INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

Bell & Howell Information and Learning
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA
800-521-0600

UMI®

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

The Impact of Managed Care on Children Living with Cancer: A View from Pediatric Oncology Social Workers

by

TONI L. CABAT

A dissertation submitted to the Graduate Faculty in Social Welfare in partial fulfillment of the requirements for the degree of Doctor of Social Welfare, The City University of New York

2000

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

UMI Number: 9959168

Copyright 2000 by
Cabat, Toni L.

All rights reserved.

UMI Microform 9959168
Copyright 2000 by Bell & Howell Information and Learning Company.
All rights reserved. This microform edition is protected against
unauthorized copying under Title 17, United States Code.

Bell & Howell Information and Learning Company
300 North Zeeb Road
P.O. Box 1346
Ann Arbor, MI 48106-1346

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

2000

TONI L. CABAT

All Rights Reserved

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

This manuscript has been read and accepted for the Graduate Faculty in Social Welfare in satisfaction of the dissertation requirement for the degree of Doctor of Social Welfare.

December 6, 1999
Date

Michael J. Smith
Chair of Examining Committee
Dr. Michael Smith

December 6, 1999
Date

Executive Officer
Dr. Michael Fabricant

Dr. Mildred Mailick

Dr. Robert Salmon

Dr. Michael Fabricant
Supervisory Committee

THE CITY UNIVERSITY OF NEW YORK

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Abstract

THE IMPACT OF MANAGED CARE ON CHILDREN LIVING WITH CANCER: A VIEW FROM PEDIATRIC ONCOLOGY SOCIAL WORKERS

By

Toni L. Cabat

Adviser: Professor Michael J. Smith

This exploratory-descriptive study researched the impact of managed care on the delivery of health care to cancer-diagnosed children, their families and their health care providers: pediatric oncology social workers.

Eighty-four (84) members of the Association of Pediatric Oncology Social Workers completed a self-administered survey questionnaire. These social workers were asked to compare managed care to traditional fee-for-service insurance coverage. The most significant results regarding the negative impact on children and their families point to fundamental managed care policies and practices. These policy and practice issues are: (1) the inaccessibility to specialists; (2) greater complexity of requirements to obtain care; (3) greater time delay in the referral process; (4) greater burden on the consumer (requiring greater parental self-reliance); (5) the lack of transferability of providers among managed care plans; and (6) reduced satisfaction with providers. There is an increased level of stress experienced by parents of cancer-diagnosed children in relationship to the amount of required advocacy, the extent of required telephone contacts and the amount of paperwork.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

On the positive side, there are several key features of managed care, as compared to fee-for-service, that improve service delivery and decrease the stress on parents. These are (1) the provision of case management; (2) the coordination of care and (3) less financial burden on families.

The impact on pediatric oncology social workers is highlighted by an increase in the workload in the areas of: (1) advocacy, (2) delivery of concrete services, (3) team coordination, and (4) financial assessment. The clinical functions of the pediatric social worker are also impacted in that there is greater use of: (1) community supports, (2) crisis intervention with parents and their children, and (3) less on-going counseling with parents and their children.

The questions raised by this survey point to managed care policies and practices that need further study and adaptation to fit the needs of this population. This study also points to the changing role of pediatric oncology social workers and the wealth of information available to them to address the needs of their oncology clients facing a changing system of health care.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

ACKNOWLEDGEMENTS

My sincere thanks to my Committee Chair, Professor Michael J. Smith, whose patience and guidance never ceased, and to Professor Mildred Mailick, who was with me when I initiated this study and supported me through many, many revisions. Additional thanks to Professor Robert Salmon, who graciously joined the team to help me across the finish line.

My heartfelt thanks to my APOSW colleagues who supported my research by taking the time from their demanding schedules to complete the study and encourage me. My special acknowledgement to the children and families, they assist daily, who live with childhood cancer, a devastating disease.

Along my professional journey there have been many exceptional colleagues who have inspired my work and achievements, as a social worker, who I would like to acknowledge: Dr. Samuel Goldstein, Dr. Arye Rubinstein, Dr. Lloyd Setleis and Dr. Grace Christ.

My long list of family supports and mentors includes those who are no longer here to see the fruits of their inspiration: Beatrice and Paul LoBue, Anna Benedetto, Rose and Louis Cabat and my beloved Dr. Jonathan Myles Cabat. They all served as my early role models demonstrating compassion, idealism and academic achievement.

Sincere thanks goes to all of my family members who will celebrate my accomplishment: JoAnne and Carl LoBue, Carolyn, Frank and Sam Ferguson, Ly and Carl LoBue, the entire Cabat family and my dear husband, Stuart Germain.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table of Contents

Chapter Page

I. Introduction 1

II. The Literature Review 8

A. The Medical and Psychosocial Needs of Chronically and Catastrophically Ill Children 8

B. Pediatric Cancer: A Significant Chronically and Catastrophically Childhood Illness 12

C. The Role of the Pediatric Oncology Social Worker and How it Relates to Managed Care 14

D. The Development of Managed Care 17

E. Recent Studies on Managed Care 20
1. Customer Satisfaction 22
2. Cost 23
3. Access to Care 25
4. Referral Process 26
5. Length of Stay 28
6. Comparable Studies with Chronically and Catastrophically Ill Adults 29

III. The Pilot Study 32

IV. Research Methodology 49

A. Overview of the Study 49

B. Instrument 50

C. Procedures: Data Collection 50

D. Sample 53

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Chapter Page

V. Findings 68

A. Impact on Children and Families
  1. Access to Care 69
    a. Overall Access 69
    b. Complexity of requirements 70
    c. Time Involved in Obtaining a Referral 76
    d. Referral Process to a Specialist 78
    e. Accessibility of Location of Providers 79
    f. Overall Satisfaction with Providers 80
  2. Coordination of Care 81
    a. Overall Coordination 82
    b. Assignment of Case Manager 83
    c. Need to Return to Primary Pediatrician 84
    d. Assignment to Pediatric Oncologist as Primary Pediatrician 85
    e. Continuity of Providers under the Same Plan 85
    f. Continuity of Providers when Transferring to Another Plan 85
    g. Transfer of Information 86
  3. Level of Stress on Parents 87
    a. Financial Burden 87
    b. Level of Advocacy 88
    c. Paperwork Required 89
    d. Telephone Contacts 90
    e. Qualitative data 91
      1. Increased Stress 92
      2. Decreased Stress 97

B. Impact Upon Service Delivery: Managed Care's Policies and Guidelines 101
  1. Time Frame 101
  2. Decision-Making 104
  3. Referral Process 109

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Chapter Page

C. Impact upon Pediatric Oncology Social Worker 112
  1. Workload 112
  2. Clinical Functions 115
    a. Availability to Provide Counseling 115
    b. Individual Work Compared to Group Work 116
    c. Crisis Intervention 117
    d. Phone Contacts 118
    e. Community-based Support 119
    f. Parent's Need for Self- Reliance 120
  3. Professional Identity 121
    a. Changes in the Role of Pediatric Oncology Social Worker 122
    b. Professional Opportunities 125
  4. New Professional Opportunities 126

VI. Summary 128

A. Impact upon Children and Families 128
  1. Access to Specialists 129
  2. Complexity of requirements 131
  3. The Time Factor in the Referral Process 133
  4. Self- Reliance: Burden on the Consumer 134
  5. Transferability of Providers among Managed Care Plans 135
  6. Satisfaction with Providers 137
  7. Increased Level of Stress 137
    a. Advocacy 138
    b. Telephone Contact Required 138
    c. Paperwork 139
  8. Decrease Level of Stress 139
    a. Assignment of a Case Manager 140
    b. Coordination of Care 140
    c. Reduce Financial Burden 141

B. Impact on the Pediatric Oncology Social Worker 142
  1. Advocacy 142
  2. Delivery of Concrete services 143
  3. Team Coordination 143
  4. Financial Assessment 144

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Chapter **Page**

5. Clinical Functions 145
6. Professional Identity 147
7. New Opportunities 148

VII. Implications 150

Appendices
Appendix A. Instrument 155
Appendix B. Cover Letter 165
Appendix C. Return Post Card 166
Appendix D. Follow-up Post Card 167
Appendix E. Follow-up Fax 168

Bibliography 169

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

List of Tables

Table Page

1 Response to Survey 55

2. Reason for Non -Participation in Survey 57

3. Years in the Field of Pediatric Oncology Social Work 58

4. Number of Years in Pediatric Oncology Social Work 59

5. Current Job Title 62

6. Percentage of Pediatric Oncology Patients under Managed Care as Compared to Other Pediatric Populations 67

7. Between the Fall of 1995 and Fall of 1997 did the Percentage of Children Living with Cancer Covered Represent an Increase or Decrease in Managed Care Enrollment? 68

8. Access to Care for the Majority of Children Living With Cancer under Managed Care to Traditional-Fee-For-Service 70

9. Comparison of Complexity of Requirements to Obtain Care for the Majority of Children Living With Cancer under Managed Care to Traditional Fee-For-Service 71

10. Examples of the Complexity of Requirement to Obtain Care for the Majority of Children Living with Cancer under Managed Care 72

11. Comparing Time Factor in Obtaining Care for the Majority of Children Living With Cancer under Managed Care to Traditional-Fee-For-Service 78

12. Compare the Referral Process to a Specialist for the Majority of Children Living With Cancer under Managed Care to Traditional-Fee-For-Service 79

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table Page

13. Comparing the Accessibility of the Location of Healthcare Providers for the Majority of Children Living With Cancer under Managed Care to Traditional-Fee-For-Service 80

14. Comparing the Level of Satisfaction with Health Care Providers for the Majority of Parents of Children Living With Cancer under Managed Care to Traditional-Fee-For-Service 81

15. Comparing the Coordination of Care for the Majority of Children Living With Cancer under Managed Care to Traditional-Fee-For-Service 83

16. Percentage of Children with an Insurance-Carrier Case Manager under Managed Care as compare to Fee-For-Service 84

17. Comparing the Level of Advocacy Required for the Majority of Parents of Children Living With Cancer under Managed Care to Traditional Fee-For-Service 89

18. Comparing the Amount of Paperwork Required by the Majority of Parents of Children Living With Cancer under Managed Care to Traditional Fee-For-Service 90

19. Comparing the Amount of Telephone Contact Required by the Majority of Parents under Managed Care to Traditional Fee-For-Service 91

20. Factors that Increase Stress for Families Covered by Managed Care 92

21. Factors that Decrease Stress for Families Covered by Managed Care 98

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table Page

22. Changes in Length of Stay (LOS) From Fall '95 to Fall '97 103

23. Which Type of Insurance Coverage Requires the Shortest Length of Stay? 104

24. Primary Decision-Maker for Support Services Under Managed Care 107

25. Primary Decision-Maker for Support Services under Fee-For-Service 108

26. Changes in the Workload from Fall '95 to Fall '97 with Reference to the Referral Process 111

27. Changes in the Workload from Fall '95 to Fall '97 114

28. The Availability of the Pediatric Oncology Social Worker Over the Last Two Years to Provide Counseling to Children and Their Parents? 116

29. Changes in the Use of Individual Work Compared to Group Work by Pediatric Oncology Social Workers with Children and their Parents in the Last Two Years 117

30. The Changes in the Last Two Years in the use of Crisis Intervention by the Pediatric Oncology Social Worker with Children and their Parents? 118

31. The Changes in the Last Two Years in the Use of Phone Contacts by the Pediatric Oncology Social Worker with Children and their Parents? 119

32. The Changes in the Last Two Years in the Use of Community-based Supports by the Pediatric Oncology Social Worker with Children and their Parents? 120

33. The Changes in the Last Two Years on Parent's Need to be Self-Reliant 121

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table Page

34. Changes in the Professional Identity of the Pediatric Oncology Social Worker in the Last Two Years 123

35. Professional Opportunities Experienced by Pediatric Oncology Social Workers in Last Two Years. 126

36. Professional Opportunities Envisioned by Pediatric Oncology Social Workers 127

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

List of Figures

Figure **Page**

1. Regional Distribution of Respondents Compared to Total Population 61

2. Percentage of Workload in Direct Pediatric Oncology Service 63

3. Percentage of Caseload in Administration of Pediatric Oncology Service 64

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Chapter I. INTRODUCTION

Managed care is sweeping our nation's health care industry in hope of containing cost, improving outcomes and making health care more accessible (Davis, 1995; Gray, 1991; Hurley, 1993, Freund & Lewit, 1993). Cost containment is achieved through a wide range of incentives, such as having physicians share the financial risk, use of the primary care physician as gatekeepers, incentives to both physicians and enrollees/members to use fewer specialists and medical ancillary services, negotiated group discounts with hospitals, physicians and other providers. Prior approval for hospitalization and all non-emergency procedures, emphasis on prevention as a means of early detection, limiting service, such as in-patient hospitalization, and restricting numbers of visits for mental health services are other cost-saving measures. Continuity of care from in-patient to outpatient, or "seamless" care, is stressed in order to improve health outcomes and decrease re-hospitalizations. Home-based services are preferred to accelerate recuperation and reduce cost of lengthy hospitalization. Case management is another device to streamline service delivery, avoid duplication, limit services and equipment to a restricted list of vendors, who have agreed to a pre-negotiated rate of reimbursement.

These managed care cost saving and health enhancing devices are based on meeting the needs of relatively healthy populations (Freund & Lewit, 1993; Gray, 1991; Hurley, 1994; Hicks, Staelmeyer & Coleman, 1993; Kongstevedt, 1993). However, as managed care has grown in popularity among employers and government insurance programs, such as Medicare and Medicaid, more disabled and health impaired

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

populations have begun to be covered by this new system of health care delivery. These populations include chronically and catastrophically ill adults and children ("Children and Managed Care", 1996; Davis, 1995; Hagland, 1996; "Medicaid and Managed Care", 1995; Rowland, Rosenbaum, Simmon & Chait, 1995; Shortell, Gillies & Anderson, 1994). This application of managed care cost saving and health enhancing devices may appear to be a logical leap since chronic illness is a great financial challenge to health care. In the US, 90 million Americans were living with chronic illness costing over $425 billion or 61% of the national health care expenditure for 1990 (Schroeder, 1994).

Within this larger population there was a total of 10.7 million children or 31% of all children, according to the 1988 National Health Interview Survey, with various disabilities including chronic conditions, developmental disabilities, learning disabilities and emotional and behavioral problems. Four and one-half million (4.5 million) infants, toddlers and children were identified as so significantly disabled that they were eligible for special education. Those with chronic conditions ranged in severity, however 5-6% of all children had a severe chronic or catastrophic condition, such as cancer, AIDS, a neurological disease or a physical limitation due to a trauma (Montgomery, Kiely & Pappas, 1986; Newacheck & Taylor, 1992; Regenstein, Meyer, Fox, et. al, 1994).

These chronically and catastrophically ill children are very intensive and expensive health care consumers. Their costs are not one-time expenses but usually are consistent with periods of intensity over long time periods. Children with prolonged and degenerative diseases have frequent high-cost episodes over their lifetime. Those

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

with congenital anomalies, for example, rank among the top five high-cost consumers of general hospitals as compared with all conditions and all age groups (Newacheck & Taylor, 1992; "Thinking about....", 1995; Stein, 1989).

Also, one out of every three children in the US depends on Medicaid or on charity to pay for their health care. In 1995, 2.5 million children with a range of chronic conditions were enrolled in Medicaid programs. Therefore, there is additional concern regarding containing Medicaid costs and improving outcomes for this population (Skolnick, 1993).

With hopes of containing these costs and improving outcomes, the growth of managed care with this population has been rapid. Since the growth has been so rapid few studies have been conducted to determine if the current managed care system(s) are truly applicable to and effective with this chronically and catastrophically impaired population (Fox, Wicks & Newacheck, 1993; Fox & Wicks, 1994; Fox, McManus & Liebowtz, undated; Freund & Lewit, 1993; Harmon; 1995; Jellinek, 1994; Karlson, Sumi & Braucht, 1990; Newacheck, Hughes, Stoddard & Halfon, 1994; Oberg, Bryant & Bach, 1994; Regenstein & Meyer, 1994; Rowland et al., 1995; Szilagyi, Rodenwald & Roghmann, 1993). There is even grave concern on the part of social workers, other health care professionals and policy analysts, that the current managed care delivery system(s) may be inadequate or need significant adaptation for chronically and catastrophically ill children (Jellinek, 1994; Mizrahi, 1993; Perloff, 1996; Weston & Lauria, 1996).

In addition to the cost factors, these children and their families have a special stake in the transformation of the health care system.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

They have much to gain if this change is successful, however, they have much to lose if this new system fails. It may result in their prolonged illness or exacerbation of their poor health status (Harmon; 1995; Harrigan, 1995; Karlson, Sumi & Braucht, 1990; Kohrman, 1994; Newacheck, Hughes, Stoddard & Halfon, 1994; Oberg, Bryant & Bach, 1994).

Chronically and catastrophically ill children are defined by their need for specialized and extensive health care services requiring provision of multiple medical and ancillary psychosocial services. In addition, this population requires linkages and coordination among Medicaid and non-Medicaid entitlements and existing public and voluntary programs (Cooke, 1993; DiVerde, 1995; Jeffrey, 1996; Jellinek, 1994; Newacheck, et al., 1994; Smith & Layne, 1994; Stein, 1989; Szilagyi, Rodenwald & Roghmann, 1993).

Pediatric social workers play a significant role in providing the linkages for chronically and catastrophically ill children, such as children living with cancer, their parents, the health care institution(s), and the myriad of required community support services and entitlement programs. They are the resource managers who increase compliance and decrease the psychosocial stress for the entire family. Pediatric social workers provide case management for these children and their families by accessing insurance benefits, coordinating the multiple services and managing the limited resources and referrals needed to sustain this population at home. Their on-going clinical interventions enhance the child's and the family's ability to adapt, cope and stabilize themselves in the community (Adams & Deveau, 1989; Adams-Greenly, 1989; Christ, 1989; Horst, 1995; Ross, 1978, 1993,

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

1995; Smith & Layne, 1994). Indeed, they are the health care team members who insure the "seamless" care that managed care hopes to achieve (Gray, 1991; Hochstadt, 1991; Karlson et al., 1990; "Pilot projects...", 1994). Despite the fact they have an advantageous perspective about the impact of the current managed care system on this population, there are no formal studies from a pediatric social work viewpoint.

Noting the overall paucity of studies and the lack of study by a pediatric social worker, this author, a pediatric social worker, will conduct an exploratory and descriptive study on the impact of managed care on chronically and catastrophically ill cancer-diagnosed children and their families. This study will also explore the impact of managed care on the role of pediatric social workers who provide essential insurance-related services. This study will make use of the existing literature to formulate the study design, as well as, a pilot qualitative study conducted by this author in 1995 based on interviewing seven well-seasoned pediatric social workers all meeting the needs of chronically and catastrophically ill children and their families. The pilot study results will be outlined in a later section.

A specific chronically and catastrophically impaired pediatric population has been selected for this study, the pediatric oncology population and their respective pediatric oncology social workers. Although pediatric cancer is relatively rare with approximately 8,300 cases diagnosed each year, it is the leading cause of death by a disease in children under 15 ("Cancer facts...", 1996; National Childhood..., 1996). Pediatric cancer has several unique qualities that present significant challenges to the current managed care system since it is

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

treated in sophisticated and costly medical centers, pediatric hospitals or cancer-specializing hospitals, not in less community-based facilities. It is a complex disease in children requiring specialized and costly treatments: pediatric surgery, chemotherapy, radiation and transplantation since it usually first appears in advanced stages. The treatment of pediatric oncology requiring multiple medical specialists, and extensive auxiliary supports, such as specialized school needs, specialized camps, transportation assistance and government entitlements. Although the mortality rate is high enough to make it the leading cause of death by an illness among children under 15, the increasing survival rate and other long term effects has moved pediatric cancer from being primarily a catastrophic terminal illness to a chronic illness. The complex treatment of pediatric cancer is intensive and extensive with costly long-term medical care.

Pediatric oncology is also unique in that it is the only childhood illness that has a professional social work organization devoted to meeting the needs of children afflicted with it. The Association of Pediatric Oncology Social Workers (APOSW) members are the health care professionals who largely coordinate the psychosocial and ancillary services for cancer-diagnosed children in medical centers. APOSW is a twenty-year old organization with a membership of 184 US and foreign pediatric oncology social workers (APOSW membership listing, 1998).

Using a sample consisting of APOSW members, this exploratory and descriptive research design will study their perceptions of three key questions: (a) What impact is managed care having upon the delivery of health care to chronically and catastrophically ill cancer-

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

diagnosed children and their families? (b) How well does the current managed care delivery system meet the medical and psychosocial needs of these children and their families? and (c) How have pediatric social workers, significant health care providers for this population, been impacted by managed care?

The literature review (Chapter II) will look at: A) the medical and psychosocial needs of chronically and catastrophically ill children; B) pediatric cancer, a unique chronic/catastrophic childhood illness; C) the role of the pediatric oncology social worker and how it relates to managed care; D) the development of managed care and E) the recent studies on the impact of managed care upon pediatric populations and chronically and catastrophically ill populations.

Chapter III will focus on the pilot study conducted by this author; Chapter IV will describe the research methodology for the present study. Chapter V will review the findings; Chapter VI will summarize and discuss the significant findings. Chapter VII will discuss the implications of this study for managed care, social work practice and recommendations for future research on the impact of managed care on children living with cancer and their families.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Chapter II. THE LITERATURE REVIEW

A. The Medical and Psychosocial Needs of Chronically and Catastrophically Ill Children

Chronic illness or a chronic condition in childhood, according to Cooke (1993), is defined as an anatomical or physiological impairment that hinders functioning. It is often marked by a long term illness, discomfort, pain, incapacitation, and financial and emotional stress. Stein (1989), however, sees chronic childhood illness in an even broader context. She describes it as a range of conditions that threaten the health and development potential of youngsters and that often require special treatments and health services. She defines chronic illness as lasting three or more months or requiring one month of hospitalization. The presumption is that both of these circumstances causes significant stress on family and children, which requires substantial time, energy and personal resources in order to cope with the situation. Stein (1989) lists kidney, liver or heart disease, diabetes, and inborn metabolic problems. Also included are a range of birth defects: cystic fibrosis, hemophilia, and severe asthma, as well as low birth weight with unresolved respiratory problems. The less severe of these chronic conditions, such as asthma and juvenile arthritis may resolve over time. At the more severe end of continuum, there is muscular dystrophy, cancer, AIDS, head trauma, seizures, spinal cord injuries, rare diseases and disorders. These conditions tend to be catastrophic requiring intensive treatment with extensive ancillary supports. Some evolve into chronic conditions if they do not result in death, while others have catastrophic episodes and almost all have lasting impact upon the child and family.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

At first glance, the figures stated earlier that 31% of all children had a chronic condition with 5-6% with a severe chronic/catastrophic condition appear exaggerated, but one must take into account the advances in medicine and the impact of the disabilities movement on families choosing to care for seriously ill children at home (Newacheck, et al., 1994; "An attack on disabled....", 1995; Schmittroth, 1994; "Thinking about..", 1995). Medical advances, for example, have increased (a) the survival of premature infants with special health needs; (b) the survival of pediatric cancer patients, so that pediatric cancer is becoming a chronic rather than a terminal condition for 70% of those effected; (c) the survival of traumatic brain injured children; and (4) the longevity of pediatric AIDS patients (Montgomery, Kiely & Pappas, 1996; Newacheck & Taylor, 1992; Stein, 1989).

In addition, medical technology has impacted upon genetic conditions improving the quality of life however; leaving children medically compromised (Regenstein & Meyer, 1994; Stein, 1989). There has been, for example, a seven fold increase in survival in children to 21 with cystic fibrosis, a chronic childhood illness, and a two-fold increase in survival for spina bifida, leukemia, and congestive heart disease (Montgomery, Kiely & Pappas, 1996; Newacheck & Taylor, 1992).

These advances in medicine have coincided with a changing social philosophy in the US culminating with the American Disabilities Act, ADA (Oberg, Bryant & Bach, 1994; Stein, 1989). Medically disabled children are less likely to languish and live abbreviated lives due to institutional care. Caregivers are supported in their decision to "take

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

home" medically dependent children. Model waiver programs for technologically dependent children have been developed in concert with the prevailing philosophy under ADA and by the economic pressure to reduce hospitalization costs by discharging children needing extensive nursing and equipment supports in the home. These model waiver programs, i.e. Kate Beckett Legislation, waive family financial criteria if the child has had 30 days of hospitalization and fulfills stringent medical criteria. All of this has significant implications regarding the nature and size of the community-based chronically and catastrophically ill pediatric population requiring extensive interface with the health care system (Stein, 1989).

In addition, children have a wider range of diseases and far more rare diseases than adults resulting in even a higher degree of medical specialization (Cooke, 1993; Stein, 1989). Conservative estimates indicate that total health care expenditures for children with disabilities are three times those of non-disabled children. Auxiliary services provided by physical and respiratory therapists, social workers, and psychologists are used six times more by disabled children than healthy children (Regenstein & Meyer, 1994).

Also, poor children experience a disproportionate burden of health problems with a higher risk of severe and chronic illness. A significant portion of the chronically ill child population is associated with lower income, less education, lower occupational level of parents, racial and ethnic minority status and other social class variables. These are further indicators of greater need for ancillary psychosocial supports (Montgomery, Kiely & Pappas, 1996).

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

The developmental needs and tasks of childhood differ also in essential ways from those of adults with chronic and catastrophic conditions such as the frail elderly (Stein, 1989). These differences, such as the need for education, place a greater responsibility on society. Children by definition are dependent upon adults and society for their care, socialization and education. This dependency is even more pronounced for chronically and catastrophically ill children since they are fully dependent upon their parents/adults to obtain and pay for their medical care and overall support.

We know that one out of every four Americans provides care for someone with a chronic illness (Schroeder, 1994). This data does not distinguish adults (parents) caring for children versus adults caring for adults. Some parents report they are actively encouraged to forsake their employment to become eligible for public assistance to qualify for Medicaid and Medicare benefits for their children. Others are required to give up employment in order to provide full time care for a child maintained in the home as opposed to an institution. In the long run this threatens pensions, Social Security status and insurance coverage for the entire family (Stein, 1989).

In summary, this population of chronically and catastrophically ill children is especially challenging to a system attempting to control the costs of health care and improve health care outcomes since their care is intensive, complex and tends to be fragmented over multiple health facilities and systems. Their illnesses require long term interventions and follow-up. The medical situation is compounded by social, psychological and economic strains not only on the child, but also on the family and society.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

B. Pediatric Cancer: A Significant Chronic and Catastrophic Childhood Illness

Childhood cancer is a unique childhood disease in that it is still rarely treated in the community by pediatricians. Childhood cancer treatment is complex using multi-modalities: highly specialized surgery, such as limb salvaging, multiple chemotherapies, stem-cell transplantation and radiation. When cancer strikes children, it is a more advanced stage of cancer than found in adults. Eighty percent (80%) of children, when first diagnosed have metastatic disease, a spread to other parts of the body, as opposed to only 20% of adults who upon first diagnosis have evidence of spread. Thus there are a significant number of children when first diagnosed are placed on demanding and experimental protocols since their disease is at an advanced stage. Due to the complexity of the treatment and the highly technical skills required to treat childhood cancer, most treatment occurs in regional centers, teaching/academic centers or children's hospitals. These realities place childhood cancer in a unique position of being a relatively expensive and intensive disease to treat from the onset ("Cancer facts..." 1996).

The causes of childhood cancer are also relatively unknown as opposed to many adult cancers that result from life style behaviors, for example, smoking, diet, occupation and other exposure. There are also no universal screening tests such as a PAP smear or breast or prostate exams to detect early malignancies. Although the frequency of cancer in childhood is low, the number of children diagnosed with cancer in the US each year puts more potential years of life at risk than any

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

other type of adult cancer (National Childhood..., 1996; "Cancer facts...", 1996).

The 1991 Cancer Statistics Review also indicates cancer among children younger than 15 is increasing in incidence. It is increasing among African American as well as white children, boys as well as girls. There is an increase in lymphnoblastic leukemia's, brain and nervous system tumors but there are no changes in Wilm's tumor, soft tissue and bone sarcomas, lymphomas and Hodgkin's disease ("Cancer facts...", 1996). Despite a small increase in incidence, the overall pediatric cancer mortality has decreased 38%. In 1996, it was estimated that 1,700 children would die from cancer with one-third from leukemia.

The current cure rate of all childhood cancer combined is 70%. Thus, pediatric cancer, once considered a fatal disease, has become a chronic disease following a rather intensive and demanding treatment course (Blyeth, 1993; "Cancer facts...", 1996). Although national data on childhood cancer is becoming more available, it is still not complete. Therefore discrete data on the financial impact of childhood cancer cannot be compared with other chronic or catastrophic childhood illnesses (Bleyth, 1993).

By the year 2000, it is estimated that 200,000 survivors of childhood cancer will have access to 30 specialty survivors' clinics throughout the US. Survivors of pediatric cancer may confront medical and reproductive problems secondary to treatment, which will add to the cost of their medical follow-up (Clark, Stoval, Leigh, Siu, Austin & Rowland, 1996).

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

C. The Role of the Pediatric Oncology Social Worker and How it Relates to Managed Care

Pediatric social workers, in medical settings, provide psychotherapeutic support, including crisis intervention following the initial diagnosis of a catastrophic illness, such as pediatric cancer, and they provide on-going interventions that enhance the child's and family's ability to adapt, cope and stabilize themselves in the community. In addition they manage the resources: financial aid, summer camps, school placements, wish (catastrophically and terminally ill children are eligible for a special desire or treat, a "wish," such as a trip to Disney or a home computer granted by a voluntary "wish" organizations) referrals, local, state and federal entitlements, and provide the linkage among public, voluntary and private resources (Cincotta, 1993; Ross, 1978, 1993; Stoval, 1993).

While there is very little literature that specifically addresses the role of pediatric social work in a managed care environment (Horst, 1995), some literature discusses the case management functions related to managing chronically ill children in a primary care practice (DiVerde, 1995; Hirsch & Barela, 1996). Although DiVerde, Hirsch and Barela elaborate upon the unique and necessary role of the case manager with this population, these authors never identify the professional base of the case manager as a pediatric social worker. The functions, however, are the same functions described in all of the pediatric social work literature (Adams-Greenley, 1983; Adams & Deveau, 1989; Cincotta, 1993; Ross, 1978, 1993). Vourlekis and Greene (1992) look at case management, a managed care function, in terms of the role of the professional social worker. They see social

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

workers in the "... front lines in designing, managing and providing case management.." (Vourlekis & Greene, 1992, p.2) As well as in the delivery of human services including health care.

Social work literature has begun to focus on the general impact managed care has upon health care recipients, as well as upon social work providers (Cornelius, 1994; Edinburg & Cottler, 1995; Hamilton, 1996; Mizrahi, 1993; Perloff, 1996; Poole, 1996; Rauch, Kaufer & Rodriquez, 1993; Shera, 1996). The Association of Oncology Social Workers (AOSW) has developed "Managed Care: A Survival Kit for the Oncology Social Worker" (1996) outlining the services provided by oncology social workers that many be of particular interest to managed care insurers. This eight page brochure makes no reference to the pediatric or adult status of the patient, however, clearly addresses the adult world of work and vocational needs rather than the developmental needs of children regarding school, peer relationships and socialization. Many of the identified interventions throughout the continuum of care: (a) pre-admission activities; (b) activities during medical interventions, in- or outpatient settings; (c) recurrence; (d) palliation and terminal care; and (e) survivorship, are applicable to the work of the pediatric social worker. There would be a few modifications considering the developmental differences between adult and pediatric patients. NASW, at national and regional levels, has established guidelines and published resource manuals to educate its constituents about the impact of managed care upon the profession ("An evaluation... ", 1994; Jackson, 1994; Rauch, Kaufer & Rodriquez, 1993). However, they have not established guidelines for pediatric social workers

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Wintersteen (Shera, 1996) offers a description of the role of social work with the severely mentally ill which is consistent with a managed care philosophy. His description of the psychiatric social worker's role also parallels the role of pediatric social work with chronically and catastrophically ill children. He describes social work with a unique history and conceptual framework to provide leadership in the organization of networks of support and services to facilitate the rehabilitation of the severally mentally ill. He outlines social workers orientation to community-based services, rehabilitation, focus on the strength of incapacitated individuals, use of family support and optimism in face of crisis and overall continuity of care as compatible with a managed care philosophy.

Similar to psychiatric social work with chronically mentally ill, pediatric social workers play a vital role in the delivery and coordination of health care to chronically and catastrophically ill pediatric population. They, therefore, can play a vital role in detailing the impact managed care is having on this vulnerable population. Pediatric oncology social workers are highly specialized health care providers in that they support and meet the needs of cancer-diagnosed children and their families. In addition to their background in social work delivery to a medically defined population, they have developed and coordinate a host of specialized services: school reentry programs, sibling programs, cancer-oriented summer camps, temporary housing, such as Ronald McDonald Houses, parent and child support groups (Adams & Deveau, 1989; Cincotta, 1993. Ross, 1978, 1993; Stoval, 1993).

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

D. The Development of Managed Care

Managed care is defined by Mosby (1994) as

> a health care system in which there is administrative control over primary health care services in a medical group practice. Redundant facilities and services are eliminated and costs are reduced. Health education and preventive medicine are emphasized. (p. 951)

This definition largely describes the Health Maintenance Organization, HMO, the most common managed care model of health care delivery. It is a group medical practice with all of the subspecialties under one roof with the primary care physician being the gatekeeper. Costs are controlled through an approval mechanism. The gatekeeper needs to approve referrals for the insured to obtain any specialized care. All specialists are selected from the insurance carrier's list of subscribing physicians who have a pre-negotiated reimbursement rate. The consumer has no or limited choice of providers.

The HMO model can be traced to the early development of managed care in the US. Managed care first appeared as a rural farm cooperative in 1929, in Oklahoma, in an attempt to solve the shortage of medical personnel (Kongstvedt, 1993). By the 1930's, prepaid not-for-profit HMO's appeared on the East and West Coast. The first HMO's included Group Health Insurance (GHI), Health Insurance Plan, (HIP) and Kaiser-Permanante (Mizrahi, 1993). These HMO's and other newly formed ones expanded through the 1973 Health Maintenance Organization Act (Mayer & Rubin, 1983). This expansion included not-for-profit and proprietary models.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

As managed care has grown in acceptance and popularity and now appeals to a wider subscriber base, the definition of this method of delivering health services has expanded from the initial HMO model. Managed care now refers to a variety of health care delivery systems and is employed by wide range of insurance plans, cost-saving health care measures and facilities. In addition to the HMO, some of these variations include the Individual Practice Association, (IPA) the Preferred Practice Organization, (PPO) the Point of Service, (POS) and network and mixed models of HMO's. Each has a variation in terms of extent of choice of physicians and ancillary services, approval mechanism and other features (Gray, 1991; Kongstvedt, 1993; Miller & Luft, 1994; Szilagyi, Rodenwald & Roghmann, 1993). The key features for these varied models are; comprehensive health care to covered members; standards for the providers; formal quality control; utilization review programs; and incentives for enrollees or members to use approved providers with an overall goal of decreasing health care costs, while delivering quality health care (Davis, 1995; Gray, 1991; Hurley, 1994; Kongstvedt, 1993).

Penetration (a term used in a managed care context to indicate level of enrollment in a geographic area) varies from region to region. States such as Tennessee, Minnesota, Arizona, Virginia and Massachusetts have more extensive experience with managed care in both the private and public sectors (Berger, Cayner, Jensen, et al, 1996; Gottlieb, 1995; Hirsch & Barela, 1996). Cities with significant increase in managed care enrollment include Houston from 15 to 28%, Boston from 36 to 55% and Seattle from 24 to 39% (Sisk, et al., 1995; "Managed care: Where...", 1997).

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Although the HMO is now the most narrowly defined model of managed care, it continues to grow in enrollment. HMO enrollment went from 12.5 million in 1989 to 50 million in 1994. Between 1994-95, HMO enrollments went from 30.9% to 37.3% of the population for the 15 largest metropolitan areas in the US. ("Managed care: Where ...", 1997) Within the Medicaid managed care population, 7.8 million Medicaid enrollees were in some form of managed care in 1994 with more than 50% of the Medicaid managed care enrollees in an HMO arrangement (Rowland, et al, 1995).

There has also been considerable growth of Medicaid managed care. In 1981, 85% of all Medicaid managed care was concentrated in four states: California, Maryland, Michigan and New York. By 1994, all states, except Alaska, Connecticut, Maine, Nebraska, Oklahoma, Vermont and Wyoming, reported having at least one Medicaid managed care program. By 1998, all states except Alaska reported Medicaid managed care enrollment. Over 53% of the Medicaid population throughout the US was enrolled in a managed care arrangement by June 1998 ("Medicaid managed care enrollment," 1998).

Minnesota became one of the first states to establish a goal of enrolling the entire Medicaid population by the year 1997. However, this target excludes the disabled population, because it is recognized that this population has special needs and is to be enrolled in demonstration programs only (Sparer, Ellwood & Schoen, 1996).

In 1993, 7% of the 1.3 million New York City Medicaid beneficiaries were under managed care with enrollment growing to 26% in 1995. Except for a demonstration project in southwest

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Brooklyn, Medicaid enrollment through 1998 was still voluntary ("Medicaid managed care legislation..." 1996).

As the influence of managed care has permeated health care, the complexity and ramifications of its cost saving devices have come into greater public view. There have been negative reports in the press of "drive through deliveries and mastectomies" referring to abbreviated lengths of stay for healthy newborns and the use of ambulatory care surgery for uncomplicated mastectomies ("Insurers assailed on childbirth stays", 1995; Dooha, 1995; Fein, 1996). The popular press has also reported denial of service and inaccessible service for those with chronic conditions (Goldstein, 1995; Harrigan, 1995; Jeffrey, 1997, Weston & Lauria, 1996).

These reports include denial of surgery for a port wine stain, a disfiguring congenital anomaly, on the face of a five year old since it was not considered an illness or disease but a cosmetic imperfection (Goldstein, 1995). In another report, a family with a cancer-diagnosed child was sent out of state on two occasions for a bone marrow transplant despite the nearby location of a highly recognized and successful pediatric bone marrow transplant program (Weston & Lauria, 1996). Additional reports of denial for further testing or treatment, after a diagnosis of cancer was made, led to proposed national bills aimed at limiting the denial power and the establishment of independent appeals boards (Mariano, 1999)

E. Recent Studies on Managed Care

The literature and studies focusing on the impact of managed care on chronically and catastrophically ill children is limited despite 85% of all employed families are under some form of managed care

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

with children being enrolled in faster pace than adults (Szilagyi, 1998). Much of the existing, but also limited literature and studies examine the impact of managed care on healthy children.

The two major reviews of the literature regarding the impact of managed care on children, in general, described a range of responses and some of them were conflictual. These included: (a) beneficiaries perceive that care was more available in managed care plan that fee-for-service; (b) managed care reduces the use of emergency room and specialist services; (c) there were no significant differences in health outcomes between managed care and fee-for-service; (d customer satisfaction was quite high; (e) cost savings range ranged from none to fifteen percent in managed care; (f) there was difficulty in educating Medicaid families about managed care and stabilizing enrollment; and (g) there was limited reduction in hospital use (Fox & Liebowitz, undated; Freund & Lewit, 1993).

Many chronically and catastrophically ill children were "waived" or exempt from managed care enrollment, especially those in any entitlement programs such as state Medicaid programs. Many of these exemptions until recently were based upon managed care's inexperience to "manage" these kinds of medical situations.

Although the numbers of chronically and catastrophically children enrolled in HMO arrangements in the 1980's and early 1990 was limited, for those enrolled, it was found that (a) parents who were able to advocate for their children were able to access services, (b) there were some limitations in access to specialty providers, and (c) the location of covered services was a barrier to meeting these children's needs (Fox, et al., 1990; Fox, Wicks & Newacheck, 1993,

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Newacheck, et al, 1994). Based on their studies of medical directors of HMO's and traditional fee-for-service companies, Fox, et al (1990) advocated that HMO's would need to make benefits required by this population available on a fee-for-service basis.

There are a few targeted studies, in addition, regarding impact of managed care on healthy children, in general, and specifically on chronically and chronically ill children. Each study looks at specific areas: (1) customer satisfaction, (2) cost, (3) access to care (4) the referral process, and (5) the length of stay (Cartland & Yudkowsky, 1989; DiVerde,1995; Hirsch & Barela, 1996; Jellinek, 1994; Karlson, Sumi, Bracht, 1990; Perrin, 1997).

1. Customer Satisfaction

Regarding overall satisfaction, Karlson, Sumi, Bracht (1990) surveyed 36 families from three HMO'S in Dane County, Wisconsin. Families surveyed were identified as having a child with an acute lymphocytic leukemia, cystic fibrosis or developmental delay. More than half were highly satisfied with the HMO. The areas of satisfaction were with their a) physician and other providers, b) overall lowered costs, and c) decrease of paperwork. A number of the reports, however, were considered "mixed" with "significant satisfaction" but were tempered with anecdotes reflecting frustration. Out of the anecdotal information they identified five major categories of frustration and dissatisfaction: (a) reliability of information, (b) coordination of care, (c) ability to obtain services, (d) need for parents to be advocates, and (e) observation of differences among HMO's. When asked about their major frustration, parents of special health needs children cited fragmentation of financing and services, having to

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

master complex standards and rules of a variety of funding sources since HMO's do not coordinate all of the entitlement and voluntary agency benefits.

> Dealing with this maze of rules and regulations is a time-consuming task that goes along with other difficult emotional and social issues for these families (Karlson et al., 1990, p. 3.)

2. Cost

Regarding cost containment, private practicing pediatricians, with a patient population of 1,000 special health needs children, found that these children require 1.5 more frequent office visits, 5-10 times greater number of hospitalizations and 2-3 more time when seeing the pediatrician than healthy children (DiVerde, 1995; Hirsch & Barela, 1996). Therefore, their data clearly demonstrates that the care of a special health care needs child would, on the average, cost more than the well child. They concluded that greater financial incentive for the pediatric practitioner is necessary in order to properly "manage" all of the needs of health impaired children within a general pediatric practice. The issue here is if managed care will recognize the psychosocial needs of these children in their reimbursement structure? The Fox, Wicks and Newacheck (1993) study of 27 HMO's, also concluded that there needed to be financial incentives for the providers to offer special services to these children.

Jellinek's (1994) more descriptive review of managed care policies affecting cost containment also address the pediatrician's use of time in meeting the psychosocial needs of these children and their families. If the psychosocial function, according to Jellinek, is not valued through a reimbursement mechanism, this component of the

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

relationship will be "dumped" into the social service or public mental health sector. Unless the psychosocial function falls into a clear psychiatric diagnosis, it is also questionable if the social service or public health sectors will provide these services.

Until recently psychosocial service support for health impaired children was built into most pediatric services. With the current pressures and the narrow definition of social work and nursing roles under managed care, much of their services are limited and related to reimbursable mechanisms. There is no reimbursement for social workers and nurses assisting and maximizing families' adjustment to medical crisis. Currently a mental health diagnosis, demonstrating significant pathology, is necessary to justify reimbursement. This jeopardizes these children and their families access to psychosocial support services.

In order to meet these multiple psychosocial needs of these children, Hirsch and Barela (1996; DiVerde, 1995), identified case management as a necessary function to provide:

> ...overall coordination of all aspects of patient care including anticipation of future medical, psychological, social and family needs, preparation of supporting documents, enabling children to acquire equipment and receive necessary therapies, attendance at conferences with representatives of schools and state agencies; and last but not least to the concerns of other family members as their well-being affects the overall well-being of the child with special health needs (Hirsch & Barela, 1996, p.62).

In short, Hirsch and Barela were able to meet the complex demands of this population only through the use of additional staffing in their

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

private practice which they was supported by an enriched rate of reimbursement. They were only able to advocate for this enriched rate based upon significant documentation of the psychosocial interventions needed by this population in their private practice. Without this kind of enhanced staffing and additional support offered by the pediatrician, special health needs children access to appropriate care would be very limited and inadequate.

3. Access to care

Cost clearly relates to access to primary care since the primary care physicians/pediatricians (PCP's) are the designated gatekeepers in a managed care system. The financial differential, in recognition of the complex demands of special health needs children, is necessary in order to broaden the pool of pediatricians who would be willing and able to accept responsibility for this population.

Access to care for the disabled pediatric population also refers to access to specialists, as well as to all services through the referral process. The PCP is the gatekeeper for a child in a managed care system. For the healthy child this usually works very well. However, with a chronically or catastrophically ill child, it may create havoc. If this child's medical needs are far too complex to be handled by a pediatrician, even with additional case management supports, then the PCP model is inadequate.

Depending upon the required treatment, a child with cancer, for example, can only be treated by a pediatric oncology specialists, for surgery by a pediatric oncology surgeon and for chemotherapy a pediatric oncologist. Specialty access has gained attention from the legal system and the popular press. In a recent California case, the

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Department of Corporations, which regulates HMO's, fined a health plan a half-million dollars for failing to provide appropriate access to a qualified pediatric surgeon for a child with a Wilm's tumor, a pediatric malignancy (Murphy, 1996).

In 1995, the National Health Council, a 77 year old coalition of groups (e.g. American Cancer Society, American Lung Association) representing people with chronic diseases, established patients' rights in response to the shift to health care under managed care. The first "right" established for this population is the right to timely access to specialty care and a reasonable choice of health care providers (Pear, 1997). Respected professional associations have also come out with policy statements regarding access to specialty care for the disabled pediatric population. Both the American Academy of Pediatrics and the National Association of Children's Hospitals and Related Institutions have favored the adoption of principles that promote access to pediatric sub-specialists especially for special health needs children, such as children with cancer (Murphy, 1996). There has been some movement among managed care providers and pediatric subspecialty groups. For example, Blue Cross/Blue Shield Association has formed a working relationship with the four of the major pediatric clinical trial study groups so that children with cancer under their managed care plan can participate in clinical trials at major medical research centers (Murphy, 1996).

4. Referral process

In the past, the pediatric specialist, in conjunction with the family and patient, made the referrals for all the additional medical care. Under the prevailing managed care system, however, the pediatric

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

specialist is not the PCP, therefore for each referral, the child must return to the PCP. Since the PCP may be unfamiliar with the specialists with the managed care plan network, the parents often must depend on lists provided by manage care customer service representatives for referrals. Harrigan (1995) in the popular press, *Newsday,* followed the plight of a young woman with cystic fibrosis who could not locate a cystic fibrosis specialist from the long lists of physicians provided by US Healthcare, one of the largest managed care companies in the New York region. Specialists, according to Harrigan's inquiry, were not identified in the long lists of preferred providers or by telephone inquiry. The customer service representative did not even know what cystic fibrosis was, let alone identify a specialist treating it.

With pressure from consumers and physicians alike, in 1996, the American Medical Association called for managed care to allow chronically ill consumers to use their specialists as their primary care physicians suggesting a new designation, "principal care." They suggested that the principal physician could be the point of first contact and coordinator of all care for the chronically ill. This call followed the publication of a study tracking 3,487 asthmatic consumers/patients over two years. Those treated by an asthmatic specialist faired better than those treated by a generalist PCP (Jeffrey, 1996).

Not only is the referral process described in the popular press but it also appears in a targeted study by Cartland and Yudkowsky (1989). Although this was a study of general pediatric practitioners, with no indications of the size of their special health needs pediatric population, one can begin to question the implications for this

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

population. They randomly sampled a group of 684 pediatricians about their experience with the referral process. Cartland and Yudkowsky found that pediatricians reported a greater incidence of barriers to the referral process for managed care pediatric patients as opposed to fee-for-service patients. There was 5.7 incidence of barriers for managed care patients versus a 2.3 incidence for fee-for-service patients. These barriers include: burdensome paperwork, time consuming telephone calls for authorization, unavailability of proper care, complex appeals processes, pressure to refer to adult specialists and sub-specialists, limited physician and facility panels, financial barriers and disincentives.

In the "Cartoon Corner" of *Oncology Times,* a journal for oncology healthcare professionals, an oncologist observes a clerk speaking on the phone. The caption reads: *How long has Tracy been on the phone getting pre-certification for that bone marrow transplant?* (Capps, 1996) Hospitals and doctor's offices are now employing a growing cadre of "assistants" who spend their time contacting managed care companies and handing out referral forms to patients in order to obtain pre-certification and access referrals for patients. As noted in Capps cartoon, this is very time consuming work, but necessary for patient care and reimbursement. This saves physicians' and nurses' time for direct patient care.

5. Length of stay

The last area of study and concern that appears in both the research and popular literature is that of abbreviated length of stays meaning fewer days in the hospital. The old adage that "time is money" serves as a rationale for this cost-saving device in managed

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

competition. This is seen most vividly in the tremendous thrust to shorten length of hospitalization. Shorter lengths of stay have its origin in the 1980 development of the cost-saving, DRG'S (diagnostic related groups). This was an attempt to curb the expenditure of Medicare funds for in-patient hospitalization (Fabricant & Burghardt, 1992: Rauch, Kaufer & Rodriquez, 1993). The rate of discharge, however, has accelerated even further under managed competition. It was recently reported that not only are the hospitals denied payment for prolonged stay but also patients are offered cash incentives if they leave the hospital prior to the proscribed time frame ("Insurers Assailed", 1995).

In a 1996 study, 51% of vaginally delivered newborns and their mothers were discharged within 24 hours and additional 37% were discharged within 48 hours. This left an enormous burden on the need for home care. Carefully monitored follow-up suggests that there are a significant number of abnormalities that do not show up within 24 hours of delivery. This has been referred to in the popular press as "drive through deliveries." Some states have now mandated 48-hour stays for normal vaginal deliveries to insure the majority of abnormalities are detected prior to discharge. The thrust to shorten the length of stay has all filtered down to shorter lengths of stay for all diagnoses including chronically and catastrophic ill children ("Insurers Assailed", 1995).

6. Comparable studies- Chronically and Catastrophically Ill Adults

There are no comprehensive longitudinal study looking at the impact of managed care upon chronically and catastrophically ill children. A recent study, however, tracked 2,235 adult and elderly people with high blood pressure, diabetes, recent heart attacks,

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

congestive heart failure and depression from 1986-90 under both a managed care and fee-for-service system (Ware, Bayliss, Rogers, Kosinki & Tarlov, 1996). These results may lend some insights to the present study since it examines a disabled adult population. The authors compared HMO's with fee-for-service enrollees. The results showed the health of 54% of chronically ill Medicare enrollees deteriorated while on managed care as compared to 28% of those on fee-for-service. Although no specific aspect of health care could be pinpointed to account for this discrepancy, any number of aspects or factors could have contributed. According to the authors these factors could be: shorter hospitalizations, less specialty care, limits on testing and overall patient-doctor relationship impacted by shorter visits or frequent changes of doctors, which occurred more frequently in managed care plans. The authors concluded that the same kinds of cost containment and quality controls could not be readily applied to the disabled elderly as to non-disabled elderly, the population with which managed care is most experienced.

Much of the current social work literature that refers to managed care is descriptive with emphasis on the advocacy and psychiatric functions social workers play in both the voluntary and private sector. The National Association of Social Workers, the Association of Oncology Social Workers and a number of social workers have published brochures and articles outlining the many functions social workers can play in managed care settings both in direct practice and in program development ("Managed Care:A Survival Kit...", 1996; Cornelius, 1994, Edingburg & Cottler, 1995; Hamilton, 1996; Jackson,

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

1994; Mizrahi, 1993; Netting and William, 1996; Perloff, 1996; Poole, 1996; Shera, 1996; Sunley, 1997).

Some of the social work literature from the 1970-1980's also has relevance since it described the role of social work in the HMO's. This literature looks at the medical and psychiatric function of social work in the contained health care environment, the HMO. This literature describes the multiples roles social workers played in HMO's (Denby, 1980; Mayer & Rubin, 1983; Poole & Braja, 1984). Until 1981, Federal laws and regulation required the provision of medical social services in HMO's. These services included pre-and post- hospitalization planning, referrals to community health and welfare agencies, family counseling and psychosocial support in helping members adapt and cope with the impact of serious illness and disability (Mayer & Rubin, 1983). With the deregulation in 1981 of social services in the HMO structure, it is suspected, there was a diminution in the use of medical social work, since no literature could be located that further elaborated upon the role of medical social work after that point.

In summary, the social work literature is descriptive about the various roles social work plays and could play in a managed care environment. In addition the literature outlined the concerns of social workers as to managed care policies and service delivery affecting a chronically ill, elderly, urban poor, and culturally diverse population (Perloff, 1996; Reamer, 1997; Resnick, 1997). No qualitative or quantitative studies by social workers could be located as to the impact of managed care on a specifically vulnerable high-risk population such as chronically or catastrophically ill children.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Chapter III- THE PILOT STUDY

Noting the limited studies on the impact of managed care on chronically and catastrophically ill children and lack of literature or studies by a pediatric social worker, this author conducted a pilot qualitative study (1995). The pilot study was based upon qualitative interviews of seven pediatric social workers working in New York and Pennsylvania. Each pediatric social worker served a population of chronically and catastrophically ill children. All the children they assisted were diagnosed with a life-threatening illness, such as cancer, or were receiving intensive rehabilitation following a trauma, such as an auto accident. The pediatric social workers had from one-and-a-half years experience working with chronically and catastrophically ill children to over eighteen years experience in this specialized field. They were all employed, at the time of the interviews, by acute/sub-acute voluntary hospitals. Some were employed in children's hospitals, while others were employed by acute-care facilities with a pediatric assignment. About 15-30% of their caseload was covered by managed care, which was consistent with the percentage of the population in New York/Pennsylvania covered by some form of managed care at the time (Pekmezaris, 1995).

Using content analysis three significant areas emerged from this pilot study. These areas were (A) the impact current managed care practices have on families, (B) managed care policies that guide service and service delivery, and (C) the impact of managed care on the professional pediatric social worker (Cabat, 1995).

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

A. Impact of managed care upon families

Karlson et al. (1990) suggests that the success of managed care for this population rested upon its ability to address the parents' needs. Drawing on this, the pilot study examined the impact managed care was having upon families of chronically and catastrophically ill children regarding (1) access to care, (2) coordination of care, and (3) level of stress.

1. Access to Care

Bernadette, (identifying information of all study participants has been altered to protect confidentiality) a pediatric social worker, describes how a parent felt after she battled with her managed care company to allow her to take her child to a specialty hospital, and then they denied her access to the hospital's home care company. (Home care refers to health support services delivered in the home such as nursing care, provision of medical equipment. These home-based services facilitate hospital discharge.

> **Bernadette:** *I can think of one boy he had an HMO....he wasn't supposed to come to our hospital but the primary care physician said this is what the parents wanted. Then they couldn't use the hospital's home care so we couldn't prepare Mom. She got really scared.*

Bernadette notes that parents, who were prepared for complex home care needs by the hospital staff in conjunction with the home care-company the hospital worked closely with, could no longer do this. Bernadette and Stephanie, another pediatric social worker in the same children's hospital, see that parents' access to care is limited. At times, where they can go for their child's home health care and whom they can contract for ancillary services is dictated by the managed care

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

companies. Rosalie, a pediatric social work supervisor at a sub-acute pediatric hospital, also found that the "restricted panels of approved hospitals" meant the local children's hospital for non-emergency care was not necessarily an "approved" hospital for each child. When the local children's hospital was not the child's approved hospital, the child had to be transported a greater distance for non-emergency care.

2. Coordination of Care

Coordination of care is another area of impact experienced by families of chronically and catastrophically ill children since parents must cope with the frustration of the fragmentation of financing and services. Parents have to master complex eligibility criteria with a maze of rules, regulations and service from a wide variety of funding sources. Karlson, et al. (1990) describes this task as time-consuming and emotionally exhausting. Managed care holds the potential to help rectify this complex system through the use of a managed care company employee, often identified as a case manager, assigned to coordinate the care of disabled consumers. Rosalie, Bernadette and Stephanie point to positive aspect of coordination of care for their client's parents.

> **Rosalie:** *Streamlining is a positive aspect of managed care .., especially if the case manager plays a pivotal role as a coordinating person. The case manager should have information about benefits and care so they can help social workers facilitate access.*
>
> **Stephanie:** *For chronically ill children having a case manger who can oversee the whole picture is good. It can be positive when you have one person you can communicate with is positive since the kids are seen all over in oncology, endocrine; seen here, there and all over.*

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

> *This person has a rounded picture. It can be bad when they just want to save money.....*
>
> **Bernadette:** *They* [a managed care company] *are exceptional, in transplant, they will pay for the parent's transportation....They look at the individual needs. They want to explore it. They ask why is this better than that? They just don't go by the book. It is more compatible with our role.*

3. Level of Stress

The third category of impact on families is the area of increased/decreased stress since these families live under a great deal of stress knowing their child may have a lifelong incapacitation or an abbreviated life span. Ellen, Allison and Jeff describe the additional stress families have experienced under managed care coverage, while Stephanie and Bernadette describe the families' experience in being denied services.

> **Ellen:** *Families are not prepared emotionally; maybe even physically to take on the care of a very sick child. It is difficult for case managers* [of the managed care companies] *to imagine such variables for families to absorb. Standards are set* [by the managed care companies] *on optimal functioning families.*
>
> **Allison:** *So it is stress for parents. If it is a new incident, which is a lot of what I see, like a car accident, brain tumor, meningitis, then they aren't aware of the limitations of their policy. It is OK if you have an ear infection, but now they find they don't have coverage for durable goods. So they have pay $1,800 out of pocket.*

B. Managed care policies that guide service and service delivery

Managed care policies that guide service and service delivery were viewed by the majority of the seven pediatric social workers in terms of negative effects of limitations and restrictions and positive benefits including (1) time frame, (2) decision-making, and (3) referral process.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

1. Time Frame

The shortened length of stay (LOS) is one of the most poignant time limitations described by most of the social workers interviewed. Jeff, a pediatric social worker for eighteen years in a children's rehabilitation hospital, and Allison, working five years with children needing intensive rehabilitation following a catastrophic illness, such as a degenerative neurological disease, or a trauma, and Ellen all observed the time limitations:

> **Jeff:** *XX managed care company gives 60 days for rehabilitation. Regardless of diagnosis. If you have a kid with a head injury. That is it-- you get better or you are not covered, that's it.*
>
> **Allison:** *Everyone has to <u>fit the same mold.</u> Even kids with chronic conditions are getting 30 days. <u>Everyone is stuck in these boxes.</u> They aren't getting what they need.*

This means that manage care limits the number of days it will pay for hospitalization/rehabilitation. Once a manage care company determines this, the parents or the hospital have to absorb the cost or the patient is discharged.

> **Ellen:** *Infants and children are not as ready as we like.*

On occasion, the child may be eligible for a governmental entitlement program, which augments private coverage. If the child is on a Medicaid managed care plan, there is no alternative coverage. An appeal is the only alternative, which is time consuming and needs to be handled by an experienced advocate. On the other hand, Ellen and Rosalie, a pediatric social worker of many years, who is a supervisor

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

under Ellen's directorship, see a benefit to children being sent home sooner.

> **Ellen:** *We are moving very successfully at discharging sooner...I think* (ponders carefully) *for the most part the changing philosophy has really benefited the kids. I feel very positive about these discharges.*

> **Rosalie:** *When I first came on to in-patient we practiced social work in luxury. We provided flawless discharges. We did not send a child unless s/he had the Board of Education plan in place. Even if that meant staying the 60 days for proper processing and placement. Now LOS is shorter. We have to let go of those things.*

Reduced stay in the hospital has more profound meaning for this population than meets the statistician's eye because time has a therapeutic value. The pediatric social worker is very cognizant of the use of time in developing a relationship with the child and the family. Time in the hospital is used therapeutically to help the child and family members adapt and cope with a diagnosis of a life-threatening illness and subsequent physical limitations. Jeff describes the therapeutic value of hospitalization, especially for the newly diagnosed catastrophically ill child:

> **Jeff:** *Yeah some of our kids wind up with very complicated medical care that will never disappear, for example, trachs, gastric tubes, spina bifida, cathetered kids, These are things parents never thought about doing for their children.*

2. Decision-Making

The shortened length of stay, according to managed care principles, is to be augmented by coordinated outpatient care that is less costly and returns the child to familiar surroundings: the home, school and the community. The experience of pediatric social workers,

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Jeff, Allison, Donna, Stephanie and Bernadette, however, is that it is the insurance company's case manager who decides what outpatient services the child may need or is entitled to. Decision-making thus has been removed from the parents and the medical team caring for the chronically or catastrophically ill child to the insurance carrier.

> **Allison:** *We have to send the kids back to the primary care physician to go on for any specialists. They are unfamiliar with any of the resources. So they go through the directory of approved providers. They have no clue, so that leaves me or the family to go to find out who takes what insurance.*

Social workers are not in the same decision-making role as they were in fee-for-service. Similar to pediatric medical specialists, pediatric social workers, now need to gain authorization for discharge planning, referral sources for durable equipment, transportation, outpatient care, specialists, mental health consultation as well as the duration of allowed service. Specific vendors and even specific kinds of equipment are dictated by the managed care company. There is a loss of choice for the consumer and a loss of autonomy for the social worker (Edinburg & Cottler, 1995).

Stephanie and Bernadette, both seasoned pediatric oncology social workers in a children's hospital, describe their loss of decision-making to the case manager. They can no longer implement their specialized medical team's prescribed discharge plan. Bernadette discusses a child with nasal rhabdomyosarcoma that left him with a hole in his palate. He could not swallow and lived on a high caloric formula. The case manager held the ultimate decision-making power whether the formula would be paid for under the policy thus altering the medical team's discharge plan.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

> **Bernadette:** *He could not swallow because of the hole in his palate. The HMO would pay for hyper alimentation because that is temporary, but his long term need was formula and they would not pay for it. Hyper alimentation costs $1,000 per month but they had a time limit on how many months they would pay for. Formula costs $200-300 per month, but they viewed in as indefinite. They would not do it.*

Stephanie described another situation where the team worked to train the mother of a cancer-diagnosed child to be able to handle many of the nursing needs. She was trained on broviac care (a temporary indwelling catheter) and hyper alimentation, (a specialized tube feeding) but the insurance company case manager refused ancillary services in the home unless a nurse visited the home. The mother didn't need the home care nurse, since she was trained and capable of administering to her child, and she did not want the intrusion in her home. The managed care company would not supply the additional services without a home care nurse. Stephanie had worked with many home care companies in the past that would accept having a mother take on these functions, but Stephanie could no longer decide which home care company to use. It was the case manager who now made that decision. The loss of decision-making is further compounded by the managed care company's regulations regarding referral process.

3. Referral Process

Allison, Bernadette, Stephanie and Donna all describe increased paperwork and telephone work associated with managed care. On one hand, the paperwork and phone contact is necessary to increase accountability and reduce unnecessary duplication of service, but on the other hand, it reduces time available for client contacts (Fabricant & Burghardt, 1992; Rodwin, 1995). Allison describes an example of

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

increased paper work. She now submits bi-weekly summaries to the insurance carrier, and she has developed a detailed intake summary form to capture all the insurance information. Stephanie and Bernadette have developed a department brochure and newsletter. The purpose of these publications is to reduce the time spent by the worker describing each program to newly diagnosed children and their families. Although initially these all increased the paperwork for these social workers, the hope was that these vehicles would help manage this increase. Donna, a pediatric oncology social worker in a university hospital, finds herself doing more paperwork in relationship to managed care.

> **Donna:** *I kid with the families. I say that I feel like I got a masters in insurance as opposed to social work.*

Along with the increase in paper work, there is an increase in telephone contact for the purposes of authorization. Allison has worked very hard at identifying a new role for herself as the hospital/team case manager. However, her "success" has led to greater phone contact with the case managers since she has now been identified as her team's conduit for the insurance companies' case managers.

> **Allison:** *Some case managers say: 'I don't want to talk to this one or that one. I just want to talk to you.'*
>
> **Interviewer:** *Is that new?*
>
> **Allison:** *I am finding it more now. They may be getting overwhelmed.*

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Prior approval process is clearly another referral process that puts an additional burden on children and families coping with major medical limitations.

> **Rosalie:** *Our kids go back and forth to the hospital that is treating them. Our appointment secretary has met with obstacles and barriers for those children on managed care. They get there and have to turnaround.* [They return without receiving service] *We are not aware that we had to get certain approvals or go through certain channels.*

Coping with these changes in the health care system not only affects the child and family but the health care providers who link them with the myriad of services and often act as a conduit between the health care system and the insurance carrier.

C. The impact of managed care on the professional pediatric social worker

Since the pediatric social worker plays such a significant role in access, coordinating, obtaining, negotiating and directly providing service, the impact of managed care upon their role is looked at regarding (1) discharge planning, (2) delivery of concrete services, (3) administrative responsibility, (4) clinical responsibility, and (5) professional identity.

1. Discharge planning

As a result of managed care, discharge planning and meeting concrete needs has become a focal point of service delivery for the hospital-based social worker. Fabricant & Burghardt (1992) note "the tasks of social work are increasing to maximize productivity with a range of tasks narrowed to include only specific discharge tasks."(p.83) As the pressure increases to discharge patients as quickly

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

as possible, the pediatric social workers see this strain on their formerly diversified role. Ellen and Allison speak to this experience.

> **Ellen:** *Discharge planning starts even before admission; more discharge planners than they were two years ago. In an introduction of disciplines to the family, social work started out with we do discharge planning.*

> **Allison:** *I usually get the kid at the beginning of an incident. So I explain to them that they only have a 30 day benefit; in-patient and then 30 days outpatient.*

The loss of professional autonomy in decision-making impacts upon their ability to effect a discharge plan. Discharge planning is often quite complex for these medically fragile children.

Stephanie and Bernadette describe losing the ability to implement a discharge plan that relates specific needs of a catastrophically ill the child. The hospital team's recommended equipment or discharge plan now must be approved by the insurance company's case manager. The case manager follows preferred provider lists based upon cost and quality. Allison describes being asked to get three prices for a piece of specialized equipment necessary for a child's discharge in order to fulfill competitive pricing requirements of one managed care company. Thus discharge planning is not only a pivotal part of the pediatric social worker's role under this new managed care system, but also one that is affected by the complexity of the managed care's rules and regulation as well as the complexity of the chronically/ catastrophically ill child's unique needs.

2.Delivery of concrete services

With the emphasis on shortened length of stay and continuity of care to the community pediatric social workers are spending a lot of

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

their time and professional energy meeting the concrete needs of these seriously ill children.

> **Allison reports:**...*social work is becoming more concrete....we are learning the resources out there that can help us do things at a reduced cost. Both social worker and other health care professionals are looking creatively at other resources. i.e. school to do PT, OT or speech therapy, if you can demonstrate it is a school related function. It is hit or miss with the schools. We all scan papers for this or that. We are using the community more, such as Kiwanis.*
>
> **Donna:** *I feel as the social worker, I take on responsibility to help find more resources for the family. I call a lot more agencies that may be able to help the family out financially. That takes up a lot more of my time.*
>
> **Jeff:** [managed care is]...*action and outcome oriented rather than process oriented. Limit goals to specific issues not the larger picture such as generalized parenting skills, but rather specific skills to effect a plan.*

3. Administrative responsibility

The focus on discharge planning and delivery of concrete services has changed the balance for many pediatric social workers toward administrative versus clinical responsibilities. Allison, Bernadette and Rosalie highlight some of the administrative aspects and the professional conflicts about this new role.

Allison sees herself as being besieged with paperwork. Her successful management of this paperwork and her collaboration with her new partner, the insurance company case manager, has led to her professional survival, but she recognizes the conflict she experiences in meeting the administrative demands.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Allison: You *do lots of paper work, justifications...helping physicians develop them. Physicians are not used to these elaborate justifications. Also weekly update, some want it in writing, some want it by phone; it may take twenty minutes to get them on the phone...*

Rosalie: *Their* [case manager's] *primary role is to contain cost. It can conflict with meeting the child's needs. Hopefully it will cut down on waste and fat in health care, since not all of the services are used appropriately. But I worry about getting the necessary personal care hours for the neediest.*

Bernadette: *What worries me, is, are they* [managed care] *going to recognize the value of what we do? Or are they only going to value that we make sure we get the kids out of the hospital or that we get the equipment from the cheapest place?*

4. Clinical Responsibility

The pediatric social workers interviewed, as well as Jellinek (1994), express concern that under the new cost constraints of managed care, little time is available for providing psychosocial counseling to families confronting chronic and catastrophic childhood illness. Allison, Jeff and Bernadette all see the erosion of the counseling aspect of their work.

Allison: *Social work is becoming more concrete. The clinical aspect is nice, when you can get it....*

Jeff: *...and the time to bond with the kids, the possibility and I can only call it a possibility-it looms so large-that we will lose their families and we will end up requiring institutions.*

Bernadette: [referring to what she values in her work] *Helping people cope, to negotiate their way through the system, to have a liaison.*

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

5. Professional Identity

Counseling has been part of the professional identity or the professional norms for pediatric social workers assisting families coping with chronic and catastrophic childhood illness. This is clearly one function, among others, of the pediatric social worker that is being impacted by managed care. Jeff, Allison and Bernadette voice concerns about how managed care is or may alter their professional identity in the pediatric medical setting. Jeff describes how social workers are being talked about in terms of cost of their "lines" rather than the value of the service they perform.

> **Jeff:** *I hear so much we are short 3 FTE's. I hate the lingo, but I am learning it. They are people and we are short three people. I tell our director not to reduce us; we are people.*

Allison describes another example of loss of professional identity. She arrives at 8 and leaves at 6 without taking a lunch hour in order to meet all the needs of her population and the reporting requirements. The reward for her" hard work" has earned her the designation as the hospital's first "case manager." This means her position is more secure than her other social work colleagues, but she recognizes it is based on her technical acumen in pediatric rehabilitation and good business rapport with the insurance companies' case managers. Despite this security, she feels conflicted about new title since it jeopardizes her professional identity.

> **Allison:** *This whole thing of changing my title to case manager-I feel I am giving up something. Case management is just one thing I do. So I am giving up something. Moving from a professional to a function. It*

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

> *has been hard. Can I still keep social worker on my name tag?, I asked.*
>
> **Interviewer:** *What do you feel you are giving up?*
>
> **Allison:** *My professional identity.*

Bernadette questions if they will value her unique contribution.

> **Bernadette:** *Are they going to value what we really do?* [a real sadness in her voice] *...helping people cope, to negotiate their way through the system, to have a liaison. They may say, my fear is, that they have a case manager over here and she can do all the stuff you do.* [Hitting her hand against the table] *We aren't going to pay for what you do. Or so what can you do?*

The importance placed on administrative functions as opposed to clinical functions is clearly related to the thrust to contain cost. Pediatric social workers, such as Bernadette, fear cost containment is becoming the primary principle underlying pediatric health care delivery rather than meeting clients needs through good medical practice, providing counseling to optimize adaptation and coping, as well as, meeting concrete needs of children and their families.

This 1995 pilot study indicated that managed care was clearly impacting upon catastrophically and chronically ill children and their pediatric social workers were a significant untapped reservoir of information. The impact of managed care on families and their children was observed in three areas: (1) access to care, (2) coordination of care, and (3) level of stress experienced by the families.

Access to care was restricted by regulations, which at times limited their choice of home care, hospitals and doctors. Coordination of care was a highlighted managed care feature for this population,

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

especially when an insurance company's case manager helped to coordinate benefits and streamline the referral process. The families did experience more stress, however, when the regulations become too complex and time-consuming and the coordination of care feature was not offered.

Three areas of managed care policy that guide service and service delivery that were noted by the pediatric social workers to be of concern were: (1) time constraints, (2) decision-making, and (3) referral process. The limitation on time spent in the hospital, commonly referral to in medical parlance as "length of stay" appeared very rigidly proscribed for such a medically and emotionally devastated population of ill children. Decision-making had shifted from the medical team providing care to the insurance company, often represented by the case manager. The referral process to obtain specialty care and auxiliary services had become impeded with paperwork and telephone approvals.

These changes impacted upon the professional pediatric social worker regarding (1) discharge planning, (2) concrete services delivery, (3) administrative), and (4) clinical functions. While discharge planning became a more central part of their role they had less decision-making power in this area. There was greater need for concrete service delivery, more time spent on administrative functions such as paperwork and concern with cost containment leaving less time for clinical activities. There were noted changes in their professional identify related to these shifts in their functions. Some experienced job title changes; the new job title was case manager

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

instead of social worker in order to fit into the new insurance company's parlance and reimbursement structure.

This pilot study pointed to the areas that needed further in-depth exploration and description. Chapter IV will describe the exploratory-descriptive research study that evolved from this 1995 pilot study. This exploratory-descriptive study is based upon a specific catastrophically/ chronically ill pediatric population, children living with cancer in order to study more carefully the impact and implications of this changing system of health care on a health impaired pediatric population. Their pediatric oncology social workers are the sample population.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Chapter IV- RESEARCH METHODOLOGY

A-Overview of the Study

An exploratory-descriptive research survey design was employed in this study utilizing an original survey instrument built upon the results of this author's pilot study and a review of the literature. An exploratory design is based upon the assumptions that through the use of relatively systematic procedures relevant hypothesis pertaining to a particular phenomena can be developed. An exploratory design's primary goal is also to develop, clarify, and modify concepts and hypotheses for further study. Both quantitative and qualitative data can be included in an exploratory study (Tripodi, Fellin & Mayer, 1983).

By combining exploratory and descriptive design a particular phenomena can be described more fully. The original survey used primarily quantitative responses with ample opportunities for qualitative elaboration to central open-ended questions. The open-ended questions looked at "...salient behaviors, events, beliefs, attitudes, structures and processes..." (Marshall & Rossman, 1989, p. 78.)

The three key questions explored were: (a) What impact is managed care having upon the delivery of health care to chronically and catastrophically ill cancer-diagnosed children and their families? (b) How well does the current managed care delivery system, as compared to the traditional fee-for-service system, meet the medical and psychosocial needs of these children and their families? (c) How have pediatric oncology social workers, significant health care providers for this population, been impacted by managed care?

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

B- Instrument

The instrument, a self-administered survey, was developed for this study based upon three significant areas and sub-areas which were identified from the qualitative pilot study conducted by this author and the existing literature. (Appendix A) The survey employed two points of time, Fall of 1995 and Fall of 1997, as a way of distinguishing the impact of managed care, since during this time period managed care experienced extensive growth. The survey also asked the participants to compare managed care with traditional fee-for-service since traditional fee-for-service was the prevailing system of health care delivery prior to the development of managed care. There is a sizable portion of insurance carriers still using a fee-for-service model.

The survey was composed primarily of fixed-response questions and some Likert scale items, which lend themselves to quantitative analysis. Open-ended questions were also employed to explore specific issues in-depth, which lend themselves to qualitative analysis.

The instrument was designed to capture the data related to the following concepts and variables: (a) impact upon the child and family regarding (1) access to care, (2) coordination of care, and (3) level of stress; (b) impact upon service delivery- managed care policies and guidelines regarding (1) time frame, (2) decision-making, and (3) referral process; (c) impact upon pediatric social worker's role, regarding changes in (1) workload, 2) clinical role, (3) professional identity, and (4) new professional opportunities.

C- Procedures: Data Collection

Four experts in pediatric oncology social work established face validity on the instrument's content. All were members of the targeted

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

professional association, Association of Pediatric Oncology Social Workers (APOSW). They reviewed the instrument for inclusively, accuracy and clarity. For each of the question items, three of the four had to agree to inclusivitly, accuracy and clarity. Where there was indication of a problem in these areas by any one of the four, the item was examined and reworded or presentation changed such as the format of a chart.

The Human Subjects Review Committee of the author's university determined the study to be low risk. The President and the Chair of Research of APOSW also determined the study to be of low risk to the membership.

A survey instrument, (Appendix A) cover letter, (Appendix B) postcard, (Appendix C) and stamped return envelope were mailed to each identified potential participant using the Total Design Method as developed by Dillman (1978). The first mailing included a survey with a cover letter from this author, an active member of the organization, with the endorsement of the survey by the President of the organization and the Chair of Research Committee. The letter reinforced the collegial relationship between author and the respondents. It stressed the high regard the author had for the respondents' professional experience and opinion. Dillman views these as “rewards.” A consultative approach, which values their contribution to the development of pediatric social work oncology research, was also emphasized in order to maximize a response rate (Dillman, 1978; Fowler, 1995).

An additional "reward" was the offering of an extensive bibliography on the subject of managed care. In order to protect

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

confidentiality, respondents were given a prepaid postcard, which could be mailed, independently of the survey to request the bibliography.

Confidentiality was assured. Identification was optional. A coding of survey envelopes was employed only as a means of follow-up of non-returned surveys. All identifying information known to the author was kept confidential

This author's address, daytime phone number, fax number and e-mail address were included in order to be available to address any questions regarding the study or participation.

A due date was established in the cover letter and reiterated on the survey instrument.

A stamped self-addressed return envelope was included to eliminate any costs or burden to the respondent.

A response deadline of ten days from the mailing date was established in the cover letter. One week after the first mailing, a colorful and attention getting post-card was used as a second mailing to reinforced the arrival of the survey. (Appendix D) This postcard thanked those who had responded and reiterated the deadline for the response. The post-card once again gave them a toll-free phone number, a mail address and an e-mail address, in event they had questions about the process or the study. A toll free phone number was given to encourage any questions and eliminate any financial burden on the participants.

If no response was received within one-two weeks of the due date, a follow-up e-mail message or fax message (Appendix E) was sent. The use of either an e-mail address or a fax number depended upon the

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

availability of the address/number in the membership directory. If in event, there was no e-mail address or fax number, a phone call was placed. Through e-mail, fax or phone potential respondents' questions were addressed.

D- The Sample

Children living cancer have been selected as a specific client population of chronically and catastrophically ill children since these children and their families are heavily involved with intensive and complex medical care and supports. This intensity is based on the fact that pediatric cancer is the leading cause of death in children under 15 and the treatment regimes: surgery, radiation and chemotherapy, stem-cell transplantation and ancillary care, are expensive and taxing on the health care system.

Pediatric oncology social workers are the vital link between cancer-diagnosed children, their families and their insurance system(s) since much of their service delivery depends upon insurance related issues. Some of these services include discharge planning, purchase or rental of durable equipment, transportation arrangements, coordination of outpatient care and ancillary care, coordination of special school needs, referral to entitlement programs and counseling. Pediatric oncology social workers, therefore, were the informants and target sample population. It was their observations and interactions with families and the health care system that they were basing their responses. In addition, to their direct interactions with managed care companies on their clients' behalf.

The Association of Pediatric Oncology Social Workers (APOSW) is the only professional pediatric social work association related to a

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

chronically and catastrophically ill pediatric population. The members of APOSW were the sample population based upon specific criteria.

The total membership in March 1998 was 184. Of the 184 members, 142 were identified as fulfilling the eligibility criteria for the study. The study criteria included (a) paid membership, as of March, 1998; (b) self-identified as an MSW or BSW on the membership list; (c) self-identified as working in a medical/hospital setting, as opposed to an organization such as American Cancer Society or the Leukemia Society; and (d) working in the US. Canadian and many European social workers practice under a socialized medical system. The APOSW members identified working outside of medical/hospital setting were excluded since they may have limited interaction with insurance issues.

Seventy-percent (99) of the APOSW members fulfilling the criteria responded by either completing the survey or indicating via mail, fax, phone or e-mail that they could not complete the survey for a specific reason. Fifty-nine percent, (84) completed the survey and returned it by mail or fax. (Table 1) There is no one to determine that those that responded were represented of the identified 142 potential respondents. In a later section, there is a comparison between those that responded to the potential 142 respondents in terms of geographical location of place of work by state. There was a higher response rate, for example, in the region the author works possibly based upon a greater professional tie to the author.

Fifty-nine percent response rate is a good response rate considering the very demanding schedule of professionals in the health care arena today. One pediatric oncology social worker who felt unable to complete the survey took the time to write a one page note

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

explaining why. His response speaks to the point of the very busy schedules of health care practitioners. John, (names have been altered by the author to protect confidentiality) in his attempt to get some of the answers to some of the survey questions, spoke to his department's "case manger and finance people." He reported, he was unable to respond since "...HMO's have everyone so swamped, its difficult to get answers." (Correspondence, 5/1/98)

Halm, Causino & Blumenthal (1997) in their recent study comparing the use of gate-keeping in managed care with traditional care also mailed a self-administered fixed response questionnaire to physicians in the Boston region. They achieved a sixty-one percent response rate and noted three other contemporary studies of health care practitioners, which yielded similar rate. They too identify under the current climate, health care practitioners have little time to spare and such a response rate is rather good.

Table 1
<u>Response to Survey</u>

Response	N	Percentage
Total Population	142	100%
Total Responses	99	70%
Completed Survey	84	59%

The fifteen respondents, who felt unable to complete the survey, took time to indicate the reasons why. As seen in Table 2, twenty-seven percent (4) did not feel they had the data to complete the questionnaire. They indicated, for example, they had minimal exposure

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

to insurance issues since their department had designated one person to handle all insurance related matters. An equal number, (4) indicated they were employed in the field too short of a time to make any comparison. The questionnaire asked participants to compare the last two years of practice. These people were in the field less than eight months. Twenty- percent (3) indicated that although they maintained membership in APOSW, they no longer worked in the field of pediatric oncology. Fourteen-percent (2) worked on the stem-cell transplant service which usually means the child is with them only during transplantation. In order to be eligible for a transplant the pediatric oncology social worker would have worked with their insurance carrier for prior approval. Once on the transplantation service there would be no or limited interaction with the insurance company. Following transplantation, most patients return to their pediatric oncology service therefore that pediatric oncology social worker once again would handle the follow-up insurance issues.

(See the following page for Table 2)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 2
Reason for Non-Participation in Survey

Reason for Non-Participation	N	%
Did not feel they had data to base responses upon	4	27%
In the field < 8 months	4	27%
Not currently working in pediatric oncology	3	20%
Working on stem-cell transplantation unit	2	14%
Program/administrative capacity	1	6%
No time to answer survey	1	6%
TOTAL	15	100%

Demographic Characteristics of the Respondents

The eighty-four respondents, who completed the questionnaire, had from three months to twenty-one years of experience in pediatric oncology social work. As shown in Table 3, the mean or average number of years of experience in pediatric oncology social work was 6.3 with the median being 5.5 years. The mean and median figures indicate that the "average" respondent has been in the field of pediatric oncology prior to the significant impact of managed care which has been in the last three years prior to the study, which was mailed in early Spring 1998.

(See the following page for Table 3)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 3

Years in the Field Of Pediatric Oncology Social Work

Measure	# of Years
Mean	6.3 years
Median	5.5 years

Thirty-nine percent (33) of the respondents had three years or less of experience in pediatric oncology. (Table 4) Nineteen-percent (16) of the respondents had four to six years of experience. Seventeen-percent (14) of the respondents had seven to nine years of experience. Fourteen-percent (12) of the respondents had ten to twelve years of experience.

This data indicates that over one-third of the respondents, who were employed under three years in the field, have been working in pediatric oncology about the same time managed care began to impact significantly upon health care. This group may not have as much experience with the traditional fee-for-service model. The exposure to managed care varies, however, across the country since as noted in the previous sections the "penetration" or numbers of enrollees in specific parts of the country varies. It is possible that a social worker who is in the field for 3-4 years in one region has not worked very much with clients under a traditional-fee-for-service, while in another region a social worker in the field the same number of years have hardly encountered managed care.

(See the following page for Table 4)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 4

Number of Years in Pediatric Oncology Social Work

# of years	N	Percentage
1-3 years	33	39%
4-6 years	16	19%
7-9 years	14	17%
10-12 years	12	14%
13-17 years	5	6%
18-21 years	4	5%
TOTALS	84	100%

Since managed care has had a stronger influence or "penetration" in certain regions of the US, this national study could answer questions about geographic regional differences. The pediatric oncology social workers had an opportunity to self-identify the city and state which their medical center is located. Their responses were organized into four major regions in the US as defined by the U.S. Census Bureau (1997) and shown in Figure 1. The greatest number of respondents, thirty-two-percent (27), were working in the South, while twenty-nine-percent (24) were working in the West. Twenty-five-percent (21) were working in the Northeast. The Midwest was represented by only thirteen-percent (11). Figure 1 also compares the rate of response to the survey by region to the total population (142) mailed the survey. In comparing the response rate by region to the total population, it its noted that the South and West regions are comparable. The responses rate from the South region was thirty-two-percent, while their representation in the total sample was thirty-one-

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

percent; the West region had a twenty-nine-percent response rate with twenty-six-percent of the total population.

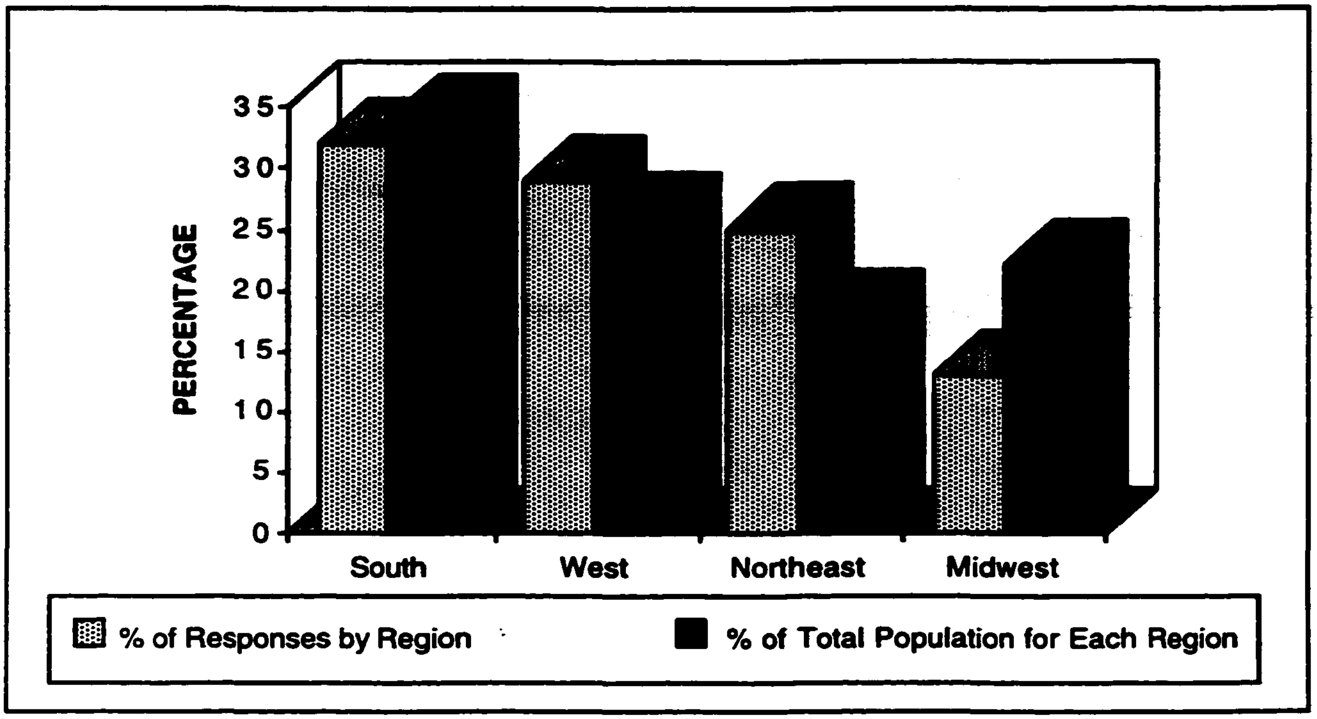
There is some difference between the response rate and the total population for the Northeast and Midwest regions, as seen in Figure 1. The Northeast response rate is higher than its representation in the total population. A possible explanation for a disproportionately higher response rate is that the author of this study also resides in the Northeast and is well known to the sample population in that region. These ties may have influenced their response rate. There is no clear explanation for the Midwest's lowest response rate by region. Although the Midwest represents twenty-two percent of the total population only thirteen percent completed the survey.

(See the following page for Figure 1)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Figure 1

Regional Distribution of Respondents Compared to Total Population



The respondents also had an opportunity to self-identify their current job title. Thirty-seven percent (31), as seen in Table 5, describe themselves as Clinical Social Workers, while twenty-six percent (22) identify their job title using the Pediatric (Oncology) Social Worker designation. Eleven percent (9) used only the Social Work designation. Eight percent (7) used the Medical Social Worker Designation, while an equal number identified an administrative title such as Supervisor, Preceptor, Director.

(See the following page for Table 5)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 5
Current Job Title

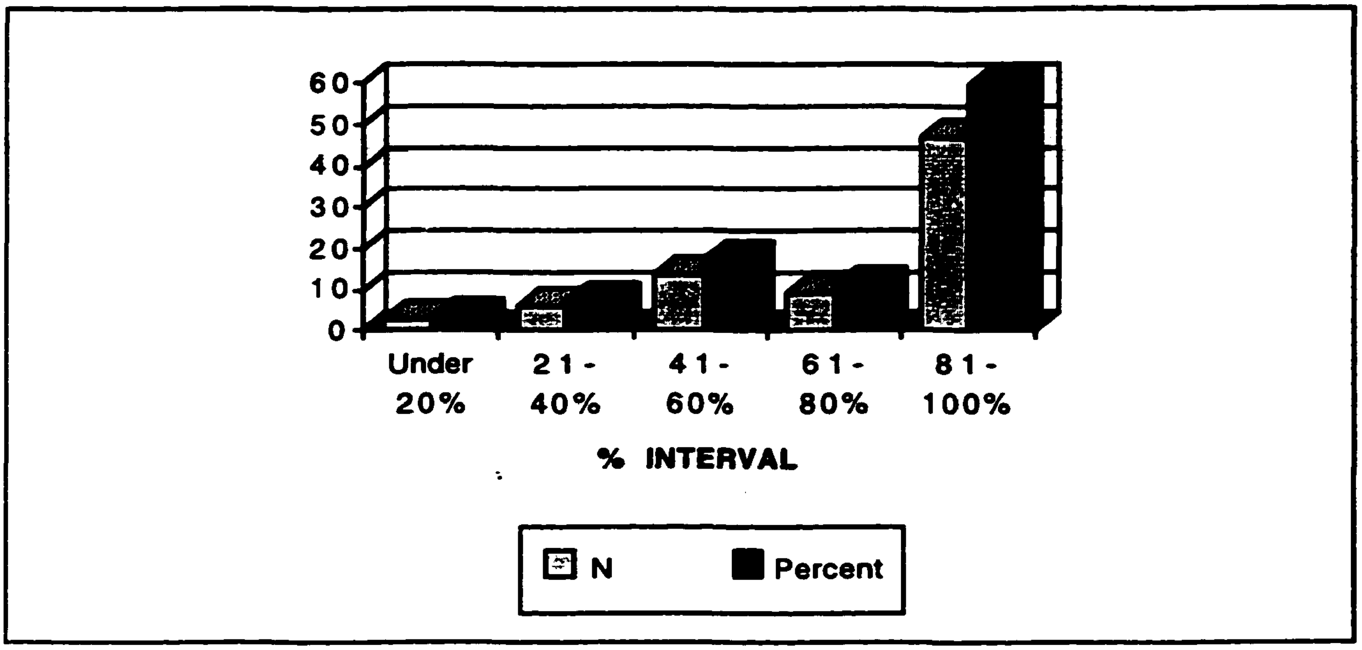
Title	N	Percent
Clinical Social Worker	31	37%
Pediatric (Oncology)	22	26%
Social Worker	9	11%
Medical Social Worker	7	8%
Administrator	7	8%
Oncology Social Worker	4	5%
Other	3	4%
No response	1	1%
TOTALS	84	100%

These job titles are partly related to the percentage of their workload that is in providing direct social work support to the pediatric oncology service. Figure 2 describes the percentage of their workload that is dedicated to pediatric oncology. The responses to this question reveal that this population spends the majority of their time in pediatric oncology. Forty-seven respondents (59.5%) devoted 81-100% of their time to pediatric oncology. Nine (11.4%) devoted 61-80% of their time to pediatric oncology. In total 70.9% of the respondents spent over 60% of their time in pediatric oncology. Thus this group overall is extremely well versed in the needs and issues

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

confronted by children with cancer and their families. Only 11.4%, (3.8% under 20% and 7.6% between 21-40%) spent less than 40% of their time meeting the needs of this population.

Figure 2
Percentage of Workload in Direct Pediatric Oncology Service

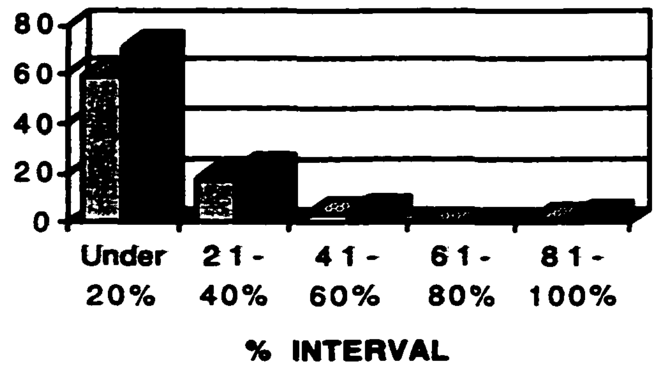


Fifty-eight (70.7%), of the respondents to this question dedicated under 20% of their workload to the administration of their pediatric oncology service. Eighteen percent (22%) dedicated 21-40% of their workload to the administration of their pediatric oncology service. Therefore as shown in Figures 2 and 3, this survey population is indeed providing direct and administrative social work services to a pediatric oncology population. Therefore they are intimately involved with the needs and service delivery issues.

(See the following page for Figure 3)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Figure 3
Percentage of Caseload in Administration of Pediatric Oncology Service



▨ N ■ Percent

Other than providing direct service to a pediatric oncology population or working in an administrative capacity, APOSW members may have secondary or joint assignment on other services. Sixty-three percent of the respondents (53) indicated they cover services other than pediatric oncology. Those who responded to this question covered between one to seven other services. With fifty-three members responding positively to this question, it indicates a majority of the respondents have some exposure to populations other than pediatric oncology. This may be an advantage since it allows the social worker to compare their pediatric oncology population insurance experience with other populations.

Twenty-seven specified they also covered pediatric hematology, which includes disorders such as sickle cell anemia, hemophilia, and Fanconi's anemia. Twenty-four listed a wide range of other pediatric

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

services such as allergy and infectious diseases, HIV, rehabilitation, cystic fibrosis, neurology, cleft palate, trauma, high-risk neonatal as well as general pediatric and child abuse service. Only five responses indicated coverage of an adult service such as oncology, high-risk pregnancy and general medical clinics.

The sample population was queried about the percentage of their pediatric oncology workload under managed care, as well as, the percentage their pediatric population other than oncology under managed care coverage.

Managed care was defined for the respondent "...as a continuum of health insurance plans with common features such as balancing access to care, cost, quality control, benefit design and flexibility. Reimbursement rates are set between the health care providers and insurance carriers. The HMO, health maintenance organization, model is one of the models, but not the exclusive model." (Survey Instrument-Appendix A) Fee-for-service was defined as "...the traditional indemnity health insurance plan where the health care providers set their own rates and are reimbursed by the patient directly." (Survey Instrument-Appendix A) In the fee-for-service model, the insurance company reimburses the patient or subscriber. The reimbursement rates vary among insurance companies and among policies.

The greatest percentage of respondents, 45.5%, (Table 6) identified that between 61-80% of their pediatric oncology population was under managed care. Another 22.1% observed 81-100% of their pediatric oncology population was covered by managed care, thus 67.6% of the respondents observed over 61% of their pediatric population were covered by managed care. When asked the same

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

question about their pediatric population other than oncology, there was a striking difference in the percentage under managed care. Only 45.2% of respondents identified that 61-100% of their pediatric population other than oncology was covered by managed care. (21.4 between 61-80% and 23.8%, between 81-100%)

There is no data to explain this difference. A possible explanation is that the cancer-diagnosed children are more likely to have working parents with commercial coverage since at the time of the study few states had mandatory enrollment for Medicaid recipients who were seriously ill. Disabled populations were still being "carved out." (Carved out refers to the practice in many states of <u>not</u> requiring the person with a preexisting condition to join the managed care plan, which gives them the option of remaining with a fee-for-service plan).

(See the following page for Table 6)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 6

<u>Percentage of Pediatric Oncology Patients Under Managed Care as Compared to Other Pediatric Populations</u>

Populations	% Under Managed Care				
	under 20%	21-40%	41-60%	61-80%	81-100%
Pediatric Oncology Population	3.9%	14.3%	14.3%	45.5%	22.1%*
Pediatric Population, Other than Oncology	16.7%	16.7%	21.4%	21.4%	23.8%**

* 61-100% = 67.6% of the pediatric oncology population

**61-100%= 45.2% of the pediatric population other than oncology

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Chapter V- FINDINGS

The pediatric oncology social workers observed an increase in enrollment in managed care for this population between the Fall '95 to Fall '97. In Table 7, 94.1% (48) of the respondents observed a change from fee-for-service to managed care coverage for this population. Therefore, it is clear that managed care has began to impact upon this population during the time period studied.

Table 7
Between the Fall of 1995 and Fall of 1997 did the Percentages of Children Living with Cancer Represent an Increase or Decrease in Managed Care Enrollment?

Response	N	Percentage
Increase	48	94.1%
Decrease	3	6.9%
TOTAL	51	100%

Children living with cancer covered by managed care are either covered through commercial plans through their parents' employment or under public plans, such as Medicaid managed care. As noted in the literature review, public sector use of the managed care model varies greatly from state to state employing not-for-profit or for-profit insurance carriers. Many states are moving toward mandatory managed care enrollment for their general Medicaid population with some states such as New York still "carving out" or exempting those with known disabilities such as those receiving Social Security Insurance.

Due to this increase in mandatory enrollment, the sample population was queried as to what percentage of their managed care

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

population was under public plans. Of the seventy-seven responses to this question, 67.6% (52) indicated between 21-60% of their managed care population was under a public or government managed care contract. For 97% (32) of the 33 respondents to a question about the change in enrollment status, this meant an increase in enrollment in Medicaid managed care from Fall 1995 to Fall 1997.

Thus pediatric oncology social workers were in a good position to observe the differences in delivery of health care services between managed care and traditional-fee-for-service since they observed considerable movement from fee-for-service to managed care coverage both under commercial and public programs.

These changes in health care were to balance cost containment with improved health outcomes by increasing: access to care, coordination of care thus decreasing the level of stress experienced by parents in obtaining the care for their children. All of the responses are from the perspective of the pediatric oncology social worker who have been established to be in a very knowledgeable position.

A-Impact upon the Child and Family

(1)Access to Care

Access to care was measured in terms of (a) overall access, (b) the complexity of requirements to obtain care, (c) time involved in obtaining a referral, (d) the number of steps in the referral process to a specialist, (e) an accessible location of health care provider and (f) general satisfaction with health care providers.

(a) Overall Access

In terms of overall access to care as seen in Table 8, 36.5% (27) of the pediatric oncology social workers noted that cancer-diagnosed

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

children under managed care had "less access" to care. An additional 50% (37) of the respondents observed that children had the "same access" to care under managed care as traditional-fee-for-service. Only one respondent, who works for a hospital owned by a managed care company, noted an "increase" access to care with 12.2%, (9) of the respondents who noted "somewhat increase" access to care for managed care insured children.

Table 8

Comparing Access to Care for the Majority of Children Living With Cancer under Managed Care to Traditional-Fee-For-Service

Access to Care	N	Percentage
Increase	1	1.4%
Somewhat Increase	9	12.2%
Same	37	50.0%
Less	27	36.5%
TOTAL	74	100.0%

(b) Complexity of Requirements to Obtain Care

Complexity of requirements to obtain care has been discussed in the popular literature, as well as, scientific literature. Managed care is most often associated with gatekeepers, primary care physicians, signed referral forms, telephone-obtained pre-authorization, in-and out-of network care, among other mechanisms to control costs, redundancy and unnecessary care. A total of 90.9%, (70) noted more "complexity" to the requirements (51.9% "more" and 39% "somewhat more") to obtain care. Only 5.2% (4) of the respondents observed "less complexity" of requirements as seen in Table 9. Many health policy

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

analysts view the complexity of requirements to obtain services as one of the most significant drawbacks to managed care (Baldor, 1996, Cartland & Yudlowsky, 1992, Spragins, 1998, Fox & McManus, 1998).

Table 9

Comparison of Complexity of Requirements to Obtain Care for the Majority of Children Living With Cancer under Managed Care to Traditional Fee-For-Service

Complexity of Requirements	N	Percentage	
More complex	40	51.9%	} 90.9%
Somewhat more complex	30	39.0%	
Same	3	3.9%	
Less complex	4	5.2%	
TOTAL	77	100.0%	

Respondents were given the opportunity to give examples, which described the level of the complexity of requirements to obtain care. Seventy-seven percent (65) of the respondents described 101 examples based upon their observations. Using content analysis the findings were organized into six categories of complex requirements: (1) referral process, (2) limitations of coverage, (3) coordination of care, (4) choice of provider(s), (5) financial burden, and (6) time-delay. As outlined in Table 10, the referral process was identified by 35% (36), the limitation of coverage was identified by 22% (22) and coordination of care by 20% (20), as the three most significant examples of complexity of requirements to obtain care.

(See the following page for Table 10)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 10

Examples of the Complexity of Requirements to Obtain Care for the Majority of Children Living with Cancer under Managed Care

Example	N	% of Respondents
Referral Process	36	35%
Limitation of Coverage	22	22%
Coordination of Care	20	20%
Lack of Choice of Provider	9	9%
Financial Burden	5	5%
Time Delay	5	5%
Other	4	4%
TOTAL	101	100%

In the respondents own words, they describe the referral process as "one must jump through hoops to get referral" which leads to "more hoops" since "the referral is dated for a specific amount of time." Once the time is up the "patient must return to the PCP [primary care pediatrician] for everything." Some families even need to return for "prior authorization to the PCP [primary care pediatrician] for each visit to see their oncologist." "Just more hoops to pass through..." making authorization for care "...more complicated and frustrating." Some managed care companies require "pre-authorization for everything...anesthesia, radiology, cardiology, neurology, radiation oncology...for meds., [medicine] home health, equip." [equipment] All of this is especially worrisome for children whose access to treatment is a life or death situation.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

In describing the "limitations of coverage" the respondents list the "decease of coverage for some services- home health, ng [nasal-gastric] feeding...many prescriptions have limitations...or are outright denied." These limitations refer to the many complex medical supports cancer-diagnosed children need on a home care basis. Home care avoids costly and lengthy hospitalization, but the many obstacles to obtaining the needed supports to provide care at home intensifies the stress and demands on families. Also, the workers point out that although home care may be less expensive than hospitalization, there are expensive medications and complex support services, if a medically ill child is to remain at home.

The request for managed care coverage for transplantation appeared to point to many inconsistencies within managed care policies and between policies. Transplantation is one of the "newer" forms of treatment of cancer compared to chemotherapy and radiation. It is the transplantation of healthy (non-cancerous) stem - cells (a specific type of cell found in bone marrow or peripheral blood) to replace the cancer- diagnosed person's cell producing system. The person usually undergoes total body radiation, rather than localized radiation and total systemic chemotherapy to bring the body into a state where the healthy transplanted cells or cell-producing system can replace the cancer-cell producing system.

There are two main issues for insurance companies regarding transplantation. Transplantation involves multiple medical steps (total body radiation and systemic chemotherapy) and involves the donation of stem cells, from a genetically matched healthy donor. The donor may be a relative or an unrelated volunteer. To even "locate" this

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

genetically matched relative, many relatives must undergo an expensive blood test. To "locate" the volunteer donor, a complex computer search of millions of donors is required.

The inconsistencies under managed care refers to coverage of some but not all of the required steps needed to achieve transplantation. According to pediatric oncology social workers, it is"... harder to obtain all tests, scans... procedures are denied for bone marrow transplants and bone marrow searches." Some respondents noted that 94

/stem-cell transplants would be approved but the cost of the search would be denied. The irony is that without a search for the "location" of a suitable donor, there can be no transplant.

Another area of concern for the pediatric oncology social workers if that for some diagnoses, transplantation is consider standard treatment while for other diagnoses, it is still considered "experimental." It is difficult to get insurance coverage for experimental treatment since there may not be sufficient data to prove it will help improve survival. According to another pediatric oncology social worker, "...patients must fall into covered diagnosis, especially for bone marrow transplant-other wise they are denied..." benefits.

The respondents examples pointed to many other peculiarities such as "managed care will not pay for neuogen [specialized medication] at home but will pay if [it is] given in the outpatient department..."

Another pediatric oncology social worker notes another peculiarity of managed care; they "... can dictate radiology and blood-work," even if the patient's doctor does not feel it is warranted.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Another pediatric oncology social worker observes that "...many leukemia children have to get their weekly shots at managed care clinic rather than [the patient's cancer] center...," thus fragmenting their care and increasing the paperwork between the two facilities only because their managed care company has a contract for these services with one specific primary care site. Quality of care and continuity of care becomes subordinate to contractual relationships.

Another pediatric oncology social worker notes "...those on HMO's have to change MD's or hospitals." The final irony, notes another pediatric oncology social worker, is that there is "more emphasis on lifetime benefits, a maximum 'lifetime cap,' on how much one can charge to his/her insurance." This is an unusual concept when a parent is fighting for their child's life and it might depending on a costly stem-cell transplant which will bring them over the "lifetime cap."

Those lucky enough to survive cannot get adequate follow-up care since one respondent notes that " ...kids off-treatment, [who have completed active treatment, and are under managed care contract] won't allow them [to see] a specialist..." [for follow-up]. They have to return to a primary care pediatrician who may never have seen a child with cancer and certainly unable to detect a long-term side effect such as learning disabilities, infertility, cardiac problems or short stature. There are also secondary cancers which can occurs which primary care pediatricians are not trained to detect.

The third most common example of the complexity of requirements noted by the respondents was coordination of care, a potentially viable strength of managed care. These twenty respondents

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

however did not give managed care a good score on the coordination of care practices they observed. One respondent noted that children on managed care "...need to go for different parts of care at different sites-blood, X-rays, ...done outside of hospital." "... more and more [patients] are forced into hands of unknown resources which complicate the specialty care." " Families have to access tests/treatment at more than one site to get all that they need." Those in desperate need of a transplant have pre-transplantation work-ups "...done at different healthcare facilities, even when both [are] in the same city." Some families "...need to travel to distant hospitals for specialty care such as bone marrow transplantation."

Another coordination of care issue observed by one pediatric oncology social worker was that "...transportation provisions through Medicaid managed care are difficulty to access-delaying chemotherapy 1-2 weeks for children coming from all over" [the city].

Many of these complexities regarding the referral process, the lack of coordination of care are seen as inconsistencies within and among managed care companies. It is best summed-up by Baldor (1996) in a cartoon with a patient lying on an operating table and the surgeon saying, "Now this may hurt a little, your insurance doesn't cover anesthetics" (p.49)

(c) Time Involved in Obtaining a Referral

The time delay is another access-to-care issue. Children living with cancer and their families are often confronted with very time-sensitive decisions regarding access-to-care since cancer is a progressive condition. Decisions regarding surgery, chemotherapy and stem cell transplantation sometimes depend on windows of

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

opportunity. Referrals to specialists, for example, when a tumor is found upon x-ray, or when states of remission are achieved or when cancer cells are found upon aspiration, [removal of cells from a tumor or bone marrow] may be controlled by a variety of cost-saving mechanisms. The need for "pre-authorization, [the] return to primary pediatrician, [the] use of another facility or in- and out-of network referrals" are just a few of these cost control mechanisms that involve time delays described by five of the respondents.

Unfortunately time is not on the side of children confronted by cancer. Despite this however, the majority of the respondents, 87.5%, in Table 11, observed that "more time" (56.9%) and "somewhat more time" (30.6%) was needed to obtain a referral in a managed care environment. None of the respondents found it took "less time" to obtain a referral under managed care. "

"The problem is cancer does not sit around and wait for you.., " (Eisenberg and Gilgoff, p. A3) according to the widow of John Masek. He died after his HMO denied a request for treatment. In 1999, New York State joined 28 other states in enacting a law that gives HMO subscribers the right to go to an independent expert with the power to overrule their insurer if their doctor says they need care that their insurer refuses to pay for. "For the first time, HMO's and insurance companies won't be the judge and jury when a consumer is denied care," (Eisenberg and Gilgoff, p. A3) according to Richard Kirsch, executive director of a consumer's group.

(See the following page for Table 11)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 11
Comparing the Time Factor in Obtaining Care for the Majority of Children Living With Cancer under Managed Care to Traditional-Fee-For-Service

Time Factor	N	Percentage	
More time	41	56.9%	}87.5%
Somewhat more time	22	30.6%	
Same	9	12.5%	
Less time	0	0	
TOTAL	72	100.0%	

(d) Number of Steps in the Referral Process

A very significant access to care issue for children living with cancer is access to specialists. Pediatric oncologists, pediatric surgeons, pediatric radiologists would all be considered specialists. Many of the life saving procedures: chemotherapy, radiation, stem-cell transplant, limb salvaging and gene-therapy would be considered by most managed care companies to be specialty procedures. The need to expedite referrals to specialists for special needs children and adults is one of the most cited areas in the literature as a limitation of managed care (Fox and McManus, 1998, Fox, Wicks, Kelly & Greaney, 1990; Fox, Wicks & Newacheck, 1993; Freund & Lewit, 1993; Ware, et al, 1996).

The overwhelming majority of the respondents (94.4%) observed that managed care required "more" (59.7%) and "somewhat more" (34.7%) steps to obtain a referral to a specialists as compared to fee-for-service. Only one respondent felt "fewer steps" were required in a managed care environment. (Table 12)

Table 12
Compare the Referral Process to a Specialist, for the Majority of Children Living With Cancer, under Managed Care to Traditional-Fee-For-Service

Steps to Obtain a Referral to a Specialist	N	Percentage	
More steps	43	59.7%	} 94.4%
Somewhat more steps	25	34.7%	
Same	3	4.2%	
Fewer steps	1	1.4%	
TOTAL	72	100.0%	

(e) Accessibility of Location

Accessibility of location is another key factor looked at in the literature, since managed care often limits referral to specific contracted providers. The providers are not contracted based on location of patient, but upon a host of cost and quality factors. Location is also a factor for in-network, as opposed, to out-of network providers. An in-network provider, who will provide the service at no additional cost or for small co-pay, may be in another city or state. An out-of-network provider maybe in the same city or state, but would require a significant out-of-pocket deductible under some managed care contracts. The fee-for-service contracts would also require a deductible but offer greater flexibility and choice of providers.

The only example of the impact of managed care on children living with cancer in the literature by a pediatric oncology social

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

worker is about the location of facility for a child requiring a transplantation (Weston & Lauria, 1996). Under the child's managed care contract, the child's two bone marrow transplants took place in two different hospitals in a state other than where s/he resided. Despite the accessible location of a very well equipped hospital offering the same procedure in the child's hometown.

In this study, (Table 13) 20.3% (15) of the respondents observed "less accessibility" of location of providers between managed care and tradition-fee-for-service. The majority of the respondents 73% (54) observed the "same accessibility" of the location of health care providers. Only 2.7% observed "more" and 4.1% observed "somewhat more accessibility" of location of providers.

Table 13

Comparing the Accessibility of the Location of Healthcare Providers for the Majority of Children Living With Cancer under Managed Care to Traditional-Fee-For-Service

Location of Health Care Providers	N	Percentage
More accessible	2	2.7%
Somewhat more accessible	3	4. 1.%
Same	54	73.0%
Less accessibility	15	20.3%
TOTAL	74	100.0%

(f) Overall Satisfaction With Providers

A sizeable percentage of respondents, 46.7% (35), observed "less satisfaction" with providers under managed care. However, 46.7% also

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

reported the "same" level of satisfaction with the providers on managed care as compared to fee-for-service. (Table 14) No parents were "more" satisfied under managed care and only 6.7% (5) respondents indicated that majority of parents were "somewhat more" satisfied under managed care. Since "customer" or consumer satisfaction is another key premise of the move to managed care, it appears from this response rate that they are not achieving their goal with almost half of the respondents observing "less satisfaction" and none "more" satisfied.

Table 14

Comparing the Level of Satisfaction with Health Care Providers for the Majority of Parents of Children Living With Cancer under Managed Care to Traditional-Fee-For-Service

Level of Satisfaction	N	Percentage
More	0	0%
Somewhat more	5	6.7%
Same	35	46.7%
Less	35	46.7%
TOTAL	75	100.

(2) Coordination of Care

Coordination of care is essential for the delivery of health care to special needs children, such as children living with cancer (Cooke, 1993; DiVerde, 1995; Fox & McManus, 1998; Ross, 1993; Smith, Layne & Garell, 1994). It is also a highlighted feature of managed care. The managed care companies often employ case managers whose responsibility is the prevent redundancy and to streamline care (Gray, 1991; Hirsch & Barela, 1996; Hicks, Staelmeyer, & Coleman, 1993). For

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

some industry-based case mangers, it may mean coordinating all the benefits and requests for health care services within the insurance plan. For others, it may require identifying outside resources, such as waiver programs. Thus improving care and reducing medical costs.

Coordination of care, in this study, is examined in terms of: (a) overall availability of coordination of care, (b) assignment of managed care company case manager, (c) need to return to primary pediatrician for referrals, (d) assignment to oncologist as primary physician, (e) continuity of providers while on same plan, (f) continuity of providers when transfer to another plan, and (g) transfer of information between insurance carrier and hospital team.

(a) Overall Coordination of Care

Sixty-one percent (61%) of the respondents observed that the majority of the children under managed care received more overall coordination of care. (Table 15) Of the 61% of the respondents, 25.4% observed "more" and 35.6% observed "somewhat more" coordination of care. This is a very positive aspect of managed care since coordination of care is so essential to this population in which it is necessary to coordinate and advocate for many medical and psychosocial support services in order to achieve a positive outcome-survival.

However, in response to the same question, 22.5% (16) of the respondents observed the "same" level of coordination of care with 15.5% (11) of the respondents observed "less" coordination of care for the majority of children under managed care. (Table 15)

(See following page for Table 15)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 15

Comparing the Coordination of Care for the Majority of Children Living With Cancer under Managed Care to Traditional-Fee-For-Service

Level of Coordination of Care	N	Percentage	
More	18	25.4%	} 62%
Somewhat more	26	36.6%	
Same	16	22.5%	
Less	11	15.5%	
TOTAL	71	100.0%	

(b) Assignment of Case Manager

A case manager often provides coordination of care from the insurance carrier's point of view. Case managers may coordinate services covered by the insurance carrier, such as outpatient referral, home care, durable goods, transportation services and hospice. They may also be able to extend their services to coordinate government entitlements, which may in turn improve health care outcomes and decrease cost to carrier (Gray, 1991; Hirsch & Barela, 1996; Hicks, Staelmeyer, & Coleman, 1993). Many more children under managed care had case managers than in fee-for-service.(Table 16) The majority of the respondents, 67.7%, observed that 41-100% of the children under managed care had case mangers, while under fee-for-service, 24.2% of the respondents indicated that 41-100%, of the children had a case manger. Case management, therefore, is significantly more available to children under managed care.

(See the following page for Table 16)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 16

Percentage of Children with an Insurance-Carrier Case Manager under Managed Care as compare to Fee-For-Service

Insurance Carrier	under 20%	21-40%	41-60%	61-80%	81-100%
Managed Care	11.9%	20.9%	28.9%	26.9%	11.9%
Fee-For-Service	45.5%	30.3%	10.6%	13.6%	0%

(c) Need to Return to Primary Pediatrician

The use of the primary pediatrician as the gate-keeper for referrals is another common feature of managed care. Usually, the insured child needs the written approval of the gate-keeper, the primary pediatrician, to obtain paid coverage for a specialist (DiVerde, 1995; Hirsch & Barela, 1996; Fox & McManus, 1998). As noted previously, this can be extremely time-consuming feature of managed care for children living with cancer.

Between 41-100% of the children had to return to their primary care pediatrician for a referral to a specialist according to 61.9% of the respondents. Of the 61.9% respondents, 38%, observed that 81-100% of children under managed care were required to use their primary pediatrician as the gate-keeper to referrals. For children living with cancer this is an added step detracting from the time and decreasing coordination of service for this population. Since most primary pediatricians know little about the complex needs and resources of this population.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

(d) Assignments to Pediatric Oncologists as Primary Physicians

An overwhelming majority, 71.6% (53) of the respondents, however, observed that less than 20% of the children under managed care were able to use their oncologist as the primary pediatrician. Only 6.8% of the respondents observed 81-100% of the children able to use their oncologist as their primary pediatrician.

Two of the coordinating research organizations, Childhood Cancer Group (CCG) and Pediatric Oncology Group (POG) are lobbying for the use of the pediatric oncologist as the primary pediatrician for this population (Murphy, 1996). This is an area that needs to be further addressed by pediatric oncologists and social workers if the vast medical needs of these children are to be met to save their lives and reduce cost.

(e) Continuity of Providers under the Same Plan

When children remained on the same plan, meaning they did not change insurance carriers, 66.2% (47) of the respondents observed "no difference" in the continuity of providers between managed care and fee-for-service. However, 19.7% of the respondents, did observed "less continuity" of providers for those children under managed care as compared to fee-for-service. This is a significant percentage considering there is no change of insurance carrier. In contrast, very few respondents (4.2%) observer "greater" continuity of providers under managed care as compared to fee-for-service.

(f) Continuity of Providers when Transferring to Another Plan

Greater disruption or change of health care providers was observed when children under managed care had to change plans. as compared to children under fee-for-service. Close to the majority of

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

the respondents, (47.9% or 34) observed that children under managed care experienced "less continuity" of providers when they had to change insurance plans than children under fee-for-service insurance plans. This is of particular concern since we are now living in an economy where people do not remain with the same employer for very long periods of time. Each change of employer may bring a change in health care insurer.

Even more complicated is when the oncologist the hospital may not be on the new plan or the reverse. Fee-for-service in comparison is a contractual relationship with the insured, therefore, it often allows for more portability thus greater continuity of providers.

Twenty-six respondents (36.6%) observe "no difference" between children under managed care or fee-for-service when there was a change in carriers. This points to the limitation of portability on fee-for-service observed by these 26 respondents.

(g) Transfer of Information

A good deal of information needs to flow between the insurance carrier and the hospital team, for example, coverage issues, coordination of care and service provider information. Close to the majority of the respondents, (48.6% or 34) observed "no difference," if the carrier was under a managed care model or a fee-for-service model. For 20.9% of the respondents, managed care did a better job than fee-for-service while, 18.6% who felt managed care did a "less" adequate job that fee-for-service with regard to the transfer of information.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

(3) Level of stress

The level of stress experienced by the families (parents) is another area of concern since families (parents) of special needs children are under considerable stress due to the child's medical and social needs (Fox and McManus, 1998; Gleason, 1998; Karlson, Sumi & Brach, 1990; Stein, 1989). Four factors related to the level of stress, experienced by families, were measured by (a) financial burden, (b) level of advocacy, (c) paperwork required and (d) time spent on telephone with insurance carrier. The pediatric oncology social workers were asked for their observation of the level of stress experienced by these families since they worked with these families on a daily basis and help them manage their stress levels. The respondents also had an opportunity to elaborate on additional factors that have either increased or decreased the stress on parents under a managed care system, as compared to a fee-for-service system.

(a) Financial Burden

Managed care presents "less" financial burden according to 44% of the respondents, while 36% see it presenting as "more" and "somewhat more" of a financial burden. Twenty percent (20%) of the respondents view managed care and fee-for-service as presenting the "same" financial burden.

Managed care can be viewed as less of a financial burden for families where their providers have contracts with their insurance carrier, thus necessitating little or no out-of-pocket expenses. Also, where medications are covered with a small co-pay, there is a saving of large sums of money when a child is on multiple medications. But it can be viewed as "more" of a burden when the providers do not have a

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

contract with the parent's insurance carrier and the parents must pay out-of network costs. These may be higher than the fee-for-service costs.

There are some managed care contracts that require a small co-pay of ten to fifteen dollars per visit which is quite nominal. But this is no longer nominal, if you have five to ten visits per week with different providers such as oncologists, radiologists, laboratory tests or five days per week of radiation for six weeks. Then these "nominal" co-pays can be expensive. Some plans limit weekly out-of-pocket co-pays while others have no stipulation for a limit.

Others may see that under managed care, some families experience more out-of-pocket costs for uncovered expenses such as experimental procedures or stem-cell searches, even though the actual stem-cell transplant is covered. Experimental procedures, which are procedures that are classified as standard treatment for a specific diagnosis, may not be covered at all. Many "standard procedures," in cancer treatment started out as experimental procedures. This distinction between standard and experimental treatment is not as clear-cut for pediatric cancer. Since "experimental procedures" may be the only hope for a cure or a remission of a rare or advance pediatric cancer diagnosis.

(b) Level of Advocacy

The level of advocacy to obtain services is another area of stress for families living with a child with cancer. How much do they have to advocate for their child to obtained desired or needed services? The literature sees advocacy as a key factor in making managed care work

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

well for special needs children (Gleason, 1998; Karlson, Sumi & Brach, 1990; Freud & Lewit, 1993; Fox & McManus, 1998).

Overall greater advocacy by the parents was observed by 86.5% of the respondents. (Table 17) Of the 86.5% respondents, 47.3% observed "greater" advocacy, while 39.2% observed "somewhat greater" level of advocacy, as compared to parents under fee-for-service. Only 2.7 percent (2) of the respondents felt that managed care required a lower level of advocacy.

Table 17
Comparing the Level of Advocacy Required for the Majority of Parents of Children Living With Cancer under Managed Care to Traditional fee-For-Service

Level of Advocacy	N	Percentage	
More	35	47.3%	} 86.5%
Somewhat more	29	39.2%	
Same	8	10.8%	
Less	2	2.7%	
TOTAL	74	100.0%	

(c) Paperwork

Burdensome paperwork was one of the areas to be streamlined under managed care, which could lead to reduction of the level of stress on parents. The paper trail is between the provider and carrier rather than the parents (insured) and the provider. This reduced paper trail was also seen as a potential cost savings. The insured were no longer required to submit forms to the provider.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

However, 64.3% of the respondents observed between overall more paperwork. Of the 64.3%, 38.6% observed "more" paperwork and 25.7% observed "somewhat" more paperwork was required by managed care, as compared to fee-for-service. (Table 18) Although managed care has reduced the transfer of forms between the insured and the provider social workers felt there was an increase of paperwork for each and every referral.

While 24.3% (17) did observe "less" paperwork and 11.4% (8) observed "no difference" between managed care and fee-for-service with regard to paperwork.

Table 18

Comparing the Amount of Paperwork Required by the Majority of Parents of Children Living With Cancer under Managed Care to Traditional Fee-For-Service

Level of Paperwork	N	Percentage	
More	27	38.6%	} 64.3%
Somewhat more	18	25.7%	
Same	8	11.4%	
Less	17	24.3%	
TOTAL	70	100.0%	

(d) Telephone Contacts

Some feel that paperwork has been replaced by burdensome telephone contact with the insurance carrier for telephone authorization, notification of use of emergency room, change of primary care physician or renewal of medications, to name a few telephone required procedures (Cartland & Yudowsky, 1992; Capps, 1996). The respondents did see a signifcant increase in a use of the telephone for managed care-covered families as compared to fee-for-service families. An overwhelming majority of respondents, 71.5% observed an overall increase in required phone use. Of the 71.5%, 42.9% of the respondents observed "more" and 28.6% respondents observed "somewhat" more of an increase in the use of telephone contacts under managed care. The same percentage, 14.3%, see the "same" or "less" amount of phone contact for managed care-covered families as compared to fee-for-service covered families.

Table 19

Comparing the Amount of Telephone Contact Required by the Majority of Parents under Managed Care to Traditional Fee-For-Service

Amount of Telephone Contact Required	N	Percentage	
More	30	42.9%	} 71.5%
Somewhat more	20	28.6%	
Same	10	14.3%	
Less	10	14.3%	
TOTAL	70	100.0%	

(e) Qualitative Data on Additional Factors that Increase or Decrease Stress

When given the opportunity to elaborate on the increase and the decrease of stress experienced by parents, 70% (59) of the respondents completed this question. Sixty-four percent of the responses elaborated on how managed care has increased stress for families, while only 30% of the responses elaborated on how managed care has decreased the stress.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Stress is a significant factor in the lives of families with cancer-diagnosed children since they must live with the uncertainty that the cancer can be fatal. In addition, treatment brings with it considerable unpleasant short-term side effects (Adams, 1989; Adams-Greenly, 1989; Gleason, 1998). In addition to medications to reduce the side effects, numerous psychosocial support programs have been designed to reduce others stresses (Adams, 1989; Cincotta, 1993; Karlson, Sumi, Bracht, 1990).

(1) Increase stress.

Content analysis of the qualitative responses related to an increase of stress yielded 6 categories: (1) the referral process, (2) the lack of choice of provider, (3) uncovered medical costs, (4) the limitation of coverage, (5) the understanding of their contract and (6) the coordination of care. "Referral process" and "lack of choice of provider" led the list of stresses experienced by families under managed care. (Table 20)

Table 20
Factors that Increase Stress for Families Covered by Managed Care

Factor	N	Percentage
Referral Process	19	27%
Lack of Choice of Provider	18	26%
Uncovered Medical Costs	11	16%
Limitation of Coverage	9	13%
Understanding Policy	7	10%
Coordination of Care	6	8%
TOTAL	70	100.0%

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

One respondent describes the referral process an"...additional logistical burden with need to go to one primary care physician for referrals before going to a specialist...and having to get a referral for every single visit."

> According to another social worker it is a:
> ...complicated system of getting authorization for every visit and treatment, especially when patient comes into the clinic sick and cannot be seen until authorization [is] acquired. It is hard for providers to sit there and wait to get telephone authorization before they can treat a child living with cancer, but if they do not, the family will have to carry the financial burden of that treatment.

> According to another social worker:
> ...not all primary physicians understand [the] medical care system...they sometimes refer to program specialists not used by the patient's system....

Thus time is lost for the patient, each time a referral is needed you start the process over again. Each time a primary care physician sends them to a specialist not covered by their plan it delay the treatment even further.

Parents are left with the added responsibility to "...make sure all the 'rules' are followed so that visits/procedures are authorized." " ...certain specialized treatments [are delayed] while asking for authorization..." The approval process includes getting authorization to purchase a piece of equipment for a particular price," "...price approval." This becomes an additional burden on families.

The second most frequent response regarding managed care's increasing the stress on families was the lack of choice of provider.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

"Parents don't like a lack of choice of doctors." Another social worker describes "...limited choice of provider[s] [which] ...may mean the insurer wants [to] transfer to a different facility..."

> Another social worker notes that:
> many parents may not be able to chose the facility or doctor they feel most comfortable with or is closest to home since their managed care insurance contract may dictate which facility or doctors may be used.

There may be great discrepancies in their choice of doctors or facilities For example, "...requirements [of the managed care company may be] to have labs ...performed at a managed care contracted sites which are not trained to handle pediatrics."

Another social worker observes that: "Many parents are surprised by services or specific providers that are not covered." Another describes: "[for] one family, the scan [done by the radiologist] was paid for but the radiologist was out of network." This means the actual scan or test was paid by the managed care company, but the radiologist's fees were not since s/he was not a participant in the plan.

"Not all specialty services are covered" which becomes a stress for families of children living with cancer when they learn they need multiple specialists due to the nature of the disease and treatment. "There is a limitation on [some services, such as] mental health services..," according to another pediatric oncology social worker.

Of the eighteen responses regarding lack of choice, eight (44%) specified a lack of choice when a stem-cell transplant was needed. It is "more difficult to get a bone marrow transplant approved..." The first issues is getting the procedure approved even if it is not considered "experimental" by the child's doctor but viewed as "experimental" by

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

the managed care company. The managed care company's understanding of the current literature may not be the same as the pediatric oncologist who is more current than the literature. It is not the child's doctor who decides this thus, it is decided by the insurance contractor. It is then "stress[full] regarding approved transplant centers-if [the] medical doctor recommend someplace not covered by insurance."

Some families even "...switch to another managed care Medicaid [plan] in order to get a bone marrow transplant from another facility..." according to one pediatric oncology social worker. Another social worker noted [there are] "...limited choice of sites for bone marrow/stem-cell transplantation."

A repeated issue identified by these social workers was that "It is very confusing to the parents when a bone marrow transplant is covered but donor search is not." One cannot have a "covered" transplant unless a donor is located and donors cannot be located without searches. All of these search procedures (previously described) involve significant costs. The quantitative data points to the inconsistencies within managed care contracts and clearly among contracts.

Sixteen-percent (11) focused on how finances related to managed care increase stress on families. Certain procedures are not covered by some managed care companies, which are commonly needed by children living with cancer. For example, there is a significant need for blood transfusions for this population. "Managed care companies do not pay for blood products, this is a big problem for hematology/ oncology patients."

Availability of cash for co-payment presents another uncovered medical cost "...sometimes 3-4 times per week." or "multiple co-payments (hospital and medical doctors) for the same OP [outpatient] visit." Families sometimes are asked for $50-60 weekly when they see three doctors and have three procedures within one week. This is not that uncommon for children receiving daily radiation or chemotherapy on an outpatient basis requiring laboratory work or physician monitoring for the procedure beside the laboratory technician or nurse's involvement.

Then there is the issue of "claims being paid out of network despite having to reprocess claims." This refers to services not covered by the in-network portion of the plan being referred to the out-of-network portion of the plan, which pays at far less lower rates, but has fewer restrictions. Managed care companies can determine the service falls under the out-of-network portion of the contract even if the insurer feels they have a right to have them considered as part of their in-network coverage.

"Reimbursements of medical services in a less timely manner to providers resulting in referrals to collection [agencies]" is another stressor. While insurance companies decide if they will cover a procedure or if they are having difficulty on their end with the paperwork trail, they will delay payment. Providers not paid in a timely fashion by a managed care company have no recourse except to bill the family since they, and not the managed care company are ultimately responsible for their child's medical expenses. Families have been known to receive bills from providers, which are in dispute with their managed care company or told they are in the process of being paid by

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

their managed care company. They learn months later from the providers' collection agency, however, that the provider has never received payment. This is clearly a stressor for families since at that point they can receive a bill for large sums of money and demands of unkind collection agencies.

Again, the family carries the ultimate responsibility, even if a provider refers to an uncovered service, the family may have to pay for the service, if it indeed is not covered by the managed care contract. One respondent indicated that "...not all primary physicians understand the medical system; they sometimes refer to a program [specialist] not used by the patient's system, so the family has to pay additional fees [out-of-network] or transfer once they get started."

(2) Decrease stress.

Managed care has also potential to decrease stress on families. Health policy analysts are interested in studying the effects of managed care on special needs populations to determine if some of the new managed care measures are beneficial. Not only in terms of outcomes, but in terms of quality of life issues such as customer or consumer satisfaction. Reduction of stress is clearly a customer satisfaction indicator (DiVerde, 1995; Fox, et al, 1990; Freund & Lewit, 1993, Hirsch & Barela, 1996; Karlson, Sumi & Bracht, 1990; Kongstevedt, 1993). For this reason, the respondents were given the same opportunity to indicate how managed care has decreased stress for these families.

Far fewer pediatric oncology social workers, however cited how managed care decreases stress than how it increases stress for families. Of the total 101 responses to questions regarding stress on families,

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

only 30% (31) of the responses chose to describe how managed care decreases stress on families. These 31 responses, however, are important to look at since they point to the positive benefits of managed care. It is clear there are some contradictions between those that indicate managed care increases financial burden on family while other point to managed care as reducing medical costs for families. This is related to the great variability of managed care contracts. Those social workers who speak of the potential for decreasing stress have experienced managed care companies offering adequate and comprehensive benefits (Fox & McManus, 1998). These responses point to where managed care features can be stress reducing for families.

The three most significant ways managed care has decreased the stress for families are: (1) reducing medical costs, (2) providing coordinated care (case management) and (3) providing comprehensive coverage. (Table 21) Some respondents may have offered more than one category.

Table 21
Factors that Decrease Stress for Families Covered by Managed Care

Factor	N	Percentage
Reduce Medical Costs	16	52%
Coordination of Care	8	26%
Comprehensive Coverage	7	23%
TOTAL	31	100.0%

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Sixteen of the respondents listed the decrease of the reduction of medical costs as the most significant way managed care as decreased the stress on families. Even though this is in contradiction to those who felt managed care increased financial burden, these respondents referred to positive aspects of some managed care contracts which were working effectively to help the families. These contracts had no or very limited out of pocket expenses, if the participant used to a contracted provider. Some contracts, according to the respondents paid for lodging when the provider was out of state. Some companies did not bill for equipment. while others required only one visit fee, per week costing $0-15. Other companies had no deductible costs, while other companies provided better prescription coverage than fee-for-service. These are fine examples of the how managed care can reduce the financial burden on these families, thus reducing their overall stress.

Coordination of care, which is usually through a case manager was the cited by 26% (8) and was second most frequent aspect of managed care that reduced stress for families. Case management is the feature of managed care that has been viewed as being most beneficial for a special health needs pediatric population (DiVerde, 1995; Fox & Mc Manus, 1998; Fox, et al, 1990; Freund & Lewit, 1993; Hirsch & Barela, 1996; Jellinick, 1994; Karlson, Sumi & Bracht, 1990; Newacheck, et al, 1994; Regenstein, et al, 1994).

The respondents see the benefits of the case manager. On social worker noted: "...there is a case manager who is on top of the child's situation which helps family versus fee-for-service where many times no one seems to know what is going on." Another social worker

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

observed that "RN case managers and social work case managers are advocates that coordinate care." Thus the case management feature of managed care is viewed as a real benefit to these families especially when evaluated by the social workers as fulfilling an advocacy or streamlining function. Although case management is viewed as a benefit, it is not consistently available even within managed care companies and differs as to availability and definition among case management companies.

Spragin (1998) indicates that HMO's had no consistent system of assignment of case management; in one survey, 61% of HMO's accepted a family request for case management, but only a very small percent of those receiving case management obtained it through a family request. Caseloads of case mangers, in the same study, varied from 14% of the plans reporting a caseload of 20 patients with 17% of the plans reporting a caseload of 120 patients per case manager. Only 65% of the case management plans coordinated outside supports. This means that 35% of the managed care companies do not coordinate benefits outside of their insurance contract, therefore they would not coordinate or refer to governmental entitlements, schools or community-based benefits. As noted in the description of this population, many of children living with cancer have multiple medical and psychosocial support needs.

The comprehensive coverage offered under some managed care plans has decreased stress for families, according to seven responses (23%). This includes benefits such as prescription plans, well-child services, optical plans, and laboratory coverage with limited co-

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

payments rather than major medical deductible that could cost hundreds of dollars per person and more per family.

(B) Impact on service delivery: Managed care's policies and guidelines

In the previous section, the survey instrument focused on the impact of managed care on the child and the family. In this section the survey instrument focused on the impact of managed care on the delivery of service. The three key identified areas of delivery of service were 1) time frame 2) decision-making and 3) referral process. All three areas were cited in the literature as crucial factors to service delivery that have been impacted by managed care.

(1) Time Frame

Time frame refers to the "length of stay" (LOS), which is the time spent in the hospital covered by the insurance carrier. This has been referred to in the popular press as the "drive through" approach to medical care (Hagland, 1997; "Insurer's assailed..," 1995; Rodwin, 1995, Schwartz, 1998; Ware, et al, 1996). The responses to such time requirements of managed care has been new legislation aimed at setting minimum standards such as "2-Day Maternity Stay Promised" (Maier, 1995).

Changes in lengths of stay for children living with cancer refers to shorter stays in the hospital, greater use of outpatient facilities and moving certain procedures, such as pre-operative work-ups from an in-patient procedure to an outpatient procedure. Day-surgical units have expanded in most hospitals to accommodate more procedures on an outpatient basis. This means children arriving at 6 AM and being discharged at 6 PM. Previously children would have been hospitalized

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

during an intensive infusion of chemotherapy, since it often results in drastic reduction of blood counts which leaves them susceptible to infections, listless and feverish. Now children are discharged right after the drug is infused and immediate reactions are not noted. For many, this lead to return within a day often rushed in via car service since they are too ill to even use public transportation.

Home care is preferred by managed care to hospitalization, which means a parent must take off more time or leave employment completely to become the caregiver, since nurses or aides can only visit for a short period of time. Even terminally ill children are sent home and nursing care is augmented with volunteers since even home-based nursing care is too expensive.

In comparing Fall '95 to Fall '97, there has been a greater thrust to reduce in-patient hospitalization under the auspices of managed care contracts. In fact, 68.6% (48) of the respondents observe a "shorter" length of stay during this time period. (Table 22) Children with cancer are being discharged home sooner. Parents thus must be more self-reliant to provide in-home care with the supports of home care services or frequent outpatient visits. Only 28.6% (25) of the respondents observed the length of stay as the "same" during this time period.

(See the following pages for Table 22)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 22
Changes in Length of Stay (LOS) From Fall '95 to Fall '97

Changes in Length of Stay	N	Percentage
Shorter LOS	48	68.6%
Same LOS	20	28.6%
Somewhat greater LOS	1	1.4%
Greater LOS	1	1.4%
TOTAL	70	100.0%

Was length of stay different under managed care as compared to tradition fee-for-service? Private or commercially provided coverage was also compared with publicly provided coverage such as Medicaid managed care. According to 49.2% (30) of the respondents, the length of stay is no shorter with managed care or fee-for-service either under private or public coverage. Length of stay, according to these 30 respondents is the result of overall change in our health care system.

Although 34.4% (2i) observed that those under private/commercial managed care policies have the shortest length of stay compared to only 6.6% (4) of those under private/commercial fee-for-service. Table 23 also indicates that the least restrictive coverage in terms of length of stay was fee-for-service/public coverage which would be a traditional Medicaid.

(See the following pages for Table 23)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 23
Which Type of Insurance Coverage Requires the Shortest Length of Stay?

Insurance Coverage	N	Percentage
No difference	30	49.2%
Managed care, private	21	34.4%
Managed care, public	6	9.8%
Fee-for-service, private	4	6.6%
Fee-for-service, public	0	0
TOTAL	61	100.%

(2) Decision-Making

This decrease in length of stay requires extensive support services offered by a wide range of health care providers who are assisting children living with cancer. Some of the significant support services needed to facilitate shorter hospitalization include: (a) discharge planning, (b) home care, (c) durable equipment, (d) transportation, (e) community support referrals, (f) mental health referral, (g) temporary housing, (h) school support, (i) 2nd opinions, and (j) hospice referral. For each of these services, one health care provider must take primary decision-making responsibility. Decision-making is a key element in managed care to reduce duplication of service, streamline procedures to improve efficiency and reduce cost. Since decision-making is so essential to accomplish these goals, the primary decision-maker for each of the outlined services was

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

studied. Table 24 indicates the primary decision-maker under a managed care system while Table 25 indicates the primary decision-maker under a fee-for-service system.

Under managed care, the primary decision-maker regarding home care and durable equipment is the insurance company case manager, while under fee-for-service, it is the hospital's case manager. Children living with cancer have home care needs, such as visiting nurses, physical and occupational therapy. Meeting these needs facilitate a speedy discharge, as well as, improve adaptation to their life-threatening illness. The success of insurance based case managers will depend on their knowledge of this special populations' needs, as well as, access to specialized vendors.

In the fee-for-service system, the hospital case manager has this specialized background and has developed relationships with specialized vendors such as a pediatric visiting nurse agency or equipment company that handles pediatric sized equipment (Fox & McManus, 1998).

Second opinion was the only other area where respondents felt there was a difference between the two systems of health care. Under managed care, the family was the primary decision-maker for second opinions, while under fee-for-service, the hospital physician was observed to be the primary decision-maker. This clearly indicates a difference in primary decision-making from a medically based one in the fee-for-service to a parent advocate one in the managed care system. The literature describes fewer referrals made to specialists, such as second opinions, under a managed care system for special needs populations (Fox & Mc Manus, 1998; Fox, et al, 1990; Freund &

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Lewit, 1993, Jellinick, 1994; Karlson, Sumi & Bracht, 1990; Ware, et al, 1996).

The hospital social worker has primary decision-making responsibility for transportation, community support referrals, mental health referrals, temporary housing, school support and hospice referrals in managed care and fee-for-service.

(See the following pages for Table 24 and 25)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 24

Primary Decision-Maker for Support Services Under Managed Care

SERVICE	PRIMARY DECISION-MAKER								
	Hosp. MD	Hosp. SW	Hosp. RN	Hosp. CM*	Ins'ce** Co. MD	Ins'ce** Co. CM*	Primary Care MD	Family	Other
1-Discharge Planning				X					
2-Home Care					X				
3-Durable Equipment					X				
4-Transportation		X							
5-Community Supports Ref'ral***		X							
6-Mental Health Referral		X							
7-Temporary Housing		X							
8-School Support		X							
9-2nd Opinion								X	
10-Hospice Referral		X							

*CM= Casemanager; **Ins'ce= Insurance; ***Ref'ral= Referral

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 25

Primary Decision-Maker for Support Services Under Fee-For-Service

SERVICE	PRIMARY DECISION-MAKER								
	Hosp. MD	Hosp. SW	Hosp. RN	Hosp. CM*	Ins'ce** Co. MD	Ins'ce** Co. CM*	Primary Care MD	Family	Other
1-Discharge Planning				X					
2-Home Care				X					
3-Durable Equipment				X					
4-Transportation		X							
5-Community Supports Ref'ral***		X							
6-Mental Health Referral		X							
7-Temporary Housing		X							
8-School Support		X							
9-2nd Opinion	X								
10-Hospice Referral		X							

*CM= Casemanager; **Ins'ce= Insurance; ***Ref'ral= Referral

(3) Referral Process

With changes in primary decision-making have come changes in the referral process. It has become more complex and time consuming (Cartland & Yudkowsky, 1992; Capps, 1996; DiVerde, 1995; Fox and McManus, 1998; Fox, et al, 1990; Harrigan, 1995). The respondents reported on changes in their workload over the last two years (Fall '95 to Fall '97) with reference to the referral process. The referral process was defined by the various mechanisms that have now been put into place by managed care contracts: (a) written approval, (b) telephone approval, (c) primary MD approval, (d) insurance company case manager's approval, (e) use of restricted panel of vendors, (f) locating approved vendors, and (g) appeal process.

Each of these steps is time consuming and may deter delivery of service. For example, if a managed care company only covers durable equipment from an approved vendor, the social worker needs to locate the vendor who will accept this managed care company's payment. The respondents reported an overall "increase" in their workload from 28.6%-48.5% for seven outlined referral processes. (Table 26) Only 16.9%-27.7% reported "no difference" in their workload and 1.4% reported a "decrease" in their workload for three of the seven outlined functions. These increases in workload were in obtaining the insurance company's case manager's approval, locating approved vendors and required primary MD approval. Managed care clearly has not lightened the workload of the pediatric social worker at all. Consequently for many social workers the demands of managed care has cut into direct service time spent with the children and families.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

From 32.9% to 42.3% reported these referral processes were "not applicable" to any changes in their workload. For the group that observed no applicable change in their workload, there are several explanations since 0-14% saw a decrease in their workload. Many of these social workers maybe in geographic areas where there is limited impact of managed care. Or their hospitals may have set up referral mechanism to manage these changes, such as a discharge planner or pre-admission coordinator who obtains all the necessary approvals from the insurance carrier. Some hospitals, for example, have designated a hospital case manager to obtain managed care approval for home care referral, for prior authorization for certain procedures, or transportation assistance.

The three areas, in Table 26, that the respondents indicated increased their workload were (a) insurance case manger's approval (48.5%), (b) locating approved vendors (42.3%), (c) appeal process (40.3%) and (d) telephone approval (38%). The greatest increase to the pediatric oncologist workload (48.5%) was obtaining the insurance company case manager's approval for a referral.

(See the following page for Table 26)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 26

Changes in Workload Between Fall '95 to Fall '97 with reference to the Referral Process

Referral Process	Increased WL*	No Difference	Decreased WL*	N/A**
1-Insurance Co. CM's Approval	48.5%	17.1%	1.4%	32.9%
2-Locating Approved Vendors	42.3%	16.9%	1.4%	39.4%
3-Appeal Process	40.3%	19.4%	0%	40.3%
4-Telephone Approval	38.0%	26.8%	0%	35.2%
5-Primary MD Approval Required	34.3%	27.7%	1.4%	38.6%
6-Written Approval	32.4%	26.8%	0%	40.8%
7-Use of Restricted Panel of Vendors	28.6%	23.9%	0%	42.3%

* WL= Workload

**N/A= Not Applicable

(C) Impact on the pediatric oncology social worker

The changes in the health care system have impacted upon children and families as well as health care professionals. Studies have begun to look at the impact these changes have had on the roles of pediatricians and nurses (Halm, Causino & Blumenthal,1997; Cartland & Yudkowsky; Hicks, Staelmeyer & Coleman, 1993; Jellineck, 1994; Grumbach et al, 1998). Pediatricians are taking more responsibility in managing the complex care of special needs children in private practice and clinic settings. Nurses have expanded their role to follow patients in the community on a home care basis as well as becoming case managers in the hospital setting and for managed care companies.

The social worker literature has looked at managed care's impact primarily in mental health, but has begun to pay attention to its impact upon medical social work (Cornelius, 1994; Mizrahi, 1993; Hamilton, 1996; Perloff, 1996). Mental health interventions are becoming short-term and crisis-oriented with a shift from individual interventions to group interventions. Medical social workers have moved from an in-patient setting to the outpatient setting with emphasis on disease and resource management.

In this final section of this study, the role of the pediatric oncology social worker is analyzed in terms of changes in functions over from Fall '95 to Fall '97. The four main areas studied are: 1) workload, 2) clinical functions, 3) professional identity, and 4) new professional opportunities.

(1) Workload

The fifteen-workload functions studied include: (a) advocacy, (b) overall administrative responsibility, (c) case management,

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

(e) overall clinical responsibility, (f) coordination with insurance carrier, (g) delivery of concrete services, (h) discharge planning, (i) financial assessment, (j) program development, (k) marketing, (l) research, (m) resource management, (n) teaching, (o) team coordination and (p) training. These functions are described in the pediatric oncology social work literature reflecting the diversity of this vital role on an oncology service. Almost all pediatric oncology social workers function as part of an oncology team in a medical setting (Adams, 1989; Adams-Greenly, 1989; Cincotta, 1993; Ross, 1978,1993).

The responses in Table 27, indicate "increased workload:" ranging from 64.3% regarding the advocacy function to 7.4% regarding the marketing function. The five functions, which represented the greatest increase in workload were: advocacy (64.3%), delivery of concrete services (49.3%), team coordination (48.6%), financial assessment (42.0%), and teaching (39.9%). The decrease in workload was far less dramatic with discharge planning (11.3%), case management (10.3%), and clinical responsibility (8.6%) listed as the three functions decreasing in the workload. Discharge planning and case management has moved from a pediatric social work function to a centralized discharge planner and or case manager in many medical centers. There were no significant results in "newly added" functions.

(See the following page for Table 27)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 27

Changes in Workload Between Fall '95 to Fall '97

Function	Increased WL*	No Difference	Decreased WL*	Newly Added
1-Advocacy	64.3%	34.3%	0%	1.4%
2-Delivery of CS**	49.3%	45.1%	5.6%	0%
3-Team Coordination	48.6%	50.0%	1.4%	0%
4-Financial Assessment	42.0%	56.5%	1.4%	0%
5-Teaching	39.9%	65.3%	2.8%	0%
6-Coord. with IC***	39.1%	55.1%	2.9%	2.9%
7-Resource M'gtment	39.1%	59.4%	1.4%	0%
8-Clinical Resp.	34.3%	55.7%	8.6%	1.4%
9-Program Dev.	34.3%	57.1%	5.7%	2.9%
10-Training	31.0%	66.2%	1.4%	1.4%
11-Case Management	30.9%	55.9%	10.3%	2.9%
12-Adm'tive Resp.****	29.2%	67.7%	3.1%	0%
13-Discharge Planning	23.9%	63.4%	11.3%	1.4%
14-Research	16.7%	74.2%	4.5%	4.5%
15-Marketing	7.4%	85.3%	2.9%	4.4%

*WL= Workload; **CS= Concrete Services; ***IC= Insurance Carrier; ***Adm'tive Resp.= Administrative Responsibility

(2) Clinical function

With an increased workload regarding advocacy, delivery of concrete services, team coordination, financial assessment, and teaching, how have the clinical functions of the pediatric oncology social worker faired? Children and their parents coping with cancer need extensive emotional support in order to deal with this life threatening diagnosis. Also they need counseling regarding managing demanding treatment protocols and making decisions, such relocating a family during a child's treatment. A parent may need counseling regarding giving up employment to care for a child or to relieve the stress on their marriage due to lengthy separation. In addition decisions such as which surgery to chose when bone cancer is the diagnosis: amputation or limb salvaging also weigh heavily on families. Learning or other cognitive disabilities secondary to brain radiation or possible future infertility secondary to chemotherapy are other areas of emotional stress for children, teens and parents. Parental support during end-stage decision-making and bereavement counseling are also significant clinical functions of pediatric oncology social workers. Respondents were queried as to: (a) availability to provide counseling, (b) the use of individual counseling as compared to group work with children and parents, (c) changes in use of crisis intervention, (d) changes in use of phone contact, and (e) changes in use of community-based support for the children and their parents. In addition, the study looked at (f) the parent's need to be self-reliant.

(a) Availability to Provide Counseling

Almost half of the respondents indicated "less availability" over the last two years (Fall '95 to Fall '97) to provide counseling to the

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

majority of the children (48.6% respondents) and their parents (45.8% respondents). (Table 28) These results correspond with the above data regarding 64.3% of the respondents seeing an increase in their advocacy function and 49.3% seeing an increase in their delivery of concrete services function with only 34.3% seeing an increase in their clinical function. Although the numbers of children diagnosed has not altered significantly in the last two years, the emotional support provided has.

Less than half of the respondents felt they had the "same availability" for the counseling the children (43.1%) and for the parents (44.4%). "Increased" availability for counseling was almost unheard of with 2.8% of respondents reporting "more" availability to both children and parents.

Table 28
The Availability of the Pediatric Oncology Social Worker Over the Last Two Years to Provide Counseling to Children and Their Parents

Availability	Target Population	
	Children	Parents
Less availability	48.6%	45.8%
Same availability	43.1%	44.4%
Somewhat more available	5.6%	6.9%
More available	2.8%	2.8%
TOTAL	100%	100%

(b) Changes in use of Individual and Group Work

Has the decrease in availability to provide counseling influenced pediatric oncology social worker practice in the use of individual or

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

group work interventions? The majority of the respondents indicate they are using individual and group at the same rate as they were two years ago for both children (62.5%) and parents (54.3%). Table 29, however, also shows that 24.3% of the respondents are doing "more" group work, while 21.4% were doing "more" individual work over the last two years with parents. These figures indicate there is no strong trend toward either intervention, however, other interventions, such as, phone contacts, advocacy and provision of concrete services has clearly increased.

Table 29

Changes in the Use of Individual Work Compared to Group Work by Pediatric Oncology Social Workers with Children and their Parents in the Last Two Years

Use of Individual/Group Work	Target Population	
	Children	Parents
Same use of individual and group work	62.5%	54.3%
More individual work	19.4%	21.4%
More group work	18.1%	24.3%

(c) Crisis Intervention

With such a sizable percentage of pediatric oncology social workers reporting "less availability" for counseling, has there been a change in the use of crisis intervention over the past two years? (Fall '95 to Fall '97) Close to the majority of the respondents (47.9%) reported "greater/somewhat greater" use of crisis intervention for children and 53.4% greater use of crisis intervention for the parents.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

(Table 30) For children, 45.2% of the respondents reported the "same" use of crisis intervention and for parents, 43.8% of the respondents reported the "same" use of crisis intervention. Parents of children living with cancer and children living with cancer are no longer afforded on-going clinical support, but crisis-oriented support under the current health care delivery system, according to these respondents. There is no data to indicate this is advantageous or disadvantageous, therefore remains an area for future study.

Table 30
The Changes in the Last Two Years in the use of Crisis Intervention Pediatric Oncology Social Workers with Children and their Parents?

Use of Crisis Intervention	Target Population	
	Children	Parents
Greater/somewhat greater use	47.9%	53.4%
Same use	45.2%	43.8%
Decrease use	6.8%	2.7%
TOTALS	100%	100%

(d) Phone Contacts

With the decrease of length of stay and the reported changes in the use of counseling and crisis intervention, have the pediatric oncology social workers changed their use of phone contacts with the children and their parents? According to the respondents in Table 31, phone use has not significantly changed in relationship to the children, but a total of 50.0% of the respondents indicate a "greater/somewhat greater" increase in the use of phone contacts with parents.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

The phone may be the substitute for in-person contacts due to shorter lengths of stay and limitations on clinical time. There are no studies available to determine if the quality of the phone contacts compares with in-person contact.

Table 31

The Changes in the Last Two Years in the Use of Phone Contacts Pediatric Oncology Social Workers with Children and their Parents

	Target Population	
	Children	Parents
Greater/somewhat greater use	24.4%	50.0%
Same use	58.1%	41.9%
Decrease use	17.6%	8.1%
TOTAL	100%	100%

(e) Community-based Supports

With shorter hospital stays, less counseling intervention and more crisis intervention, community-based supports have been viewed as needed resource for children and parents. These community supports include: financial aid, camps, special trips/events, holiday gifts, school placements, "wish" referrals, transportation assistance, cancer-specific counseling, psychoeducational programs, free prosthetic devices, local, state and federal entitlements (Cincotta, 1993; Ross, 1978, 1993).

The respondents reported 67.5% greater use, of community-based supports for both children and parents over the last two years (comparing Fall '95 to Fall '97). Only 29.7% of the respondents reported the "same use" of community-based supports, as seen in Table 32.

These responses correspond to the responses on Table 27 where 64.3% of the respondents indicated their workload has increased due to advocacy and 49.3% indicated a workload increase due to delivery of concrete services. use of community resources has clearly been increased in the last two years, comparing Fall '95 to Fall '97.

Table 32

The Changes in the Last Two Years in the Use of Community-based Supports Pediatric Oncology Social Workers with Children and their Parents

Use of Community-based supports	Target population	
	Children	Parents
Greater/somewhat greater use	67.5%	67.5%
Same use	29.7%	29.7%
Decrease use	2.7%	2.7%
TOTALS	100%	100%

(f) Parental Self-Reliance

Have shorter lengths of stay, less available counseling and greater use of community-based supports required parents of cancer-diagnosed children to be more self-reliant over the past two years? The majority of the respondents (65.7%) viewed an increase of parental self-reliance over the last two years. (Table 33) Although self-reliance is a life goal for most, while under the emotional and financial assault brought upon by childhood cancer most parents need to rely upon relatives, friends and health care professionals to help them weather this family crisis. There are no studies on the benefits or detriments of

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

increase of parental self-reliance while coping with a cancer-diagnosed child. An earlier reported on question regarding the possible effects managed care had on increasing or decreasing stress for these parents revealed that these social workers responded in the overwhelming majority of situations that managed care increased stress. There was no question in this study nor are any other studies available that determines the benefits or deterrents of greater parent self-reliance in terms of increasing or decreasing stress.

Table 33

The Changes in the Last Two Years on Parent's Need to be Self-reliant

Parental Self-reliance	Percentage
More/somewhat more	65.7%
Same	32.9%
Decrease	1.4%
TOTAL	100.0%

(3) Professional Identity: Changes in the Role of the Pediatric Oncology Social Worker

As the health care system has changed over the last two years, impacting upon children living with cancer and their families the functions, role and professional identity of health care practitioners has changed. The literature cites that health care professionals, such as nurses or pediatricians, have begun to adapt their roles to the driving force of managed care. For instance, Hicks et al. (1993) describe a range of roles nursing has and can take on in this new environment.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

They note"...professionals are being forced to change their practice styles and delivery modes." (p. 41) Cartland and Yudkowsky (1989) They also see pediatricians balancing the role of patient advocate and resource manager. Since there was no literature on how managed care has changed the roles of pediatric oncology social workers, this study raised this issue.

(a) Changes in the role of the pediatric oncology social worker

Pediatric oncology social workers in this study were asked about their perceptions of their professional identity under these changes in health care delivery over the past two years.

The respondents are about evenly divided regarding any changes in their professional identity. (4) Thirty-six respondents (49.3%) view "significant/somewhat significant" change in their professional identity as pediatric oncology social workers, while 50.7% see "no change" over the last two years. (Table 34) Considering 39% of the respondents reported they were in the field less than three years, the 50.7% probably reflects that population and a small margin of respondents with more than three years. It is suspected that the great majority of those with over three years experience observe the changes in professional identity since they are in the field longer.

(See the following page for Table 34)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 34
Changes in the Professional Identity of Pediatric Oncology Social Workers in the Last Two Years

Amount of change	N	Percentage
Significant/somewhat change	36	49.3%
No change	37	50.7%
TOTAL	73	100%

When given the opportunity to elaborate on the changes regarding their professional identity over the last two years, twenty-five responded identifying twenty-seven changes. Employing content analysis, the responses fell into two major categories: role change (13) and administrative change (9). The remaining responses (5) did not fit into any categories.

Some social workers focused on "shifts in 'priorities' in the social work role "...less counseling and more... concrete resources, referral and crisis [intervention]...more outreach than in previous years." "Less time to do formal therapy/counseling...." Many felt that social work had to "...continue to fight for [our] existence since we do not generate revenue." Others noted the increased importance of the role of social workers in such resource scarce times with opportunities for research. These conflictual sentiments about their professional identity is captured by one respondent who described ongoing changes in her title since 1995, "...all social workers were called *discharge planners* in 1995, then switched back to *social workers.*" This worker captures how

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

in some departments titles and/or functions have changed and even reverted back to original titles and/or functions.

The administrative changes they cited that affected their professional identity related to departmental changes that included: "...department shifts from having a social work director to everyone being 100% front line." "A focus back on social work accountability and supervision leadership from an initial *mush* of one department comprised of social work, pastoral [care], child life, volunteers." While another department was moving toward the *mush* of "social work, case management (new department of RNs), and performance improvement ... blended into Outcomes Management. RN is supervisor." One reported a department that was downsized by 1/3-"now is coming back [with a] number of positions." Professional identity has been influenced by "lots of staff changes and the directorship has changed various times and ways."

When given the opportunity to describe any other changes in their clinical role in the past two years, 23% (20) responded by writing one to four sentences about these changes. Of the twenty responses, twelve referred to "more" or "increase" with reference to work with children and families. They describe "...more unusual array of clinical work-picking up some pieces-more bereavement work-more work that doe snot fit into other categories...such as increase involvement with oncologist in family conferences...developing/enhancing more programs or more groups... more financial problems with families [and increased need for] concrete sources."

Less availability to "...do much medical play [form of play therapy] with kids, ...shorter sessions with parents-much more directive in approach." "Less time overall for social work interventions...Less time spent on parent education." Another social worker observed that "...crisis intervention now entails getting parent dated authorization...I'm stretched too thin- has been getting worse."

(b) Professional opportunities

Have the changes or shifts in the professional identity for some pediatric oncology social workers also meant changes in professional opportunities? These respondents indicate that the last two years has meant 46.1% increased opportunities with 14.5% "more" and 31.6% "somewhat more" professional opportunities. Table 35 identifies that 35.5% saw the same opportunities over the last two years while 18.4% saw "fewer opportunities." The increase of professional opportunities may appear to be conflictual since they describe the reduction of counseling but at the same time have been asked to be involved in new areas and "spread thin" to take on increased responsibilities. Thirty-seven of the eighty-four respondents took the opportunity to describe the new professional opportunities they have experienced in the last two years. These included program development/marketing, clinical, administrative, teaching/training, conference attendance and participation and research opportunities. The thirty-seven respondents were enthusiastic about these varied and challenging opportunities, but do they see future opportunities for the professions?

(See following page for Table 35)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 35
<u>Professional Opportunities Experienced by Pediatric Oncology Social Workers in Last Two Years</u>

Amount of opportunities	N	Percentage	
More opportunities	11	14.5%	}46.1%
Somewhat more opportunities	24	31.6%	
Same opportunities	27	35.5%	
Fewer opportunities	14	18.4%	
TOTAL	76	100.0%	

4.New Opportunities

The respondents were not as optimistic about future professional opportunities as they were about opportunities afforded them over the last two years. Whereas a total of 46.1% viewed "more" professional opportunities in the last two years, only a total of 39.5% viewed "more" professional opportunities in the future. Just about a same percentage of respondents felt there were "fewer "professional opportunities in the last two years, 18.4%, as those who felt there will be "fewer" professional opportunities, 18.3% in the future. Table 36 illustrates the responses regarding future professional opportunities. The future seems a bit less promising than the past two years to some of the respondents.

(See following page for Table 36)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 36

<u>Professional Opportunities Envisioned by Pediatric Oncology Social Workers</u>

Amount of opportunities	N	Percentage	
More opportunities	10	14.1%	39.5%
Somewhat more opportunities	18	25.4%	
Same opportunities	30	42.3%	
Fewer opportunities	13	18.3%	
TOTAL	71	100%	

Only 26% (22) respondents elected to elaborate more on how they envisioned professional opportunities. This compares with 44% (37) who elected to elaborate on new opportunities they had in the last two years. The two areas most frequently identified were program development (10) and clinical opportunities (7). The two other areas identified, however each area had only three respondents were case management and research.

The following section will summarize the significant findings in terms of service delivery to cancer-diagnosed children and their families, as well as implications for pediatric oncology social workers.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Chapter VI SUMMARY

The purpose of this exploratory and descriptive research project was to study the impact of managed care on children living with cancer and their families from a pediatric oncology social worker perspective. Eighty-four members of Association of Pediatric Oncology Social Workers (APOSW) completed a closed and open-ended self-administered survey which was designed by this author based upon a review of the literature and a 1995 qualitative pilot study. The thrust of the survey was on service delivery to cancer-diagnosed children and their families and the impact of managed care on the role of the pediatric oncology social worker. The pediatric oncology social workers who participated in the study were well informed regarding the issues since the mean years of experience in pediatric oncology was 6.3 years with 50% of them having between 4-12 years experience. Also 67.6% of the respondents reported that over 61% of their pediatric oncology patients were covered by managed care at time of the study.

This final section will highlight and summarize the most significant results of the study. Attention will be paid to the observations of the respondents as they have experienced the impact of managed care, as well as to recent literature that underscores and elaborates upon their observations. In addition, suggested alternative models from the literature will be discussed where the respondents point to an inadequacy in existing policies or guidelines.

(A) Impact upon Children and Families

The most significant results regarding the impact upon children and families point to cornerstone managed care policy and practice issues that affect the delivery of health care to this population.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

These policy and practice issues are: (1) access to specialists, (2) complexity of requirements to obtain care, (3) the time delay in the referral process, (4) the burden on the consumer (requiring greater parental self-reliance, (5) the transferability of providers among managed care plans, (6) satisfaction with providers, (7) increased level of stress on families and (8) decrease level of stress on families.

The increased level of stress experienced by parents of cancer-diagnosis children was in relationship to: the amount of required advocacy, the extent of required telephone contacts and the amount of paperwork.

On the positive side, there are several key features of managed care, as compared to fee-for-service, that improve service delivery and decrease the stress on parents. These are the provision of case management, coordination of care and less financial burden on families.

(1) Access to specialist

Managed care's concept of gate-keeping through the use of the primary care physician may be effective in producing good health outcomes and reducing medical expenditure on specialty care and expensive procedures for a healthier population. The pediatrician, in terms of children, would be the primary care physician. This policy, however, according to 94.4% of the respondents, viewed managed care as placing more steps to access specialty care for cancer-diagnosed children. This process of obtaining specialist care has not been in the best interest of this medically needy population.

Jeffrey (1996) and Harrigan (1995), respectively, in lead newspaper articles observe "Doctors battle over who treats the

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

chronically ill" and "HMO's score low on providing answers to the chronically ill looking for specialists." As each title implies, doctors are now in competition to treat the chronically ill. The gatekeepers for children, pediatricians, are now managing large numbers of chronically ill children in their general pediatric practices. Some pediatricians and health care policy analysts have begun to "accept" that chronically ill children can be treated by primary care pediatricians in what has been called a "medical home" (DiVerde, 1995 ; Hirsch & Barela, 1996 Fox & McManus, 1998; Szilagyi, 1998). They note there may be a need for additional training, an enriched reimbursement rate to compensate for extra time needed to meet the children's complex needs and additional staff to coordinate benefits and support services. Most of the special needs children described include those with developmental disabilities or chronic conditions such as asthma.

Although a "medical home" concept may be viable for some chronically and catastrophically ill children, it is hardly possible for cancer-diagnosed children. A wide range of sub-specialists depending on the nature and site of the malignancy treats pediatric cancer. The pediatric surgeon who would remove a kidney tumor would not be the same pediatric surgeon who would perform limb-salvaging surgery on a child with bone cancer. Children are treated with surgery, chemotherapy, gene-therapy, radiation and a wide range of transplantations. Each procedure requires a highly skilled specialist. The same child might require all of the above specialists in order to attempt to cure his/her cancer.

Following treatment, additional specialists may be needed to treat the long-term side effects: learning disabilities, short stature and

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

infertility. These complex processes are usually treated in major research centers or specialized children's hospitals. The respondents overwhelmingly noted that managed care polices and practices regarding accessing specialty care did not meet the needs of this population. Fox and McManus (1998) discuss the concept of "co-management" between a specialty service such as oncology and the primary pediatrician. This may be the more appropriate gate-keeping model for this population.

A very small percentage (6.8%) of the respondents indicates that managed care companies have acknowledged the pediatric oncologist as the child's gatekeeper. This is a practice that pediatric oncologist through their research groups have tried to lobby for with some of the major managed care providers (Murphy, 1996). This would prevent the enormous burden placed upon families to "go through hoops" in the words of several pediatric oncology social workers, to obtain timely access specialists.

(2) Complexity of Requirements

Over 90% of the respondents viewed the complexity of requirements to obtain care as the second most significant limitation of managed care. Managed care requirements were viewed as more/somewhat more complex than fee-for-service. In fee-for-service, the insured is free to seek treatment in a wider range of settings. Under managed care, the insurance company may be limited geographically such as XX Health Care which contracts with medical facilities in the greater XYZ area, thus would not reimburse a major cancer center in a nearby city. It is not uncommon when a child has a form of cancer treated by a few teams of oncologists around the country, the insured

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

would have to go through complex and burdensome prior authorization requirements to get this approved (Cartland and Yudowsky, 1992; Karlson, Sumi & Bract, 1990; Szilagyi, 1998). Prior authorization is time consuming and denial of treatment results in even more time consuming appeals. Due to the managed care consultants limited knowledge of a specific form of pediatric cancer, they may even disapprove payment to a medical center, which is not part of their managed care's system. This medical center, however, may be the only one in the area that has a pediatric oncologist specializes in this child's form of cancer. Paid access to such an appropriate specialist may take several denials until the medical needs of the child are truly understood by the managed care company.

When a transplantation of stem cells is required, as it is increasingly so with many leukemia diagnoses, the most common childhood cancer, the requirements appear to be even more complex. Transplantation, as note previously, involves several medical steps: systemic chemotherapy and radiation and the location of a donor. If a family member is not a matched donor, then a "search" through a national registry is required. The testing of family members or the search involves extensive costs. The social workers in this study often note the complexity of the requirements of many managed care companies, which pay for only part of this interdependent process. It almost appears some of the managed care companies do not understand the transplant process when they approve payment for the "transplant" but deny the reimbursement of testing family members or costs associated with a non-relative search. This testing can cost

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

hundreds and even thousands of dollars depending on the numbers of relatives available for testing or the extent of the non-relative search.

Spragins (1998) identifies a "disease management" approach developed by the Harvard Community Health Plan in 1986 in response the HIV/AIDS crisis, which is an applicable model to pediatric cancer. This well-known managed care program established an HIV/AIDS Team, which manages the care of those insured by the plan with HIV/AIDS. They help navigate the insurance company system, become knowledgeable about resources and entitlements to insure quality care with cost savings. With this approach they saw a reduction of hospital stay, a cost saving factor.

State legislature bodies are also addressing the complexity of requirements that leads to disapproval of life saving interventions. In New York State, for example, in 1997 the governor proposed legislature that would offer a uniform appeal process in cases where experimental treatments were denied to terminally ill people. Cancer advocates felt this legislature did not go far enough to simplify the complex requirements to obtain experimental treatment. Experimental treatment maybe the only alternative for those with malignancies that do not respond to conventional treatment.

(3) The Time Factor in the Referral Process

The referral process in a managed care system aims to reduce redundancies, streamline costs and improve the delivery of care, however, it becomes time consuming to already burdened parents. Time is limited for these families by the demands of treatment, absence from home due to hospitalization and long stays (5-7 hours per day) in day units. These situations often leave one parent, in a two-parent

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

household, to give up employment and to relinquish the care of sibling(s) when there are other children at home. For single parent households, it has meant reliance on public assistance if no other relatives could be of assistance.

Over eight-seven percent (87.5%) of the respondents reported it took more/somewhat more time for parents to go through the referral process in managed care as compared to fee-for-service. Schwartz (1998), a noted physician, whose 40 year old lawyer son was diagnosed with lung cancer, recommended that managed care companies need to be more "flexible in their arrangements." He advocates for an "open-access" arrangement for those diagnosed with a catastrophic illness such as cancer. Child health advocates describe managed care plans that permit some fee-for-service features, which allow parents flexibility in the referral process (Fox, et al., 1990; Freund & Lewit, 1993). The trend, as observed by many health care analysts, has been toward a "point of service" approach. This offers, at higher premiums, features of both systems, which the insured can access at his will provided the insured has the ability to pay higher deductibles and co-payments.

(4) Self-reliance: Burden on the Consumer

The lack of access to specialty care, the complexity of requirements to obtain care and the time delay in obtaining a referral places additional burden on the parents. The majority of the respondents (65.7%) viewed an increase in parental self-reliance over the last two years. This means that parents, consumers of managed care, need to fend more for their children. Spragins (1998) quotes a

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

mother with a child with mild cerebral palsy, who describes this new self-reliance she has had to take on.

> My husband and I have been our daughter's case manager. HMO's and preferred provider organizations (PPO's) have not. We are the ones who fought for what she needed and fought to get it paid for (p.102).

Another parent with a spina bifida, severe epileptic and hydrocephalic child describes the situation she sees parents with special health needs children in.

> My perspective is based on my personal experiences with my medically fragile son, Aaron. I have seen the best and the worst of both the old fee-for-service and managed care... This journey left me with many unanswered concerns about managed care, and a determination to help find solutions. (Gleason, 1998. p.134)

(5) Transferability of Providers among Managed Care Plans

The fifth managed care practice that rated the attention of 47.9% of the respondents was that of lack of continuity of providers when one transfers from one plan to another. Since managed care plans contract with providers, mobility between and among providers is based not upon the relationship between the provider and the patient, but between the managed care plan and selected physicians. Three different managed care plans in one region may have each selected a different pediatric oncologist as an approved plan doctor. Thus when the child is covered by one plan s/he has to go to that plan's selected pediatric oncologist. However, if the child transferred to another plan, s/he might be required to change her/his pediatric oncologist or hospital affiliation.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Fox and McManus (1998) in recommending the requirements of state managed care plans address the issue of standard setting. As long as there are no standards of care for children with catastrophic and chronic conditions the variability will be great among plans. They call for "standards [that] specify the types of providers, with pediatric expertise who must be participating in the network or available through other arrangements... " (Fox & McManus, 1998, p.108)

This variability of standards and providers is especially troubling when parents depend upon health insurance coverage from employment and the employer can change plans or the parent can change employers. Any of these results in the child's not being able to continue treatment with the same pediatric oncologist or even hospital.

Medicare recipients in New York recently experienced this difficulty when their HMO's announced suspension of Medicare coverage. Medicare recipients who selected to join the HMO, as opposed to fee-for-service, based upon the extensive nature of the HMO coverage and the network of doctors found themselves *Scrambling for a new HMO* (Eisenberg, 1998). Once they found a new HMO, they would have to make a new selection of doctors once again. One Medicare recipient indicated he changed his doctor of 40 years to join the HMO, only to have to change doctors again.

Schwartz (1998) sees the growth of physician groups, which may provide more flexibility since one, may have more than one oncologist to chose from. There has also been a trend in consolidation of plans. Where there were many plans, working with different hospitals and doctors, the consolidation of several major plans may allow for greater

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

control of the "marketplace." Now larger insurance companies, hopefully, may contract with more providers.

(6) Satisfaction with Providers

Customer satisfaction is another area addressed by managed care through survey and monitored telephone inquires for service (Fox & McManus, 1998). Despite concern expressed by managed care for customer satisfaction, pediatric oncology social workers reported 46.7% of the parents were less satisfied with managed care providers than fee-for-service providers. Family involvement with managed care plans is essential since they are the ones who actualize home-based therapy, monitor and identify changes in their children's health status. Parents are essential partners in keeping children out of emergency rooms and hospitals, if given the proper support (Fox and McManus (1998; Karlson, Sumi, Bracht, 1990). Pediatric health care policy advocates suggest parents should be consulted on policy development as informed consumers of the service. A service industry that is not attuned to customer satisfaction and needs may be doomed to failure. Surveys of parents of special health needs children will insure monitoring and quality control in delivery of service (Fox and McManus, 1998).

(7) Level of Stress on Parents

Customer satisfaction is partly related to a decrease in the level of stress experienced by these burdened parents. But the respondents observed, parental self-reliance has increased under managed care since (a) greater advocacy, (b) more phone, and (3) more paperwork is required.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

(a) Advocacy

A significant portion of the respondents (86.5%) observed that parents under managed care as compared to fee-for-service were required to advocate for their children. This adds a burden to these already stressed families, but due to the obstacles of gate-keepers, prior approvals and limitation of some contracts, parents are constantly on the telephone, obtaining or completing paperwork to secure the needed and, often, not understood needs of their children. Karlson, Sumi and Bracht (1990) observed that overall parents were satisfied with managed care, however, they obtained the best care for their children when they were strong advocates.

(b) Phone Contacts

The significant proportion of the respondents (71.5%) observed that parents under managed care as compared to fee-for-service were burdened with extensive phone contacts to obtain necessary care for their children. Phones are used for contract information since contracts are so complex and always in flux, obtaining referrals, prior authorization and ordering medications. With the advent of mail-order pharmacies, medications are obtained through phone requests rather than through the corner drugstore.

The pediatric oncology social workers viewed this as an additional burden on parents since they may be required to make multiple calls and endure complex phone messages and long waiting time. Some parents report rising extra early to get through before they get put on extended holds or reach busy lines with messages to call back on non-heavy use hours. Fox and McManus (1998) include "telephone call-back waiting time" as one of standard industry wide

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

quality assessment indicators since so much of service delivery is based upon telephone contacts and responses.

(c) Paperwork

The excessive burden of phone contacts is followed by the stress of paperwork as reported by 64.3% of the respondents. In some managed care contracts, parents need to obtain and complete referral authorization for each and every referral for each medical or auxiliary support visit. Every need for medication, for some managed care contracts, is to be accompanied not only by the doctor's prescription but by a consumer completed form and a co-payment. According to the pediatric social workers, managed care paperwork increases the stress for these families, as compared to fee-for-service. The paperwork associated with prior authorization and referrals is another industry-wide quality assessment indicator advocated by Fox and McManus (1998).

(8) Decreased Stress on Families

Managed care has the potential to decrease the level of stress on these families and improve outcomes for cancer-diagnosed children through several system innovations. The study indicated that pediatric oncology social workers viewed use of (a) case management, (b) increased coordination of care, and (c) less financial burden on families in managed care environments as compared to fee-for-service environments. These three components built into many managed care plans were experienced as stress reducing for these families and with great potential to improve the delivery of health care to these children.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

(a) Assignment of a Case Manager

Case management has great potential for improved service delivery for a population, which needs multiple medical and ancillary supports. 67.7% of the respondents observed case management assignment for 41-100% of the children under managed care, while only 24.2% observed the assignment of a case manager under fee-for-service for 41-100% of the children. The case management function is better utilized in a managed care system than in a fee-for-service system. The case management model has been so widely accepted by the health care industry that hospitals now employ a similar model. Often times the hospital case manager and the insurance company case manager become the two health care providers that help stressed families navigate a complex system of requirements and multiple needs. The standardization of the assignment of a case manager should be a uniform feature of managed care and all insurance systems.

(b) Coordination of Care

Industry wide use of case management leads to better coordination of care, essential to this population's survival in a complex system of multiple providers. The study demonstrated that 62% of the pediatric oncology social workers viewed more coordination of care under managed care as compared to 24.2% of the respondents who viewed more coordination of care under fee-for-service. This coordination of care model has been cited repeatedly in the literature and by study participants as one of the most beneficial features of managed care (Cooke, 1993; DiVerde, 1995; Fox & McManus, 1998; Hirsch & Barela, 1996; Ross, 1993; Smith, Layne & Garell, 1994; Sparer, Ellwood & Schoen, 1996).

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

(c) Reduce Financial Burden

With 44% of the respondents viewing managed care as reducing financial burden and 36% viewing it as increasing this burden, one sees the positive potential in this area. This discrepancy points to the variability of contracts. The qualitative data reflects where a contact streamlines costs into limited copays of $5-$20 from hefty annual deductible of $500-$2,000 per family under fee-for-service, families save money. Where managed care contracts cover medication with limited co-pays, as opposed to no or more limited medication coverage under many major medical fee-for-service contracts, considerable savings are noted.

Also when a managed care plan contracts with a pediatric oncology specialists as an in-network provider, families experience extensive savings. They have only to cover the co-pay out-of-pocket as compared to many fee-for-service plans which covers far less of these costs.

Preventive care is often a fully covered expense under many managed care policies, whereas an uncovered expenses under many fee-for-service which only covers diagnosable illness. Although cancer is not a preventable disease among children, on-going preventive care coverage is a considerable saving to all parents.

These cost saving aspects of managed care: limited co-pays, medication coverage, in network providers and no cost for preventive care should be standardized among managed care plans since these prove to be the most beneficial aspects for the families.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Just as managed care has had a significant impact upon families living with a child with cancer, it has impacted upon their health care providers-pediatric oncology social workers.

(B) The Impact upon the Pediatric Oncology Social Worker

The impact on pediatric oncology social workers was highlighted by an increase in the workload in the areas of: (1) advocacy, (2) delivery of concrete services, (3) team coordination, and (4) financial assessment. The clinical functions of the pediatric social worker were also impacted in that it changed significantly in the greater use of: (a) community supports, (b) greater use of crisis intervention for parents and for children, and (c) less on-going counseling to children and to parents. There was no significant difference in the use of individual or group work in the last two years. (Fall '95 compared to Fall '97)

An almost equal number of pediatric oncology social workers observed no significant change in their professional identify as compared to those who experienced a significant/somewhat significant change in their professional identity. The respondents experienced more professional opportunities in the last two years (46.1%), but were not quite as optimistic about future professional opportunities. Only 39.5% anticipated more/somewhat more professional opportunities.

(1) Advocacy

Pediatric oncology social workers noted the greatest impact upon their role was in advocacy, an increased function according to 64.3% of the respondents. There appears to be a parallel process for both the social worker and parent in the pediatric oncology arena to advocate

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

for needed services in the current health care system strongly influenced by managed care principles.

(2) Delivery of concrete services

In addition to an increase in advocacy, the delivery of concrete services was viewed as increasing the workload by 49.3% of the respondents. Workers find themselves in the position to advocate more for families and children living with cancer while delivering more concrete services. All of this has been influenced by the shorter length of stay reported by 68.6% of the respondents. Although 49.2% observed no difference in length of stay between managed care as compared to fee-for-service, 34.4% observed children under managed care contracts were discharged sooner.

Children needing hospital services, therefore, are getting more of it delivered on an outpatient basis under the current managed care philosophy. Thus necessitating more assistance with transportation to the hospital on a daily basis, more assistance with temporary housing to accommodate parents who do not live within commuting distance to the hospital and more home care referrals. In addition, the financial burden of the illness necessitates location of more concrete services, such as financial aid or child-care for sibling(s) while parent(s) commute to the hospital.

(3) Team Coordination

Team coordination is another pediatric oncology social worker function. The team approach encourages coordination of services and sharing of expertise to meet the child and family needs. Service delivery is provided through this health care team usually consisting of pediatric oncologist(s), nurse(s), other allied health professional(s),

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

(physical therapist, dietitian, recreational therapist, child-life specialists), hospital-based teachers and social worker(s). Leadership of this team varies depending upon the culture of the medical facility, the team and, at times, the personalities. It is not uncommon for the social worker to assume a good deal of the coordination functions. Close to the majority of the respondents (48.6%) reported that team coordination had increased their workload in the last two years. (Fall '95 to Fall '97) Some of this increase in team coordination is clearly related to the demands of managed care to obtain referrals for any specialty care. One team member has to assume this function in support of the family. Team members are often unaware of the various demands of each family's insurance carrier. Some hospitals have identified one person to coordinate with the insurance companies. For the hospitals that have not identified a coordinator with the insurance companies, most often, the social work takes on that role.

(4) Financial Assessment

Tied into advocacy and delivery of concrete services, is the financial assessment function that 42% of the respondents report has increased their workload over the last two years. (Fall '95 to Fall '97) Pediatric social workers have become the central person to locate and manage resources and coordinate all of the psychosocial needs with the medical team in this fast paced health care system. This management of resources is connected to financial assessment. Entitlement programs such as Social Security Insurance, state mandated health insurance programs and many voluntary agencies' resources are income based. Free or discounted airline tickets for travel related to medical appointments, for example, is partially based upon financial

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

eligibility. A pediatric oncology social worker often prepares and forwards the required letter describing the family's financial situation.

(5) Clinical functions

With this increasing demand to advocate for the family and deliver more concrete service based upon financial assessments, the clinical functions have been impacted. More (a) community supports, (b) more crisis intervention for parents and children, and (c) more phone contacts with parents are employed. No significant changes were noted in the use of individual work or group work over the last two years. What does this mean, not only for the social worker, but also for the family?

Studies need to address if families fare any differently as the result of getting more concrete assistance than psychological assistance. Social workers generally feel that families under such a crisis need psychological support, but since many report (48.6% were less available to children and 45.8% were less available to parents) less availability to offer it, there should be further study to evaluate the impact of this.

This study's findings point to an increase of parental self-reliance, but this study does not address the benefits or impediments of self-reliance. With 65.7% of responding pediatric oncology social workers observing greater parental self-reliance, it suggests that parental self-reliance needs to be further assessed.

Self-reliance is a concept supported by managed care programs that have shifted greater responsibility onto to the consumer to maintain and improve their health status, especially through health prevention. Weight-loss, healthy diets, exercise and smoking cessation

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

programs are all supported through many managed care plans either through health education literature they provide subscribers or through in-network programs. Thus self-reliance and consumer education is a part of the managed care movement that should be further evaluated since it holds much promise, but can become a overwhelming burden for families coping with a child diagnosed with cancer.

The clinical function most impacted by the change in the current health care system was the use of community supports according to 67.5% of the respondents. Pediatric oncology social workers find themselves referring to community-based organizations and local chapters of national organizations that offer a wide range of clinical and concrete services. Since children and families often travel to the specialized hospitals for care and now remain in-patient for shorter periods of time, community supports referrals is in great use by these social workers to support these families. Community-based support organizations have grown on a local and national level. Organizations that formerly raised money primarily for research have added significant direct service support components to meet these needs. This translates into more referral opportunities for the pediatric oncology social worker.

As the provision of on-going counseling has decreased for pediatric oncology social workers, the use of crisis intervention as a counseling modality has increased. Under the current health care delivery system, the respondents report a greater/somewhat greater use of crisis intervention. The use of crisis intervention has increased according to 53.4% of the respondents in their work with parents,

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

while 47.9% of the respondents observe the increase in their work with the children. Again there are no studies to indicate if crisis intervention is a more effective and efficient model of intervention with this population.

Respondents reported an increase use of telephone contact and support. It increased for 50% of the respondents in their work with parents. Short stays also influence this that bases the parents in the home or local Ronald McDonald houses rather than long stays in the hospital. Both professional and parents report greater use of the telephone to deliver and receive service. Some pediatric oncology social workers are even delivering counseling via telephone due to the short hospital stays. These are often scheduled "sessions" which meet by telephone. Several national cancer support organizations have moved toward offering several on-going and educational support programs via telephone. Thus this has been an area of growth for pediatric oncology social workers and has shifted their practice from an in-person to a telephone-based practice.

(6) Professional Identity

These role changes appear to affect a significant/somewhat significant change in the professional identify for 49.3% of the respondents, while 50.7% of the respondents observed no change in their professional identity. Twenty-five of the respondents took the opportunity to describe the changes in their professional identity in their own words. Some note less clinical opportunities, while others pointed to the positive aspects of resource management in times when resources are much sought after.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

This almost evenly divided view of the changes of professional identity for the pediatric oncology social worker in the last two years (Fall '95 to Fall '97) may reflect the ever-changing landscape of health care. One social worker noted that since 1995, the social work title changed three times and now is back to *social worker* from *discharge planner.* Social work identity has expanded and contracted just as hospitals and health care systems have mergerd, been acquired and dissolved.

These changes in role and professional identity are not without conflict since many social workers pointed to the positive aspects of their new roles and others see them as negative. Cartland and Yudkowsky (1989) also note role changes for physicians with inherent conflict between financial incentives and patient care.

(7) Professional opportunities

With all of the changes in the health care system, 46.1% of the respondents experienced more/somewhat more professional opportunities, while 35.5% experienced no change in professional opportunities in the last two years. (Fall '95 to Fall '97) Thirty-seven of the respondents felt so strongly about the issue of professional opportunities they described them in one to three sentences. They described enjoying the opportunity to attend the national conference of the Association of Pediatric Oncology Social Workers as a paid benefit of the department of pediatric oncology. As well as the opportunity to develop patient-oriented programs such as sibling programs, weekend programs for bereaved families and teen support groups.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

However fewer were optimistic about future opportunities. 39.5% felt there would be more/somewhat more future opportunities with 18.3% foreseeing fewer professional opportunities. This less optimistic view maybe captured by Rosalie, when she describes the shift she has observed in how she practices social work now.

> **Rosalie:** *When I first came on to in-patient we practiced social work in luxury. We provided flawless discharge .We did not send a child unless s/he had the Board of Education plan in place. Even if that meant staying the 60 days for proper processing and placement. Now LOS is shorter. We have to let go of those things.*

Social workers are not in the same decision-making role as they were in fee-for-service, which some view as affecting their professional opportunities. Similar to pediatric medical specialists, pediatric social workers, now need to gain authorization for discharge planning: making referrals for durable equipment, transportation, outpatient care, specialists, mental health consultation; as well as the duration of allowed service. Specific vendors and even specific kinds of equipment are dictated by the managed care company. There is a loss of choice for the consumer and a loss of autonomy for the social worker (Edinburg & Cottler, 1995).

The implications of these significant findings from this study are the focus of the final chapter, Chapter VII. Choice and autonomy are key issues, as well as cost-savings, coordination of care and the need for advocacy by families and pediatric oncology social workers.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Chapter VII IMPLICATIONS

The breadth of this study, a national sample of pediatric oncology social workers, is of great value in the area of health care policy and advocacy. It reflects the practice wisdom and experiences of those health care professionals-pediatric oncology social worker- who work daily with the impact of managed care on a cancer-diagnosed population. This population, children living with cancer, is a significant population since these children are most vulnerable in terms of life expectancy. The medical complexity of their health needs allows health care professionals to examine the implications of managed care practices and guidelines on disabled medically dependent populations.

Their reported data has limitation since is not based upon statistics, but on observations, recollections and experiences. Another limitation of this study is that it is relying on the self-reporting of respondents. Pediatric oncology social workers' interest or motivation to participate, their level of knowledge about insurance related issues and the clarity of the instrument are also crucial to the efficacy of the process and the accuracy of the data.

Their experience or perception may indeed be different than the actual data, if it exists within hospital or insurance companies' records. Their perceptions may also be different than the parents; if they were available to answer questions regarding how has this new system of health care delivery aided or impeded their child's care.

Despite the limitation of this study the findings point to a beginning effort to explore and describe the impact of managed care on children living with cancer and their health care providers-

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

pediatric oncology social workers. Consumer-advocates, the public and the popular press have already identified some of these same issues.

On the negative side, the managed care model guiding many insurance companies employs gate-keeping and referral practices which present obstacles to many children living with cancer to obtain health care. These obstacles prevent timely access to specialists and referrals to the myriad of ancillary services and supports needed by this population of catastrophically ill children and their families. The complex requirements of many managed care companies, also, result in parents spending more time and energy in advocating for their children both by telephone and through extensive paperwork
The key issues: access to specialists, the complexity of requirements and the burden on the consumer to be self-reliant, however have also been echoed in the hallways of state and federal legislators. The US Congress has been working on legislation that would give patients the right to sue their health plans for wrongful denial of medical care. As many as 30 states have similar legislation in place to protect many managed care consumers access to specialists. Missouri passed one of the nations toughest medical consumer protection laws, giving patients the right to see specialists without prior approval from their health plan (Shutting Out Gatekeepers, 1999).

United Health Plan, one of the largest managed care companies in the US, announced in the fall of 1999 that their was no savings to their complexity prior approval requirements. Indeed now they feared legal repercussions from these policies. Doctors, affiliated with United Health Plan, will regain the right, without the insurance company

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

interference, to refer their patients to specialists (Shutting Out Gatekeepers, 1999).

Spragins (1998) suggests another model, which has been employed by at least one managed care company in treating HIV/AIDS. This is a "disease management model" in which the managed care company sets up an internal management team of experts that manage the disease specific cases. In the case of pediatric oncology, there would be a team of pediatric oncology health care specialists. Murphy (1996) suggests another model in which the pediatric oncologist serves as the primary care pediatrician for children treated for cancer. It appears that a small percentage of pediatric social workers (6.8%) observed assignment of the pediatric oncologist as the primary care pediatrician by managed care companies.

Continuity of care is also jeopardized for these children who depend upon their parents' insurance coverage when there is a change in plans or coverage. This is another obstacle to care for this population under a managed care system which contracts with limited number of providers and is not universally accepted by health care providers.

Schwartz (1998) advocates for "open access" for medically disabled populations, which means they would have greater flexibility than normally allowed by the plan. Fox and McManus (1998) advocate the use of "standards of practice" that would cut across plans when it came to delivery of health care to special needs pediatric populations so that there would not be such variability among plan thus a lack of portability when changing plans.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Parents, with all of the demands of managed care, have to be more self-reliant and need to advocate more for their children. Self-reliance and advocacy has not in itself been studied to determine the benefits or burden it presents such families.

From the perspective of pediatric oncology social workers, managed care has potential benefits in offering case management to coordinate care and to reduce the financial burden on families. These benefits do not exist in all managed care contracts, however where they exist, they are especially supportive to this population. They should be considered to be standard practice in all managed care contracts covering such health system dependent children.

. Pediatric social workers roles parallel some of the same changes observed for the parents. These social workers are experiencing an increase in their workload in the areas of advocacy, delivery of concrete services, team coordination and financial assessment. Their clinical functions have shifted towards greater use of community - based support, crisis interventions and phone contacts while being less available for on-going counseling. These effects need to be further studied as to determine how this is effecting the role of pediatric oncology social work in the hospital setting, as well as the needed skill training. What does it mean for the social workers do offer less on-going clinical support? Where do these parents get this service from or are they doing without it?

Do parents, for example, do just as well, if not better with less on-going support and more crisis intervention and phone contacts? How has this increase in community-based support benefited these

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

families? Has it shifted the role of the pediatric oncology social worker from the medical setting to the community-based setting?

The questions raised by this study also point to the wealth of information available to pediatric oncology social workers to address the needs of their clients under a changing system of health care. Their observations and voices have potential to shape the future of managed care since it is in its infancy as a model of delivery to a catastrophically ill pediatric population. Pediatric oncology social workers are also in a unique position since they understand the insurance needs of this population. There are a very limited number of health care providers who have this vantage point.

As noted earlier by a caregiver, "The problem is cancer does not sit around and wait for you. " (Eisenberg & Gilgoff, p. A3). Thus further studies need to look at the issues highlighted by this exploratory study before children living with cancer lose any opportunity for timely treatment.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Appendix A

Survey Instructions: Please answer all questions based upon your experience as a pediatric oncology social worker. All information will be kept absolutely confidential. Your name, address and phone are requested only for the purpose of follow-up where indicated. You may withdraw from participation at anytime. PLEASE CHECK THE MOST APPROPRIATE ANSWER OR ELABORATE WHERE INDICATED. Return in enclosed envelope by ______/______/98

A-SECTION : DEMOGRAPHICS

The following set of questions focuses on demographic information about you and your organization. Several questions in this section may require obtaining information from other departments. If this information is not readily available, please answer to the best of your ability.

RESPONDENT'S CHARACTERISTICS

1- What is your current title?

____

2- How many years have you been working in pediatric oncology?

__________# of years

3- What percentage of your caseload is direct pediatric oncology service?
a- ☐ under 20% b- ☐ 21%-40% c- ☐ 41-60% d- ☐ 61-80% e- ☐ 81-100%

4- What percentage of your caseload is direct service other than pediatric oncology ?
a- ☐ under 20% b- ☐ 21%-40% c- ☐ 41-60% d- ☐ 61-80% e- ☐ 81-100%

5- Please list the pediatric or adult service(s) other than pediatric oncology that you cover.

a-____________________ b-____________________

c-____________________ d-____________________

6- What percentage of your workload is administrative pediatric oncology services i.e. supervision, management?
a- ☐ under 20% b- ☐ 21%-40% c- ☐ 41-60% d- ☐ 61-80% e- ☐ 81-100%

7- Is any of the above different from what it was in Fall, 1995? ☐ Yes ☐ No

8- If Yes, describe the difference.

____

____

9- What percentage of your pediatric oncology caseload is under some form of managed care as opposed to fee-for-service? (Define managed care as: a continuum of health insurance plans with common features, such as, balancing access to care, cost, quality control, benefit design and flexibility. Reimbursement rates are set between the health care providers and insurance carriers. The HMO, health maintenance organization, model is one model but not the exclusive model. Define fee-for-service as the traditional indemnity health insurance plan where the health care provider s set their own rates and are reimbursed by the patient directly. The patients/subscribers are reimbursed by their insurance company.)
a- ☐ under 20% b- ☐ 21%-40% c- ☐ 41-60% d- ☐ 61-80% e- ☐ 81-100%

10- Were these percentages the same 2 years ago in Fall '95? ☐ Yes ☐ No

11- If no, the change indicates an - ☐ increase or - ☐ decrease?

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

12- What percentage of your pediatric oncology managed care caseload is under a public or government funded program? e.g. Medicaid Managed Care?
a- ☐ under 20% b- ☐ 21%-40% c- ☐ 41-60% d- ☐ 61-80% e- ☐ 81-100%

13- Were these percentages the same 2 years ago in Fall '95? ☐ Yes ☐ No

14- If No, the change indicates an ☐ increase or ☐ decrease?

15- If you have a portion of your caseload that is not pediatric oncology, what percentage of that caseload, is under some form of managed care as opposed to fee-for-service?
a- ☐ under 20% b- ☐ 21%-40% c- ☐ 41-60% d- ☐ 61-80% e- ☐ 81-100%

16- Were these percentages the same 2 years ago in Fall '95? ☐ Yes ☐ No

17- If No, the change indicates an ☐ increase or ☐ decrease?

HOSPITAL CHARACTERISTICS

18- What is the location of the hospital/medical center where you work?

City:____State:_________________

19- What is the affiliation or ownership of this hospital/medical center? Check as many as apply.

a- Public, local
b- Public- state,
c- Public- federal
d- Public, military
e- Private, profit
f- Voluntary, nonprofit-sectarian
g- Voluntary, nonprofit-nonsectarian
h Academic
i- Regional
j- Community
k Specialty- Children
l- Specialty- Cancer

Other, describe: ____

B- IMPACT UPON CHILD/ FAMILY

This section focuses on the impact of managed care on the family/child. The questions ask you to indicate how children/parents experience recent changes in health care delivery. In answering these questions, please focus on your pediatric oncology caseload only.

1- Access to Care

a-Which statement best describes access to care for the majority of children under managed care as compared to the majority of children under fee-for-service?
1- ☐ increased access to care 2- ☐ somewhat increased access to care 3- ☐ same access to care 4 - ☐ less access to care

b-Which statement best describes the requirements to obtain care, as reported by the majority of parents under managed care as compared to the majority of parents under fee-for-service?
1- ☐ more complex requirements 2- ☐ somewhat more complex requirements 3- ☐ same requirements 4- ☐ less complex requirements

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

c- Please give a few examples that more fully describe your response.

1-____

2-____

d- Which statement best describes the time factor to obtain a referral for any service for the majority of children under managed care as compared to the majority of children under fee-for-service?
1- ☐ more time to obtain a referral 2- ☐ somewhat more time to obtain a referral 3- ☐ same time to obtain a referral 4- ☐ less time to obtain a referral

e- Which statement best describes the referral process to a specialist for the majority of children under managed care as compared to the majority of children under fee-for-service?
1- ☐ more steps to obtain a referral to a specialist 2- ☐ somewhat more steps to obtain a referral to a specialist 3- ☐ the same steps to obtain a referral to a specialist 4- ☐ fewer steps to obtain a referral to a specialist

f- Which statement best describes the accessibility of the location of health care providers for the majority of children under managed care as compared to the majority of children under fee-for-service?
1- ☐ more accessible 2- ☐ somewhat more accessible 3- ☐ same accessibility 4- ☐ poor accessibility

g- Which statement best describes overall satisfaction with health care providers as reported the majority of parents under managed care as compared to the majority of parents under fee-for-service?
1- ☐ more satisfied 2- ☐ somewhat more satisfied 3-☐ the same satisfaction 4- ☐ less satisfaction

2- Coordination of Care: (This refers to an identified health care provider, usually a case manager, taking responsibility to coordinate or organize the myriad of needed health care services.)

a- Which statement best describes coordination of care for the majority of children under managed care as compared to the majority of children under fee-for-service?
1- ☐ more coordination of care 2- ☐ somewhat more coordination of care 3- ☐ same coordination of care 4- ☐ less coordination of care

b- What percentage of children under managed care have an insurance carrier case manager?
1- ☐ under 20% b- ☐ 21%-40% c- ☐ 41-60% d- ☐ 61-80% e- ☐ 81-100%

c- What percentage of children under fee-for service have an insurance carrier case manager?
1- ☐ under 20% b- ☐ 21%-40% c- ☐ 41-60% d- ☐ 61-80% e- ☐ 81-100%

d- What percentage of children under managed care have to return to their primary pediatrician for most referrals?
1- ☐ under 20% b- ☐ 21%-40% c- ☐ 41-60% d- ☐ 61-80% e- ☐ 81-100%

e- What percentage of children under managed care have their pediatric oncologist as their primary physician?
1- - ☐ under 20% b- ☐ 21%-40% c- ☐ 41-60% d- ☐ 61-80% e- ☐ 81-100%

f- Which statement best describes the continuity of health care providers (meaning that providers remain constant) while on the same plan for the majority of children under managed care as compared to the majority of children under fee-for-service?
1- ☐ greater continuity of providers 2- ☐ somewhat greater continuity of providers

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

3- ☐ same continuity of providers 4- ☐ less continuity of providers

g- Which statement best describes the continuity of health care providers (meaning that providers remain constant) for the majority of children under managed care as compared to the majority of children under fee-for-service when they have to change from one insurance carrier to another?
1- ☐ greater continuity of providers 2- ☐ somewhat greater continuity of providers
3- ☐ same continuity of providers 4- ☐ less continuity of providers

h- Which statement best describes the transfer of information between the insurance carrier and the hospital/medical team for the majority of children under managed care as compared to the majority of children under fee-for-service?
1- ☐ better transfer of information 2- ☐ good transfer of information 3- ☐ same transfer of information 4- ☐ poorer transfer of information

3- Level of Stress: The amount of stress experienced by the family.

a- Which statement best describes the financial burden of health care costs for the majority of parents under managed care as compare to the majority of parents under fee-for-service?
1- ☐ more financial burden 2- ☐ somewhat more financial burden 3- ☐ same financial burden
4- ☐ less financial burden

b- Which statement best describes the level of advocacy required of the parents, for the majority of children under managed care as compared to the majority of parents under fee-for-service?
1- ☐ greater level of advocacy 2- ☐ somewhat greater level of advocacy 3- ☐ same level of advocacy 4- ☐ lower level of advocacy

c- Which statement best describes the amount of paperwork required of the majority of parents under managed care as compared to the majority of parents under fee-for-service?
1- ☐ more paperwork 2- ☐ somewhat more paperwork 3- ☐ same paperwork
4- ☐ less paperwork

d- Which statement best describes the amount of time spent on the telephone by the parents with the insurance carrier for the majority of parents under managed care as compared to the majority of parents under fee-for-service?
1- ☐ more time spent on the telephone 2- ☐ somewhat more time spent on the telephone
3- ☐ same time spent on the telephone 4- ☐ less time spent on the telephone

e- Can you describe any additional factors for parents that have led to increased level of stress under managed care?

____

____

____

____

f- Can you describe any additional factors for parents that have led to decreased level of stress under managed care?

____

____

____

____

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

C- INSURANCE CARRIER'S GUIDELINES & POLICIES

This section refers to the impact of managed care, in general, on your delivery of service to your pediatric oncology caseload. When you are asked to compare the last two years, please compare Fall '95 with Fall '97.

1- Time Frames

a- Which statement best describes the change in the in-patient length of stay (LOS) over the last two years on your pediatric oncology service?

1- ☐ greater LOS 2- ☐ somewhat greater LOS 3- ☐ same LOS 4- ☐ shorter LOS

b- What is it now? __. __days (approximately) or __. __days (exactly)

c- What was it two years ago? ___. __days (approximately) or ___. __days (exactly)

d- Which statement best describes which type of insurance coverage requires the shortest length stay?

1-☐ fee-for-service-private coverage 2- ☐ fee-for-service-public coverage 3- ☐ managed care-private coverage 4- ☐ managed care- public coverage 5- ☐ no difference

2- Decision-Making

2a-This question focuses on who has the primary decision making power in obtaining each indicated service for the majority of children under managed care. Please answer for each service by circling the number corresponding to the identified decision-maker for each listed service. Please focus on your pediatric oncology caseload.

SERVICE **PRIMARY DECISION-MAKER**

	Hosp. MD	Hosp. SW	Hosp. RN	Hosp. Case Manager	Insurance Co. MD	Insurance Co. Case Manager	Primary Care MD	Family	Other
a-Discharge Planning	1	2	3	4	5	6	7	8	9
b-Home Care	1	2	3	4	5	6	7	8	9
c-Durable Equipment	1	2	3	4	5	6	7	8	9
d-Transportation	1	2	3	4	5	6	7	8	9
e-Community Supports Referral	1	2	3	4	5	6	7	8	9
f-Mental Health Referral	1	2	3	4	5	6	7	8	9
g-Temporary Housing	1	2	3	4	5	6	7	8	9
h-School Support	1	2	3	4	5	6	7	8	9
i-2nd Opinion	1	2	3	4	5	6	7	8	9
j-Hospice Referral	1	2	3	4	5	6	7	8	9
k Other Services	1	2	3	4	5	6	7	8	9

l. Elaborate on Other services:

____

____

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

2b-This question focuses on who has the primary decision making power in obtaining each indicated service for the majority of children under fee-for-service. Please answer for each service by circling the number corresponding to the identified decision-maker for each listed service. Please focus on your pediatric oncology caseload.

SERVICE **PRIMARY DECISION-MAKER**

	Hosp. MD	Hosp. SW	Hosp. RN	Hosp. Case Manager	Insurance Co. MD	Insurance Co. Case Manager	Primary Care MD	Family	Other
a-Discharge Planning	1	2	3	4	5	6	7	8	9
b-Home Care	1	2	3	4	5	6	7	8	9
c-Durable Equipment	1	2	3	4	5	6	7	8	9
d-Transportation	1	2	3	4	5	6	7	8	9
e-Community Supports Referral	1	2	3	4	5	6	7	8	9
f-Mental Health Referral	1	2	3	4	5	6	7	8	9
g-Temporary Housing	1	2	3	4	5	6	7	8	9
h-School Support	1	2	3	4	5	6	7	8	9
i-2nd Opinion	1	2	3	4	5	6	7	8	9
j-Hospice Referral	1	2	3	4	5	6	7	8	9
k-Other Services	1	2	3	4	5	6	7	8	9

l-Elaborate on Other Services:

3-Referral Process:

3a- Please indicate by circling the number corresponding to the phrase that best describes a change in your overall workload, in the past 2 years (compare Fall '95 with Fall '97), for each of the referral processes. For example, written approvals are now required for referrals thus increasing workload.

REFERRAL PROCESS **CHANGES IN YOUR WORKLOAD FROM FALL '95 to FALL '97**

	Increased Workload	No Difference	Decreased Workload	Not Applicable
a-Written Approval	1	2	3	4
b-Telephone Approval	1	2	3	4
c-Primary MD Approval Required	1	2	3	4
d-Insurance Co. Case Manager's Approval	1	2	3	4
e-Use of Restricted Panel of Vendors	1	2	3	4
f-Locating Approved Vendors	1	2	3	4
g-Appeal Process	1	2	3	4

h-Elaborate on other referral processes that have changed your workload:

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

D- CHANGES IN PEDIATRIC ONCOLOGY SOCIAL WORKER'S ROLE

This section will focus on the impact of **managed care, in general,** upon your role as a pediatric oncology social worker.

1- Please indicate by circling the number corresponding to the phrase that best describes a change in your pediatric oncology workload, in the past 2 years (compare Fall '95 with Fall '97), for each of the identified functions.

FUNCTION	CHANGES IN YOUR WORKLOAD FROM FALL '95 to FALL '97			
	Increased Workload	**No Difference**	**Decreased Workload**	**Newly Added Function**
a-Advocacy	1	2	3	4
b-Administrative Responsibility	1	2	3	4
c-Case Management	1	2	3	4
d-Clinical Responsibility	1	2	3	4
e-Coordinate with Insurance Carrier	1	2	3	4
f-Delivery of Concrete Services	1	2	3	4
g-Discharge Planning	1	2	3	4
h- Financial Assessment	1	2	3	4
i-Program Development	1	2	3	4
j-Marketing	1	2	3	4
k-Research	1	2	3	4
l-Resource Management	1	2	3	4
m-Teaching	1	2	3	4
n-Team Coordination	1	2	3	4
o-Training	1	2	3	4

p-Elaborate on other functions that have changed your workload:

2- This section focuses on changes in your clinical role for your pediatric oncology caseload between the Fall '95 and Fall '97, a two year time frame.

a- Which statement best describes any changes in your availability to provide counseling to the majority of children over the last two years?

1- ☐ more available 2- ☐ somewhat more available 3- ☐ same availability 4- ☐ less availability

b- Which statement best describes any changes in your availability to provide counseling to the majority of the parents over the last two years?

1- ☐ more available 2- ☐ somewhat more available 3- ☐ same availability 4- ☐ less availability

c- Which statement best describes any changes in your use of crisis intervention with the majority of the children over the last two years?

1- ☐ greater use of crisis intervention 2- ☐ somewhat greater use of crisis intervention
3- ☐ same use of crisis intervention 4- ☐ decreased use of crisis intervention

d- Which statement best describes any changes in your use of crisis intervention with the majority of the parents over the last two years?

1- ☐greater use of crisis intervention 2- ☐ somewhat greater use of crisis intervention

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

3- ☐ same use of crisis intervention 4- ☐ decreased use of crisis intervention e- Which statement best describes any changes in your phone contact with <u>the majority of the children</u> over the last two years?
1- ☐ greater use of phone contact 2-☐ somewhat greater use of phone contact 3- ☐ same use of phone contact 4- ☐ decreased use of phone contact

f- Which statement best describes any changes in your phone contact with <u>the majority of the parents</u> over the last two years?
1- ☐ greater use of phone contact 2- ☐ somewhat greater use of phone contact 3- ☐ same phone use of contact 4- ☐ decreased use phone contact

g- Which statement best describes any changes in your use of community based supports for <u>the majority of the children</u> over the last two years?
1- ☐ greater use of community based supports 2- ☐ somewhat greater use of community based supports 3- ☐ same use of community based supports 4- ☐ decreased use of community based supports

h- Which statement best describes any changes in your use of community based supports for <u>the majority of the parents</u> over the last two years.
1- ☐ greater use of community based supports 2- ☐ somewhat greater use of community based supports 3- ☐ same use of community based supports 4- ☐ decreased use of community based supports

i- Which statement best describes any changes in parent's need to be self-reliant (meaning parent's need to do more for themselves and their children) <u>for the majority of the parents</u> over the last two years?
1- ☐ more parental self reliance 2- ☐ somewhat more parental self reliance
3- ☐ same parental self-reliance 4- ☐ decreased of parental self reliance

j- Which statement best describes any changes you have made in use of individual work as compared to group work <u>for the majority of the children</u> over the last two years?
1- ☐ more individual work 2- ☐ more group work 3- ☐ same use of individual and group work

k- Which statement best describes any changes you have made in use of individual work as compared to group work <u>for the majority of the parents</u> over the last two years?
1- ☐ more individual work 2- ☐ more group work 3- ☐ same use of individual and group work

l- Please describe any other changes in your clinical role in the past two years:

____

____

____

____

____

____

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

3- Which statement best describes any changes in your professional identity as a professional social worker in your medical setting over the last two years?
a- ☐ significant changes in your professional identity b- ☐ somewhat significant changes in your professional identity c- ☐ no changes in your professional identity

4- Did your title change over the last two years?
a- ☐ Yes b- ☐ No

5- If yes, what was it in Fall ' 95?

____

6- Has there been any change in designation of the department to which you report? (For example your position moved from one dept. to another)
a- ☐ Yes b- ☐ No

7- If yes, which department did you report to in the Fall '95?

____

8- If yes to above, which department did you report to in the Fall '97?

____

9- Please list any additional changes regarding your professional identity over the last two years.

____

____

____

10- New Opportunities- These questions focus on new professional opportunities. Opportunities are defined as new ways the role of the pediatric oncology social worker has been enhanced in your setting.

a- Which statement best describes new professional opportunities you have experienced as a pediatric oncology social worker over the last two years?
1- ☐ more professional opportunities 2- ☐ somewhat more professional opportunities
3- ☐ same professional opportunities 4- ☐ fewer professional opportunities

b-Please describe these opportunities:

____

____

____

____

____

c- Which statement best describes professional opportunities you foresee for pediatric oncology social workers in a managed care model of health care delivery?
1- ☐ foresee additional professional opportunities 2- ☐ foresee somewhat additional professional opportunities 3- ☐ foresee same professional opportunities 4- ☐ foresee fewer professional opportunities

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

d- Please describe any professional opportunities you foresee:

11- Can I contact you if I need to clarify any answers? You may chose not to be identified.
☐ Yes ☐ No If Yes, please complete the below information. (None of this data will be used in any reporting or summary)

Name:____________________

Address:____________________

City:__________ State:__________ Zip:__________

Daytime Phone: (____) __________ Fax: (____)__________

e-mail address:____________________

If your would like a copy of an extensive bibliography about the managed care delivery system please use the enclosed self-addressed postcard. This allows you to receive the bibliography without Identifying yourself on this survey.

If you have any questions, please feel free to contact me, Toni Cabat, 212-255-1160, Monday-Thursday, 9-5 ET or fax 212-255-1495 or e-mail tcabat@email.gc.cuny.edu. Your effort and responses are highly valued.

Mail in the enclosed stamped envelope to:
Toni Cabat CSW, 1752 White Street, Bellmore, New York 11710

Thank you,

Toni Cabat CSW

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Appendix B

Toni Cabat CSW
1752 White Street
Bellmore, New York 11710
tcabat@email.gc.cuny.edu
1-212-255-1160-work

March 12, 1998

Dear APOSW Colleague:

I would highly value your response to my dissertation study regarding, *The Impact of Managed Care on Children Living with Cancer: A View from Pediatric Oncology Social Work.* To my knowledge there is no comprehensive study looking at this new health care delivery system from a pediatric oncology social work point of view. As a member of APOSW since 1991, I am committed to meeting the needs of these children and their families, just as you are. Some of you may know me as the Director of Family Services and Organizational Development at Chai Lifeline or from my previous position as the Assistant Director of Social Work at Memorial Sloan-Kettering Cancer Center, both located in New York City.

I have developed this survey in consultation with several APOSW members and have the full support of our President, Karen Tilley, and our Research Chair, Nancy Cincotta, in mailing this survey to you. Your insight and experience with this vulnerable population, children and families coping with pediatric cancer, can make a significant contribution to how managed care meets the needs of this population. In addition, the data may be useful in describing the role pediatric social work can play in shaping this evolving healthcare delivery system.

I recognize this will take 20 minutes of your valuable time, but your efforts will be very well appreciated by me and may help contribute to greater understanding about the changes in our health care system. As part of my research I have an extensive bibliography on the subject, which I would gladly mail to you, if you indicated your interest and return the enclosed postcard

Please feel free to contact me at 1-212-255-1160, Monday- Thursday 9-5 ET or fax me at 212-255-1495 or e-mail me at <tcabat@email.gc.cuny.edu> if you have any questions. Please use the enclosed stamped envelope to return this survey to me by ______/_____/1998.

Again your valuable time, efforts and insight will be highly valued by me and will remain **absolutely confidential.**

Sincerely,

Toni Cabat CSW
DSW Candidate at the Graduate Center
City University of New York

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Appendix C

Return Post Card

March 12, 1999

Dear Toni:

I am interested in receiving a copy of your bibliography on the impact of managed care on children living with cancer. Please mail it to:

Name: ______________________________
Address:
____
City: State: Zip Code:
____

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Appendix D

Follow-up Post Card

March 26, 1999

Dear APOSW Colleague:

I hope you have received my survey: Impact of Managed Care On Children Living With Cancer. If you have returned it, thanks. If you have any questions, or need another copy, please call me
at 1-800-343-2527.
Your responses are very important to me. I look forward to receiving your completed survey by ___/___/____.

Thank You,

Toni Cabat, CSW
APOSW member

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Appendix E

COVER SHEET

FAX

To: ______________________APOSW COLLEAGUE
Fax #: ( ) -
Subject: Toni Cabat's Survey
Date: April 10, 1998
Pages: cover sheet only.

COMMENTS:

Dear APOSW Colleague:

I eagerly await your completion of the survey I mailed to you a few weeks ago.

Your response to my survey is <u>very important</u> to me and I feel it can make a real contribution to the field of pediatric oncology and pediatric oncology social work.

If you have mailed it, THANKS.

If not, and have any questions or need another copy, please call me at 1-800-343-2527.

I look forward to your response.

Toni Cabat

Toni Cabat MSW
Memeber of APOSW
DSW candidate at CUNY,
Graduate Center of NY

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Bibliography

Adams, D. & Deveau, E. (1989). Coping with childhood cancer: Where do we go from here? Ontario, Canada: Kinbridge Publications.

Adams-Greenly, M. (1989). Psycho social interventions in childhood cancer and their management. In Holland, J. C. & Rowhard, S. H. (Eds.). Handbook of psycho-oncology. NY: Oxford Press.

An attack on disabled children. (1995, June 7). New York Times, p. 26.

An evaluation of Medicaid managed care: Social work issues and recommendations and the social work role in managed care. (1994, January). NY: NASW, NYC Chapter.

Association of Pediatric Oncology Social Workers Membership List, (1998, March).

Baldor, R. A. (1996). Managed care made simple. Cambridge, MA: Blackwell Science.

Berger, C. S., Cayner, J., Jensen, G., Scesny, A., Trachtenberg, J. (1996). The changing scene of social work in hospitals: A report of a national study by the Society for Social Work Administrators in Health Care and NASW. Health and Social Work, 21 (3), 167-177.

Berger, J. (1996, September 9). In Westchester, welfare meets managed care. New York Times, pp. A1, B4.

Bleyer, W.A. (1993, May 15). What can be learned about childhood cancer? Cancer statistics review 1973-88. Cancer, 71 (10), 329-338.

Cabat, T. (1995). Medicine by finance: Pediatric social workers of catastrophically ill children view managed care. Unpublished paper.

Cancer facts & figures, 1996. (1996). NY: American Cancer Society.

Capps, J. L. (1996, May). Cartoon Corner. Oncology Times, 28 (5), 2.

Carpenter, M. C. & Platt, S. (1997, Fall). The professional identity for clinical social workers: Impact of changes in health care delivery systems. Clinical S. W. Journal, 25 (3), 337-350.

Cartland, J. D. & Yudkowsky, B. K. (1992, February). Barriers to pediatric referral in managed care systems. Pediatrics, 89 (27), 183-192.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Children and managed care. (1996, August). PolicyLine: Current issues in health care, NY: United Hospital Fund, pp. 1-8.

Christ, G. (1989). Social work in oncology. In Holland, J. C. & Rowhard, S. H. (Eds.). Handbook of psycho oncology. NY: Oxford Press.

Cincotta, N. (1993). Special programs for children with cancer and their families. In Sterns, N. M., Lauria, M. M., Herman, J. F. & Fogelberg, P. R. (Eds.). Oncology social work. Atlanta, GA: American Cancer Society.

Clark, E. J., Stoval, E. L., Leigh, S., Siu, A. L., Austin, D. K. & Rowland, J. H. (1996). Imperative for quality care: Access, advocacy, action and accountability. Washington, DC: National Coalition of Cancer Survivors.

Cooke, R. (1993). Caring for children with chronic illness. Journal of Ambulatory Care Management, 16 (1), 49-56.

Correspondence. (1998, May 1) G.T., APSOW member in response to survey.

Cornelius, D. S. (1994). Managed care and social work: Constructing a context and response. Social work in health care, 20 (1), 47-63.

Davis, K. (1995, July). Managed care: The patient's perspective. NY: Commonwealth Fund.

Deal, L. W., Shiono, R. H., Behrman, R. E. (1998, Summer/Fall). Children and managed health care: Analysis and recommendations. The Future of Children, 8 (2), 4-24.

Denby, A. (1980, Summer). Preventive intervention in an HMO: The social worker's role in a marital separation program. Social work in health care, 5 (4), 351-360.

Dillman, D. (1978). Mail and telephone surveys. NY: John Wiley & Sons.

DiVerde, M. (1995, January). Effective strategies for managed care programs: An Arizona practice shares its experience. Catch Quarterly, 4 & 8.

Dooha, S. (1995, June 21). Are HMO's bad for your health? Presentation at Long Island Coalition for Health Reform. Plainview, NY.

Edinburg, G. M. & Cottler, J. M. (1995). Managed Care. In Encyclopedia to social work. Washington, DC: NASW Press.

Eisenberg, C. (1998, October 27). Scrambling for a new HMO. Newsday, p. A27.

Eisenberg, C. &Gigoff, H.(1999,July). Second opinions, Newsday, p. A3 & 5.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Fabricant, M. & Burghardt, S. (1992). The welfare state and the transformation of social services. Armonk, NY: M. E. Sharpe.

Fein, E. (1996, July 3). Cost-cutting by hospitals to accelerate. New York Times, pp. B1 & 5.

Fowler, F. J. (1995). Improving survey questions. Thousand Oaks, London, New Delhi: Sage Publications.

Fox, H. B. & McManus, M. A. (1998, Summer/Fall). Improving state medicaid contracts & plan practices for children with special needs. The Future of Children, 8 (2), 105-118.

Fox, H. B., McManus, M. A., Leibowitz, A. (Undated). What do we know about managed care for children? Portland, ME: National Academy for State Health Policy.

Fox, H. B. & Wicks, L. B. (1994, July). Medicaid managed care resource center. Portland, ME: National Academy for State Health Policy.

Fox, H. B., Wicks, L. B., Kelly, R. & Greaney, A. (1990, September). An examination of HMO policies affecting children with special health needs. Washington, DC: Maternal & Child Health Bureau.

Fox, H. B., Wicks, L. B. & Newacheck, P. (1993, Fall). State Medicaid Health Maintenance Organization policies and special needs children. Health Care Financing Review, 15 (1), 25-38.

Freund, D. A. & Lewit, E. M. (1993, Summer/Fall). Managed care for children and pregnant women: Promises and pitfalls. The Future of Children, 3 (2), 92-122.

Gleason, C. S. (1998, Summer/Fall). A parent's perspective: Defining the challenge and opportunities for children in managed health care. The Future of Children, 8 (2), 134-138.

Goldstein, M. (1995, April 24). A stain on managed-care plan. Newsday, p. A8.

Gottlieb, M. (1995, October 2). A free-for-all in swapping Medicaid for managed care. New York Times, pp. A1, 14, 16.

Gray, W. (1991). Implementing managed health care. NY: The Conference Board.

Grumbach, K., Osmond, D., Vranizan, K., Jaffe, D. & Bindman, A. B. (1998, November 19). Primary care physicians' experience of financial incentives in managed-care systems. NEJM, 339 (21), 1516-1521.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Hagland, M. (1997, February 5). A case against cookie cutter care. Hospital and Health Network, pp. 78-80.

Halm, E. A., Causino, N. & Blumenthal, D. (1997, November 26). Is gate keeping better than traditional coverage: A survey of physicians' attitudes. JAMA, 278 (20), 1677-1681.

Hamilton, D. (1996, December 1). Managed care and social work: Oppression or opportunity. NYS NASW Newsletter, p. 2.

Harmon, W. E. (1995). Management of children with serious renal disorders in the era of managed care. Current Opinions in Pediatrics, 7 (2), 157-158.

Harrigan, S. (1995, March 13). HMO's score low on providing answers to the chronically ill looking for specialists. Newsday, pp. C1 & C5.

Hicks, L. L., Staelmeyer, J. M. & Coleman, J. R. (1993). Role of the nurse in managed care. Washington, DC: American Nurses Publishing.

Hirsch, P. & Barela, T. (1996). Children with special health care needs and managed care. Exceptional Parent, 26 (3), 60-64.

Hochstadt, N. J. & Yost, D. M. (Eds.). (1991). The Medically Complex Child. NY: Harwood Academic Publishers.

Horst, M. L. (1995). Model for management of services to low income pediatric asthma patients. Social Work in Health Care, 21 (1), 129-136.

Hurley, R. E., Freund, D. A., & Paul, J. E. (1993). Managed care in Medicaid. Ann Arbor, MI: Health Adm. Press.

Insurers assailed on childbirth stays. (1995, June 21). Newsday, p. A16.

Jackson, V. H. (1994). A brief look at managed mental health care. Washington, DC: NASW Press.

Jeffrey, N. A. (1996, December 11). Doctors battle over who treats chronically ill. The Wall Street Journal, p. B1E.

Jeffrey, N. A. (1997, October 23). Tests over time. The Wall Street Journal, p. R6.

Jellinek, M. S. (1994). Managed care: Good or bad news for children? Developmental and Behavioral Pediatrics, 15 (4), 273-274.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Karlson, T., Sumi, M. D. & Braucht, M. B. (1990). The impact of HMO's on accessibility, satisfaction and cost of health care for children with special needs. Madison, WI: Center for Health Systems Research and Analysis.

Kohrman, A. F. (1994, March). Financial access to care does not guarantee better care for children. Pediatrics, 93 (3), 506-508.

Kongstvedt, P. (1993). The managed care handbook. Gaithersburg, MD: Aspen Publications.

Maier, T. (1995, June 22). 2-Day Maternity Stays Promised. Newsday, p. A6.

Managed care: A survival kit for the oncology social worker. (1966). Baltimore, MD: AOSW.

Managed Care: Where it's at. (1997, January 20). Hospital and Health Networks, p. 19.

Mariano, W. (1999,July 12) Patients Tell of HMO Woes. Newsday, p.A21.

Marshall, C. & Rossman, G. B. (1989). Qualitative research. Newbury Park, CA: Sage Publications.

Mayer, J. B. & Rubin, G. H. (1983, February). Is there a future for social work in HMO's? Social Work, 8 (4), 283-289.

Medicaid and managed care: Policy brief. (1995, April). Washington, DC: The Kaiser Commission on the Future of Medicaid.

Medicaid managed care enrollment. (1998, June 30). Internet site, www.hcfa.gov/medicaid/mcdata98.htm

Medicaid managed care legislation passed. (1996, Fall). Currents, 1 (3), 1, 5 & 6.

Miller, R. H. & Luft, H. S. (1994). Managed care plan performance since 1980. JAMA, 271 (19), 1512-1519.

Mizrahi, T. (1993). Managed care and managed competition: Primer for social work. Health and Social Work, 8 (2), 86-91.

Montgomery, L. E., Kiely, J. C. & Pappas, G. (1996) The effects of poverty, race, family structure on US children's health: Data from the NHIS 1978 through 1980 and 1989 through 1991. American Journal of Public Health, 86 (10), 1401-1406.

Mosby's Medical, Nursing and Allied Health Dictionary, 4th Edition. (1994). St. Louis, MO: Mosby-Year Book, Inc.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Murphy, S. B. (1996). Cooperative Groups and Managed Care: New Network for Pediatric Cancer Care. Oncology Times, 28 (5), 2-3.

National Childhood Cancer Foundation. (1996, November 3). Internet site, www.nccf.org.

Netting, F. E. & Williams, F. G. (1996). Casemanager-physician collaboration: Implications for professional identity, roles and relationships. Health and Social Work, 21 (3), 216-240.

Newacheck, P. W., Hughes, D. A., Stoddard, J. J. & Halfon, N. (1994). Children with chronic illness and Medicaid management. Pediatrics, 93, 497-500.

Newacheck, P. W. & Taylor, W. R. (1992). Childhood chronic illness: Prevalence, severity and impact. American Journal of Public Health, 82, 364-371.

Oberg, C., Bryant, N. & Bach, M. (1994, August). Ethics, values and policy decisions for children with disabilities: What are the costs of political correctness? Children's Health Care, 64 (6), 223-228.

Pear, R. (1997, July 8). Name-calling becomes part of the struggle to define the health care debate. New York Times, pg. A12.

Pekmezaris, R. (1995, July 13). Medicaid managed care: What will it mean for HIV/AIDS services on Long Island? Presentation at Nassau-Suffolk HIV Health Services Council meeting.

Perloff, J. D. (1996). Medicaid managed care and urban poor: Implications for social work. Health and Social Work, 21 (3), 189-195.

Perrin, J. M. (1997). Monitoring health care for children with chronic conditions in a managed care environment. Maternal & Child Health Journal, 1 (1), 15-23.

Pilot projects aim to build system for chronically ill. (1994). Building Health Systems, 1 (1), 1 & 3.

Poole, D. (1996, August). Keeping managed care in balance. Health and Social Work, 21 (3), 163-166.

Poole, D. L. & Braja, L. J. (1984). Does social work in HMO's measure up to professional standards? Health and Social Work, 9 (4), 305-313.

Rauch, A., Kaufer, S. & Rodriquez, P. (1993). Views from the Front Line. NY: NASW, NYC Chapter.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Reamer, F. G. (1997). Managing ethics under managed care. Families in Society, 78 (1), 96-101.

Regenstein, M. & Meyer, J. (1994, August). Low income children with disabilities: How will they fare under health care reform? Portland, ME: National Academy for State Health Policy.

Regenstein, M., Meyer, J. A., Fox, H. B., McManus, M., Riley, T. & McGaughey, K. (1994, April). Challenges for decisionmakers: How managed competition could affect children with special health care needs. Portland, ME: National Academy for State Health Policy.

Resnick, C. & Tighe, E. G. (1997). The role of multidisciplinary community clinics in managed care systems. Social Work, 47 (1), 91-98.

Rodwin, M. A. (1995). Conflicts in managed care. NEJM, 332 (9), 604-606.

Ross, J. (1978). Social work intervention with families of children with cancer: The changing critical phases. Social work in health care, 4 (2), 221-231.

Ross, J. (1993). Understanding the family experience with childhood cancer. In Sterns, N. M., Lauria, M. M., Herman, J. F. & Fogelberg, P. R. (Eds.). Oncology social work. Atlanta, GA: American Cancer Society.

Ross, J. (1995). Hospital social work. In Encyclopedia to Social Work. Washington, DC: NASW Press.

Rowland, D., Rosenbaum, S., Simon, L. & Chait, E. (1995). Medicaid and managed care: Lessons from the literature. Washington, DC: Kaiser Commission on the Future of Medicaid.

Schmittroth, L. (Ed.) (1994). Statistical record of children. Detroit, Washington, DC & London: Gale Research, Inc.

Schroeder, S. A. (1994). Cost containment: The Robert Wood Johnson Foundation annual report. Princeton, NJ: Robert Wood Johnson Foundation.

Schwartz, W. (1998). Life without disease. Berkley, CA: University of CA Press.

Shera, W. (1996, August). Managed care and people with severe mental illness: Challenges and opportunities for social work. Health and Social Work, 21 (3), 196-201.

Shortell, S. M., Gillies, R. R. & Anderson, D. A. (1994, Winter). The new world of managed care: Creating organized delivery system. Health Affairs, 13 (5), 46-64.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Shutting out gatekeepers. (1999, November 22). St. Louis Post-Dispatch, p. B 6-7.

Sisk, J. E., Gorman, S. A., Resinger, A.L., Giled, S. H., DuMouchel, W. H. & Hynes, M. M. (1996, July 3). Evaluation of Medicaid managed care. JAMA, 276 (1), 50-55.

Skolnick, A. A. (1993). Children's hospitals say about health care reform. "One size won't fit all." JAMA, 270 (18), 2151-2152.

Smith, K., Layne, M. & Garell, D. (1994). The impact of care coordination on children with special health care needs. Children's Health Care, 23 (4), 251-266.

Sparer, M. S., Ellwood, M. R. & Schoen, M. A. (1996). Managed care and income populations: A case study of managed care in Minnesota. Washington, DC: Mathematica Policy Research, Inc.

Spragins, E. (1998). Choosing and using an HMO. Princeton, NJ: Bloomberg Press.

Stein, R. E. K. (Ed.). (1989). Caring for children with chronic illness: Issues and strategies. NY: Springer Publishing Co.

Stoval, A. (1993). Social work services for the child and family. In Sterns, N. M., Lauria, M. M., Herman, J. F. & Fogelberg, P. R. (Eds.). Oncology social work. Atlanta, GA: American Cancer Society.

Sunley, R. (1997). Advocacy in the new world of managed care. Families in Society, 78 (1), 84-94.

Szilagyi, P. G. (1998, Summer/Fall). Managed care for children: Effects on access to care and utilization of health services. The Future of Children, 8 (2), 39-59.

Szilagyi, P. G., Rodenwald, L. E. & Roghmann, K. J. (1993). Managed health care for children. The Journal of Ambulatory Care Management, 16 (1), 57-70.

Tripodi, A., Fellin, P. & Mayer, H. J. (1983). The assessment of social research: Guidelines for use of research in social work and social science. Itasca, IL: F. E. Peacock Publishers.

U. S. Bureau of Census. Statistical abstract of US: 1997. (1997). 117th edition. Washington, DC.

U. S. General Accounting Office. (1993). Medicaid: States turn to managed care to improve access and control costs. (HRD, 93-46, Medicaid, 072291). Washington, DC: GAO.

Vourlekiss, B. S. & Greene, R. R. (Eds.). (1992). Social work case management. NY: A. deGruyter.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Ware, J. E., Bayliss, M. S., Rogers, W. H., Kosinski, M. & Tarlov, A. R. (1996, October 2). Difference in 4 year health outcomes for elderly and poor chronically ill patients treated in HMO and fee-for-service system. JAMA, 276 (13), 1039-1047.

Weston, B. & Lauria, M. (1996). Patient advocacy in the 1990's. NEJM, 334 (18), 543-544.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.