PSYCHOSOCIAL RESEARCH ON PEDIATRIC HOSPITALIZATION AND HEALTH CARE

PSYCHOSOCIAL RESEARCH ON PEDIATRIC HOSPITALIZATION AND HEALTH CARE

A REVIEW OF THE LITERATURE

By

RICHARD H. THOMPSON, Ph.D.

Director of the Child Life and Family Education Department Wyler Children's Hospital, University of Chicago Chicago, Illinois



CHARLES CTHOMAS • PUBLISHER

Springfield • Illinois • U.S.A.

Published and Distributed Throughout the World by

CHARLES C THOMAS • PUBLISHER 2600 South First Street Springfield, Illinois 62717

This book is protected by copyright. No part of it may be reproduced in any manner without written permission from the publisher.

© 1985 by CHARLES C THOMAS • PUBLISHER ISBN 0-398-05070-8 (cloth) ISBN 0-398-06457-1 (paper)
Library of Congress Catalog Card Number: 84-16464

With THOMAS BOOKS careful attention is given to all details of manufacturing and design. It is the Publisher's desire to present books that are satisfactory as to their physical qualities and artistic possibilities and appropriate for their particular use. THOMAS BOOKS will be true to those laws of quality that assure a good name and good will.

Printed in the United States of America SC-R-3

Library of Congress Cataloging in Publication Data

 $Thompson,\,Richard\,H.$

Psychosocial research on pediatric hospitalization and health care.

Bibliography: p.
Includes index.
1. Children — Hospital care — Psychological aspects.
I. Title. [DNLM: 1. Child, Hospitalized — psychology.
WS 105.5.H7 T475p]
RJ242.T49 1985 362.1'1'088054 84-16464
ISBN 0-398-05070-8. — ISBN 0-398-06457-1 (pbk.)

To Lynn

ACKNOWLEDGEMENT

Completion of this review was made possible, in part, by a grant from the Association for the Care of Children's Health, 3615 Wisconsin Avenue, N.W., Washington, D.C. 20016.

| 1 1 1 1 1 1 |
|----------------------------|
| |
| |
| |
| |

CONTENTS

| | | Page |
|------------|--|------|
| Chapter 1: | FOCUS OF THE LITERATURE REVIEW | 3 |
| | SELECTION OF THE RESEARCH | |
| | TO BE REVIEWED | 3 |
| | THE RESEARCH IDENTIFIED | 5 |
| | FORMAT OF THE LITERATURE REVIEW | 7 |
| Chapter 2: | CHILDREN'S RESPONSES TO | |
| _ | HOSPITALIZATION AND HEALTH CARE | 12 |
| | ASSESSING PSYCHOLOGICAL UPSET | 12 |
| | Assessment of Immediate Responses | 13 |
| | Assessment of Posthospital Responses | 15 |
| | Interrelationships of Psychological | |
| | Upset Measures | 16 |
| | THE IMMEDIATE RESPONSES | |
| | OF CHILDREN TO HEALTH CARE | 17 |
| | Alteration in Immediate Behavior | |
| | as a Coping Response | 21 |
| | Summary of Research on the | |
| | Immediate Responses to Hospitalization | 24 |
| | THE POSTHOSPITAL RESPONSES | |
| | OF CHILDREN | 25 |
| | The Duration of Posthospital Responses | 29 |
| | CHILDREN'S RECOLLECTIONS | |
| | OF THEIR HOSPITAL EXPERIENCES | 33 |
| | ILLNESS AS A SOURCE OF | |
| | PSYCHOLOGICAL UPSET | 35 |
| | FACTORS ASSOCIATED WITH | |
| | CHILDREN'S PSYCHOLOGICAL UPSET | 36 |

| : | x | Pediatric Hospitalization and Health Care |
|---|---|---|
| | | |

| | Sociodemographic Factors | 36 | |
|------------|---|----|--|
| | Age | 36 | |
| | Sex | 39 | |
| | Family Configuration | 40 | |
| | Socioeconomic Status | 41 | |
| | Interpersonal Factors | 42 | |
| | Separation | 42 | |
| | Emotional Responses of Parents | 44 | |
| | Parent-Child Relationships | 45 | |
| | Parent and Child Relationships with the Staff | 47 | |
| | Intrapersonal Factors | 48 | |
| | Unfamiliarity | 48 | |
| | Conceptions and Perceptions | | |
| | of Hospitalization and Illness | 49 | |
| | Personality | 50 | |
| | Prehospital Emotional Adjustment | 51 | |
| | Health Care Experience Factors | 53 | |
| | Prior Health Experiences | 53 | |
| | Aspects of Current Treatment | 55 | |
| | SUMMARY | 56 | |
| Chapter 3: | CHILDREN'S CONCEPTIONS OF | | |
| | HOSPITALIZATION, ILLNESS, AND | | |
| | MEDICAL CARE | 59 | |
| | ILLNESS, HEALTH CARE, | | |
| | AND SELF-CAUSATION | 60 | |
| | Hospitalized Children's Views | | |
| | of Illness as Punishment | 61 | |
| | Healthy Children's Views | | |
| | of Illness as Punishment | 62 | |
| | Studies Examining Healthy and Ill Children | 64 | |
| | Summary | 66 | |
| | AGE-RELATED CHANGES IN | | |
| | CHILDREN'S CONCEPTIONS OF ILLNESS | | |
| | AND HEALTH CARE | 67 | |
| | The Decline of Belief | | |
| | in Self-Causation and Punishment | 68 | |

| | Contents | хi |
|------------|--|-----|
| | Increase in Complexity of Health Care Concepts | 68 |
| | Explanations of Illness and Health | 68 |
| | Understanding of Body Parts | 71 |
| | Summary | 73 |
| | Stages of Health Care Understanding | 74 |
| | Identification of Stages | 74 |
| | Relationship between Health Concept Stages | |
| | and General Cognitive Functioning | 78 |
| | THE INFLUENCE OF ILLNESS | |
| | OR HOSPITALIZATION ON CHILDREN'S | |
| | HEALTH CARE CONCEPTS | 81 |
| | Impact on Cognitive Level | 81 |
| | Impact on Knowledge of Health and Illness | 84 |
| | CHILDREN'S CONCEPTS OF OTHER | |
| | HOSPITAL-RELATED PHENOMENA | 85 |
| | Concepts of Medical Procedures and Instruments | 85 |
| | Concepts of Medical Personnel | 87 |
| | Concepts of Isolation Technique | 89 |
| | Concepts of Research Hospitalization | 90 |
| Chapter 4: | RESEARCH ON SPECIFIC PROCEDURES | |
| | AND ENVIRONMENTS | 92 |
| | HOSPITAL PROCEDURES | |
| | AND TREATMENTS | 92 |
| | Injections | 92 |
| | Factors Associated with Upset | |
| | During Injections | 93 |
| | Approaches to Reducing Upset | |
| | During Injections | 94 |
| | Self-report of Pain During Injections | 96 |
| | Immobilization | 97 |
| | Rectal Temperatures | 100 |
| | Binocular Bandaging | 101 |
| | Anesthesia Induction | 102 |
| | Responses to Anesthesia | 102 |
| | Effects of Age | 103 |
| | Effects of Parent Presence | 104 |

| | Effects of Preparation | 104 |
|------------|---|-----|
| | Variations in Induction Techniques | 105 |
| | Birth Order | 106 |
| | Cardiac Catheterization | 106 |
| | SPECIFIC HOSPITAL ENVIRONMENTS | 108 |
| | Intensive Care Units | 108 |
| | Children's Reactions in the ICU | 109 |
| | Levels of Consciousness and Recall of the ICU | 111 |
| | The Effects of Play on Children's Behavior | |
| | in the ICU | 112 |
| | Parent Responses to the ICU | 113 |
| | The Recovery Room | 115 |
| | Isolation Units | 115 |
| | Children's Concepts of Isolation | 116 |
| | Children's Responses to Isolation | 116 |
| | Emergency Rooms | 119 |
| | Children's Responses to | |
| | Emergency Room Care | 119 |
| | Admission to the Hospital | |
| | via the Emergency Room | 121 |
| Chapter 5: | SEPARATION AND ROOMING-IN | 124 |
| | SUBSTITUTE CAREGIVERS | 125 |
| | THE EFFECTS OF | |
| | PARENTAL ROOMING-IN | 127 |
| | Immediate Effects of Rooming-in | |
| | and Unlimited Visitation | 128 |
| | Posthospital Effects of Rooming-in | 130 |
| | Posthospital Behavior | 131 |
| | Posthospital Physical Recovery | 133 |
| | SEPARATION DURING | |
| | MEDICAL PROCEDURES | 134 |
| | CARE-BY-PARENT UNITS | 137 |
| | PARENT VOICE RECORDINGS | 139 |
| | AVAILABILITY AND ADEQUACY | |
| | OF SERVICES PROVIDED FOR PARENTS | 141 |

| | Contents | xiii |
|------------|---|------|
| Chapter 6: | PARENT AND SIBLING RESPONSES | |
| • | TO HOSPITALIZATION | 144 |
| | PARENT RESPONSES | 145 |
| | Prevalence of Parent Anxiety | 145 |
| | The Relationship between Parent | |
| | and Child Anxiety | 146 |
| | The Impact of Communication on Parent Anxiety | 149 |
| | Factors Influencing Parent Participation | |
| | During Hospitalization | 154 |
| | Parent Rooming-in and Visitation | 154 |
| | Parent Participation in the | |
| | Acquisition of Information | 158 |
| | Parent Participation in Children's Care | 161 |
| | A Note on Father Participation | 165 |
| | SIBLING RESPONSES | |
| | TO HOSPITALIZATION | 168 |
| Chapter 7: | ADOLESCENT HOSPITALIZATION, | |
| | HEALTH CARE, AND ILLNESS | 174 |
| | ADOLESCENT HEALTH CARE CONCEPTS | |
| | AND ATTITUDES | 176 |
| | Conceptions of Health and Illness | 176 |
| | Health Concerns of Adolescents | 177 |
| | Attitudes Toward Adolescent Health Clinics | 178 |
| | THE HOSPITALIZED ADOLESCENT | 181 |
| | Diagnoses of Hospitalized Adolescents | 181 |
| | Adolescent Responses to Hospitalization | 182 |
| | Adolescent Visitation Patterns | 186 |
| | Adolescent Preferences | |
| | for Information Providers | 187 |
| | Parent Responses to the Illness | |
| | and Hospitalization of Adolescents | 189 |
| | Adolescent Units | 192 |
| | Staff Members' Knowledge and Perceptions | |
| | of Adolescents | 196 |
| Chapter 8: | THE HOSPITAL MILIEU | 198 |

| | THE ACTIVITIES OF | |
|-------------|---|-----|
| | HOSPITALIZED CHILDREN | 198 |
| | Television Viewing Habits | 199 |
| | CHILDREN'S INTERACTIONS WITH OTHERS | |
| | IN THE HOSPITAL | 201 |
| | Amount of Contact with Others | 201 |
| | The Nature of Children's Contacts with Nurses | 202 |
| | Interpersonal Communications | 204 |
| | Documentation of Communication Patterns | 204 |
| | The Effects of Interpersonal Communication | 207 |
| | THE SLEEP PATTERNS OF | |
| | HOSPITALIZED CHILDREN | 210 |
| Chapter 9: | PLAY AND THE HOSPITALIZED CHILD | 213 |
| 1 | THE EFFECTS OF HOSPITALIZATION | |
| | ON CHILDREN'S PLAY | 215 |
| | Disruption of Play | 215 |
| | Aggression in Play | 217 |
| | THE USE OF PLAY | |
| | BY HOSPITALIZED CHILDREN | 218 |
| | Spontaneous Therapeutic Activities | 218 |
| | Selection of Relevant Play Materials | 219 |
| | THE EFFECTS OF PLAY INTERVENTIONS | 226 |
| | Play Interventions and Children's Upset | 226 |
| | Play Interventions and Children's Behaviors | 230 |
| | Infant Stimulation | 232 |
| | Use of Music | 234 |
| | DEVELOPMENT OF HOSPITAL-BASED | |
| | PLAY PROGRAMS | 235 |
| Chapter 10: | PSYCHOLOGICAL PREPARATION FOR | |
| - | HOSPITALIZATION AND | |
| | HEALTH CARE PROCEDURES | 237 |
| | BASIC INFORMATIONAL APPROACHES | 241 |
| | Information about Medical Conditions | 242 |
| | Information about Hospitalization | |
| | and Surgical Procedures | 244 |

| Contents | xv |
|----------|----|
| | |

| | Information about Dental Procedures | 245 |
|-------------|---|-----|
| | The Value of Information | 246 |
| | SENSORY INFORMATION | 248 |
| | THE USE OF PLAY IN PREPARATION | 251 |
| | THE USE OF MODELING | |
| | IN PREPARATION | 257 |
| | Modeling in Medical Settings | 257 |
| | Modeling in Nonhospital Settings | 263 |
| | Modeling in Dental Settings | 264 |
| | Filmed Modeling Versus Nonintervention | 265 |
| | Modeling Versus Other Techniques | 265 |
| | Variations Due to Subjects' Previous | |
| | Experience and the Modeling Film Format | 269 |
| | Summary of Modeling Research | 270 |
| | INSTRUCTION IN COPING SKILLS | 272 |
| | PARENT PREPARATION | 275 |
| | THE CONTRIBUTION OF | |
| | EMOTIONAL SUPPORT | 279 |
| | STRESS POINT PREPARATION | 282 |
| | NONEXPERIMENTAL | |
| | PREPARATION STUDIES | 285 |
| | The Adequacy of Children's Preparation | 286 |
| | Participation in Preparation Activities | 287 |
| | Family Characteristics | 289 |
| | Children's Responses | 290 |
| | THE PREVALENCE AND FUNCTIONING | |
| | OF PREPARATION PROGRAMS | 293 |
| Chapter 11: | SUMMARY AND CONCLUSIONS | 293 |
| | DOES HOSPITALIZATION | |
| | PRODUCE UPSET? | 293 |
| | Immediate Responses | 294 |
| | Posthospital Responses | 294 |
| | Long-Term Responses | 294 |
| | DETERMINANTS OF UPSET | 295 |
| | Age | 295 |
| | | |

xvi Pediatric Hospitalization and Health Care

| Unfamiliarity | 296 | | | | | |
|---|-----|--|--|--|--|-----|
| Separation Prehospital Personality | | | | | | |
| | | | | | Other Factors | 297 |
| LIMITATIONS OF THE RESEARCH | | | | | | |
| Adequacy of Descriptions | 298 | | | | | |
| Control of Observer Bias Use of Statistical Tests Confounding of Theoretical Implications | | | | | | |
| | | | | | Measurement of Direct Effects | 301 |
| | | | | | Concern for Reliability and Validity Consideration of Psychological Benefits | |
| ADDITIONAL CONCERNS | | | | | | |
| Limited Research on Involvement of Fathers | | | | | | |
| and Siblings | 304 | | | | | |
| Restricted Range of Subjects | | | | | | |
| used in Experimental Research | 304 | | | | | |
| Restricted Range of Interventions Examined | 306 | | | | | |
| REFERENCES | 307 | | | | | |
| INDEX | 333 | | | | | |

PSYCHOSOCIAL RESEARCH ON PEDIATRIC HOSPITALIZATION AND HEALTH CARE

| | | | I |
|--|--|--|------|
| | | | 1 |
| | | | 1 |
| | | | |
| | | | 1 |

Chapter 1

FOCUS OF THE LITERATURE REVIEW

The past two decades have witnessed a tremendous increase in the literature concerning the psychosocial aspects of child-hood hospitalization and health care, the magnitude of which may be illustrated by comparing the volume of recent publications to that existing prior to 1965. In their classic review of the literature on the hospitalization and illness of children, Vernon, Foley, Sipowicz, and Schulman (1965) cite some 208 articles including theoretical and descriptive pieces, case studies, and reports of more formally structured research projects. A relatively small percentage of these articles fall into the latter category, providing data collected through formal research procedures. However, since 1965 alone more than 300 reports of formal research pertaining to childhood hospitalization and health care have been published. It is this body of research literature, published in 1965 or later, that will be the subject of the present review.

SELECTION OF THE RESEARCH TO BE REVIEWED

An effort has been made to conduct a comprehensive search of the psychosocial research literature on the hospitalization of children and adolescents. The research literature concerning children in other health care settings (i.e., outpatient medical or dental clinics) has also been examined to identify studies relevant to a given topic, such as children's reactions to specific medical procedures or psychological preparation for health care encounters. However, the nonhospital-based research is less exhaustively reviewed in the present volume than is that concerning childhood or adolescent hospitalization.

The studies to be discussed in the following chapters (all of which have been published in journals or books, or are dissertations available through University Microfilms International) were located by several methods. Computerized searches of the Psychological Abstracts, Dissertation Abstracts, Educational Resources Information Center (ERIC), and Medline data bases were conducted. On the basis of a preliminary review of the literature, topic areas considered to be of greatest importance were selected to focus the computerized search process. These topics included: 1) children's concepts of hospitalization, illness, and health care, 2) children's psychological responses to hospitalization and health care, 3) responses of other family members to a child's hospitalization, 4) non-medical aspects of children's hospital experience, such as their everyday activities and their interactions with parents and staff, and 5) interventions designed to minimize children's psychological upset, including parental presence, preparation, and play experiences.

In addition to the computerized literature searches, other published bibliographic references were examined, including *The Hospitalized Child* by Akins, Mace, and Akins (1981). Citations of potential relevance were located and their content assessed. Finally, as research articles were identified, the reference list of each was examined for further related studies.

Research has been selected for inclusion in the present review if, in addition to relevant subject matter, it is characterized by systematic attempts to define a question of interest, to collect data pertinent to the question in a methodical manner, to analyze the data (not necessarily using statistical methods), and to discuss their implications. Case studies have been typically excluded from consideration. However, an exception has been made if a particular study includes a minimum of four subjects and provides information on a topic of considerable interest to health care professionals for which little other research exists. Examples of such topic areas include children's reactions to isolation or intensive care units.

Studies otherwise appropriate for inclusion in the review, yet providing information specific to a single illness or condition, are also typically omitted. A wealth of literature exists, for example, on children's reactions to various forms of chronic illness or the accompanying treatment, but consideration of this literature would extend the present review beyond the manageable. Research

pertaining to children with specific illnesses is, however, included when its focus is not solely on the illness, but rather provides information on conditions applicable to other categories of patients as well. Thus included are studies on topics such as the preparation of cardiac patients for surgery or the effects of rooming-in by parents of cancer patients.

THE RESEARCH IDENTIFIED

Using the criteria described above, a total of 306 research reports have been identified. For purposes of this and other summary figures provided in the text, results of research reported in more than one source (e.g., a dissertation that is subsequently published in article form) are counted as a single study. Nevertheless, all citations are given in the text to provide the reader with greater flexibility in locating the material. Separate articles reporting on different aspects of a research project, though drawn from the same sample, are counted individually.

The 306 identified reports have been categorized on the basis of their research design. Seventy-seven of the studies are experimental, incorporating deliberate assignment of subjects to varying treatment conditions. Forty-three use nonexperimental designs, wherein differences among preexisting groups of subjects are compared. The groups compared typically consist of subjects who have or have not, of their own accord, participated in intervention programs such as preadmission visits to the hospital or parent rooming-in. Another 72 studies are correlational in nature, examining relationships among varying levels of child and/or parent characteristics. Among the relationships commonly investigated is that between parent and child anxiety or the association between child variables (e.g., age, measures of personality characteristics, length of hospitalization, etc.) and indices of children's psychological upset. Seventy studies are descriptive, documenting the frequency and distribution of subjects' activities, behaviors, and contacts with others, without using the data gathered to formally test hypotheses. Also in this group are studies exploring children's conceptions of health care and illness. A final group of 44 studies are surveys, which either assess patient, parent, or staff attitudes