionals and family caregivers should discuss how to access the following services:

1. Emotional and decision making support.
2. Individual counseling, on site or in the community.
3. Support groups, on site or in the community.

Other Needs as Appropriate

From Levine, C. 1998. Rough crossings: Family caregivers' odysseys through the health care system. New York City: United Hospital Fund of New York. Outlines may be copied and used without permission, but may not be republished without prior written permission of the publisher.

COVERING THE BASICS FOR FAMILY CAREGIVERS

Discharge to Home

For patients discharged home from hospitals, nursing homes, rehabilitation centers, or other health care facilities.

DISCUSSION

Health care professionals, family caregivers, and the patient (if appropriate) should discuss the following before discharge:

1. The patient's condition, and any changes that may have occurred as a result of treatment at the facility.
2. Any likely symptoms, problems, or changes that may occur when the patient is at home.
3. The patient's care plan, the caregiver's needs, and any adjustments that must be made to meet these needs.
4. The potential impact of caregiving on the caregiver; warning signs of stress; techniques for reducing stress.

PLANNING

With consent of the patient, health care professionals and family caregivers should make the following plans/arrangements before discharge:

1. Readying the home by arranging for equipment rentals, home modifications, hiring of aides, etc.
2. 24-hour phone number a caregiver can call to speak with a health care professional.
3. Transportation home for the patient.
4. Follow-up appointment.

TRAINING

Health care professionals should provide family caregivers with applicable training before discharge:

1. Specific instructions on medication regimen, along with a written medication list with information about possible side effects and duration of regimen.
2. Adequate training in techniques, procedures, equipment, medications, recognition of symptoms, and other elements of patient care.

REFERRALS

Health care professionals, caregivers, and patients should explore available support services before discharge:

1. Community sources of social support for caregivers and patients.
2. Community-based agencies that provide services such as transportation, equipment maintenance, respite care, home care, volunteer services.
3. Information resources such as books, pamphlets, videos, web sites, etc.

OTHER NEEDS AS APPROPRIATE

From Levine, C. 1998. *Rough crossings: Family caregivers' odysseys through the health care system*. New York City: United Hospital Fund of New York. Outlines may be copied and used without permission, but may not be republished without prior written permission of the publisher.

COVERING THE BASICS FOR FAMILY CAREGIVERS

Working with Home Care Agencies and Vendors

For patients discharged home who require home care and equipment.

INFORMATION

Hospital staff and home care agencies should work together to ensure that the patient and family caregiver know the following:

1. How the home care plan is developed, and how the patient and family can participate in creating it.
2. The level of training home care staff have completed (RN, home health aide, etc.).
3. The number of hours per day and days per week the aide and/or nurse will visit.
4. The types of services the aide and/or nurse will perform.
5. The types of services the aide and/or nurse is not expected to perform.
6. Whether the same aide and/or nurse will be consistently available.
7. The availability of backup support.
8. Fee structure.
9. If the service is paid for by insurance or a government program, the approximate length of time the service will be available.
10. Others who will be involved in home care (therapists, nutritionist, etc.).
11. The process for resolving problems and complaints among patient, caregiver, and aide or nurse.

CONSIDERATION

Home care agencies should serve patients and family caregivers while considering:

1. Patient preferences about daily routines, likes, and dislikes.
2. Special family traditions around religious rituals, food, visits, etc.

SERVICE

Home health care vendors who supply equipment, supplies, or transportation should provide patients and family caregivers with:

1. Prompt, courteous, respectful delivery and/or service.
2. Training on equipment in use at home, which may differ from that used in hospital.
3. Service or consultation on an emergency basis.
4. Prompt attention to repairs and replacements.
5. Information on how to register complaints.

OTHER NEEDS AS APPROPRIATE

From Levine, C. 1998. *Rough crossings: Family caregivers' odysseys through the health care system*. New York City: United Hospital Fund of New York. Outlines may be copied and used without permission, but may not be republished without prior written permission of the publisher.

COVERING THE BASICS FOR FAMILY CAREGIVERS

When the Patient Has a Terminal Illness

For terminally ill patients in hospitals or nursing homes.

INFORMATION

With consent from the patient, if competent, a designated member or members of the health care team should provide family caregivers with information about:

1. The patient's condition in clear, lay-language terms.
2. Treatment options in terms of risks, benefits, financial coverage, and likely outcome.
3. The importance of health care proxy designation, if not already in place.
4. Options of palliative care or hospice, at home or as an inpatient.

DISCUSSION

The patient, if competent, the family caregiver, and a designated member of the health care team should discuss:

1. Preferences for how to make decisions about end-of-life care.
2. Decisions for sustaining or withdrawing treatment, DNR orders, palliative care, etc.
3. These wishes should be put into a written statement and included in the patient's medical chart, if he or she remains hospitalized.

SUPPORT

Health care professionals should provide family caregivers and patients with:

1. Spiritual support for patients and family members from staff clergy or members of the patient's own faith community.
2. Bereavement counseling before and after patient's death.
3. Follow-up contact after death.

Appendix A

Families and Health Care Project National Advisory Committee 1997-1998

EMILY ABEL, PH.D.
Professor of Public Health
and Women's Studies
University of California
Los Angeles, California

BARBARA BERKMAN, D.S.W.
Professor of Social Work
Columbia University School of Social Work
New York City

HARRISON BLOOM, M.D.
Vice Chairman for Clinical Affairs
Department of Geriatrics
Mt. Sinai-NYU Medical Center and
Health System
New York City

HENRY CHUNG, M.D.
Medical Director
Chinatown Health Clinic
New York City

KENNETH COVINSKY, M.D., M.P.H.
Assistant Professor of Medicine
Division of General Internal Medicine
Case Western Reserve University
School of Medicine
Cleveland, Ohio

NESSA COYLE, R.N., M.S.
Director, Supportive Care Program
Department of Neurology Pain Service
Memorial Sloan-Kettering Cancer Center
New York City

PAMELA DOTY, PH.D.
Senior Policy Analyst
Office of the Assistant Secretary for
Planning and Evaluation
U.S. Department of Health and Human
Services
Washington, D.C.

NANCY DUBLER, L.L.B.
Director, Division of Legal and Ethical
Issues in Health Care, Epidemiology, and
Social Medicine
Montefiore Medical Center
Bronx, New York

MINDY FULLILOVE, M.D.
Associate Professor of Psychiatry
New York State Psychiatric Institute
New York City

RUBY GREENE, M.P.A.
Director, Patient Relations
The Long Island College Hospital
Brooklyn, New York

JIMMIE HOLLAND, M.D.
Chief, Department of Psychiatry
Memorial Sloan-Kettering Cancer Center
New York City

GAIL GIBSON HUNT
Executive Director
National Alliance for Caregiving
Bethesda, Maryland

ROSALIE KANE, D.S.W.
Director, Long-Term Care Resource Center
University of Minnesota
Minneapolis, Minnesota

LEN McNALLY
Program Director
New York Community Trust
New York City

LIDIA POUSADA, M.D.
Chief, Division of Geriatrics and
Gerontology
Geriatric Institute of Westchester
Sound Shore Medical Center
New Rochelle, New York

CAROL RAPHAEL
President and Chief Executive Officer
Visiting Nurse Service of New York
New York City

GARY ROSENBERG, PH.D.
Senior Vice President
Mt. Sinai-NYU Medical Center and
Health System
New York City

WILLIAM RUDDICK, PH.D.
Professor of Philosophy
New York University
New York City

ANDREA SANKAR, PH.D.
Professor of Medical Anthropology
Wayne State University
Detroit, Michigan

R. KNIGHT STEEL, M.D.
Director
The Homecare Institute
Hackensack, New Jersey

PATRICIA STILL
Support Group Leader
Well Spouse Foundation
New York City

RICK SURPIN
President
Cooperative Home Care Associates
Bronx, New York

RABBI GERALD WOLPE
Har Zion Temple
Penn Valley, Pennsylvania

Appendix B

Guiding Principles for Effective Partnerships between Family Caregivers and the Health Care System*

The U.S. health care system is changing. As a result of fewer hospitalizations and shorter stays, and a market-based approach to health care financing, family caregivers confront increasing responsibilities, burdens, and challenges.

While family members have always been important providers of direct care and emotional support for their ill loved ones, their role is now even more critical. Some reasons are:

- Chronic illnesses, rather than acute illness, are the most prevalent forms of disease.
- High-technology care has moved from hospitals to homes.
- More women, the traditional caregivers, are in the labor force and less available to provide full-time care.
- An aging population requires more care, especially with progressive neurological diseases.
- Successes in acute-care medicine have saved lives but have left many people with long-term care needs.

Most families feel an obligation to help an ill loved one, and those who assume the demanding role of family caregiver typically do so because of their close attachment to the person or because of a combination of practical, emotional, and social reasons. The impulse to provide care cannot thrive without support from many sources. The Families and Health Care Project of the United Hospital Fund offers these principles as a basic framework to guide the relationships among patients, families, and professionals. The goal is a partnership based on mutual trust, respect, and cooperation.

*From Levine, C. 1998. Rough crossings: Family caregivers' odysseys through the health care system. New York City: United Hospital Fund of New York. Guiding Principles may be copied and used without permission, but may not be republished without prior written permission of the publisher.

Principle 1: FAMILY CAREGIVERS ARE AN ESSENTIAL PART OF THE HEALTH CARE SYSTEM

Family caregivers have been largely invisible in the current system. They have been “silent partners,” whose contribution has been taken for granted. A new approach is urgently needed to make family caregivers valued partners in care. Family members who take on caregiving responsibilities must be well prepared, provided with ongoing training and support, and given information about a full range of options for themselves and their loved ones.

Principle 2: HEALTH CARE PROFESSIONALS, INSTITUTIONS, AND INSURERS HAVE RESPONSIBILITIES TOWARD FAMILY CAREGIVERS

The primary responsibility for initiating and continuing the discussions and negotiations that flow from these principles lies with the health care professional or team leader who provides medical care to the ill family member. This may be a physician, physician assistant, nurse, social worker, or other professional. Institutions have responsibilities to train professionals to fulfill this responsibility and to develop programs that improve the process. Managed care organizations, private insurers, and public programs have responsibilities to set realistic and achievable limits on the type and amount of care family caregivers are expected to provide. Family caregivers may also initiate and direct the process, but they should not be assumed to know all the aspects that are and will become important to them.

Principle 3: EACH FAMILY HAS DIFFERENT STRENGTHS, LIMITATIONS, RESOURCES, AND CAPACITIES FOR CAREGIVING

“Family” should be broadly defined. Legal definitions of “family” do not reflect the diversity of relationships that often make up an individual’s support network. Family caregivers include people related by blood, marriage, or adoption as well as individuals who have longstanding emotional ties to the care recipient.

All families should not be expected to provide the same level of care that some families are able to provide. Family caregivers come from many different cultures, religions, ethnicities, and socioeconomic groups; even within these broad groups, individual family caregivers have different personal goals, priorities, and values. In developing and evaluating care plans, health care professionals should assess each family situation and avoid

stereotyping family caregivers on the basis of their gender, relationship to the care recipient, age, income, educational status, or other characteristics. Some family members are not appropriate caregivers, either because of their own health needs, other family responsibilities, substance abuse, mental illness, or hostility toward the care recipient.

Principle 4: FAMILY CAREGIVERS SHOULD BE INCLUDED IN DECISION MAKING

Family caregivers' decisions to provide care should be based on an informed negotiation with health care providers. Just as patients' treatment decisions are guided by their informed consent or refusal, similar discussions of potential risks or harms, benefits, and available sources of support and alternatives should precede family caregivers' agreements to provide significant levels of care, especially at home and for long periods.

In decisions about patient care that significantly affect the interests and well-being of family caregivers, an ethic of accommodation is more appropriate than patient autonomy alone. Both the care recipient's autonomy and preferences and the interests and well-being of the family caregiver are important considerations in decisions, for example, to discharge a seriously ill or disabled person to home care. Turning a home into a quasi-hospital involves considerable sacrifice of privacy, sanctuary, and other important values. The care recipient may be reluctant to accept caregiving from anyone but the primary family caregiver, but this preference should be balanced by the caregiver's own needs and other responsibilities.

Principle 5: FAMILY CAREGIVERS NEED INFORMATION, EDUCATION, AND SUPPORT

Family caregivers should be given consistent, accurate, and up-to-date information about the care recipient's condition and current and foreseeable caregiving needs. Physicians should discuss with patients and family caregivers the boundaries of patient confidentiality and whenever possible should obtain consent for discussing the patient's condition and care with family caregivers. When there are many members of a health care team—either in an institution or at home—it is especially important that the team leader introduce each member and define his or her role and responsibility. Team members should be consistent with each other in their communications with family caregivers.

Family caregivers should be provided initial and ongoing education and training. Family caregivers need an orientation process that may take many sessions. This training should

From Levine, C. 1998. *Rough crossings: Family caregivers' odysseys through the health care system*. New York City: United Hospital Fund of New York. Guiding Principles may be copied and used without permission, but may not be republished without prior written permission of the publisher.

include, at a minimum, practice in the skills they are expected to master, whether they involve medical procedures or therapies, behavioral management, or other aspects of providing personal care. One-time-only training, when the family caregiver is anxious and in an unfamiliar environment like a hospital, is insufficient.

Family caregivers should be given emotional support and counseling. Typically family caregivers experience anxiety, stress, fatigue, isolation, and sadness. They also frequently gain satisfaction from their role. They need support from other members of the family, friends, clergy, and health care professionals in adjusting to their frequently ambivalent reactions.

Family caregivers should be offered appropriate services or referrals to community-based agencies and other sources for assistance with home care, financial management, support groups, and other services. These offers should be repeated frequently, since family caregivers often do not recognize their own needs until they are overwhelmed by their tasks. Family caregivers need respite both on a short-term basis and for vacations.

Principle 6: FAMILY CAREGIVERS NEED OPPORTUNITIES TO REEVALUATE THEIR RESPONSIBILITIES AND, IF NECESSARY, TO REASSIGN THE TASKS

Family caregivers should be given regular opportunities to reevaluate their situation and to make changes in the care plan. Family caregiving is a dynamic role. Transitions in the care recipient's condition, care setting, family structure or financial status, or the primary family caregiver's health may all be occasions to reevaluate the care plan. At some point the primary caregiver may no longer be able to provide care; this should not be seen as a failure. An appropriate transition should be arranged.

Family caregivers, care recipients, and professionals should have access to a sensitive process to mediate conflicts. Conflicts may arise over confidentiality, informing the patient of prognosis, cultural traditions, end-of-life decisions, and many other issues. These conflicts should be avoided if possible or resolved in a respectful, fair, and balanced way through a process that allows full consideration of all viewpoints. Conflicts between different agencies, institutions, or professionals should be resolved without jeopardizing patient care or the family's stability.

Principle 7: FAMILY CAREGIVERS NEED GUIDANCE FOR END-OF-LIFE CARE AND DECISIONS

Patients and family caregivers should be encouraged to talk about end-of-life decisions, as well as to identify persons to act as health care proxies and, if desired, to prepare advance directives. Health care professionals should begin this dialogue at an early stage, and in ongoing discussions should explain all the options for care, including palliative care and hospice, as well as continued aggressive cure-oriented treatment. Respect for cultural values and traditions should inform these decisions. Trained clergy can play a crucial role in addressing the spiritual dimensions of end-of-life care.

Physicians and administrators should honor advance directives and the decisions of health care proxies. Honoring patients' wishes at the end of life is well established in law and ethics, but less so in clinical practice. The principles outlined here are intended to support a joint decision making process that will result in consensus about the goals of care and the most compassionate way to achieve them.

Principle 8: AS PARTNERS IN CARE, FAMILY CAREGIVERS ASSUME OBLIGATIONS

Family members who assume the role of caregiver have an obligation to perform their role to the best of their abilities, to work toward developing constructive relationships with professional caregivers, and to seek help when they encounter problems that jeopardize quality of care or their own health or well-being. In a well-functioning system that implements these principles, family caregivers will be better prepared to perform their tasks and more readily recognize their strengths and limitations. By knowing what they can do and being better prepared and assisted to do it—and by knowing what responsibilities they cannot sustain—family caregivers will work more closely with professionals in a mutually advantageous way.

Appendix C

Focus Group Methodology

The United Hospital Fund's Families and Health Care Project conducted six focus groups of family caregivers in September 1997 in New York City. The following details the methodology that was employed.

Recruitment. A professional focus group firm in New York City was retained to recruit the participants, provide space for the sessions, and handle the arrangements. The focus group firm recruited family caregivers from its database, advertisements in local newspapers, and other outreach activities. In addition, the Well Spouse Foundation sent information about the focus groups to its support group leaders. A professional focus group facilitator worked with Families and Health Care Project staff to develop a questionnaire (a "screener") provided to the firm. The screener asked questions about demographics, level of caregiving provided, number and types of transitions, patient disease, when the care was provided, and whether the patient had since died (see Appendix E). Participants who had ever been in a focus group about health or in any focus group in the past year were excluded. Recruitment was reviewed with project staff on a weekly basis.

While focus group organizers frequently report that many people who agree to participate fail to show up, the focus group firm's intensive and persistent contact with participants resulted in excellent participation rates in all the groups. Participants were paid an honorarium for their time, transportation, and any costs involved in hiring substitute caregivers. For each group, approximately 13 participants were recruited, because it was expected that some would not attend. When more than ten participants arrived for a group, which occurred in four groups, ten were selected based on information in the screener. Participants who were dismissed at the time of the session were paid.

Focus group format. Groups were audiotaped, videotaped, and observed by Fund staff, all with permission of the participants. Participants were assured confidentiality, that their last names would not be used, that there was no connection with the medical care their family member was receiving, and that the tapes would be available only to the study team. Following the groups, Fund staff contacted participants to ask further written permission to use parts of the videotape for presentations related to the project. A 15-minute video was created for educational purposes. Fund staff also requested written permission to print the vignettes that appear in Sections I and II of this report.

The Moderator's Guide consisted of three sections (see Appendix D). First, participants were asked to describe the condition of the person they care for and about the kinds of care they provide. Next, they were asked to think of a significant transition and any difficulties they may have had providing care during this transition. Finally, they were asked to think of what would have helped to make the transition easier.

Groups lasted from one-and-a-half to two hours each. All six groups proceeded smoothly with enough opportunity for each group member to participate. At many times during the groups, there was lively conversation, expressions of mutual support, and emotional statements. Several participants spoke openly about their depression. One participant in the bereaved group was so overcome at the beginning of the session that he could barely say his name but later participated fully. Another man in the same session was reluctant to leave at the end of the session and engaged the moderator in extended conversation. It was apparent that many participants had not had any prior opportunity to discuss their experiences. In several groups a participant spontaneously said that what was needed was "more support groups like this one."

Participant demographics. Characteristics of the caregivers are presented in Table 1. A total of 56 people participated. The participants ranged in age from 20 to 70. Women—the traditional caregivers—and men participated. There was significant ethnic diversity, including African-American, Caribbean black, Greek, Hispanic, Irish, Italian, Jewish, and Native American caregivers. About half of all participants had gone to college but more than half had family incomes of less than \$25,000 per year. Participants in the focus groups came from the New York metropolitan region, and from both urban and suburban locations.

Table 1

Demographics of 56 Focus Group Participants

Gender/Age	No.	Race/Ethnicity	No.	Education/Income	No.
Women	45	White	35	No College	30
Men	11	Black	17	College	26
		Hispanic	3		
		Native American	1		
Age				Annual Family Income	
20–29	8			Low (less than \$24,999)	32
30–39	16			Moderate (\$25,000 to \$49,999)	15
40–49	18			High (\$50,000 and up)	9
50–59	6				
60–70	8				

Appendix D

Focus Group Moderator's Guide*

1. **Welcome participants:** Thank you for coming. We appreciate your help.
2. **Tell very briefly about the project:**

This group is sponsored by a philanthropy called the United Hospital Fund. The purpose of the project is to help professionals understand the concerns and needs of caregivers. Eventually the goal is to help health care professionals and family caregivers form more effective partnerships.

We will be talking today about the experiences you've had as family caregivers and especially about the times when the patient moved from one place to another, such as home from the hospital or from the hospital to a nursing home. We will ask you to discuss how the move affected you as a caregiver.
3. **We have some ground rules for the group today:**
 - No right or wrong answers.
 - We need to hear from everyone.
 - Just give your own opinions (don't try to convince or get people to agree).
 - We have several topics to cover so we will not want to talk about every aspect of your experience. Most everyone's experience could take two or more hours to discuss in detail.
 - We want to give everyone an opportunity to talk about each topic, so each person needs to be somewhat brief.
 - I may sometimes need to stop you so we can get back on focus and get through all of our topics.
 - Discussion is being taped (audio and video) (easier, don't have to take notes).
 - Since we are taping, we all need to speak up, one person at a time.
 - The discussion in this group is anonymous. This group is not connected with any health care facility, provider, or funder. That means we won't be connecting your name with what you say and your information will not be available to anyone outside the study team without your permission.

*The focus group guide that appears here was used for groups of current caregivers. The same guide, with minor changes to the text, was used for groups of bereaved caregivers.

- Location of bathroom (we'll take a break halfway through the group).
 - Refreshments.
 - Usually people enjoy these groups as an opportunity to talk with others. Please relax and be as open as possible.
4. **Introductions:** first, I'd like to go around the room and ask each of you to give your first name and tell us about the illness of your family member.

Probe for:

- relationship
- age of patient
- condition of the patient
- history of care and transitions

Elapsed time = 30 minutes

Most of the time, the focus of questions is on the patient. For the purposes of this group, though, we will ask you to focus on your experiences as a caregiver. In other words, tell us how it was for you (how you felt and how you were treated), not what happened to the patient.

Thinking back to the last move the patient made (specify for each participant) write the one word that best describes the biggest problem you faced as a caregiver.

PAUSE

Under it write the next biggest problem you faced as a caregiver.

PAUSE

Then the next. What did you write? Please explain.

Encourage interaction

Probe for:

- **Feelings:** how did you feel when this happened?
- **Specific needs:** What responsibilities did you have? Did you have all the information you needed? Were you able to get everything you needed?
- **Interactions and communication:** Were you included in decisions? How were you treated by doctors, nurses, social workers, or other staff members? Were staff members helpful or not? Concerned about you? Annoyed or angry with you? Did you know what was going on?

Elapsed Time = 60 minutes

Break = 10 minutes

Thinking back, again, to the time the patient moved from one place to another, how could it have gone more smoothly? What was needed? Please describe the ideal situation in detail.

Probe for:

- all issues mentioned earlier
- specify everything needed
- anything else

Elapsed Time = 100 minutes

Thank you for coming. Your participation may help other families who are caregivers. I hope everything goes well for you and your family in the future.

Appendix E

Focus Group Recruitment Screener for Current and Bereaved Caregivers

Form A

1. Hello, my name is _____ with _____ organization. We are conducting a survey for the United Hospital Fund. I am calling to talk with people who have some experience taking care of someone who is ill or disabled. May I ask you a few questions?
2. Are you now taking care of someone for at least a year who is ill or disabled or did you take care of someone in the last three years who has since died?
☐ Yes—Patient died (Skip to Form B)
☐ Yes—Current
☐ No—Terminate
3. How old is the person you care for?
Age _____. If less than 18, terminate.
4. What is the condition of the patient and how long has he or she been in this condition?

Disabled means needing regular care from another person for walking, eating, or going to the bathroom or having memory or speech problems requiring regular care—for at least a year.

If not disabled, terminate.

5. What does your caregiving entail? In other words, what do you have to do for the patient?

Significant level of care includes regular ongoing help with walking, eating, bathing, or going to the bathroom (or managing someone else doing this care). It also means doing tasks for someone with memory, thinking, or speech problems.

If not significant level of care, terminate.

-
6. Has the patient been in a hospital, nursing home, or another care setting (other than home) for any time while you've been taking care of him or her?
- ☐ Yes—Continue
- ☐ No—Terminate
7. Please tell me the times s/he has moved from home to another setting (such as a hospital or nursing home or rehab center) or from the other setting to home (or gone from having a paid caregiver to having no paid caregiver at home).
1. _____
2. _____
3. _____
- If less than three moves or changes, review with project staff.**
8. What is your age? _____ Years
9. Have you ever been in a focus group?
- ☐ Yes—What was the topic? **See below***
- ☐ No—Continue
10. How would you describe your race?
- ☐ White
- ☐ Black—Record below
- ☐ Asian—Record below
- ☐ Hispanic—Record below
- ☐ Other—Record below
11. Do you have a college degree?
- ☐ Yes
- ☐ No—Record below
12. Are you employed for pay?
- ☐ Yes
- ☐ No

*Group should not include participants who know each other or are related in any way. None may have been in a health-related group ever or any group in the last year. All groups should have **at least** three non-whites and **be either** all female or an even mix of males and females. Groups 3 and 4 should have all members with family income less than \$25,000 and no college degree. Patient disease, age of patient, age of caregiver, relationship of caregiver, and employment status of caregiver should be mixed.

Check recruitment table to see if respondent is needed.

If no, terminate.

If yes, say:

We would like you to participate in a group discussion to be conducted at our facility on _____ at ____:____. The discussion will last approximately two hours and you will be paid \$75.00 for your time and any expenses you incur. Will you be able to attend?

Form B

1. Did you take care of a family member or friend for at least a year before he or she died?

☐ Yes—Continue

What was the person's relationship to you? _____

☐ No—Terminate

2. How old was the person you cared for?

Age _____. If less than 18, terminate.

3. What was the condition of the patient and how long was he or she in this condition?

Disabled means needing regular care from another person for walking, eating, or going to the bathroom or having memory or speech problems requiring regular care—for at least a year.

If not disabled, terminate.

4. What did your caregiving entail? In other words, what did you have to do for the patient?

Significant level of care includes regular ongoing help with walking, eating, bathing, or going to the bathroom (or managing someone else doing this care). It also means doing tasks for someone with memory, thinking, or speech problems.

If not significant level of care, terminate.

5. Was the patient in a hospital, nursing home, hospice, or another care setting (other than home) for any time while you were taking care of them?

☐ Yes—Continue

☐ No—Terminate

6. Please tell me the times s/he moved from home to another setting (such as a hospital or nursing home or rehab center) or from the other setting to home (or gone from having a paid caregiver [or outpatient hospice] to having no paid caretaker at home).

1. _____

2. _____

3. _____

If less than three moves or changes, review with project staff.

7. What is your age? _____ Years
8. Have you ever been in a focus group?
☐ Yes—What was the topic? **See below***
☐ No—Continue
9. How would you describe your race?
☐ White
☐ Black—Record below
☐ Asian—Record below
☐ Hispanic—Record below
☐ Other— Record below
10. Do you have a college degree?
☐ Yes
☐ No—Record below
11. Are you employed for pay?
☐ Yes
☐ No

Check recruitment table to see if respondent is needed.

If no, terminate.

If yes, say:

We would like you to participate in a group discussion to be conducted at our facility on _____ at __:__. The discussion will last approximately two hours and you will be paid \$75.00 for your time and any expenses you incur. Will you be able to attend?

*Group should not include participants who know each other or are related in any way. None may have been in a health-related group ever or any group in the last year. All groups should have **at least** three non-whites and **be either** all female or have an even mix of males and females. Group 5 should have four or more members with family income less than \$25,000 and no college degree. Patient disease, age of patient, age of caregiver, relationship of caregiver, and employment status of caregiver should be mixed.

Appendix F

Excerpts from the United Hospital Fund

Family Caregiving Grant Initiative Planning Grant

Application

OVERVIEW

The Family Caregiving Grant Initiative will support the development and testing of programmatic responses to the unmet needs of family caregivers providing care for seriously ill or disabled adults, where hospitalization and admission to and from other care settings is common. The Initiative will address family caregivers' needs through a two-phase, multi-year process, beginning with planning grants averaging \$20,000 to approximately 15 hospitals. These grant awards will be made in May 1998 with the goal of developing program proposals by December 1998. The Initiative will award five to seven implementation grants in February 1999.

PLEASE BE SURE TO ADDRESS THE FOLLOWING:

1. **Project Summary** (1/2 page)

Summarize the goals of your project and the analytic and planning activities you propose to undertake. Please be sure to describe:

- Your target population of family caregivers and the general characteristics of the patients for whom they provide care.
- The methods you will use to involve family caregivers in the planning process.
- Your plans for exploring possible partnerships with community-based organizations or other health care providers.

2. **Background** (3-4 pages)

In the current health care delivery and financing environment, there are many reasons to develop innovative family-centered care and support programs. These reasons include an increase in the number of patients with chronic illnesses requiring ongoing care at home with intermittent hospitalizations; shorter and fewer inpatient stays with discharge plans that increasingly depend on family caregivers; building integrated care networks; enhancing consumer satisfaction and loyalty; improving quality of patient care; avoiding staff conflicts with families; and others.

- A. *Describe the current situation in your hospital. You may use case examples to illustrate your response. Include the following and any other relevant information:*
- Your hospital's reasons for participating in this grant initiative.
 - Specific adult patient groups for whom unpaid, "informal" family caregivers provide significant levels of care over time at home.
 - Current educational and training initiatives in your hospital to educate clinicians about family caregivers' roles in patient care and decision making and the problems family caregivers face in fulfilling these roles.
 - Current educational and training initiatives in your hospital to educate family caregivers about their roles in patient care and decision making and how to meet the challenges they face.
 - Any non-medical services or programs in your hospital that address the psychosocial, emotional, or spiritual care needs of family caregivers dealing with chronic or terminal illness.
 - Current programs that link family caregivers to services in the community, either while their loved one is hospitalized or after discharge.
- B. *Describe what you consider the most significant and challenging barriers within your hospital to the effective involvement of family caregivers in patient care and decision making and in providing services that are directed at family caregivers themselves.*

3. **Project Description: Planning Phase (4-5 pages)**

Describe your planning strategy, relating it to the goals, conditions, and obstacles described above:

- Describe in detail the methods you plan to use with family caregivers, patients, and staff—e.g., surveys, focus groups, interviews—to assess the unmet needs of family caregivers and to identify areas for improvement and opportunities for demonstration projects.
- Describe any tools or materials you will need to help conduct your planning strategy.
- Describe how the proposed planning strategy engages the commitment of hospital leadership.
- Describe how you plan to ensure the multidisciplinary participation of staff (physicians, nurses, social workers, chaplains, physical or occupational therapists, or others) in the planning phase.
- Describe how you plan to ensure active family caregiver involvement in the planning process.

- Describe how you plan to explore forming relationships with one or more community partners (community-based organizations or health care providers). If you already have chosen a partner, describe the relationship and include a letter of agreement.
- If you anticipate engaging consultants for any aspect of project planning, please describe the anticipated use; and, if possible, identify the consultants and provide appropriate background material.

ANSWERS TO FREQUENTLY ASKED QUESTIONS

Q: What do you mean by “family caregivers”?

A: Family caregivers, sometimes called “informal” caregivers, are unpaid individuals who provide significant levels of care and management for a patient with a chronic, serious, or terminal illness or a severe disability. The care may include obtaining and supervising medications, changing bandages, monitoring symptoms or home care equipment like oxygen, supervising activities, feeding, shopping, cleaning, assisting with bathing and toileting, arranging transportation, accompanying the patient on medical visits, or many other activities that the patient cannot manage independently. Family caregivers are distinguished by the ongoing nature of their responsibilities (as opposed to helping a patient for a few days after coming home from the hospital) and by the level of their responsibilities, which extend far beyond providing emotional support or intermittent companionship, which many other people may also provide.

Q: Do family caregivers have to be related legally?

A: No. Family caregivers include many people in non-traditional relationships. They may be friends, neighbors, or partners who undertake significant levels of care.

Q: Are family members who provide care to ill or disabled children a target population under this grant initiative?

A: No. Although we recognize the significant challenges facing parents and caregivers of children, this initiative is limited to family caregivers of adult patients.

Q: Why is a “community partner” an important component of the initiative?

A: A continuum of care requires coordination of many different services and agencies. Community-based providers and service organizations are important elements in comprehensive patient care. Community partners can provide significant assistance when patients and family caregivers make transitions from hospital to home or nursing home or other facilities.

Q: What kinds of groups are eligible to be “community partners”?

A: Community partners may be home care agencies, nursing homes, or rehabilitation facilities; patient/family advocacy and support groups, usually focused on a specific disease or condition; general social service or mental health community-based agencies that assist patients and families in coping with the financial, emotional, and social impact of illness; community-based health care providers such as ambulatory clinics; fraternal, civic, or religious organizations.

Q: What will be the selection criteria for awarding planning grants?

A: Selection criteria will include: a demonstration of top-level administrative and clinical commitment to the project; an interdisciplinary approach; a thorough review of current practices involving family caregivers in some key area of service delivery; level of involvement of family caregivers and patients in information gathering and planning; and plans for exploring partnerships with community-based organizations or other health care providers.

Appendix G

Hospitals Awarded First-Phase Planning Grants under the Family Caregiving Grant Initiative

Sixteen hospital grants totaling \$320,000 at \$20,000 each were awarded to the following New York City hospitals in May 1998:

Beth Israel Medical Center
The Brooklyn Hospital Center
Cabrinì Medical Center
Calvary Hospital
Harlem Hospital Center
Jamaica Hospital Medical Center
Lincoln Medical and Mental Health Center
The Long Island College Hospital
Maimonides Medical Center
Montefiore Medical Center
The Mount Sinai Medical Center
The New York and Presbyterian Hospital
New York University Medical Center
Peninsula Hospital Center
Saint Vincents Hospital and Medical Center
Sisters of Charity Health Care System

Current Publications

Better Jobs, Better Care: Building the Home Care Work Force *Paper Series*

This paper presents specific strategies to meet home care workers' needs for more defined career opportunities, improved supervision and support, and better training.

#7038 56 pages 1994 \$10.00

Beyond the Clinic: Redefining Hospital Ambulatory Care *Paper Series*

Based on the Fund's Ambulatory Care Services Initiative, this report distills case histories from 12 New York City hospitals' programs to increase and improve outpatient services. Sections on reengineering the outpatient department, developing and implementing networked information systems, and training primary care providers and other staff are supplemented by examples of new tools and job descriptions.

#7348 64 pages 1997 \$12.00

The Challenge of Caring for Patients near the End of Life: Findings from the Hospital Palliative Care Initiative *Paper Series*

This report describes findings from the first phase of the Fund's Hospital Palliative Care Initiative, in which 12 New York City hospitals gathered information about deaths in their hospitals. The report identifies areas for improvement in current hospital practice and necessary institutional commitments to change, and concludes with recommendations for developing new models to promote palliative care.

#7372 64 pages 1998 \$15.00

Health Care Annual: Data on Hospitals in New York City, Long Island, and the Northern Metropolitan Area, 1998 Update

This annual data publication presents updated information about the capacity and utilization of hospital inpatient and ambulatory care services in southern New York, and includes information on physical medicine and rehabilitation, psychiatry, and substance abuse care. Ten-year trend data are included, along with a directory of hospitals and maps showing hospital locations.

#7429 80 pages 1998 \$20.00

Health Care for Children: What's Right, What's Wrong, What's Next

With 17 chapters by pediatric and health policy experts, this book examines the health status of U.S. children and describes how they currently get health care, including, increasingly, through managed care arrangements. The book outlines needed improvements in children's health services, and assesses the prospects for reform in today's political climate. It concludes with a broad-ranging agenda for change.

#7313 416 pages 1997 \$40.00

Hospital Watch: A Quarterly Report on Hospital Finance and Utilization

This report examines key indicators of the current trends in the utilization, operations, and financial performance of hospitals in New York City. The most recent issue is available upon request.

No charge*

How to Choose a Nursing Home: A Guide to Long-Term Care in New York City, 1998 Guide

This pocket-sized publication helps consumers, families, and friends obtain the information needed to choose a nursing home. The guide offers step-by-step instructions, and lists 179 New York City nursing homes, providing information on their locations and ability to accommodate special care needs.

First copy, no charge (each additional copy \$1)

Mediating Bioethical Disputes *A Practical Guide*

This publication provides an overview of the use of alternative dispute resolution strategies, particularly mediation, to resolve bioethical disputes. A step-by-step process is described for mediating such disputes. Case studies, glossary, and bibliography are included.

#7194 104 pages 1994 \$20.00

Medicaid Home Care Services in New York City: Service Utilization and Family Involvement

This data book documents the health status, needs, and makeup of New York City's Medicaid home care population, including their health conditions and impairment levels, demographic profiles, and the availability of family support.

#7402 28 pages 1998 No charge*

Medicaid Managed Care Currents

This quarterly newsletter discusses developments in New York's Medicaid managed care program. It is based on research and analytic work of the New York Consortium for Health Services Research. The most recent issue is available upon request.

No charge*

Meeting Patients' Needs: Quality Care in a Changing Environment *Paper Series*

Based on a Fund conference, this paper summarizes and evaluates methods to define, measure, and demonstrate the quality of hospital care and reorganize the delivery of hospital services, with a special focus on two current trends: reengineering and patient-centered care.

#7275 36 pages 1995 \$12.00

*These publications are also available at the Fund's web site: <http://www.uhfny.org>

Monitoring Medicaid Managed Care: Developing an Assessment and Evaluation Program A Special Report

Based on an invitational conference, this report discusses the information, reporting, and analytic systems that would support meaningful evaluation of Medicaid managed care in New York City. The report focuses on three key dimensions: enrollment, quality, and cost.

#7259 52 pages 1995 \$25.00

New York City Community Health Atlas, 1994

Designed for use by health care planners and analysts, the *Atlas* integrates demographic, economic, health services, and health status data to provide a picture of health needs and service patterns in 41 New York City communities. Borough and neighborhood data profiles describe demographic and health service patterns, which are also graphically illustrated by detailed maps and charts.

#7003 192 pages 1994 \$50.00

New York City Medicaid Managed Care Enrollment Atlas

This data resource presents citywide and zip code-level information on Medicaid managed care eligibility and enrollment in New York City as of June 1997. City and borough maps show the geographic distribution of each plan's enrollees and the percentage of Medicaid beneficiaries enrolled in managed care, and tables provide program eligibility and plan enrollment statistics by aid category, as well as total enrollment, for 175 zip codes, each borough, and citywide.

#7380 104 pages 1998 \$40.00

Reshaping Inpatient Care: Efficiency and Quality in New York City Hospitals Paper Series

This report on Fund initiatives in length of stay and patient-centered care describes targeted efforts among two groups of hospitals in New York City to identify and change practices that unnecessarily prolong inpatient stays and to deliver care that is highly responsive to the personal needs and preferences of patients and their families.

#7291 44 pages 1996 \$12.00

Rough Crossings: Family Caregivers' Odysseys through the Health Care System A Special Report

Based on focus groups conducted by the Fund's Families and Health Care Project, this publication chronicles the troubling experiences that caregivers of chronically ill or disabled family members face when encountering the health care system. Drawing from applications to the Fund's Family Caregiving Grant Initiative, it also provides perspectives on the subject from hospital staff. The report concludes by offering recommendations for systemic improvement.

#7437 88 pages 1998 \$15

The State of New York City's Municipal Hospital System, Fiscal Year 1997

Based on the findings of the Fund's City Hospital Visiting Committee, a 125-year-old citizens' group, this annual publication reports on conditions affecting patient care in New York City's public hospitals.

#7364 48 pages 1997 \$10.00

State Strategies for Financing Graduate Medical Education A Special Report

This special report describes various options for funding graduate medical education and examines how different states are using GME funding to address public policy goals.

#7356 56 pages 1997 \$25.00

Taking Steps, Losing Ground: The Challenge of New Yorkers without Health Insurance A Special Report

This publication presents a thorough and revealing analysis as to why the numbers of uninsured in the country, and in New York State in particular, have risen dramatically in the last several years. It offers various feasible, concrete strategies for expanding coverage to the uninsured in the state.

#7410 72 pages 1998 \$25.00

An Unfinished Revolution: Women and Health Care in America

This 16-chapter book describes women's special contributions to health care in the United States and takes a hard look at the challenges that remain, providing perspectives on women's roles as consumers of health services, health care professionals, research subjects, informal caregivers, and health care leaders.

#7178 304 pages 1994 \$20.00

Zip Code Area Profiles, 1994

This companion volume to the *New York City Community Health Atlas* integrates demographic, economic, health services, and health status data to provide a picture of health needs and service patterns in 165 zip code areas.

#7208 358 pages 1994 \$100.00 (book)

\$250 (Disk—*please specify Lotus or SPSS*. Includes hard copies of *New York City Community Health Atlas* and *Zip Code Area Profiles*.)

To order, please write to the United Hospital Fund, Publications Program, Empire State Building, 350 Fifth Avenue, 23rd Floor, New York, NY 10118. Checks should be made payable to the United Hospital Fund and include postage and handling (see chart). For information about bulk orders or for a complete list of publications, please call 212-494-0700 or visit the Fund's web site at <http://www.uhfnyc.org>.

Shipping and handling charges	
Order amount	Charge
Up to \$40.00	\$3.50
\$40.01-\$99.99	5.00
\$100.00 and over	7.50

*These publications are also available at the Fund's web site: <http://www.uhfnyc.org>

Additional copies of this United Hospital Fund Special Report, @ \$15.00 plus \$3.50 per order for postage and handling, may be ordered from the Publications Program, United Hospital Fund, Empire State Building, 350 Fifth Avenue, 23rd Floor, New York, NY 10118.

Raymond L. Rigoglioso, *Editor*

Lipman Hearne, *Cover Design*

Liza Buffaloe, *Production*



**United
Hospital Fund**

Shaping New York's Health Care:
Information, Philanthropy, Policy.

Empire State Building
350 Fifth Avenue, 23rd Floor
New York, NY 10118
(212) 494-0700
<http://www.uhfnyc.org>

ISBN: 1-881277-43-7