

**RELIABILITY AND VALIDITY OF THE FIN-PED: AN INSTRUMENT  
TO MEASURE CARE NEEDS OF MOTHERS OF  
CHILDREN WITH CANCER**

BY

**E. MARILYN GOODYEAR WHITELEY**

A Thesis

Submitted to the Faculty of Graduate Studies  
in Partial Fulfilment of the Requirements for the Degree of

**MASTER OF NURSING**

Faculty of Nursing, University of Manitoba  
Winnipeg, Manitoba

(c) September, 1996



National Library  
of Canada

Acquisitions and  
Bibliographic Services Branch

395 Wellington Street  
Ottawa, Ontario  
K1A 0N4

Bibliothèque nationale  
du Canada

Direction des acquisitions et  
des services bibliographiques

395, rue Wellington  
Ottawa (Ontario)  
K1A 0N4

*Your file    Votre référence*

*Our file    Notre référence*

**The author has granted an irrevocable non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of his/her thesis by any means and in any form or format, making this thesis available to interested persons.**

**L'auteur a accordé une licence irrévocable et non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de sa thèse de quelque manière et sous quelque forme que ce soit pour mettre des exemplaires de cette thèse à la disposition des personnes intéressées.**

**The author retains ownership of the copyright in his/her thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without his/her permission.**

**L'auteur conserve la propriété du droit d'auteur qui protège sa thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.**

ISBN 0-612-16142-0

**Canada**

*Dissertation Abstracts International* and *Masters Abstracts International* are arranged by broad, general subject categories. Please select the one subject which most nearly describes the content of your dissertation or thesis. Enter the corresponding four-digit code in the spaces provided.

Nursing

SUBJECT TERM

0569

UMI

SUBJECT CODE

## Subject Categories

## THE HUMANITIES AND SOCIAL SCIENCES

## COMMUNICATIONS AND THE ARTS

Architecture	0729
Art History	0377
Cinema	0900
Dance	0378
Fine Arts	0357
Information Science	0723
Journalism	0391
Library Science	0399
Mass Communications	0708
Music	0413
Speech Communication	0459
Theater	0465

## EDUCATION

General	0515
Administration	0514
Adult and Continuing	0516
Agricultural	0517
Art	0273
Bilingual and Multicultural	0282
Business	0688
Community College	0275
Curriculum and Instruction	0727
Early Childhood	0518
Elementary	0524
Finance	0277
Guidance and Counseling	0519
Health	0680
Higher	0745
History of	0520
Home Economics	0278
Industrial	0521
Language and Literature	0279
Mathematics	0280
Music	0522
Philosophy of	0998
Physical	0523

Psychology	0525
Reading	0535
Religious	0527
Sciences	0714
Secondary	0533
Social Sciences	0534
Sociology of	0340
Special	0529
Teacher Training	0530
Technology	0710
Tests and Measurements	0288
Vocational	0747

## LANGUAGE, LITERATURE AND LINGUISTICS

Language	
General	0679
Ancient	0289
Linguistics	0290
Modern	0291
Literature	
General	0401
Classical	0294
Comparative	0295
Medieval	0297
Modern	0298
African	0316
American	0591
Asian	0305
Canadian (English)	0352
Canadian (French)	0355
English	0593
Germanic	0311
Latin American	0312
Middle Eastern	0315
Romance	0313
Slavic and East European	0314

## PHILOSOPHY, RELIGION AND THEOLOGY

Philosophy	0422
Religion	
General	0318
Biblical Studies	0321
Clergy	0319
History of	0320
Philosophy of	0322
Theology	0469

## SOCIAL SCIENCES

American Studies	0323
Anthropology	
Archaeology	0324
Cultural	0326
Physical	0327
Business Administration	
General	0310
Accounting	0272
Banking	0770
Management	0454
Marketing	0338
Canadian Studies	0385
Economics	
General	0501
Agricultural	0503
Commerce-Business	0505
Finance	0508
History	0509
Labor	0510
Theory	0511
Folklore	0358
Geography	0366
Gerontology	0351
History	
General	0578

Ancient	0579
Medieval	0581
Modern	0582
Black	0328
African	0331
Asia, Australia and Oceania	0332
Canadian	0334
European	0335
Latin American	0336
Middle Eastern	0333
United States	0337
History of Science	0585
Law	0398
Political Science	
General	0615
International Law and Relations	0616
Public Administration	0617
Recreation	0814
Social Work	0452
Sociology	
General	0626
Criminology and Penology	0627
Demography	0938
Ethnic and Racial Studies	0631
Individual and Family Studies	0628
Industrial and Labor Relations	0629
Public and Social Welfare	0630
Social Structure and Development	0700
Theory and Methods	0344
Transportation	0709
Urban and Regional Planning	0999
Women's Studies	0453

## THE SCIENCES AND ENGINEERING

## BIOLOGICAL SCIENCES

Agriculture	
General	0473
Agronomy	0285
Animal Culture and Nutrition	0475
Animal Pathology	0476
Food Science and Technology	0359
Forestry and Wildlife	0478
Plant Culture	0479
Plant Pathology	0480
Plant Physiology	0817
Range Management	0777
Wood Technology	0746
Biology	
General	0306
Anatomy	0287
Biostatistics	0308
Botany	0309
Cell	0379
Ecology	0329
Entomology	0353
Genetics	0369
Limnology	0793
Microbiology	0410
Molecular	0307
Neuroscience	0317
Oceanography	0416
Physiology	0433
Radiation	0821
Veterinary Science	0778
Zoology	0472
Biophysics	
General	0786
Medical	0760
EARTH SCIENCES	
Biogeochemistry	0425
Geochemistry	0996

Geodesy	0370
Geology	0372
Geophysics	0373
Hydrology	0388
Mineralogy	0411
Paleobotany	0345
Paleoecology	0426
Paleontology	0418
Paleozoology	0985
Palynology	0427
Physical Geography	0368
Physical Oceanography	0415

## HEALTH AND ENVIRONMENTAL SCIENCES

Environmental Sciences	0768
Health Sciences	
General	0566
Audiology	0300
Chemotherapy	0992
Dentistry	0567
Education	0350
Hospital Management	0769
Human Development	0758
Immunology	0982
Medicine and Surgery	0564
Mental Health	0347
Nursing	0569
Nutrition	0570
Obstetrics and Gynecology	0380
Occupational Health and Therapy	0354
Ophthalmology	0381
Pathology	0571
Pharmacology	0419
Pharmacy	0572
Physical Therapy	0382
Public Health	0573
Radiology	0574
Recreation	0575

Speech Pathology	0460
Toxicology	0383
Home Economics	0386

## PHYSICAL SCIENCES

## Pure Sciences

Chemistry	
General	0485
Agricultural	0749
Analytical	0486
Biochemistry	0487
Inorganic	0488
Nuclear	0738
Organic	0490
Pharmaceutical	0491
Physical	0494
Polymer	0495
Radiation	0754
Mathematics	0405
Physics	
General	0605
Acoustics	0986
Astronomy and Astrophysics	0606
Atmospheric Science	0608
Atomic	0748
Electronics and Electricity	0607
Elementary Particles and High Energy	0798
Fluid and Plasma	0759
Molecular	0609
Nuclear	0610
Optics	0752
Radiation	0756
Solid State	0611
Statistics	0463

## Applied Sciences

Applied Mechanics	0346
Computer Science	0984

Engineering	
General	0537
Aerospace	0538
Agricultural	0539
Automotive	0540
Biomedical	0541
Chemical	0542
Civil	0543
Electronics and Electrical	0544
Heat and Thermodynamics	0348
Hydraulic	0545
Industrial	0546
Marine	0547
Materials Science	0794
Mechanical	0548
Metallurgy	0743
Mining	0551
Nuclear	0552
Packaging	0549
Petroleum	0765
Sanitary and Municipal	0554
System Science	0790
Geotechnology	0428
Operations Research	0796
Plastics Technology	0795
Textile Technology	0994

## PSYCHOLOGY

General	0621
Behavioral	0384
Clinical	0622
Developmental	0620
Experimental	0623
Industrial	0624
Personality	0625
Physiological	0989
Psychobiology	0349
Psychometrics	0632
Social	0451

Nom \_\_\_\_\_

*Dissertation Abstracts International* est organisé en catégories de sujets. Veuillez s.v.p. choisir le sujet qui décrit le mieux votre thèse et inscrivez le code numérique approprié dans l'espace réservé ci-dessous.



SUJET

CODE DE SUJET

## Catégories par sujets

### HUMANITÉS ET SCIENCES SOCIALES

#### COMMUNICATIONS ET LES ARTS

Architecture .....	0729
Beaux-arts .....	0357
Bibliothéconomie .....	0399
Cinéma .....	0900
Communication verbale .....	0459
Communications .....	0708
Danse .....	0378
Histoire de l'art .....	0377
Journalisme .....	0391
Musique .....	0413
Sciences de l'information .....	0723
Théâtre .....	0465

#### ÉDUCATION

Généralités .....	515
Administration .....	0514
Art .....	0273
Collèges communautaires .....	0275
Commerce .....	0688
Économie domestique .....	0278
Éducation permanente .....	0516
Éducation préscolaire .....	0518
Éducation sanitaire .....	0680
Enseignement agricole .....	0517
Enseignement bilingue et multiculturel .....	0282
Enseignement industriel .....	0521
Enseignement primaire .....	0524
Enseignement professionnel .....	0747
Enseignement religieux .....	0527
Enseignement secondaire .....	0533
Enseignement spécial .....	0529
Enseignement supérieur .....	0745
Évaluation .....	0288
Finances .....	0277
Formation des enseignants .....	0530
Histoire de l'éducation .....	0520
Langues et littérature .....	0279

Lecture .....	0535
Mathématiques .....	0280
Musique .....	0522
Orientation et consultation .....	0519
Philosophie de l'éducation .....	0998
Physique .....	0523
Programmes d'études et enseignement .....	0727
Psychologie .....	0525
Sciences .....	0714
Sciences sociales .....	0534
Sociologie de l'éducation .....	0340
Technologie .....	0710

#### LANGUE, LITTÉRATURE ET LINGUISTIQUE

Langues	
Généralités .....	0679
Anciennes .....	0289
Linguistique .....	0290
Modernes .....	0291
Littérature	
Généralités .....	0401
Anciennes .....	0294
Comparée .....	0295
Médiévale .....	0297
Moderne .....	0298
Africaine .....	0316
Américaine .....	0591
Anglaise .....	0593
Asiatique .....	0305
Canadienne (Anglaise) .....	0352
Canadienne (Française) .....	0355
Germanique .....	0311
Latino-américaine .....	0312
Moyen-orientale .....	0315
Romane .....	0313
Slave et est-européenne .....	0314

#### PHILOSOPHIE, RELIGION ET THÉOLOGIE

Philosophie .....	0422
Religion	
Généralités .....	0318
Clergé .....	0319
Études bibliques .....	0321
Histoire des religions .....	0320
Philosophie de la religion .....	0322
Théologie .....	0469

#### SCIENCES SOCIALES

Anthropologie	
Archéologie .....	0324
Culturelle .....	0326
Physique .....	0327
Droit .....	0398
Économie	
Généralités .....	0501
Commerce-Affaires .....	0505
Économie agricole .....	0503
Économie du travail .....	0510
Finances .....	0508
Histoire .....	0509
Théorie .....	0511
Études américaines .....	0323
Études canadiennes .....	0385
Études féministes .....	0453
Folklore .....	0358
Géographie .....	0366
Gérontologie .....	0351
Gestion des affaires	
Généralités .....	0310
Administration .....	0454
Banques .....	0770
Comptabilité .....	0272
Marketing .....	0338
Histoire	
Histoire générale .....	0578

Ancienne .....	0579
Médiévale .....	0581
Moderne .....	0582
Histoire des noirs .....	0328
Africaine .....	0331
Canadienne .....	0334
États-Unis .....	0337
Européenne .....	0335
Moyen-orientale .....	0333
Latino-américaine .....	0336
Asie, Australie et Océanie .....	0332
Histoire des sciences .....	0585
Loisirs .....	0814
Planification urbaine et régionale .....	0999
Science politique	
Généralités .....	0615
Administration publique .....	0617
Droit et relations internationales .....	0616
Sociologie	
Généralités .....	0626
Aide et bien-être social .....	0630
Criminologie et établissements pénitentiaires .....	0627
Démographie .....	0938
Études de l'individu et de la famille .....	0628
Études des relations interethniques et des relations raciales .....	0631
Structure et développement social .....	0700
Théorie et méthodes .....	0344
Travail et relations industrielles .....	0629
Transports .....	0709
Travail social .....	0452

### SCIENCES ET INGÉNIERIE

#### SCIENCES BIOLOGIQUES

Agriculture	
Généralités .....	0473
Agronomie .....	0285
Alimentation et technologie alimentaire .....	0359
Culture .....	0479
Élevage et alimentation .....	0475
Exploitation des pâturages .....	0777
Pathologie animale .....	0476
Pathologie végétale .....	0480
Physiologie végétale .....	0817
Sylviculture et taune .....	0478
Technologie du bois .....	0746
Biologie	
Généralités .....	0306
Anatomie .....	0287
Biologie (Statistiques) .....	0308
Biologie moléculaire .....	0307
Botanique .....	0309
Cellule .....	0379
Écologie .....	0329
Entomologie .....	0353
Génétique .....	0369
Limnologie .....	0793
Microbiologie .....	0410
Neurologie .....	0317
Océanographie .....	0416
Physiologie .....	0433
Radiation .....	0821
Science vétérinaire .....	0778
Zoologie .....	0472
Biophysique	
Généralités .....	0786
Médicale .....	0760

#### SCIENCES DE LA TERRE

Biogéochimie .....	0425
Géochimie .....	0996
Géodésie .....	0370
Géographie physique .....	0368

Géologie .....	0372
Géophysique .....	0373
Hydrologie .....	0388
Minéralogie .....	0411
Océanographie physique .....	0415
Paléobotanique .....	0345
Paléocéologie .....	0426
Paléontologie .....	0418
Paléozoologie .....	0985
Palynologie .....	0427

#### SCIENCES DE LA SANTÉ ET DE L'ENVIRONNEMENT

Économie domestique .....	0386
Sciences de l'environnement .....	0768
Sciences de la santé	
Généralités .....	0566
Administration des hôpitaux .....	0769
Alimentation et nutrition .....	0570
Audiologie .....	0300
Chimiothérapie .....	0992
Dentisterie .....	0567
Développement humain .....	0758
Enseignement .....	0350
Immunologie .....	0982
Loisirs .....	0575
Médecine du travail et thérapie .....	0354
Médecine et chirurgie .....	0564
Obstétrique et gynécologie .....	0380
Ophtalmologie .....	0381
Orthophonie .....	0460
Pathologie .....	0571
Pharmacie .....	0572
Pharmacologie .....	0419
Physiothérapie .....	0382
Radiologie .....	0574
Santé mentale .....	0347
Santé publique .....	0573
Soins infirmiers .....	0569
Toxicologie .....	0383

#### SCIENCES PHYSIQUES

##### Sciences Pures

Chimie	
Généralités .....	0485
Biochimie .....	0487
Chimie agricole .....	0749
Chimie analytique .....	0486
Chimie minérale .....	0488
Chimie nucléaire .....	0738
Chimie organique .....	0490
Chimie pharmaceutique .....	0491
Physique .....	0494
Polymères .....	0495
Radiation .....	0754
Mathématiques	
Physique	
Généralités .....	0605
Acoustique .....	0986
Astronomie et astrophysique .....	0606
Électrique et électricité .....	0607
Fluides et plasma .....	0759
Météorologie .....	0608
Optique .....	0752
Particules (Physique nucléaire) .....	0798
Physique atomique .....	0748
Physique de l'état solide .....	0611
Physique moléculaire .....	0609
Physique nucléaire .....	0610
Radiation .....	0756
Statistiques .....	0463

##### Sciences Appliquées Et Technologie

Informatique .....	0984
Ingénierie	
Généralités .....	0537
Agricole .....	0539
Automobile .....	0540

Biomédicale .....	0541
Chaleur et ther modynamique .....	0348
Conditionnement (Emballage) .....	0549
Génie aérospatial .....	0538
Génie chimique .....	0542
Génie civil .....	0543
Génie électronique et électrique .....	0544
Génie industriel .....	0546
Génie mécanique .....	0548
Génie nucléaire .....	0552
Ingénierie des systèmes .....	0790
Mécanique navale .....	0547
Mécatronique .....	0743
Métallurgie .....	0794
Science des matériaux .....	0765
Technique du pétrole .....	0551
Technique minière .....	0554
Techniques sanitaires et municipales .....	0545
Technologie hydraulique .....	0346
Mécanique appliquée .....	0428
Géotechnologie .....	0795
Matériaux plastiques (Technologie) .....	0796
Recherche opérationnelle .....	0794
Textiles et tissus (Technologie) .....	

#### PSYCHOLOGIE

Généralités .....	0621
Personnalité .....	0625
Psychobiologie .....	0349
Psychologie clinique .....	0622
Psychologie du comportement .....	0384
Psychologie du développement .....	0620
Psychologie expérimentale .....	0623
Psychologie industrielle .....	0624
Psychologie physiologique .....	0989
Psychologie sociale .....	0451
Psychométrie .....	0632



THE UNIVERSITY OF MANITOBA  
FACULTY OF GRADUATE STUDIES  
COPYRIGHT PERMISSION

RELIABILITY AND VALIDITY OF THE FIN-PED:  
AN INSTRUMENT TO MEASURE CARE NEEDS OF MOTHERS OF  
CHILDREN WITH CANCER

BY

E. MARILYN GOODYEAR WHITELEY

A Thesis/Practicum submitted to the Faculty of Graduate Studies of the University of Manitoba in partial fulfillment of the requirements for the degree of

MASTER OF NURSING

E. Marilyn Goodyear Whiteley © 1996

Permission has been granted to the LIBRARY OF THE UNIVERSITY OF MANITOBA to lend or sell copies of this thesis/practicum, to the NATIONAL LIBRARY OF CANADA to microfilm this thesis/practicum and to lend or sell copies of the film, and to UNIVERSITY MICROFILMS INC. to publish an abstract of this thesis/practicum..

This reproduction or copy of this thesis has been made available by authority of the copyright owner solely for the purpose of private study and research, and may only be reproduced and copied as permitted by copyright laws or with express written authorization from the copyright owner.

**ABSTRACT**

Only a limited number of studies are available in the literature on the needs of parents of children with cancer. The purpose of this study was to develop and test an instrument to measure the care needs of mothers of children with cancer, and the extent to which these needs were met (FIN-PED). Phase I of the study involved the development of the items to be included in the FIN-PED. Phase II pilot tested the FIN-PED for clarity, apparent internal consistency, and content validity, using an expert panel of six mothers whose children had cancer. Phase III tested the FIN-PED for reliability.

From a list of cancer patients, 303 FIN-PED questionnaires with demographic questionnaires were mailed to mothers of children with cancer. Questionnaires were returned by 110 mothers. These 110 mothers were mailed a second copy of the FIN-PED. Fifty of these retest questionnaires were returned.

The Needs subscale of the FIN-PED instrument achieved an internal consistency estimate of .94 for the initial response to the questionnaire, as measured by Cronbach's standardized alpha coefficient. The Needs-met subscale of the FIN-PED instrument achieved an internal consistency

reliability score of .94. Chi-square tests showed a significant level of test-retest reliability for both scales.

The results showed that 85% of the needs items had means of greater than 4.0, indicating that the mothers rated the 85% of the needs as very important or close to very important. Needs-met scores for mothers working outside the home were significantly lower than needs-met scores for mothers not working outside the home. Overall needs scores for mothers who lived in Winnipeg were significantly lower than the needs scores for mothers who lived outside of Winnipeg. Mothers living from 101 to 240 km from Winnipeg had significantly higher needs-met scores than mothers living further than 240 km from Winnipeg.

This study showed that this group of mothers had a large number of needs that they rated as very important, and that a number of these needs were identified as either being only partly met or unmet. Implications for nursing practise and future research were identified.

### **ACKNOWLEDGEMENTS**

I would like to express my sincere gratitude to my thesis chairperson Dr. Linda Kristjanson who taught me the challenges and enjoyment of research. I also thank my other committee members Dr. Lesley Degner and Dr. Rochelle Yanofsky for their advice and assistance. Mr. Bryan Mueller and Ms. Linda Balneaves provided valuable assistance with the data collection and analyses. Special recognition needs to be given to the mothers of children with cancer who so graciously gave of their time to participate in this study. I also thank my family for their support and encouragement.

This project was supported by grants from the Manitoba Association of Registered Nurses Foundation, Canadian Nurses Foundation, and the Health Sciences Centre Nursing Research Foundation.



**TABLE OF CONTENTS**

	Page
ABSTRACT .....	iii
ACKNOWLEDGEMENTS .....	v
LIST OF TABLES .....	ix
LIST OF APPENDICES .....	x
<b>CHAPTER I STATEMENT OF THE PROBLEM</b>	
Introduction.....	1
Developmental Stages.....	3
Parents and Parenting.....	6
Siblings.....	9
Family Structure.....	13
Purpose of the Study .....	14
Significance of the Study.....	15
Problem Statement.....	18
Summary.....	18
<b>CHAPTER II CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW</b>	
Introduction.....	19
Conceptual Framework .....	19
Review of the Literature.....	22
Family Care Needs.....	22
Social Supports.....	24
Cross-Cultural Aspects of Social Supports.....	26
Clinical Observations on Social Supports.....	28
Social Supports and Self-help Groups.....	29
Parents' and Professionals' Perceptions of Supports.....	29
Conclusions.....	31

Stress and Coping Behaviours.....	32
Care of the Family.....	37
Education Needs.....	38
Communication Needs.....	39
Psychosocial Needs.....	40
Psychosocial Needs During Midstage of the Illness.....	41
Needs During the Terminal Stage of Illness.....	42
Needs of Parents of Long Term Survivors of Cancer.....	43
Instrument Development.....	44
Summary.....	46

### **CHAPTER III    METHODOLOGY**

Introduction.....	47
Research Method.....	47
Phase I.....	48
Pilot Study: Phase II.....	49
Introduction.....	49
Sample and Selection Criteria.....	50
Procedure.....	51
Clarity of Items.....	52
Apparent Internal Consistency.....	52
Content Validity.....	53
Pilot Testing Versus Focus Groups.....	54
Phase III.....	55
Introduction.....	55
Sample and Selection Criteria.....	55
Recruitment Procedure.....	56
Data Collection.....	56
Data Analyses.....	57
Ethical Considerations.....	59
Summary.....	60

### **CHAPTER IV    RESULTS**

Introduction .....	61
--------------------	----

Phase II - Pilot test - Data analysis .....	61
Introduction .....	61
Clarity of Items .....	62
Apparent Internal Consistency .....	63
Content Validity .....	63
Additional Needs .....	64
Summary .....	65
Phase III: FIN-PED Survey Results .....	66
Introduction .....	66
Description of Sample .....	66
Distribution of Scale Ratings .....	71
Needs Subscale .....	71
Needs-met Subscale .....	73
Internal Consistency Reliability .....	75
Needs Subscale .....	75
Needs-met Subscale.....	76
Test-Retest Reliability .....	76
Internal Construct Validity .....	78
Relation of Needs and Needs-met to Demographic Variables .....	82
Content Analysis .....	87
Summary .....	91
 <b>CHAPTER V DISCUSSION</b>	
Introduction .....	92
Reliability and Content Validity of the FIN-PED .....	92
Methodological Issues.....	94
Findings in Relation to the Literature on Mothers' Needs .....	97
Relation of Needs and Needs-met to Demographic Variables .....	101
Family Systems .....	102
Research Implications .....	103
Clinical Implications .....	105
Conclusions .....	108
References .....	109

## LIST OF TABLES

	Page
1. Age and Marital Status.....	67
2. Educational Level of Mothers.....	68
3. Distance Mothers Lived Outside Winnipeg.....	68
4. Occupation of Mothers.....	69
5. Children's Diagnoses .....	69
6. Number of Admissions to Hospital.....	70
7. Reason for Admissions to Hospital.....	70
8. Percentage of Children with Brothers and Sisters .....	71
9. Mean, Standard Deviation, and Range of Scores for each Need Item .....	72
10. Needs Items Ranked by Mean Needs Rating.....	74
11. Number of Respondents Categorized at Each Level of Need .....	77
12. Number of Respondents Categorized at Each Level of Needs-met .....	78
13. Factor Loading and Percent of Variance Explained for the First Thirteen Factors.....	79
14. Factor Analysis of FIN-PED - Needs Subscale ....	80
15. Mean Needs and Needs-met Scores for Mothers with Different Educational Levels .....	84
16. Mean Needs and Needs-met Scores for Occupational Groups .....	84
17. Mean Needs and Needs-met Scores by Number of Hospital Admissions .....	86
18. Mean Needs and Needs-met Scores by Diagnostic Category .....	87

**LIST OF APPENDICES**

	Page
A. Pilot Testing Request.....	115
B. Pilot Testing Information.....	116
C. Pilot Testing Consent Form.....	117
D. Pilot Test - Clarity.....	118
E. Pilot Test - Internal Consistency.....	119
F. Pilot Test - Content Validity.....	120
G. Pilot Family Inventory of Needs - Paediatrics..	122
H. Cover Letter to Mothers.....	126
I. Demographic Questionnaire.....	127
J. Family Inventory of Needs - Paediatrics.....	130
K. Follow-up Letter.....	135

**CHAPTER 1****STATEMENT OF THE PROBLEM**Introduction

A family with a child who has cancer faces many stressful events over an extended period of time. These events produce a complex set of needs that must be met by health care providers. The paediatric oncology nurse plays a key role in assessing and supporting families whose children have been diagnosed with cancer (Heiney, 1988). The limited empirical literature related to families of paediatric cancer patients suggests that health professionals may be instrumental in guiding cancer families towards creating functional health patterns, while families experience recurring stressful events (Johnson & Norby, 1981). Knowledge of the care needs of family members is essential for nurses to support families through this process (Moore, Kramer, R.F, & Perin, 1986).

In their study on reducing hospital-related stress in parents of children with cancer, Hayes and Knox (1983) reported on the importance of nurses being aware of parents' needs in advance. If a parents' needs have become apparent, or if a parent had to ask that a need be met, that need has

already become a source of stress, according to these authors.

There are few studies in the paediatric literature assessing the care needs of families of children with cancer. Parents, however, identify needs such as honesty, support, information about their child's condition, a need to be involved in the care of their child, and a need to take an active part in the decisions being made about their child's treatment (Chesler & Barbarin, 1984; Wallace, Bakke, Hubbard & Pendergrass, 1984; Williams, 1992). No studies were found in the paediatric literature assessing the needs of families of children with cancer that used a valid and reliable instrument. It is therefore necessary to develop and test an instrument that can index these needs.

A search of the adult cancer literature revealed a limited number of studies using instruments assessing family needs. The Family Inventory of Needs (FIN) developed by Kristjanson, Atwood and Degner (1995) was found to be a concise, valid and reliable instrument. The instrument also is composed of need statements that are similar to needs of parents of children with cancer reported in the literature. This instrument was therefore chosen to be used as a basis for the development of a paediatric instrument, the FIN-PED.

The following four areas: developmental stages, parents and parenting, siblings, and family structure are reviewed in this introduction to present background information relevant to understanding the needs of mothers with a child hospitalized for cancer treatment. All four of these areas are important to the care of the hospitalized child and the impact that hospitalization has on members of the family.

#### Developmental Stages

Parents' needs may vary depending on the developmental stage of their child. Several authors have described the effects of hospitalization on children of different ages (Adams & Deveau, 1988; Foster, Hunsberger & Anderson, 1989; Maul-Mellott & Adams, 1987). The relationship between the child's stage of development and the needs of parents have not been examined. It seems likely that some parental needs are affected by the developmental stage of the child, such as the need for caregiving; whereas others, such as needs for information, do not differ as a function of the child's stage of development.

Petrillo and Sanger (1980) related Erikson's developmental theory to childhood hospitalizations. In the first stage, Erikson's theory proposes that infants acquire basic trust. Trust develops when the infant's needs are



consistently met by caregivers. In a hospital setting, the emotional and physical needs of the infant may not always be met. If these needs are not met, infants may then develop a pessimism about the world.

In the second stage of development, Erikson's theory proposes that the toddler can develop a sense of autonomy. Toddlers have a great fear of separation and abandonment, and these feelings can be elicited by hospitalization. They do not have a sense of time, but expect all their needs to be met immediately, and it may be difficult to address their needs in a timely fashion in a hospital. These factors suggest that hospitalization may result in the development of a sense of guilt on the part of the child.

The pre-schooler may view hospitalization with a sense of guilt, and intrusive procedures may be seen as punishment. Their frustration and despair is often demonstrated in bouts of anger and rage. The pre-schooler can tolerate separation better than the toddler, but above all needs truthfulness and trust.

The school age child can respond to hospitalization and separation from family and peers with anger and depression. They will tolerate procedures better if given explanations in advance. Successful adaptations by six to eleven year olds to their schools and neighbourhoods, lead to the

development of industry by this age group. Unsuccessful adaptations can lead to feelings of inferiority (Petrillo & Sanger, 1980).

The adolescent responds to lack of control with mood swings. Their predominant values are those of their peer group. Erikson's theory predicts that unsuccessful outcomes for the adolescent will lead to identity diffusion (Petrillo & Sanger, 1980). Bryne, Stockwell and Gudelis (1984) have documented a range of anticipatory pre-treatment behaviours in adolescents from verbal expressions to nausea and vomiting.

The above theoretical analysis suggests that some parental needs are likely to be affected by the developmental stage of their children. For example, parents with infants and preschool children may have greater needs than parents of school-aged children to be present in the hospital so that they can provide direct physical care, such as breast feeding. From the standpoint of Erikson's theory, such parenting will facilitate the infant's development of trust. A paediatric needs assessment instrument should be appropriate for parents with children in each developmental stage.

Parents and Parenting

The main theme identified by Hayes and Knox's (1983) research, involving hospital-related stress in parents of children with cancer, was the increase in stress experienced by parents due to the change in their parenting role during hospitalization. Their research documented that parents have their own parenting guidelines and expectations. When a child is hospitalized a parent must share the care of her or his child with other caregivers. Often parents have little time to adjust to their own feelings and needs before they must support the child and other family members in coping with the diagnosis of cancer. One parent described caring for a hospitalized child with cancer as "having a job without a job description" (Hayes & Knox, 1983, p. 27). Parents do, however, have expectations of their role in caring for their child in hospital. They often expect, and need to be involved in, caring for and protecting their child. Parents also have reported feelings of appreciation when health care professionals exhibit their own personal concern and regard for their child (Chesler & Barbarin, 1984).

The initial diagnosis of cancer in a child is consistently reported to be a crisis event for the family (Moore, Kramer & Perin, 1986; Reed, 1991; Thorne, 1985;

Wallace, Bakke, Hubbard & Pendergrass, 1984). The emotional impact of this diagnosis on the family has been recognized for over two decades (Moore et al., 1986). Parents must cope with this devastating diagnosis, their emotions and concerns for their ill child, the response of the ill child's siblings, and the response of other family relations and family friends (Wallace, Bakke, Hubbard & Pendergrass, 1984). The literature identifies many needs expressed by parents such as their needs for support, honesty, information from health care workers, and help to regain at least some control over what is happening to their child (Adams & Deveau, 1988; Chesler & Barbarin, 1984; Hayes & Knox, 1983). Chesler and Barbarin (1984) interviewed 75 parents of surviving children with cancer. Although the study was mainly concerned with investigating relationships between parents and physicians, it also included relationships with nursing staff. Parents reported seven issues in staff-parent interactions. These issues, summarized as most frequently reported (52% of parents) to least frequently reported (42% of parents) were: conflict resolution, interpersonal contact, empathy with the child, acceptance of parental efficacy, transmission of information, communication, and staff competence.

Conflict resolution mainly involved parents' concerns and questioning of treatments and procedures. The researchers reported that conflicts were more likely to escalate if parents did not consider the staff sensitive to their child's needs. Parents wanted their interactions with health care personnel conducted in an atmosphere of mutual respect and caring. Parents expected staff to be attentive to the amount of pain or side-effects caused by treatments, but respected staff who could maintain a balance between empathy and some control over behaviour.

In addition, parents expected to be treated as knowledgeable collaborators in discussing their child's treatment. Parents complained about lack of control and being excluded from the care of their child. There were conflicting reports from parents with respect to the issue of transmission of information. Many said that they did not retain information given to them at the time of the initial diagnosis. Others stated that years later they could remember verbatim the initial diagnostic conference. Some parents reported that they were discouraged by professionals when they tried to read medical articles on cancer and obtain clarification regarding this information.

Parents identified the need for open and honest communication and specified that they expected information

to be communicated to them in lay language. The issue of staff competence arose from parents' observations of staffs' skills when conducting initial diagnoses, monitoring their child's care, and administering medications and intravenous treatments. Parents also reported that although their paediatrician and staff at local community hospitals were caring, they did not believe that they had the competence of staff at larger teaching centres. Parents in this study identified a number of unmet needs, reinforcing the necessity for further research to develop and test a paediatric needs assessment instrument.

### Siblings

In addition to supporting the child diagnosed with cancer, parents have the task of supporting other children in the family. Siblings are required to adjust to a disruptive family situation, while coping with their own fears and concerns for themselves and their sibling diagnosed with cancer. For example, anecdotal literature documents how regular family outings are now disrupted by clinic visits and treatments (Adams & Deveau, 1988). The altered relationships experienced by siblings often lead them to feel jealous or left out. Research reports that changes such as these are stressful to siblings (Walker,

1988). Anecdotal and research literature documents that the effects of the cancer experience on siblings of cancer patients also adds an extra stress on parents (Koch, 1985: & Walker, 1988).

Walker (1988) interviewed fifteen families with 26 siblings between the ages of 7 and 11 years of age. All instruments used in this study were designed by the researcher. Open-interviews were administered to both parents and siblings. The interviews were designed to elicit both perceptions of stressful events and coping strategies. In addition, questionnaires were administered to the parents, and the researcher and children participated in puppet play, creating family drawings and cartoon storytelling about their experiences. These techniques allowed children to symbolically discuss experiences in the third person. There is no mention of reliability and validity testing for any of the data collection methods used.

Three themes were revealed by the analysis of the sibling data: loss, fear of death, and change (Walker, 1988). Both groups were asked to discuss responses of siblings and coping mechanisms used by siblings of children with cancer. Five parents (8 siblings) could not identify any coping mechanisms. Parents described coping strategies for 18 siblings. However, when comparisons were made

between parents' and siblings' reports of how siblings coped, only 22% of the coping strategies were given by both groups, 33% of coping strategies were partially agreed upon by both groups, and 44% of the coping strategies received no agreement between groups. Parents reported that siblings' responses included physiological changes such as sleep disturbances and headaches; changes in social functioning, such as decreased ability to have fun; and changes in the affective domain manifested by aggression, irritability, and sadness. Parents described siblings' use of coping mechanisms such as denial of feelings, verbalizing problems to parents and acting out. Siblings' coping strategies were categorized as denial, information seeking, attention seeking, and needing time out. The results of this study have shown that an understanding of sibling needs and coping cannot necessarily be based on parental reports. Given the small sample, further research is required to replicate the relationship between parents' and siblings' perceptions of sibling stress, coping strategies and needs.

In a 1985 qualitative study, Koch interviewed siblings and parents of 32 paediatric cancer patients to study the effects of a child with cancer on both siblings and parents collectively. Each interview contained open and closed ended questions, and provided an opportunity for all



participants to discuss related topics as they arose. Her research found five patterns of behaviour in response to the cancer diagnosis: an increased negative effect in terms of feelings of anger and fear, families engaging in repression or denial of feelings, the emergence of behaviour and health problems, role changes in terms of more time being focused on the ill child, and in some of the families, an increase in closeness.

Walker's 1990 review article outlines the major findings in terms of both negative and positive consequences for siblings. Only a small number of studies reported positive effects on siblings. These effects were an increased empathy and sensitivity for the ill child, maturation in siblings, and increased cohesion in family members. A greater number of negative findings for siblings included: loss of parental availability, loneliness, anxiety and depression, low self worth and behavioural problems.

No research could be found identifying parents' needs in coping with, or supporting siblings of children with cancer. The findings in studies of siblings of children with cancer indicate that parents experience an additional stress in dealing with siblings and in meeting their needs (Koch, 1985; Walker, 1988). There is a need for research

identifying parents needs in supporting siblings of children with cancer.

### Family Structure

Authors of clinical and anecdotal literature stress that family-centred paediatric care involves being aware of the family structure and composition and how this status may affect the care needs of parents (Maul-Mellott & Adams 1987). Wallace et al., (1984) document that the family's lifestyle may be altered as members cope with treatments and hospitalizations. Consequently, parents' marriages or other family relationships may be challenged.

A greater stress occurs to families when distance separates them from their immediate family and relatives (Aitken & Hathaway, 1993). Financial constraints can make it difficult for siblings and sometimes fathers to visit. Family dynamics are altered and discord can develop among family members. When remarriage has occurred, step-parents and step-children may be attempting to resolve feelings of grief and loss of the previous family. These emotions may influence their abilities to cope with a new crisis. Different expectations and priorities in the new family may complicate decision making. Friesen and Manitt, in their 1990 case study, examined the remarried family in a

palliative care setting. They reported the advantages of using a genogram as part of the initial admission to determine the family structure and relationships.

Birenbaum's 1990 study on family coping with childhood cancer documents how parents' abilities to manage their problems on a daily basis affect their ill child and other members of the family. Anecdotal literature states that the greatest stress is experienced by the single parent when she/he receives the catastrophic news of a child's cancer diagnosis. Stresses, such as arranging hospital visits around a work schedule and coping with the demands of other children, add an extra burden on a single parent (Adams & Deveau 1988).

From this literature review, it is evident that many needs have been identified by families of children with cancer. A valid and reliable instrument for measuring these needs would provide a way for families to express their needs and allow nurses to provide care that more sensitively responds to family needs.

#### Purpose of the Study

The purpose of this study was to develop an instrument to measure the care needs of mothers whose children have been diagnosed with cancer. Mothers' care needs were

investigated because prior research suggests that mothers are usually the primary care givers (Hayes & Knox, 1983). A three phased approach was be used to develop and test the instrument the FIN-PED. Phase I involved the development of a list of care needs pertinent to mothers whose children have been diagnosed with cancer. These needs were based on the literature and the author's clinical experience. The Family Inventory of Needs (FIN) was then modified to include these needs, producing the FIN-PED. Paediatric needs were added based on the literature and the author's clinical experience.

Phase II used an expert panel of six mothers recruited from the Manitoba Cancer and Treatment Research Foundation (MCTRF) paediatric oncology department to assess the clarity, apparent internal consistency, and the content validity of the FIN-PED. Phase III involved testing the FIN-PED for reliability and validity using a sample of mothers whose children had been diagnosed with cancer.

#### Significance of the Study

Internationally, paediatric cancer has increased slightly from 12.3/100,000 per year in 1974 to 13.5/100,000 per year in 1990 (Hammond et al. 1993). Overall mortality rates continue to decrease. In Manitoba, annually, 33 to 54

newly-diagnosed children with cancer receive care and treatment from the paediatric oncology team at the Manitoba Cancer and Treatment Research Foundation and Children's Hospital, Health Sciences Centre.

Malignant diseases in children are the second leading cause of paediatric deaths (Aitken & Hathaway, 1993). Twenty-five years ago a child diagnosed with cancer did not usually live beyond six months (Foley, 1989). From 1974-76, 55.2% of children suffering from cancer lived for five years or more. By 1981-87, 66.8% of children survived beyond five years (Bleyer, 1993). However, these children will minimally require annual visits to their physician to check for recurrence of the original disease. They may also develop late side effects of treatment which can include second malignancies, and mental and cognitive changes. Parents are again challenged to cope with yet another phase of cancer with needs to be assessed and met.

Marked improvement in outcomes in paediatric cancer can be attributed to advances in medical treatments. Treatments, however, produce considerable fear in a child, are accompanied by a number of side effects, and are often painful (Birenbaum, 1990). Immediate and delayed morbidity and mortality may also be outcomes of cancer treatments (Foley, 1989). When this information is given to parents,

their anxiety increases. Literature that documents this anxiety provoking uncertainty and the accompanying stressors associated with the hospitalization and treatment of the child with cancer, points to the need to identify health care needs for a family whose child has been diagnosed with cancer.

A valid and reliable instrument measuring the care needs of mothers of children with cancer has a number of practical uses. It could be used to improve outcomes in meeting the needs of mothers of children with cancer. The instrument has a potential to be used as a screening tool, or as part of a nursing or medical data base. This would allow health care providers to respond more effectively in meeting individual needs. The FIN-PED could also be used as a method of program evaluation within paediatric oncology programs. Interventions to meet needs could be developed and tested with mothers of children with cancer in future research. This instrument could also be used as a tool to evaluate costs within an oncology program, i.e., evaluating the cost to the system and care outcomes to mothers if services directed toward meeting needs are not provided.

Problem Statement

This research study has refined and tested an instrument to measure the care needs of mothers of children with cancer. The FIN was used as a basis for developing this paediatric instrument, the FIN-PED.

The research questions to be addressed were:

1. To what extent is the FIN-PED tool reliable for identifying the care needs of mothers whose children have been diagnosed with cancer?
2. To what extent is the FIN-PED tool a valid instrument for identifying the care needs of this population?

Summary

This chapter has included a discussion of the impact on families of a child diagnosed with cancer. The developmental stages of the child with cancer, parents and parenting roles, siblings of the child with cancer, and the family structure of these children, all affect the needs of mothers whose children have been diagnosed with cancer. The purpose of the present study was to develop and test FIN-PED based on the Family Inventory of Needs Scale (FIN).

## CHAPTER II

### CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

#### Introduction

Chapter II presents a discussion of family systems theory as a basis for its use as a conceptual framework. A review of the research literature related to the care needs of families whose children have been diagnosed with cancer is presented and evaluated. Instrument development literature is also reviewed.

#### Conceptual Framework

A conceptual framework plays an integral role in guiding the nursing research process (Meleis, 1991). Family systems theory provided the conceptual framework upon which this study was built (Ell & Northen, 1990; Steinglass, 1987). Paediatric health care providers recognize the family as the primary and continuing provider of care for the child. Health care agencies that use the family-centred care approach incorporate the family into the assessment and nursing care plan for the child (Friedman, 1992). At both Children's Hospital and the Manitoba Cancer Treatment and Research Foundation, the sites for cancer care of children



in this province, family-centred care is recognized as a basic component of nursing practice.

According to family systems theory (Shapiro, 1983; Steinglass, 1987) the family system is an open one that is affected by both environmental and social factors. This theory is used to better understand the human responses to changes imposed upon the family. Within this context, physical illness is considered an adaptation-related disorder occurring in interaction with social, community and environmental factors (Ell & Nothen, 1990). Doherty and Campbell (1988) recommended family systems theory as a conceptual framework to be used in clinical settings.

Leahey and Wright (1987) described wholeness, organization and patterning as key concepts in family systems theory. Wholeness refers to the axiom that the whole is greater than the sum of its parts (Jacob, 1987). Organization refers to the organized relationships established between individual members of the family (Jacob, 1987). Patterns of behaviour or patterning allude to the repetitive behaviours employed by one or more family members (Jacob, 1987). Friedman (1992) reported that a serious or chronic illness of any family member affects the family and its methods of functioning. Initially the family experiences a time of confusion as it struggles to develop

new coping patterns to adjust to a crisis (Doherty & Campbell, 1988). The anxiety created by a life-threatening illness within a family system can alter the roles, patterns of communication and relationships among family members (Minuchin, 1974; Cassileth & Hamilton, 1979). This anxiety may also predispose some family members to illness (Doherty & Campbell, 1988).

Gilliss, Highley, Roberts and Martinson (1989) advocated family systems theory as a sound theoretical basis for nursing research. They based this recommendation on the axiom that any change occurring in one member in a family system can affect the whole system or family, and that these same families will show constant change in response to external or internal stresses. Gilliss et al. (1989) reported systems theory to be an empirically useful model for family research because no family member is overlooked. They reported that the use of an individual health framework may not allow understanding of how the dysfunction of a family member may actually be holding the family together.

Chronic illness may seriously alter both individual and family developmental tasks (Friedman, 1992). The family's reaction to this serious or chronic illness is a

contributing factor to the outcome in terms of functioning of both the family and the child (Shapiro, 1983).

The assessment of the needs of mothers of a child with cancer could lead to an understanding about how needs occur in the broader family context. The extent to which needs of one family member are met (e.g., mothers) may influence the needs of other family members (e.g., children) and the extent to which their needs are met. Family systems theory is a logical conceptual framework to guide this research question because the human responses or needs of one family member (mother) are embedded within the larger family context and the developmental stage of the family.

### Review of the Literature

The review of literature for this study will be discussed according to two classifications. The first part of the review will discuss care needs of families of children who have been diagnosed with cancer. The second classification of literature will describe research related to instrument development in the area of health care needs.

### Family Care Needs

A review of anecdotal paediatric literature, covering a ten year period, revealed that there is a great deal of

sensitivity on the part of health care workers to the plight of families whose children have been diagnosed with cancer (Foster & al., 1989). There are however, few research studies addressing the care needs of these families. Care needs for the purpose of this study are defined as the judgements made by a family member about whether or not their perceived needs have been satisfied by health professionals (Kristjanson & al., 1995). No studies were found in the paediatric literature related to care needs of families of children who had been diagnosed with cancer that had used a valid or reliable instrument.

Studies reviewed in the paediatric literature in the area of care needs were grouped into three categories: a) social supports for the family b) stress and coping behaviours of family members, and c) care of the family whose child has been diagnosed with cancer. These three categories included most of the literature on care needs.

A number of design limitations were noted in these studies. Most of these studies used descriptive designs and small convenience samples ranging from 18 to 107. The modal sample size category was from 20 to 30 subjects. Operational definitions of needs were not consistent across these studies. However, these studies revealed some care

needs that could be included as items in the FIN-PED instrument.

Social Supports:

Research on social supports in the paediatric literature is limited (Williams, 1988). A standard definition of social support did not exist in the literature, nor was attention paid to the context in which supports were given (i.e., frequency of support offered or temporary changes in support). However, the limited research related to social supports revealed a need for supports to parents as they adjust to the knowledge that their child has cancer and as they cope with the impact this diagnosis has on their daily lives (Morrow, Hoagland & Morse, 1982; Nugent, 1988; Williams, 1992).

Individuals received support from a variety of sources: spouse, family, health care professionals, and other parents (Morrow, Hoagland & Carnrike, 1981). A number of authors reported social support as having a positive effect on families whose child has been diagnosed with cancer (Adams & Deveau, 1988; Nugent, 1988; Williams, 1988). However, Morrow, Carpenter, and Hoagland (1984) documented that although "there is evidence that social support can help mitigate problems associated with other life stresses,

little empirical research has been conducted on the effects of social support on psychosocial problems of the family when a member is being treated for cancer" (p.317). Fife, Norton and Groom (1987) found that families describing themselves as having stable relationships and having adequate supports in place were able to maintain the quality of life they were used to even under stress.

Morrow et al. (1981) documented stages that were particularly difficult for families of cancer patients, and stages when support is needed. The initial diagnosis, the implementation of treatment during which the child experiences adverse side effects, and the bereavement period are especially stressful illness stages for a family. Waiting for news of the outcome of a treatment is also a difficult time for family members.

Morrow, Carpenter and Hoagland (1984) investigated the role of social supports in relation to parental adjustment to paediatric cancer with 107 parents. They found that younger parents (<30 years of age, n = 14) demonstrated poorer adjustment on several dimensions of adjustment than older parents (>30 years of age, n = 93). For the parent whose child was undergoing treatment, support was accepted from a number of sources. For the parent whose child was not undergoing treatment, support from relatives appeared to

be the only source that helped to temper adjustment problems. Difficulties in adjustment were documented in their domestic environment, extended family relationships, sexual relations, personal psychological, and psychosocial adjustment. This was particularly true for those parents whose child was in treatment.

#### Cross-Cultural Aspects of Social Supports

Williams (1988) found that social supports are necessary and useful to cancer patients and their families across a number of different cultures. Cross-cultural research describes the way in which families of different cultures support each other while caring for a family member with cancer. Lindsey, Dodd, and Chen (1985a) reported that "the meaning that is attributed to the cancer experience is influenced by the individual's social and cultural background which in turn influences the patient's behaviour in coping with the illness" (p. 149). The three cross-cultural social support studies reviewed here used convenience samples of approximately forty patients and employed the Norbeck Social Support Questionnaire. Results of each study were compared to a normative sample of 136 employed healthy Americans (Lindsey et al., 1985;

Kesselring, Lindsey, Dodd, & Lovejoy, 1986; Lindsey, Ahmed, & Dodd, 1985b)

Lindsey et al. (1985a) studied the social support of hospitalized Taiwanese cancer patients. The subjects stated that 60% of their support came from family and relatives. This finding was similar to the findings for the American group. Friends, neighbours and work associates were listed as supports with much less frequency.

Kesselring et al. (1986) studied the social network and support perceived by Swiss-German families. The social network of support reported was the smallest average network size (9.3 persons), but extended for a long period of time, over five years. Kesselring et al. (1986) reported this finding as suggestive of network stability. Family and spouses were listed as providing 70% of the total functional support.

Lindsey et al. (1985b) studied the social support network as perceived by Egyptian cancer patients. Egyptian patients reported a stable network of support with family and relatives providing the greatest support. More family and relatives were included in this network; however, spouses were perceived to provide more support than friends and neighbours. Lindsey et al. (1985b) reported more frequent contact and longer duration of relationships with



the Egyptian group than the American group. Sixty-five percent of Egyptians did not include a single work associate. The Americans had a mean of 1.02 persons included in this category.

The researchers in these cross-cultural studies reported the importance of the family as support for many of these adult cancer patients. What may differ is the size of and the duration of social support. It is important that nurses include the names of members of the support network in the nursing care plan. Studies are needed in the paediatric area to investigate cross-cultural support groups in relation to the needs of mothers caring for children with cancer.

#### Clinicians Observations on Social Supports

The role of social support has received some attention from clinicians. Clinical writings suggest that grandparents may be a family's best support by providing the extra attention, love and care needed by both the ill child and her or his siblings (Adams & Deveau, 1988). These authors also suggest grandparents may be an added burden to an already distressed family. This burden can occur as grandparents often experience the same guilt parents feel in terms of being responsible for the child's illness. They

may offer well meaning but inappropriate advice and at times may blame a daughter or son-in-law for the cause of the illness (Adams & Deveau, 1988). This conflict is an added source of stress to parents and suggests that the role of grandparents in the area of support be researched and related to needs research.

#### Social Supports and Self-help Groups

Chesler, Barbarin, and Lebo-Stein (1984) studied patterns of participation in self-help groups as supports for parents of children with cancer. Their findings showed that parents who perceived themselves as having a high degree of stress, those living close to the hospital and those whose children had been diagnosed one to four years previously were more apt to participate in a self-help group. Chesler et al. (1981) found that the groups parents chose for support were related to their socio-economic status. Parents in higher socio-economic brackets used friends for their supports while lower socio-economic brackets depended more on health professionals.

#### Parents' and Professionals' Perceptions of Supports

Williams (1992) compared health care professionals' perceptions and definitions of support to the perceptions

and definitions of support by parents of children with cancer. In this study the author found two problems that exist in the support literature. These are professionals' lack of respect for parents' expertise and conflict resolution between the staff and parents.

Parents defined support from an emotional perspective as someone who cared, who would hold them when they cried, who would listen to them and be available to talk to them. Health professionals had difficulty defining support, but generally thought that it meant being available. Their definition also had an emotional component; being available to help parents cope with difficult times or to share a joke at other times. Staff also described a knowledge component in their definitions of support. Support included being knowledgeable and sharing this knowledge with parents. Staff felt knowledge was important in helping parents to manage. Parents perceived support in terms of managing household activities and care of siblings. Family members were the primary care givers assisted by friends and neighbours. Parents of children with cancer developed their own support groups with each other. They stated that only another parent could understand what they were going through (Williams, 1992).

Professionals perceived caring as the main component of their enacted support. Caring meant knowing and interacting with family members as individuals. Education was perceived as a supportive activity. In contrast, parents rarely perceived education as a supportive activity. The author suggested that this difference in perception could be attributed to the professionals' view of education as an expected or given component of health care. Health professionals rarely were able to identify the support person for a family; they believed that hospital staff were the most supportive (Williams, 1992).

Nugent studied a convenience sample of 24 family caregivers of terminal cancer patients documenting their social support requirements (1988). Caregivers were most often spouses or adult children of the cancer patient. The instrument used in this study was the Social Support Questionnaire. Nugent found nurses received the caregivers' highest score for supporting the caregivers' actions or thoughts. Family caregivers commented that nurses appeared to understand their behaviours and concerns (Nugent, 1988).

### Conclusions

Williams (1988) suggested that more research is needed to examine supports at different stages of the illness,

especially for those patients categorized as long term survivors of cancer. She also recommended that paediatric nurses include parental perception of support as part of initial and long-term assessments. Maul-Mellott and Adams (1987) described social supports as one of the major components in enabling parents to cope. Given the fact that families are the main social support, research is needed to document family needs as they enact social support roles. Mothers are most often the primary caregivers for children with cancer. Before appropriate interventions can be offered to mothers, it is important to identify and understand their needs. Therefore, an instrument to assess needs of mothers of children with cancer (the FIN-PED) is required.

#### Stress and Coping Behaviours

Research studies in the areas of stress and coping behaviours of parents of children with cancer document the intense anxiety experienced by parents when their child is first diagnosed (Hughes & Liberman, 1990). The literature reports that continued adjustment problems may be manifested by some parents (Hughes & Liberman, 1990), but that not all parents continue to have difficulty coping with this diagnosis (Barbarin, Hughes, & Chesler, 1985).

The concepts of stress and coping however, are not always clearly defined in the studies reviewed in this paper. Time frames are not always mentioned, making it impossible to discern if the child is newly diagnosed, at the mid-or end-stage of the disease, or in remission. Different stages of the disease offer different problems to a parent, challenging their coping abilities, or requiring them to learn new behaviours (Krulik, 1982). It is also difficult to factor in control, or isolate other stressors that a parent or family may be coping with during the course of their child's disease.

Adjustment and coping behaviours are not always consistent in all spheres of a parent's life. Parents can appear to have a positive adjustment in their personal life, but exhibit a negative one in their work environment (Morrow et al., (1981). The results of the studies varied in the intensity of adjustment problems reported by individual parents.

Powzeck, Payne, Goff, Paulson, and Stagner (1980) studied 35 families and children with acute lymphoblastic leukaemia. Several psychometric instruments were completed. Of particular note is the finding that during the first year of treatment, mothers showed consistently high levels of psychosocial maladjustment such as depression and anxiety.

Schulman (1983) found that prior good coping skills increased the chances of effective coping in a new situation and that effective coping is enhanced if there are no other additional stresses for the parent at the time of diagnosis. Schulman (1983) suggested that families with poor coping skills may be in the minority, but that their needs are much greater.

Hughes and Liberman (1990) studied the psychological stresses of 18 parents of children with cancer. They used the 30-item General Health Questionnaire, the Leeds Self-Assessment Scales for Anxiety, and semi-structured interviews. All mothers ( $n = 10$ ) acknowledged a period of intense anxiety at the time of initial diagnosis. However, the intensity of the anxiety diminished over time for most of the mothers, and they were able to feel a little more hopeful. Three of the 10 mothers experienced intense and continuing anxiety and depression. Behaviours reported by mothers consisted of self-neglect, under-eating, and over-eating. The fathers in the study documented psychological symptoms, but of a lower intensity. Thirteen of the eighteen parents in the study exhibited anxiety symptoms above the normal range. Six of these parents' symptoms were considered severe. Communication difficulties with staff, friends and spouses were also documented.

Barbarin, Hughes, and Chesler (1985) found in their random sample study of 32 married couples that not all families cope in a negative way, and that not all marriages suffer negative effects. A 60-to 90-minute semistructured interview followed by a structured questionnaire was used to elicit the effects of a child's cancer on the family. Some families reported an initial closeness. Most parents in this study stated that their feelings for each other were unchanged or changed in a positive direction, and that their families became closer as an outcome of the illness and treatment. The researchers acknowledged that the length of time from diagnosis may have influenced reports of marital problems or adjustments. Upon further analysis, the authors noted that parents whose children had been diagnosed more than three years previously evaluated their marriages less favourably than parents whose children had been diagnosed less than three years ago. Barbarin et al. (1985) also noted that the more positive findings may have been attributed to the fact that the children of all the parents in their study were still living. Previous studies had included a higher proportion of parents whose children were deceased.

Birenbaum (1990) studied family coping with childhood cancer using the Coping Health Inventory for Parents (CHIP).



The CHIP is a 45-item self-administered questionnaire that has demonstrated construct and criterion validity.

Birenbaum used the definition of coping from Lazarus and Folkman (1984); namely, "constantly changing cognitive and behavioural efforts to manage external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p.141). Birenbaum compared the results of this study with previous childhood chronic illness family coping research. Birenbaum reported that these 45 families coped well while living with childhood cancer, and that parent's coping was similar to other samples of families with childhood chronic illness.

Aitken and Hathaway (1993) related the stress and coping behaviours of parents to the distance they lived from the tertiary care centre. They found that parents living greater than 100 miles from the treatment centre have different and greater needs than parents living less than 100 miles from the centre. This independent variable is of particular relevance to the present study because the research sites used in this study were both located in Winnipeg, and these were the only facilities available for children diagnosed and treated for cancer in Manitoba and northern Ontario.

This review of studies of stress and coping behaviours of parents demonstrated a range of coping capacities and adjustments in parents living with childhood cancer. No research examined the needs of parents with respect to their stress levels and coping behaviours. A valid and reliable instrument that indexes individual parental needs is a necessary step towards better understanding the stress and adjustment skills of parents. Once needs are accurately assessed, further work to examine relationships among needs, stress, and coping skills can be undertaken.

#### Care of the Family

Care needs identified by the family at different stages of the child's illness is a theme addressed in this section of the review. These studies have been included in the review because the sample of mothers to be used in this study included those who have children at different stages of treatment or in remission. These studies suggest that families may have different needs at various stages of the disease. However, the studies are limited by the cross-sectional nature of the designs, clouding conclusions about stability of needs. Definitions of needs reported in the literature are not precise. In the present study the stage of the disease was documented for each child.

Moore, Kramer, and Perrin (1986) reviewed studies conducted from 1980 to 1986 and found three areas of care needs in the care of the family with a child during the diagnostic and early stages of treatment: education, communication and psychosocial supportive care.

### Education Needs

Parents want to be educated to receive more information about their child's illness and treatment. Parents indicated an interest in formal structured education formats (Wallace & al., 1984). A structured education program for parents of children with cancer was developed by the Children's Orthopaedic Hospital and Medical Centre in Seattle, Washington. The program has been evaluated in six paediatric oncology centres in the United States (Wallace et al., 1984). The nurses offering this program found that the program increased parents' knowledge base and decreased parents' feelings of isolation. The program offered an organized way to provide information to parents and an opportunity for staff to meet with parents and to discuss the educational program with them (Wallace et al., 1984).

Moore et al.(1986) concluded in their research review that educational programs allowed families an opportunity to communicate with staff in an informed manner, gave them a

feeling of competence in caring for their child, and also offered them more control over their lives. Educational sessions are a need for parents over the child's various stages of illness and treatment (Moore et al., 1986).

#### Communication Needs

Effective communication between family members and staff is a second need that has been identified, and it is an important component in the family's ability to cope with childhood cancer (Moore et al., 1986). An initial nursing assessment or family conference can identify a family's patterns of communication. In the event of any communication problems, the nurse can model effective patterns of communication and also stress to parents the importance of open and honest communication (Adams & Deveau, 1988; Moore et al., 1986). In the event of severe communication problems, parents would be referred to a psychologist or social worker for counselling. Parents also believe that effective communication includes recognizing their role as competent parents. In including parents in the care of the child, they expect mutual respect and sincere caring for them and their child from all oncology staff (Chesler & Barbarin, 1984).

Psychosocial Needs

A third need is psychosocial support of families. The initial nursing assessment can identify and discuss needs described either by the family or the nurse; for example, changes in a parent's routine or lifestyle that will occur as a result of the cancer diagnosis and treatments (Moore et al., 1986). These changes include frequent clinic visits and hospitalizations, the need to provide special care and observation for their child, and financial concerns resulting from decreased work hours or job loss. By helping parents plan in advance, it is believed that their psychosocial adjustment can be modified (Moore et al., 1986).

Barbarin et al., (1985) found that spouses demonstrate different needs or ways of defining psychosocial support from each other. Mothers defined support from their spouses in terms of the role of information seeker and involvement in the child's care. Nurses can assist fathers in this role by including them in information sessions, and encourage their involvement in and care of the child. A father's expectations in terms of psychosocial support were defined by the time mother was able to spend at home with the family (Chesler et al., 1985).

Psychosocial Needs During Midstage of the Illness

According to Krulik (1982), parents experience a whole new set of psychosocial challenges during the midstage of the illness. Midstage occurs when the child has their first relapse and ends when curative treatment is no longer required. During this time parents experience a feeling of loss of hope. They question the meaning of the illness, the value of treatment, and the devastating effects of the disease on the child and the family. Parents can be tired and extremely angry during this stage, and the response of the nursing staff in terms of caring for and supporting parents is crucial (Krulik, 1982).

During the midstage of the illness, parents can be confronted with a relapse occurring at a different developmental stage for their child. Instead of holding and comforting a toddler terrified of a venipuncture and quite happy with the "awesome" hat they are wearing to cover their hair loss, they may be confronted with an angry teen refusing social contact with his friends because of hair loss.

Parents need psychosocial support from health care staff in the midstage period as they face new decisions regarding their child's treatment, the need for a new regime in their daily tasks, and the altered management of their

time. There is a recurrence of feelings of loss of control, fear, guilt and doubt. They may experience a feeling of being trapped if the child's condition worsens and their own loneliness escalates (Krulik, 1982). This is a time for nurses to listen and gently guide parents in terms of daily management. Effective psychological support of parents at this time can enhance their sense of control and improve their trust and interaction with health care staff (Krulik, 1982).

#### Needs During the Terminal Stage of Illness

Limited research is available on caring for the family in the terminal stages of cancer. Paediatric literature is based on clinical experience. Families generally agreed that psychological support from nurses should be directed towards comfort and care of the dying (Hull, 1989; Lewandowski & Jones, 1988). Families of adult patients see this time as a patient centred and not a family centred time. They turned to relatives and friends for most of their own support. They describe efforts from nurses encouraging family to ventilate their feelings as least supportive (Hull, 1989; Lewandowski & Jones; 1988).

Needs of Parents of Long Term Survivors of Cancer

Wallace, Reiter and Pendergrass (1987) investigated the needs of parents of long term survivors of childhood cancer. The researchers defined long term survivors as children 2 to 15 years from diagnosis and who were not receiving any cancer treatment. Ninety-three questionnaires were returned with 75% of the responses from mothers. Concerns are reported according to frequency of responses. The most frequently reported concerns were reported worries about their child's abilities to have children (74%), followed by concerns about physical side affects, marriage, dating, and the child getting other illnesses. Low on the list were worries about parental and sibling relationships, and the child's fear of death. The least frequent concern was the child's fear of pain. When parents were asked if they had sought help for these concerns, nearly 40% responded that they had never thought about it and only 10% had frequently considered it. Thirty-three percent of parents indicated an ongoing need for support after treatment had stopped, but rated having written materials and educational programs as most needed.

From this review of the literature, it is evident that families of children with cancer have a great many needs at all stages of the family's cancer journey. A valid and



reliable instrument for measuring these needs would assist nurses in caring for these families.

### Instrument Development

The second topic in this literature review concerns instrument development. As there is no valid and reliable instrument for measuring health care needs in families whose children have been diagnosed with cancer, it was necessary to review the adult cancer literature. A search of the nursing and medical literature in the area of instrument development revealed a limited number of studies, using a variety of instruments and different methodologies. Five studies using a variety of instruments and assessing family needs were found. These studies will be examined here.

Hinds (1985) investigated the needs of families who care for parents with cancer at home. A 46-item scale was used in this study. Tringali (1986) asked families to rate the importance of 53 need statements. A four-point Likert-type scale was used. In both these studies however, the psychometric properties of the scales were not reported and the theoretical frameworks used were not clear.

Longman, Atwood, Sherman, Benedict and Shang (1992) used an exploratory descriptive design to study the care needs of home based patients as assessed by both the

patients and the caregivers. Five instruments were used to gather data related to personal characteristics, health status, and patients' abilities. In addition, the researchers developed a 114-item Patients' Needs Scale and 90-item Caregivers Needs Scale. Face validity was built into the needs scale, however the scale was too long for use in this study.

Wingate and Lackey (1989) used a descriptive exploratory design to identify the needs of non-institutionalized cancer patients and their primary caregivers. Non-institutionalized cancer patients and their care givers were asked to complete two forms of an opened ended instrument, the Objects Content Test. The instruments in this study were not tested for validity and reliability. No questions to determine if needs were met were asked. Also, the term, "need" was not defined.

The instrument chosen for this research project is the Family Inventory of Needs developed by Kristjanson & al., (1995). The FIN is a valid and reliable instrument that is designed for use by one member of the family. The FIN measures the care needs of a family member and the extent to which these needs have been met. It consists of a 20-item scale. Needs are ranked from 1 to 5, 1 being the least important and 5 being the most important. This instrument

is straight forward and easy to administer. It is described by its authors as "brief and simple and practical for use with highly stressed populations" (p. 15). The decision to use this instrument is based on the size of the FIN and the population for which it was designed, one member of a family with cancer.

#### Summary

In this chapter family systems theory was described as the conceptual framework used in this study. Literature in the area of health care needs for families whose children have been diagnosed with cancer was reviewed. Finally the Family Inventory of Needs instrument was designated as the instrument to be adapted to the FIN-PED for measuring health care needs in families whose children have been diagnosed with cancer.

### **CHAPTER III**

### **METHODOLOGY**

#### Introduction

This chapter discusses the methodology used to develop and test the FIN-PED instrument. A description of the pilot study process and sample selection criteria is given. Data analyses and ethical considerations are reviewed.

#### Research Method

A three-phased methodological approach was used to develop the FIN-PED to measure the care needs of mothers of children with cancer. Phase I involved the development of the items to be included in the FIN-PED. Phase II pilot-tested the FIN-PED using an expert panel of six mothers whose children have cancer to determine clarity, apparent internal consistency, and content validity of the FIN-PED. Phase III tested the FIN-PED instrument for reliability using a sample of mothers whose children have been diagnosed with cancer.

The sample of participants were mothers of children with cancer. Mothers' care needs were investigated because prior research suggested that mothers are usually the

primary care givers (Hayes & Knox, 1983), and focusing on mothers would provide a homogeneous sample. When both parents are involved in providing care, they may be at different stages of adaptation and may have different needs (Hayes & Knox, 1983).

Data on sociodemographic variables were also collected. A review of the literature revealed that age, gender, marital status, educational level, stage of disease, distance from the treatment centre, and treatment plan may impact on parents' care needs (Aitken & Hathaway, 1993; Barbarin et al., 1985; Friesen & Manitt, 1990; Krulik, 1982; Morrow et al., 1984; Wallace et al., 1987). Levels of care needs were correlated with sociodemographic variables to see if significant relationships were present.

### Phase I

The first phase of the study identified care needs to be included in items for the FIN-PED. Care needs have been defined as the judgments made by a family member about whether or not his or her perceived needs have been satisfied by health professionals (Kristjanson et al., 1995). The FIN (Kristjanson et al., 1995) was used as a basis to develop the FIN-PED.

The FIN measures care needs of family members of cancer patients and the extent to which these care needs have been met. The FIN has been tested with families in which cancer has been diagnosed in adult members of the family. The FIN has been shown to have good validity and reliability (Kristjanson et al., 1995).

Paediatric needs were added to the FIN based on a review of the relevant literature and the author's clinical experience. Items already included in the FIN were reviewed for inclusion in the FIN-PED. The structure of the FIN was used as a basis for the development of the FIN-PED. The FIN had twenty items. The pilot version of the FIN-PED had 40 items (Appendix G). Participants ranked needs on each item between 1 and 5, 1 being least important, and 5 being most important.

### Pilot Study: Phase II

#### Introduction

The pilot testing phase refined the items in the FIN-PED in terms of their clarity, apparent internal consistency, and content validity. Participants were asked to evaluate the extent to which the items in the instrument were: (a) clearly worded; (b) belonged together, and (c)

actually measured the needs of mothers of children with cancer.

Imle and Atwood (1988) described a method for assessing a scale's clarity, apparent internal consistency, and content validity. This method was first used with their Transition to Parenthood Concern Scale. Imle and Atwood (1988) developed their method to evaluate whether the meaning inherent in qualitatively generated concepts could be retained in scales constructed for a quantitative instrument. This method is applicable to the evaluation of items in the FIN-PED which have been developed from a qualitative review of previous research.

Imle and Atwood's (1988) method was a three part psychometric assessment. Each item was rated for clarity, then for apparent internal consistency, and finally, for content validity. Imle and Atwood (1988) stated that this order for rating the items is necessary to ensure appropriate and logical responses to questions. For example, clarity of items must be established before the rater can assess apparent internal consistency.

#### Sample and Selection Criteria

Six mothers was recruited from the Manitoba Cancer Treatment and Research Foundation to review the FIN-PED.

Mothers were contacted by staff at the MCTRF who asked for permission for the researcher to telephone them (Appendix A). If permission was granted, the researcher telephoned the mothers to explain the study and arrange a time to interview them (Appendix B). All mothers were over the age of eighteen years with the ability to read and write English. Mothers whose children had been diagnosed within the last two months or those whose children had died were not included in the pilot-test. Mothers participated separately as it proved too difficult to arrange a time when all six participants could be available together.

#### Procedure

All participants were asked where they would prefer to be interviewed. Four of the participants were interviewed in the Health Sciences Centre cafeteria, one at home and one in her daughters room at Children's Hospital. Participants signed a consent form (Appendix C). The investigator reviewed the method of rating each set of items with each mother. They were given an instruction and response sheet for each section of the pilot test. Each mother was then asked to rate the clarity, apparent internal consistency, and content validity of the instrument.



Clarity of items. Clarity, the first rating procedure, consisted of two parts: rating the clarity of the scale instructions and rating the clarity of the scale items as either "Clear" or "Unclear". Raters were asked to determine if the instructions clearly explained how the respondents were to complete the scale. Raters were then asked to determine if each item in the scale clearly described a need (Appendix D). Space for comments were included and time was allotted for discussion of comments. The raters decisions and comments regarding the clarity, format, and reading level were incorporated into the instrument.

The wording of an item was considered clear if there was 83 percent agreement (i.e., 5 of 6 mothers rated the item "Clear"). The same cut-off was used to define an acceptable level of clarity for instrument instructions. This is consistent with Lynn's (1986) conclusion that five of six participants must agree (83%) to achieve a .05 level of significance.

Apparent internal consistency. The second dimension to be rated was apparent internal consistency. Imle and Atwood (1998) defined this concept as the degree to which all scale items group together, that is, the homogeneity of content. With respect to the entire set of questions on the FIN-PED, the participants were asked, "Do these items generally

belong together?". For items on the FIN-PED, they were asked, "Does each item belong in the questionnaire?" (Appendix E). The a priori criterion for agreement was 83 percent.

Content validity. The third component of the pilot-testing procedure assessed content validity. Content validation assesses how well and how adequately scale items express the meaning of the conceptual domain without redundancy. With respect to the whole set of items, participants were asked, "In general, does the label and definition of the scale fit the whole set of items?" With respect to each individual item, the respondents were asked, "Does it belong to the label and definition?" and "Is this item unique (not repetitious)?" Finally, the participants were asked whether there were needs left off the list they think should be included (Appendix F). The criterion for content validity used by Imle and Atwood (1988) was 83 percent agreement for each of the first three questions. This criterion was also used in this study. Any of the items that did not achieve clarity, apparent internal consistency, and content validity as defined above were modified or deleted.

Pilot Testing Versus Focus Groups

This pilot testing process differs from a focus group approach in a number of ways. Krueger (1988) defined focus groups as people possessing certain characteristics who will provide data of a qualitative nature in a focused discussion. The group members generally are unfamiliar with each other and "the intent of the focus group is to promote self-disclosure among participants" (Krueger, 1988, p. 23). The six mothers pilot testing the FIN-PED have a high probability of knowing each other from clinic visits or hospital admissions and may or may not have participated in previous group discussions or support groups. Krueger (1988) stated "the group discussion is conducted several times with similar types of participants to identify trends and patterns in perceptions" (p. 18). In this study, the investigator met with the six mothers separately and only on one occasion.

Morgan (1988) documented that "the hallmark of focus groups is the explicit use of the group interaction to produce data and insights that would be less accessible without the interaction found in a group" (p. 12); that is, the focus group is the source of primary data collection. The method of data collection used to compile the items in the FIN-PED was primarily a review of quantitative and

qualitative research. The method used to test the reliability and validity of the FIN-PED has been outlined.

After each mother had completed her responses for clarity, content validity, and apparent internal consistency, the investigator spent time with each participant separately to respond to questions, suggestions, and concerns, regarding the instrument and the instrument testing process. Overall, the procedure used in Phase II does not correspond closely to the characteristics of a focus group.

### Phase III

#### Introduction

The purpose of Phase III of the study was to measure internal consistency and test-retest reliability of the FIN-PED.

#### Sample and Selection Criteria

The third phase of the research involved selecting mothers from the Manitoba Cancer Treatment and Research Foundation Paediatric Oncology Department. All mothers were over 18 years of age with the ability to read and write English. Mothers whose children were newly diagnosed (less

than two-months since diagnosis) and mothers whose children had died were not approached. Two hundred and fifty mothers were sent letters. The recruitment process began after the project received approval from the University of Manitoba Faculty of Nursing Ethics Committee and access approval from the Manitoba Cancer Treatment and Research Foundation.

#### Recruitment Procedure

A list of children diagnosed with cancer over the past ten years was compiled by clerical staff at the MCTRF. This list was reviewed by a paediatric oncologist and staff from the MCTRF to establish which mothers of these children met the selection criteria. In a number of cases the MCTRF staff could not identify children on the research list. The researcher reviewed their charts to clarify diagnosis and current addresses. Approximately one hundred charts were reviewed.

#### Data Collection

The list of mothers initially identified by the staff of the Manitoba Cancer Treatment and Research Foundation were mailed: (a) a letter explaining the research study and inviting them to participate (Appendix H), (b) the demographic questionnaire (Appendix I), and (c) the FIN-PED

instrument (Appendix J). These items were sent directly from the MCTRF. As other children on the list were verified, their mothers were also sent the same material. This initial complete mailout was conducted over a four month period. A reminder letter to return the initial information, was sent one week after the first mail-out. One week after the first set of materials were returned a letter explaining the importance of completing the questionnaire a second time to ensure stability of the instrument over time (Appendix K) and a second FIN-PED questionnaire were sent to the participants. All mail-outs included stamped self-addressed envelopes. The return address used was Dr. Linda Kristjanson, St. Boniface General Hospital Research Centre. All responses were kept in a locked file at the St. Boniface General Hospital Research Centre.

### Data Analysis

Descriptive statistics were used to determine the mean, mode, standard deviation, and frequency of the items on the scale. Internal consistency reliability was tested using Cronbach's alpha coefficient. This coefficient is an accepted method for measuring internal consistency (Politt & Hungler, 1991). A criterion of .70 was pre-set as the

standard for acceptable internal consistency (Nunnally, 1967). Nunnally (1967) also recommended that inter-item correlations should be between .30 and .70, and that item to total correlations should be between .40 and .60.

Test-retest reliability was measured, using an appropriate correlation coefficient, to relate scores on the first questionnaire with scores on the second questionnaire for participants who complete both questionnaires. A correlation of .70 was set as a criterion for satisfactory test-retest reliability.

The effects of demographics on illness variables were tested. For demographic variables that involved comparing two groups, a t-test was used. For demographic variables with three or more groups, one-way analyses of variance (ANOVA) were used. The assumptions for these tests are that the variances are equal, interval data are used, and the scores are normally distributed.

In order to ensure that all concerns were elicited from mothers, two open ended questions were posed at the end of the needs items in the questionnaire. Content analysis was used to examine the responses to these questions. Content analysis is defined as "a procedure for analyzing written or verbal communications in a systematic and objective fashion,

typically with the goal of quantitatively measuring variables" Polit & Hungler, 1991 p. 642).

### Ethical Considerations

Before the study began, ethical approval was obtained from the University of Manitoba Faculty of Nursing Ethical Review Committee, and access approval from the Manitoba Cancer Treatment and Research Foundation. Participants in the pilot study were asked to sign a consent form (Appendix C). Participants in both the pilot study (Phase II) and the testing of the FIN-PED (Phase III) were informed that their participation was voluntary and that they had the right to withdraw from the study at any time without any affect on their child's care (Appendices C and H). The only anticipated risk could have been an emotional response to recent or old memories. This risk was judged to be slight.

Participants were ensured that their names and responses were confidential. Demographic data and instrument responses were identified by reference to a numerical code only. Data collected and codes are stored separately in locked files accessible only to the researcher, Dr. Kristjanson and the research assistant hired for the project.



Summary

This chapter has described the methodology used in this study to develop and test an instrument to measure the care needs of mothers of children with cancer. The research study procedures, sample and selection criteria, data analysis and the ethical considerations have been discussed.

## CHAPTER IV

### RESULTS

#### Introduction

The purpose of this study was to develop and test an instrument to measure the care needs of mothers whose children had been diagnosed with cancer. Pilot testing, Phase II, was conducted to refine the items in the instrument in terms of their clarity, apparent internal consistency, and content validity. Participants in the pilot study were also given the opportunity to add other needs to the instrument if they identified any missing ones. Phase III of the study was conducted to measure internal consistency and test-retest reliability of the FIN-PED. The outcomes of Phase II and Phase III are reported in this chapter.

#### Phase II - Pilot test - Data Analysis

##### Introduction

Six mothers were identified as potential participants by the nurse clinician from the paediatric oncology department to participate in the pilot study. All six mothers agreed to participate in the pilot study. They rated the 40 items on

the pilot version of the FIN-PED questionnaire for clarity, apparent internal consistency, and content validity.

### Clarity of Items

Clarity of the instructions and clarity of the items were rated separately. The instructions were rated as being clear by all participants. Five participants rated all items as clear and one participant rated two items as unclear. This level of agreement met the preset criteria of greater than 83% for the directions and all items on the questionnaire. The first item rated unclear, was item 16 "be allowed to discuss the terminal stage of my child's illness." The use of the words "terminal stage" concerned her because the phrase sounded as though a terminal phase would be inevitable. She stated that this did not apply to her child's diagnosis. This concern appeared to focus on the sensitive nature of this item rather than its clarity. In the revised version of the FIN-PED the following statement was added to acknowledge the sensitive nature of this question, "The following question is sensitive in nature but your response would be helpful to us." The second item rated as unclear was item 31 "have health care professionals guide me in setting limits for my child." This item was edited by changing the ending to "limits for my child's behaviour." None of the remaining items were rated unclear by any of the participants, but a few wording changes

were recommended; namely, (a) changing the word "symptoms" to "side effects", (b) adding "where possible" to item 19 ("know how much time I can take in making decisions"), and (c) adding "depending on child's age" when referring to information sharing with children (items 21, 22, 39, 40). The revised FIN-PED is presented in Appendix J.

#### Apparent Internal Consistency

The first question for rating apparent internal consistency asked respondents to indicate whether the items in the questionnaire belonged together. All respondents answered this question affirmatively. The respondents then rated whether each question belonged in the needs questionnaire. In all cases each respondent verified the inclusion of each item. This level of agreement met the preset criteria of greater than 83% for the items of the instrument.

#### Content Validity

The third rating procedure for the pilot test was an assessment of the content validity of the scale. Content validity assesses how well and how adequately instrument items express the meaning of the conceptual domain without redundancy. Three questions were asked of each participant to verify content validity. The first two questions were: "In general, does the label Family Inventory of Needs -

Paediatrics fit the questionnaire?" and, "In general, does the definition Instrument intended in this study to measure the needs of mothers of children with cancer fit the questionnaire?" The third question was "Is each item on the questionnaire unique (i.e., not repetitious)?" All participants agreed that the label and definition fit the entire questionnaire and that none of the items were repetitious. These 100% levels of agreement met the preset criteria of greater than 83%.

#### Additional Needs

The last part of this pilot testing procedure offered the participants an opportunity to suggest needs that might be added to the questionnaire. As a result of their suggestions 12 items were added to the pilot version of the FIN-PED, resulting in the revised FIN-PED (Appendix J). They suggested including needs of their child and needs of other children in their family. Although this instrument was designed to assess mothers' needs, some participants said that meeting their child's needs helped to meet their own needs. Five items concerning meeting the child's needs were added: "know how to handle my child's feelings" (item 10), "know that health care professionals accept my child even when he/she is angry or upset" (item 27), "have my child participate in decisions about his/her care (appropriate to his/her age) (item 34),

"know that where appropriate health care professionals will ask my child's permission to do things to my child" (item 35), and "know how to handle the feelings of my other children" (item 52).

Mothers also identified several needs related to health care professionals. The following three items were added to include these needs; namely, "know that the knowledge of health care workers fit my child's needs" (item 3), "know to whom I should direct my questions" (item 5), and "know to whom to turn if conflict situations arise" (item 32).

Other areas of need identified by the participants were included by adding the following four items: "know where things are in the hospital" (item 46), "know where things are in the city" (item 47), "know where to park at the hospital/clinic" (item 45), "have financial assistance to help cope with the costs of my child's illness (e.g., parking, food, transportation and medicine) (item 48). The first two items were suggested by mothers who lived outside Winnipeg. The second two items were concerns expressed by all the pilot test mothers.

### Summary

The results of the pilot test phase indicated that the instrument met criteria for clarity, apparent internal consistency and content validity. As a result of the pilot

phase, 12 items were added to the 40-item pilot version of the FIN-PED, resulting in a revised FIN-PED instrument with 52 items.

### Phase III: FIN-PED SURVEY RESULTS

#### Introduction

This section describes the sample, and the results of the analyses of the responses received from mothers who completed the FIN-PED. These analyses examined distribution of ratings, internal consistency reliability, test-retest reliability, and the internal construct validity of the FIN-PED instrument. The data were also examined to identify relationships between demographic variables and needs and the extent to which needs were met.

#### Description of the Sample

From a list of cancer patients obtained from the Manitoba Cancer Treatment and Research Foundation, 303 FIN-PED questionnaires and demographic questionnaires were mailed to mothers of children with cancer. Eighteen packages were returned indicating subjects were not living at the mailing address. Three packages were not responded to for the following reasons: 1) a problem with English, 2) the child had died, and 3) the child was over 17 years of age. These three

families were missed on the screening process and should not have been included in the study because they did not meet the criteria for inclusion. As stated in Chapter 3, the list of patients covered a ten-year period, making tracking of changes in mailing addresses difficult. One hundred and ten mothers completed the FIN-PED scale and demographic questionnaires. Fifty mothers also completed the retest FIN-PED questionnaire.

The demographic data on the mothers participating in the study are shown in the following tables. Table 1 presents their age and marital status and Table 2 presents their level of education.

Table 1: Age and Marital Status (N = 106)

Category	Percent
Under 40 years	65
Over 40 years	35
Single	11
Not single	89



Table 2: Educational Level of Mothers (N = 105)

Education	Frequency	Percent
Less than High School	26	25
High School	27	26
College/Vocational	26	25
Undergraduate Degree	12	11
Graduate Degree	13	12

All of the mothers (N = 105) in the study reported their residence location; 53 of the mothers lived in the city of Winnipeg and 57 of the mothers lived outside the city of Winnipeg. Of those mothers who lived outside Winnipeg, the distance from Winnipeg and the percentage of mothers living at each distance is shown in Table 3:

Table 3: Distance Mothers Lived Outside Winnipeg (N = 56)

Distance	Percent
Less than 100 km	27
100 to 240 km	29
Greater than 240 km	45

Seventy-one percent of mothers reported that they worked outside the home and 29% indicated that they did not work outside the home. Of those mothers employed outside the home, 39% reported that they worked full time and 33% reported part-time employment. The occupation of the mothers is presented

in Table 4 and their childrens' diagnoses are reported in Table 5.

Table 4: Occupation of Mothers (N = 105)

Occupation	Frequency	Percent
Clerical	14	13
Nurse	8	8
Teacher	10	9
Other Profession	9	9
Other Job	31	29
Not Working	33	31

Table 5: Children's Diagnoses

Diagnosis	Frequency	Percent
Leukemias	39	36.4
Solid Tumors	40	37.4
Brain Tumors	10	9.3
Others	18	16.8

Fifty-four of the children were males and 55 were females. The mean age of the children with cancer was 10.9 years with a standard deviation of 5.9 years. Table 6 shows the number of children experiencing low, medium, and high numbers of admissions to hospital. The range of admissions to hospital was from one to twelve; the mean number of admissions was nine, and the modal number of admissions was one.

Table 6: Number of Admissions to Hospital

Admissions	Frequency	Percent
1-4	44	45.8
5-19	36	37.5
Over 20	16	16.7

Reasons for admission to hospital are shown in Table 7. The majority of reasons for admissions were for cancer treatment or other reasons such as fever, neutropenia, and infections.

Table 7: Reason for Admission to Hospital

Admission	Frequency	Percent
Original Diagnosis	41	6.4
Treatment	360	56.0
Relapse	5	0.8
Other	237	36.9

A separate question asked of mothers was "Has your child had any recurrences or relapses?" Nine percent of respondents reported that their child had a relapse or recurrence during the course of the illness. Not all of these relapse episodes necessarily required re-admission to the hospital. At the time of the survey, 19% of the children of respondents were receiving chemotherapy, and 2.8% were receiving radiotherapy.

Ninety percent ( $N = 105$ ) of the children in the sample for whom complete data on sibling gender was available had

other siblings. As shown in Table 8, the mean number of siblings was one brother and one sister, and the mean age of siblings was 12 years.

Table 8: Percentage of Children with Brothers and Sisters

Gender	Percent	Mean Number	Range	Mean age	Age Range
Brothers ( <u>N</u> = 90)	74	1	0 - 4	12	1 - 29
Sisters ( <u>N</u> = 79)	59	1	0 - 3	12	1 - 26

Distribution of Scale Ratings

Needs subscale. The respondents used a slightly abbreviated range of the Needs subscale. The possible range for these items was between 1 and 5 (1 = not at all important, 5 = very important). The mean, standard deviation, and range of scores for each need item are shown in Table 9. The range of means for the needs statements was 2.94 to 4.94 with standard deviations between .30 and 1.72. For most items, the scores were slightly negatively skewed.

Table 9: Mean, Standard Deviation, and Range of Scores for each Need Item

Item Number	Needs				Needs-met			
	Mean	S.D.	Min	Max	Mean	S.D.	Min	Max
1	4.94	0.30	3	5	1.17	0.41	1	3
2	4.92	0.31	3	5	1.14	0.35	1	2
3	4.81	0.52	2	5	1.23	0.41	1	2
4	4.85	0.62	1	5	1.21	0.45	1	3
5	4.65	0.77	1	5	1.31	0.51	1	3
6	4.80	0.61	1	5	1.24	0.43	1	2
7	4.54	0.97	1	5	1.25	0.48	1	3
8	4.80	0.62	1	5	1.26	0.48	1	3
9	4.41	1.02	1	5	1.45	0.58	1	3
10	4.57	0.94	1	5	1.57	0.61	1	3
11	4.91	0.37	3	5	1.22	0.48	1	3
12	4.90	0.47	1	5	1.11	0.34	1	3
13	4.41	1.10	1	5	1.59	0.64	1	3
14	4.82	0.64	1	5	1.16	0.39	1	3
15	4.87	0.59	1	5	1.21	0.41	1	2
16	4.87	0.58	1	5	1.28	0.50	1	3
17	4.77	0.77	1	5	1.36	0.56	1	3
18	4.91	0.56	1	5	1.13	0.34	1	2
19	4.95	0.40	1	5	1.14	0.35	1	2
20	4.93	0.30	3	5	1.23	0.47	1	3
21	4.27	1.09	1	5	1.22	0.47	1	3
22	4.56	0.94	1	5	1.27	0.55	1	3
23	4.36	1.30	1	5	1.24	0.54	1	3
24	4.31	1.31	1	5	1.41	0.60	1	3
25	4.68	0.85	1	5	1.29	0.54	1	3
26	4.89	0.48	1	5	1.15	0.36	1	2
27	4.67	0.91	1	5	1.23	0.47	1	3
28	4.50	0.90	1	5	1.07	0.26	1	2
29	4.87	0.53	1	5	1.09	0.32	1	3
30	4.74	0.78	1	5	1.16	0.38	1	3
31	4.81	0.57	1	5	1.21	0.41	1	2
32	4.44	1.11	1	5	1.54	0.70	1	3
33	4.87	0.57	1	5	1.27	0.47	1	3
34	4.23	1.34	1	5	1.31	0.61	1	3
35	4.39	1.19	1	5	1.22	0.49	1	3
36	3.39	1.64	1	5	1.49	0.70	1	3
37	4.10	1.32	1	5	1.30	0.58	1	3
38	4.26	1.25	1	5	1.35	0.61	1	3
39	4.33	1.22	1	5	1.20	0.46	1	3
40	4.67	0.88	1	5	1.43	0.57	1	3
41	3.67	1.45	1	5	1.56	0.67	1	3
42	2.96	1.64	1	5	1.85	0.86	1	3
43	3.15	1.59	1	5	1.72	0.75	1	3
44	3.73	1.40	1	5	1.61	0.70	1	3
45	3.49	1.63	1	5	1.60	0.80	1	3
46	4.06	1.36	1	5	1.39	0.61	1	3
47	2.94	1.69	1	5	1.53	0.71	1	3
48	3.39	1.72	1	5	1.80	0.81	1	3
49	4.61	1.11	1	5	1.58	0.78	1	3
50	4.18	1.38	1	5	1.75	0.81	1	3
51	4.09	1.40	1	5	1.76	0.81	1	3
52	4.27	1.36	1	5	1.85	0.80	1	3

As shown in Table 10, 18 of the 52 items (35%) had means of over 4.8; 29 of the 52 items (56%) had means greater than 4.5; and 44 of the 52 items (85%) had means of greater than 4.0. The remaining eight of the 52 items (15%) had means between 2.94 to 3.73.

Needs-met subscale. The possible range for the met subscale was between 1 and 3 (1 = Met, 2 = Partly Met, 3 = Unmet). The mean, standard deviation, and range of met scores for each item are shown in Table 9. The range of means for the Needs-met scales was 1.07 to 1.85 with standard deviations between .26 and .81. Most of the scales had somewhat positively skewed distributions of Needs-met scores.

Table 10: Needs Items Ranked by Mean Needs Rating

Item Number	Needs				Needs-met			
	Mean	S.D.	Min	Max	Mean	S.D.	Min	Max
19	4.95	0.40	1	5	1.14	0.35	1	2
1	4.94	0.30	3	5	1.17	0.41	1	3
20	4.93	0.30	3	5	1.23	0.47	1	3
2	4.92	0.31	3	5	1.14	0.35	1	2
11	4.91	0.37	3	5	1.22	0.48	1	3
18	4.91	0.56	1	5	1.13	0.34	1	2
12	4.90	0.47	1	5	1.11	0.34	1	3
26	4.89	0.48	1	5	1.15	0.36	1	2
15	4.87	0.59	1	5	1.21	0.41	1	2
29	4.87	0.53	1	5	1.09	0.32	1	3
16	4.87	0.58	1	5	1.28	0.50	1	3
33	4.87	0.57	1	5	1.27	0.47	1	3
4	4.85	0.62	1	5	1.21	0.45	1	3
14	4.82	0.64	1	5	1.16	0.39	1	3
3	4.81	0.52	2	5	1.23	0.41	1	2
31	4.81	0.57	1	5	1.21	0.41	1	2
6	4.80	0.61	1	5	1.24	0.43	1	2
8	4.80	0.62	1	5	1.26	0.48	1	3
17	4.77	0.77	1	5	1.36	0.56	1	3
30	4.74	0.78	1	5	1.16	0.38	1	3
25	4.68	0.85	1	5	1.29	0.54	1	3
27	4.67	0.91	1	5	1.23	0.47	1	3
40	4.67	0.88	1	5	1.43	0.57	1	3
5	4.65	0.77	1	5	1.31	0.51	1	3
49	4.61	1.11	1	5	1.58	0.78	1	3
10	4.57	0.94	1	5	1.57	0.61	1	3
22	4.56	0.94	1	5	1.27	0.55	1	3
7	4.54	0.97	1	5	1.25	0.48	1	3
28	4.50	0.90	1	5	1.07	0.26	1	2
32	4.44	1.11	1	5	1.54	0.70	1	3
9	4.41	1.02	1	5	1.45	0.58	1	3
13	4.41	1.10	1	5	1.59	0.64	1	3
35	4.39	1.19	1	5	1.22	0.49	1	3
23	4.36	1.30	1	5	1.24	0.54	1	3
39	4.33	1.22	1	5	1.20	0.46	1	3
24	4.31	1.31	1	5	1.41	0.60	1	3
21	4.27	1.09	1	5	1.22	0.47	1	3
52	4.27	1.36	1	5	1.85	0.80	1	3
38	4.26	1.25	1	5	1.35	0.61	1	3
34	4.23	1.34	1	5	1.31	0.61	1	3
50	4.18	1.38	1	5	1.75	0.81	1	3
37	4.10	1.32	1	5	1.30	0.58	1	3
51	4.09	1.40	1	5	1.76	0.81	1	3
46	4.06	1.36	1	5	1.39	0.61	1	3
44	3.73	1.40	1	5	1.61	0.70	1	3
41	3.67	1.45	1	5	1.56	0.67	1	3
45	3.49	1.63	1	5	1.60	0.80	1	3
48	3.39	1.72	1	5	1.80	0.81	1	3
36	3.39	1.64	1	5	1.49	0.70	1	3
43	3.15	1.59	1	5	1.72	0.75	1	3
42	2.96	1.64	1	5	1.85	0.86	1	3
47	2.94	1.69	1	5	1.53	0.71	1	3

Internal Consistency Reliability

The FIN-PED is a 52 item instrument measuring two subscales, Needs and Needs-met. Internal consistency reliability was assessed separately for each of the subscales.

Needs subscale. The Needs subscale of the FIN-PED instrument achieved an internal consistency estimate of  $\alpha = .94$  for the initial responses to the questionnaire, as measured by Cronbach's standardized alpha coefficient. This score is well above the criterion of  $\alpha = .80$  recommended by Nunnally (1978) for acceptable internal consistency reliability.

The total score on the Needs subscale was also correlated with each item score. Zeller and Carmines (1980) suggest that item-to-total correlations should be between  $r = .40$  and  $.70$ . Scores above  $.70$  indicate redundancy of information, and scores below  $.40$  indicate the item may not contribute information about needs that are similar to the other scale items. Thirty-eight of the 52 items (73%) on the Needs subscale achieved item-to-total Pearson Product Moment correlations between  $.40$  and  $.70$ . No items had item-to-total correlations over  $.70$ .

Another criterion for internal consistency suggested by Nunnally (1978) is that for a given item, 50% of the correlations between it and the other items in the scale



should be between  $\underline{r} = .30$  and  $\underline{r} = .70$ . Eleven of the 52 items (21%) met this criterion.

Needs-met subscale. The Needs-met subscale of the FIN-PED instrument achieved an internal consistency estimate as measured by Cronbach's standardized alpha coefficient of .94. This score is well above the criterion of  $\alpha = .80$ , indicating satisfactory internal consistency reliability.

Thirty-six of the 52 items (69%) on the Needs-met subscale achieved item-to-total correlations between  $\underline{r} = .40$  and .70. No items had item-to-total correlations over .70. Six of the 52 items (11%) met the criterion of 50% of item-to-item correlations between .30 and .70, and the remaining 46 items were below 50%.

#### Test-Retest Reliability

Fifty of the 110 respondents completed and returned the retest questionnaire. Given this relatively small sample for assessment of test-retest reliability, a decision was made to categorize respondents into high and low needs categories. As well, the Needs-met subscale was dichotomized to two categories: Met and Unmet. A Chi-square test was then used to examine whether respondents fell into the same category at Time 1 and Time 2.

Table 11 shows the number of respondents who were categorized into the same or different level of needs at Time 1 and Time 2.

Table 11: Number of Respondents Categorized at Each Level of Need

Need Level/Time	Low at Time 2	High at Time 2	Total
Low at Time 1	12	6	18
High at Time 1	2	29	31
Total	14	35	49

Eighty-four percent of subjects remained in the same category from Time 1 to Time 2 for the Needs subscale. This indicates a significant level of test-retest reliability ( $\chi^2 = 17.39$ ,  $p < .0001$ ).

Table 12 shows the number of respondents that were categorized into the same or different level of Needs-met at Time 1 and Time 2. Eighty-eight percent of the subjects remained in the same response category from Time 1 and Time 2 for the Needs-met subscale. This indicates a significant level of test-retest reliability ( $\chi^2 = 23.19$ ,  $p < .0001$ ).

Table 12: Number of Respondents Categorized at Each Level of Needs-met

Needs-met Level	Unmet at Time 1	Met at Time 2	Total
Unmet at Time 1	26	3	29
Met at Time 1	3	16	19
Total	29	19	48

### Internal Construct Validity

Factor analysis was used to identify possible subdimensions of the FIN-PED. "Factor analysis refers to a variety of statistical techniques whose common objective is to represent a set of variables in terms of a smaller number of hypothetical variables" (Kim & Mueller, 1978a, p. 9). The aim of factor analysis is "to summarize the interrelationships among the variables in a concise but accurate manner as an aid in conceptualization" (Gorsuch, 1983, p. 2). In order to assess the internal construct validity of the instrument, factor analysis of the Needs scale using principal axis factoring with varimax rotation was performed.

Determining the number of factors was based on an examination of the scree plot (graph of eigenvalues) and an expectation that interpretable factors would have eigenvalues of at least 1.0 (Kim & Mueller, 1978b). Thirteen factors had eigenvalues greater than 1.0, explaining 82% of the variance. The scree plot also suggested that the first thirteen factors

should be examined. Table 13 shows the eigenvalues and percent of variance for each of the first 13 factors.

Table 13: Factor Loading and Percent of Variance Explained for the First Thirteen Factors

Factor Number	Eigenvalue	Percent of Variance
I	13.93	27
II	5.73	11
III	3.77	7
IV	3.17	6
V	2.85	5
VI	2.43	5
VII	1.98	4
VIII	1.89	4
IX	1.65	3
X	1.53	3
XI	1.26	2
XII	1.25	2
XIII	1.13	2

Criteria for deciding which items to include in each factor were item loadings of greater than .40 on the factor, with a difference of at least .15 between loadings on different factors. Five items loaded on more than one factor and were not interpretable. The items assigned to each factor and their factor loadings are shown in Table 14. Content analysis of the items in each factor resulted in the factor labels shown in Table 14.

Table 14: Factor Analysis of FIN-PED Needs Subscale

Need	Factor 1: Positive Involvement in Child's Care	Loading
18	- feel there is hope	.92
17	- know when to expect side effects to occur	.82
16	- know what side effects the treatment can cause	.82
25	- have thorough information about how to care for my child at home	.73
30	- know that health care professionals offer me the opportunity to participate equally in my child's care	.61
40	- have trust in the health care system	.55
Need	Factor 2: Information Specific to Child's Plan of Care	Loading
19	- be informed of changes in my child's condition	.94
12	- know what treatment my child is receiving	.92
26	- feel that the health care professionals are sincere in caring about my child	.81
6	- have explanations given in terms that are understandable to me	.69
14	- be told when and why changes are being made in my child's treatment plan	.62
Need	Factor 3: Other Children's Needs	Loading
51	- know how to give information to my other children (appropriate to his/her age)	.92
50	- know what information to give to my other children (appropriate to his/her age)	.91
52	- know how to handle the feelings of my other children	.78
Need	Factor 4: Open and Clear Response to Questions	Loading
4	- know I can ask questions anytime	.86
5	- know to whom I should direct my questions	.84
8	- know the probable outcome of my child's illness	.84
Need	Factor 5: Managing Conflict and Differences	Loading
32	- know to whom to turn if conflict situations arise	.83
37	- know health care professionals will respect my family values regarding my child's behaviour	.74
Need	Factor 6: Sharing Information With Ill Child	Loading
23	- know what information to give to my child with cancer (appropriate to his/her age)	.84
24	- know how to give information to my child with cancer (appropriate to his/her age)	.82

Table continued ....

Table 14: Factor Analysis of FIN-PED Needs Subscale (continued)

Need	Factor 7: Knowledge of Child's Care	Loading
11	- know why things are done to my child	.92
15	- be assured that the best possible care is being given to my child	.90
Need	Factor 8: Honest and Competent Professionals	Loading
1	- have my questions answered honestly	.93
2	- believe that health care professionals caring for my child are competent	.88
Need	Factor 9: Support of Other Parents	Loading
41	- meet with other mother/parents dealing with similar issues	.87
42	- be involved in a support group	.78
Need	Factor 10: Involved in Decision Making	Loading
20	- be involved in decisions about my child's care	.93
Need	Factor 11: Mothers' Concerns	Loading
43	- have someone be concerned with my health	.82
44	- be told about people who could help with my concerns	.47
Need	Factor 12: Contacting of Health Professionals	Loading
29	- know how to contact the health professionals involved in my child's care	.97
Need	Factor 13: Knowledge of Parking	Loading
45	- know where to park at the hospital/clinic	.87

To confirm internal consistency reliability of these subdimensions, a correlation matrix was reexamined to assess inter-item correlations. In the Factor I subdimension all item correlations fell between  $r = .38$  and  $.77$ . In Factor II there may be slight redundancy because item 19 and 12, and item 19 and 26 achieved inter-item correlations greater than  $.70$ . Factor III inter-item correlations were all above  $.70$ . All of the items in factor III referred to interactions with siblings; which might explain the higher inter-item

correlations. Inter-item correlations for items on factor nine were between .49 and .73. Factors 10 and 12 contained only one item each. These results are further evidence that the items were internally consistent within the subscales created by factor analysis with minimal redundancy.

To further assess whether or not the Needs scale was multidimensional, a Theta coefficient was calculated [ $\theta = (N/N-1)(1-1/\lambda)$ ]. This calculation is based on factor analysis results. According to Carmines and Zeller (1979), if a scale is multidimensional the Theta coefficient should be higher than the Cronbach's alpha coefficient. In this instance Cronbach's alpha coefficient was 0.94 and the Theta coefficient was 0.95. As well, if a scale is unidimensional, the first extracted component (factor) should account for at least 40% of the variance in the items. Factor I in this scale accounted for 27% of the variance in the items suggesting that the Needs scale may be multidimensional.

#### Relation of Needs and Needs-met to Demographic Variables

Differences in the importance of needs and the extent to which needs were met were examined in relation to demographic variables. An overall Needs score (PTneed) was calculated for each mother by summing the number of needs rated higher than 1 (totneed), dividing this total by the number of needs rated by the mother (nmneed), and multiplying by the number of needs

items; that is,  $(\text{totneed}/\text{nmneed}) \times 52$ . An overall needs-met score was calculated for each mother by dividing the number of needs that were met by the PTneed score and multiplying by 52. A met need was defined as a need item that was rated higher than 1 on the Needs scale and then rated as met on the met scale.

Mothers under the age of 40 years ( $N = 69$ ) were compared to mothers over the age of 40 years ( $N = 36$ ) in terms of mean overall needs and needs-met scores. A  $t$ -test for unequal variances was used to compare these two groups. There was no statistically significant difference in overall needs scores between mothers under the age of 40 ( $M = 49$ ) and mothers over the age of 40 ( $M = 47$ );  $t(48) = 1.34$ ,  $p = .19$ . A  $t$ -test comparing mean needs-met scores for mothers over versus mothers under 40 years of age ( $M = 32$  and  $M = 34$ , respectively) also found no significant difference;  $t(103) = .91$ ,  $p = .37$ . Comparisons of needs scores for single mothers ( $M = 50$ ) and not-single mothers ( $M = 48$ ) found no significant difference;  $t(24) = 1.59$ ,  $p = .12$ . The difference in mean needs-met scores for single and not-single mothers was not significant;  $t(103) = .20$ ,  $p = .84$ .

Mean needs and needs-met scores for mothers at each of five levels of education are shown in Table 15. Separate analyses of variance were carried out on each set of scores with level of education as the between-subjects variable. No



significant differences were found for needs scores;  $F(5, 98) = .25$ ,  $p = .94$ . Similarly, differences between needs-met scores were nonsignificant;  $F(5, 98) = 1.31$ ,  $p = .27$ .

Table 15: Mean Needs and Needs-met Scores for Mothers with Different Educational Levels

Education	Mean Needs	Mean Needs-met
Less than High School	49	38
High School	48	36
College/Vocational	49	31
Undergraduate Degree	47	30
Graduate Degree	48	29

Mean needs and needs-met scores for mothers at each of five occupational groups are shown in Table 16. Separate analyses of variance found no significant differences amongst the needs or needs-met scores;  $F(5, 98) = .35$ ,  $p = .88$ , and  $F(5, 98) = 1.87$ ,  $p = .11$ , respectively.

Table 16: Mean Needs and Mean Needs-met Scores for Occupational Groups

Occupation	Mean Needs Score	Mean Met Score
Clerical	48	29
Nurse	47	22
Teacher	48	33
Other Profession	47	33
Other Job	49	35
Not Working	49	37

Mothers who were working outside the home ( $N = 77$ ) were compared to mothers not working outside the home ( $N = 31$ ) in terms of overall needs and needs-met scores. There was no difference in needs scores between mothers working outside the home ( $M = 48$ ) and mothers not working outside the home ( $M = 48$ );  $t(106) = .34$ ,  $p = .73$ . Needs-met scores for mothers working outside the home ( $M = 31$ ) were significantly lower than needs-met scores for mothers not working outside the home ( $M = 40$ );  $t(106) = 3.0$ ,  $p = .003$ . In addition, mothers working part-time were compared with mothers working full-time. There was no difference in needs scores between mothers working full-time ( $M = 47$ ) and mothers working part-time ( $M = 49$ );  $t(74) = 1.28$ ,  $p = .20$ . Needs-met scores for mothers working full-time ( $M = 29$ ) were not significantly different from needs-met scores for mothers working part-time ( $M = 34$ );  $t(101) = 1.73$ ,  $p > .05$ .

The overall needs scores for mothers who lived in Winnipeg ( $M = 47$ ) were significantly lower than the needs scores for mothers who lived outside of Winnipeg ( $M = 49$ );  $t(92) = 2.01$ ,  $p = .047$ . There was no significant difference between the needs-met scores for mothers who lived in Winnipeg ( $M = 32$ ) and outside of Winnipeg ( $M = 35$ );  $t(107) = .32$ ,  $p = .13$ . The distance a mother lived from Winnipeg was categorized from 0 to 100 km, 101 to 240 km and greater than 240 km from Winnipeg. Distance from Winnipeg did not

significantly affect needs ( $\bar{M}$  = 50, 49, and 49, for 0 to 100 km, 101 to 240 km, and greater than 240 km, respectively);  $F(2, 53) = .32$ ,  $p = .72$ . However, the distance a mother lived from Winnipeg did significantly affect the degree to which her needs were met;  $F(2, 53) = 5.12$ ,  $p = .009$ . Pairwise comparisons using Scheffe's test with alpha set at .05 indicated that those living from 101 to 240 km from Winnipeg ( $\bar{M}$  = 42) had significantly higher needs-met scores than mothers living further than 240 km from Winnipeg ( $\bar{M}$  = 30). The needs-met scores for the mothers who lived 0-100 km from Winnipeg ( $\bar{M}$  = 34) did not differ significantly from the other two groups.

Mean needs and needs-met scores for mothers with children who had varying numbers of admissions are shown in Table 17. Separate analyses of variance on needs and needs-met scores found no significant differences for these groups of mothers;  $F(2, 92) = 1.04$ ,  $p = .36$  for needs scores, and  $F(2, 92) = 1.19$ ,  $p = .31$  for needs-met scores.

Table 17: Mean Needs and Needs-met Scores by Number of Hospital Admissions

Number of Admissions	Mean Needs	Mean Needs-met
1-4	47	35
5-19	49	33
Over 20	49	29

Mean needs and needs-met scores for mothers whose children had one of four diagnoses are presented in Table 18. Separate analyses of variance on needs and needs-met scores found no significant differences amongst these groups;

$F(3, 102) = 1.22, p = .31$  for needs scores, and

$F(3, 102) = 1.68, p = .18$  for needs-met scores.

Table 18: Mean Needs and Needs-met Scores by Diagnostic Category

Diagnosis	Mean Needs	Mean Needs-met
Leukemias	48	37
Solid Tumors	49	29
Brain Tumors	50	34
Others	47	34

### Content Analysis

Content analyses of the two final questions on the questionnaire are presented here. The first question was, "Please tell me anything else health care providers could do to improve the care for you and your child." Seventy-two responses to this question were obtained at Time 1 and Time 2 surveys. Responses varied in length from a few sentences to a full page. The responses identified other health care needs, elaborated on needs already identified in the questionnaire, and documented praise and concerns about the care received by their child. The praise and thank-you's received from mothers were greater in number than the

concerns, but concerns were strongly expressed. In addition, mothers related their stories of the cancer experience for themselves and their families.

Needs identified that were not covered in the questionnaire included the following topics. Need to prepare the entire family for the long term effects and changes that this diagnosis will have on them was suggested by one mother. She proposed developing a survival kit for distribution at the time of diagnosis. Other comments indicated that this suggestion would be helpful. The need for information about "life after cancer" was also identified (e.g., chances of recurrence in adulthood, concerns when approaching motherhood, and the availability of counselling services for all members of the family).

The need for babysitting services, especially for those from out of town was expressed. Concern over the long waiting periods at the clinic when at an appointment was also documented. Respondents suggested that health care system problems be addressed internally, such as less waiting time to transfer a patient from the clinic to a hospital bed that same day and waiting time for results. One mother commented that she would have preferred health care professionals to be more accurately defined (i.e., doctor, nurse intern or student).

Seventy percent rated item 39 "feel encouraged by health care professionals to maintain a normal lifestyle," as very

important, i.e., response of 5. There were however, references that the impact of this diagnosis on a family is not 'normal' in any way, and maintaining a 'normal lifestyle' is an impossible expectation.

A frequent theme in the responses was a plea voiced by mothers to have health care professionals respect mother's knowledge level and listen to their 'intuition' when they say that their child needs a particular intervention.

Mothers perceived differences in the knowledge base of those caring for cancer patients. Mothers stated that staff at the clinic had a more complete and specific understanding of the care of a child with cancer. Health care providers working in rural areas were perceived as lacking knowledge about care of the child with cancer. Mothers living in rural areas stated that their needs for more information and supports were often unmet. In addition, frustration was expressed towards interns because of their perceived lack of knowledge about cancer care, and their manner in dealing with parents of children with cancer.

The second question asked mothers to, "Please tell me anything you would like to about the questions I have asked you". Sixty-eight responses were recorded to this question combining Time 1 and Time 2 questionnaires. The value of the questionnaire in addressing mothers' needs was documented. Consistent with responses to the first question, the support

that families received was stressed along with their thanks to health care professionals.

Significant themes emerged in response to this question, including the need for both counselling and physical supports. Mothers recommended that counselling for all members of the family be available from the time of diagnosis of their child's cancer. Counselling must be available for each child, sibling, and parent as needed. Comments such as the following one were typical of mothers responses, "We are not prepared psychologically for what is ahead of us." Mothers felt overwhelmed with the many issues they had to address in dealing with a family where a child has been diagnosed with cancer.

Another theme was the commitment, courage, and strength required in mothers who have to care for a child with cancer. These themes emphasized a pledge mothers and family members had taken to support their child with cancer. Mothers discussed 'accepting being our own person' or 'being aware of our own growth during this time of stress'. Examples of this theme are also documented by statements such as, "you have to be able to do some things on your own," "I became much stronger physically and emotionally because I had to keep up the spirits of my child," and "I feel that in our lives there are trials to be won no matter the outcome it is how we cope that truly makes winners." Mothers recognized however, that

they could not do this alone and identified how health care providers could assist them.

The content analysis of these two questions added a richer and more personal component to the responses and offered suggestions to be considered in future testing of this instrument.

### Summary

This chapter included a report of the results of Phase II, the pilot testing. Phase III, the reliability and validity of the FIN-PED instrument was also reported. The Needs and Needs-met subscales for the initial responses had internal consistency scores of .94 as measured by Cronbach's standardized alpha coefficient. Chi-square tests showed a significant level of test-retest reliability for both scales.

Eighty-five percent of the needs items had mean ratings greater than 4.0, indicating that mothers rated 85% of the needs as very important or close to very important. Needs-met scores for mothers working outside the home were significantly lower than needs-met scores for mothers not working outside the home. Overall needs scores for mothers who lived in Winnipeg were significantly lower than the needs scores for mothers who lived outside of Winnipeg. Mothers living from 101 to 240 km from Winnipeg had significantly higher needs-met scores than mothers living further than 240 km from Winnipeg.



## CHAPTER V

### DISCUSSION

#### Introduction

The purpose of this study was to test the reliability and validity of an instrument designed to measure needs of mothers of children with cancer. This chapter assesses the reliability and validity of the FIN-PED, as well as other methodological implications of the results. The findings from this needs questionnaire are compared to the literature on mothers' needs. Theoretical and clinical implications of the study and directions for future research are reviewed.

#### Reliability and Content Validity of the FIN-PED

The FIN-PED is a 52 item instrument measuring two subdimensions, Needs and Needs-met. Internal consistency reliability was assessed separately for each of the subscales using three measures. Both scales had high internal consistency, as measured by Cronbach's standardized alpha coefficient. Item-to-total and inter-item correlations met the preset criterion (50% of correlations between .40 and .70). Inter-item correlations on both scales did not fall in

the pre-specified criteria (.30 to .70). However, examination of inter-item correlations for the 13 factors revealed in the factor analysis found internal consistency within the factors, suggesting that the instrument may be multidimensional. Caution must be used in interpreting this factor analysis due to the low case (subject) to item ratio. However, further testing with this instrument would allow examination of the stability of the factor structure with the possibility of deleting items to achieve a more internally consistent and parsimonious instrument.

Examination of the factor analysis results revealed that nine factors contained only one or two items. Factors I to IV identified groups of needs labelled: Positive Involvement in Child's Care, Information Specific to Child's Plan of Care, Other Children's Needs, and Open and Clear Responses to Questions. The purpose of this study was to develop a comprehensive set of mothers' needs. It is not surprising that some items identified needs unrelated to needs described by other items; for example, needs for knowledge about child's care and needs for support from other parents.

Further assessment of FIN-PED reliability was carried out using a test-retest procedure. Forty-five percent of the respondents completed and returned the retest questionnaire. Respondents were dichotomized into high and low needs categories based on their responses to the first

questionnaire. When they were categorized again using responses to the retest questionnaire, 84% fell into the same category. In the case of the needs-met subscale, 88% fell into the same group (needs met or needs unmet) based on test and retest answers. In general, both scales exhibited satisfactory test-retest reliability using this measure.

Content validity assesses how well and how adequately instrument items express the meaning of the conceptual domain without redundancy. The six mothers interviewed in Phase II verified that the FIN-PED questionnaire label (Family Inventory of Needs - Paediatrics) was appropriate and that the definition of the purpose of the FIN-PED (Instrument intended in this study to measure the needs of mothers of children with cancer) was suitable. They also confirmed that each item belonged in the needs questionnaire. Content validity of the items was further confirmed by the high mean need ratings given to the items by the mothers who completed the instrument in Phase III. All of the items received mean ratings greater than 2.9 on a 5-point scale.

#### Methodological Issues

Response rates are an important methodological issue in survey research. In the present study, 36% of the mothers returned the first questionnaire, and 45% of mothers completing the first questionnaire also returned the retest

questionnaire. The mothers included in this mailout survey had been involved with the clinic over the previous 10-year period. One problem with this time frame was that a number of children were no longer patients at the clinic and current addresses were not available, resulting in questionnaires being returned with no forwarding address. In addition, a small number of mothers returned the questionnaire stating that they did not believe their responses would be helpful, as their child's cancer experience was so long ago. A recommendation for a future study would be to limit a similar mailout to children treated within the previous five years.

Higher rates of return for the retest questionnaire might have been achieved using an alternative methodology (Kilpatrick, 1995; Kluka, 1992; Kristjanson, 1991). In these studies, the investigator met with the participants in either the hospital or their homes to administer the first questionnaire. The participant was given the retest questionnaire at this meeting and asked to return it within a 2-day period. The one-on-one personal contact provided an opportunity to explain any questions the participant might have had about the first or second questionnaire. This method also might enlist more personal involvement in the study. However, the costs of this type of data collection method are high in comparison to the mail-out approach used in the present study.

Another methodological issue associated with instrument development is the social desirability factor. Social desirability refers to the phenomenon that, "The more favourable the social desirability response of an item, the greater the likelihood of its endorsement under standard test-taking instructions" (Waltz, Strickland, & Lenz, 1991). The social desirability factor in this study would be mothers' beliefs that they should rate the items in the questionnaires as needs because these would be the socially approved responses. Given the stringent process used to identify mothers needs; including, a literature review, extensive clinical experience of the investigator, reviews by other health care clinicians, a pilot test in Phase II, and use of a the FIN (Kristjanson et al., 1991) as the basis for the construction of the FIN-PED, it is unlikely that social desirability was a strong factor in influencing the mothers' high ratings of the need items. In order to assess the influence of social desirability on mothers' responses to the FIN-PED, consideration should be given to administering the FIN-PED along with a valid and reliable instrument measuring social desirability.

In general, the respondents who answered the questions provided a complete set of responses and did not appear to have difficulties with the wording of the questions. One exception was that on the demographic questionnaire, 12% of

the respondents changed the word "has" to "had" in the first question, "How old is your son/daughter who has cancer?" It would be better to have several questions that request: (a) the age of the child at the time of diagnosis, (b) the current age of the child, (c) whether the child is in remission, and (d) if in remission, how long the remission has been.

#### Findings in Relation to the Literature on Mothers' Needs

Needs identified previously in the literature and included in this instrument were validated again by the mothers in this study. This section will relate observations from previous studies to the responses of the mothers in this study.

Needs for information about the child's treatment and condition were found to be very highly rated by mothers in the present study. For example, ninety-four percent of the respondents rated information needs, such as knowing why things are done to their child and what treatment their child is receiving, as very important. Wallace & al., (1984) describe parents' desire to receive more information about their child's illness and treatment, especially in formal structured education programs. Moore et al. (1986) found that educational programs gave parents an opportunity to communicate with staff in an informed manner, gave them a feeling of competence in caring for their child, and offered

them more control over their lives. Involvement in care of their children was another highly rated set of needs. In the area of gaining some control over what is happening to their child, mothers rated the following items as very important to them: be involved in decisions about my child's care, be informed of changes in my child's condition, and know that health care professionals offer me the opportunity to participate equally in my child's care. The desire by mothers to regain some control over what is happening to their child has also been reported in previous studies (Chesler & Barbarin, 1984; Hayes & Knox, 1983). Chesler and Barbarin (1984) found that parents expected to be treated as knowledgeable collaborators in discussing their child's treatment and plan of care.

Communication with staff was another area of important need found in previous studies (e.g., Moore et al., 1986). This area of need was confirmed in the present study. For example, ninety-two percent of mothers rated knowing how to contact health professionals involved in their child's care as very important. Ninety-six percent of mothers in the present study indicated that having their questions answered honestly was very important to them, and having a respectful relationship with the health care professionals caring for my child was rated by 87% of mothers as very important. Parents' needs for honesty was also found to be an important need by

Chesler & Barbarin (1984) and Hayes & Knox (1983). These authors found that parents reported having problems in conflict resolution, interpersonal contact, communication. In the present study, knowing to whom to turn if a conflict situation arose was identified by 75% of the respondents as an important need.

Staff attitudes towards and interactions with their child were mentioned as important concerns by many mothers. For example, item 35, know that where appropriate health care professionals will ask my child's permission to do things to my child was identified by 74% of mothers as very important. Item 26, feel that health care professionals are sincere in caring about my child was rated by 93% of mothers as very important. These findings are consistent with Chesler and Barbarin (1984) who found that parents expect mutual respect and sincere caring from all oncology staff caring for their child.

Needs for social supports was another area explored in the present study. Morrow et al. (1981) identified support for parents as coming from a variety of sources: spouse, family, health care professionals and other parents. In the present study, two items on needs for peer social supports were not ranked as highly as many other items. For example, be involved with a support group was the only ranked very important by 30% of mothers, and meet with other



mothers/parents dealing with similar issues was ranked as very important by 44% of mothers.

The literature and study findings in terms of the highest ranked needs were also consistent. Although most of the needs were ranked as important by the mothers, the five highest ranked needs were: (a) be informed of changes in my child's condition (item 19), (b) have my questions answered honestly (item 1), (c) be involved in decisions about my child's care (item 20), (d) believe that the health care professionals caring for my child are competent (item 2), and (e) know why things are done to my child (item 11).

The five lowest ranked needs (a) be involved with a support group (item 42), (b) have someone be concerned with my health (item 43), (c) know where things are in the city (item 47), (d) meet with other mothers/parents dealing with similar issues (item 41), and (e) be told about people who could help with my concerns (item 44).

All the highest ranked needs involved needs of/for the child with cancer and the lowest ranked needs were primarily needs of the mothers. Kristjanson (1989) also found that families of cancer patients ranked the needs of their relative with cancer higher than their own needs.

Relation of Needs and Needs-met to Demographic Variables

This study found that the needs scores of mothers who lived in Winnipeg were significantly lower than the need scores for mothers who lived outside of Winnipeg. When mothers needs were examined according to the categories from 0 to 100 km, 101 to 240 km and greater than 240 km from Winnipeg no difference was found in these needs scores. It would appear that the distance from Winnipeg was not a factor in needs scores only the fact that mothers did not live in Winnipeg.

There was no significant difference between the needs-met scores for mothers who lived in Winnipeg and mothers who lived outside of Winnipeg; however, when the distance a mother lived from Winnipeg was analyzed according to the categories from 0 to 100 km, 101 to 240 km and greater than 240 km from Winnipeg differences in needs-met scores were found in the two second categories. Those mothers living from 101 to 240 km from Winnipeg had significantly higher needs-met scores than mothers living further than 240 km from Winnipeg. In terms of the distance mothers lived from Winnipeg, those living greater distances from Winnipeg, i.e., greater than 240 km, had fewer of their needs met than those living 101 to 240 km from Winnipeg. Aitken and Hathaway (1993) demonstrated that parents living greater than 100 miles from the treatment centre had fewer of their needs met, for example many of the

parents in Aitken's and Hathaway's study believed that they did not get enough information about their child's condition.

Age of mother was not related to overall needs or needs-met scores in the present study. Morrow et al. (1984) found that parents under the age of 30 years demonstrated poorer adjustments than parents over the age of 30 years, suggesting that younger mothers might have higher needs or more needs unmet. In the present study, mothers under 40 years of age were compared to mothers over 40 years because forty years of age was the approximate median age for mothers that responded to the questionnaire. As only 9% of mothers ( $N = 10$ ) were under 30 years of age, this group was not compared with the other mothers. The failure to find an effect of age in the present study could be due to the difference in age cut-off in the two studies. It could also be due to the fact that a measure of needs was not used in the Morrow et al. (1984) study.

### Family Systems

Family systems theory provides a useful conceptual framework for understanding some of the needs identified by mothers in this study. According to this framework, any change occurring in one member in a family system can affect the whole system or family (Gilliss et al., 1989). It is obvious from the results of the present study, that mothers

were directly affected in many ways by having a child with cancer. They identified feelings of being overwhelmed with the many issues they had to address in dealing with a family where a child has been diagnosed with cancer. In addition, they reported needs relating to other members of their family; for example knowing how to handle the feelings of their other children.

The responses to open-ended questions, which asked for additional suggestions and comments regarding the care of mother and child, also indicated the pervasive effect on the family of a child with cancer. They stated that the entire family needed preparation for the long term effects and changes that this diagnosis will have on them. Mothers also described the need for counselling and supports from the first day of diagnosis for all members of the family. The impact and change on a family is demonstrated by these statements from mothers in families where a child has been diagnosed with cancer. These results are consistent with Friedman's (1992) description of how chronic illness may seriously alter both individual and family developmental tasks.

#### Research Implications

Further research is needed to confirm the test-retest reliability of the FIN-PED, considering the relatively small number of scores available for testing this type of

reliability in the present study. Shortening the questionnaire by removing items that are not concerned with the child's care should also be considered as a means of simplifying the factor structure. Separate assessment tools for measuring siblings' and fathers' needs could be developed to supplement the FIN-PED. Multi-site testing of the FIN-PED is recommended to establish the generalizability of the present findings concerning needs of mothers of children with cancer.

Replication of the findings relating needs and needs-met scores to demographic variables is also needed in view of the small number of significant effects relative to the total number of comparisons; that is, some of these significant differences could be due to chance.

Once further tests of the FIN-PED have confirmed its reliability and validity, the instrument could be used for program evaluation studies within paediatric oncology programs. Needs-specific interventions could be developed and tested with mothers of children with cancer in future research. This instrument could be used as a tool to evaluate costs within an oncology program (i.e., evaluating the cost to the system and care outcomes to mothers if services directed toward identified needs are not provided).

Clinical Implications

The FIN-PED was designed to measure the needs of mothers of children with cancer, and the degree to which these needs were met. The results of this study show that this group of mothers had a large number of needs that they rated as very important, and that a number of these needs were identified as either being only partly met or unmet.

It is interesting to examine a number of items that 20% of mothers scored as unmet or partly met. Further research should be done on these items to understand why they are not being met in such a high percentage of cases. Health care providers may be able to meet these needs by educational programs or in some instances counselling for parents and/or families may need to be provided. These needs include: item 10, "know how to handle my child's feelings" (51%); item 13, "know what situations I can and can not control while my child is in hospital" (50%), and item 32, "know to whom to turn if conflict situations arise," (42%), item 9, "know what my child's stay in the hospital will be like," (41%), and item 36, "have health care professionals guide me in setting limits for my child" (38%). Items 16 and 17, "know what side effects the treatment can cause," and "know when to expect side effects to occur" were unmet or partly met 26% and 32% of the time respectively. The latter need was also reported as unmet by Hayes and Knox (1983).

Item 49, "be allowed to discuss the terminal stage of my child's illness," also had a high percentage of unmet or partly met responses (40%). The issue of communicating about the terminal stage of the illness needs to be explored further by health care providers. Unmet parental needs could be due to a distancing effect by either parents or health care providers. These results could also reflect a need for education of parents and health care providers.

The distance a mother lived from Winnipeg was related to the number of needs that were met. Allowing time for discussion of questions or concerns before a mother returns to her community may be helpful. Providing a telephone number and name of a resource person(s) in Winnipeg could also be of assistance to families living outside of Winnipeg.

Further needs were identified in the content analysis section of the questionnaire. Mothers stated that there should be family supports and counselling from the time of diagnosis, as there are many issues to be resolved for the child with cancer, parents, and siblings. Counselling should be available on an individualized basis for each child, sibling, and parent.

Mothers living in rural areas stated that their needs for more information and supports were often unmet. It is important for health care providers to be aware of this need

and discuss information and supports with families in rural areas before they return home from the hospital or clinic.

Because most families are involved in 24-hour care they have identified the need for a room on each unit for the care givers. This room would have a fridge and a microwave, to store and heat food for a parent, and a child whose eating habits have changed. The room would also be furnished with comfortable furniture to support us in caring for our child.

As the task of caring for a child with cancer unfolds for a family, they will identify a variety of needs that must be addressed; as one parent said, "we'll accept, but let us tell you what we need to cope." The FIN-PED instrument is potentially useful as a screening tool or as part of a nursing data base on admission, identifying mothers' needs and the degree to which these needs are being met. This would allow health care providers to respond more effectively to needs of mothers of children with cancer.



Conclusions

The FIN-PED has been developed to identify the needs of mothers whose children have been diagnosed with cancer. This instrument is intended to assist in the care planning for children with cancer. A firm research base has been established for further programmatic research. In order for this instrument to be used with clinical confidence further reliability and validity testing is recommended. Multi-site testing is also recommended to establish needs of mothers of children with cancer irrespective of treatment centre.

## REFERENCES

- Adams, D.W., & Deveau, E.J. (1988). Coping with childhood cancer: Where do we go from here. Hamilton: Kirkbridge Publications.
- Aitken, T. J., & Hathaway, G. (1993). Long distance related stressors and coping behaviours in parents of children with cancer. Journal of Paediatric Oncology Nursing, 10, 3-12.
- Bakke, K., & Pomietto, M. (1986). Family care when a child has late stage cancer: A research review. Oncology Nursing Forum, 13, 71-76.
- Barbarin, O.A., Hughes, D., & Chesler, M.A. (1985). Stress, coping, and marital functioning among parents of children with cancer. Journal of Marriage and the Family, 47, 473-480.
- Birenbaum, L. K. (1990). Family coping with childhood cancer. The Hospice Journal, 6, 17-33.
- Broome, M. E., Bates, T. A., Lillis, P. P., & McGahee, T. W. (1990). Children's medical fears, coping behaviours, and pain perceptions during a lumbar puncture. Oncology Nursing Forum, 17, 361-367.
- Byrne, C. M., Stockwell, M., & Gudelis, S. (1984). Adolescent support groups in oncology. Oncology Nursing Forum, 11, 36-40.
- Cassileth, B. R., & Hamilton, J. N. (1979). The Cancer Patient. Philadelphia: Lea & Febiger.
- Chesler, M. A., & Barbarin, O. A. (1984). Relating to the medical staff: How parents of children with cancer see the issues. Health and Social Work, 49-65.
- Doherty, W. J., & Campbell, T. L. (1988). Families and health. California, Sage Publications.
- Ell, K., & Northen, . (1990). Families and Health Care. New York. Adeline De Gruyter.
- Foley, M. K. (1989). Children with cancer: ethical dilemmas. Seminars in Oncology Nursing, 5, 109-113.

Foster, R. L., Hunsberger, M.M., & Anderson, J. J. (1989). Family-Centred Nursing Care of Children. Toronto: W. B. Saunders Company.

Friedman, M. M. (1992). Family nursing: Theory and practice. Norwalk, Connecticut. Appleton and Lange.

Friesen, P., & Manitt, J. (1990). Nursing the remarried in the palliative care setting. Journal of Palliative Care, 6, 32-39.

Gibbons, M. B., & Boren, H. (1985). Stress reduction: a spectrum of strategies in paediatric oncology nursing. The Nursing Clinics of North America, 20, March, 83-103.

Gilliss, C. L., Highley, B. L., Roberts, B. M., & Martinson, I. M. (1989). Toward a science of family nursing. California. Addison-Wesley.

Gorsuch, R. L. (1983). Factor Analysis (2nd ed.). New Jersey. Lawrence Erlbaum.

Hammond, G. D., Haase, G. M., Krawiec, V., Bleyer, W.A., Severson, R.K., & Bernstein, L. (1993). Patterns of care. Cancer, 71, 3202-3205.

Hayes, V., & Knox, J. E. (1983). Reducing hospital-related stress in parents of children with cancer. Canadian Nurse, 79, 24-28.

Heiney, S. P. (1988). Assessing and intervening with dysfunctional families. Oncology Nursing Forum, 15, 585-590.

Heiney, S. P., Wells, L. M., Ettinger, R. S., Ettinger, S., & Cannon, B. (1989). Effects of group therapy on parents of children with cancer. Journal of Paediatric Oncology Nursing, 6, 63-69.

Hinds, C. (1985). The needs of families who care for patients with cancer at home: Are we meeting them? Journal of Advanced Nursing, 10, 575-581.

Hockenberry, M.J. (1988). Relaxation techniques in children with cancer: the nurses role. Journal of the Association of Paediatric Oncology Nurses, 5, 7-11.

Hughes, P. M., & Lieberman, S. (1990). Troubled parents: vulnerability and stress in childhood cancer. British Journal of Medical Psychology, 63, 53-64.

Hull, M. (1989). Family needs and supportive nursing behaviours during terminal cancer: A review. Oncology Nursing Forum, 16, 787-792.

Imle, M., & Atwood, J. (1988). Retaining qualitative validity while gaining quantitative reliability and validity: Development of the transition to parenthood concerns scale. Advances in Nursing Science, 11, 61-75.

Inman, C. E. (1991). Analyzed interaction in a children's oncology clinic: the child's view and parent's opinion of the effect of medical encounters. Journal of Advanced Nursing, 16, 782-793.

Jacob, T. (1987). Family interaction and psychopathology. New York: Plenum Press.

Johnson, J. L., & Norby, P. A. (1981). We Can Weekend: A program for cancer families. Cancer Nursing, 23-27.

Kesselring, A., Lindsey, A. M., Dodd, M. J., & Lovejoy, N.C. (1986). Social network and support perceived by Swiss cancer patients. Cancer Nursing, 9, 156-163.

Kim, J. & Mueller, C. W. (1978a). Introduction to factor analysis: What it is and how to do it. Newbury Park: Sage.

Kim, J., & Mueller, C.W. (1978b). Factor analysis: Statistical methods and practical issues. Newbury Park: Sage.

Koch, A. (1985). "If only it could be me": The families of paediatric cancer patients. Family Relations, 34, 63-70.

Kramer, R. F. (1984). Living with childhood cancer: impact on healthy siblings. Oncology Nursing Forum, 11, 44-51.

Kristjanson, L. (1992). Conceptual issues related to measurement in family research. The Canadian Journal of Nursing Research, 24, 37-49.

Kristjanson, L. (1991). Family satisfaction with palliative care: a test of four alternative theories. Doctoral dissertation. University of Arizona.

Kristjanson, L., Atwood, J., & Degner, L. (1995). Validity and reliability of the family inventory of needs (FIN): Measuring the care needs of families of advanced cancer patients. 3, 109-126.

Krueger, R.A. (1988). Focus Groups: A practical guide for applied research. Newbury Park: Sage.

Krulik, T. (1982). Helping parents of children with cancer during the midstage of illness. Cancer Nursing, 5, 441-445.

Leahey, M., & Wright, L. M. (1987). Families and life-threatening illness. Pennsylvania: Springhouse Corporation.

Lewandowski, W., & Jones, S. L., (1988). The family with cancer: Nursing interventions throughout the course of living with cancer. Cancer Nursing, 11, 313-321.

Lindsey, A. M., Ahmed, N., Dodd, M. J. (1985). Social support: Network and quality as perceived by Egyptian cancer patients. Cancer Nursing, 8, 37-42.

Lindsey, A. M., Dodd, M. J., & Chen, S. (1985). Social support network of Taiwanese cancer patients. International Journal of Nursing Studies, 22, 149-164.

Longman, A. J., Atwood, J. R., Sherman, J. B., Benedict, J., & Shang, T. (1992). Care needs of home-based cancer patients and their caregivers. Cancer Nursing, 15, 182-190.

Lynn, M. (1986). Determination and quantification of content validity. Nursing Research, 35, 382-385.

Maul-Mellott, S. K., & Adams, J. N. (1987). Childhood cancer a nursing overview. Boston: Jones and Bartlett.

McEvoy, M., Duchon, D., & Schaefer, D.S. (1985). Therapeutic play group for patients and siblings in a paediatric oncology ambulatory care unit. Topics in Clinical Nursing, 10-18.

Meleis, A. I. (1991). Theoretical nursing: Development and process. Philadelphia: Lippincott.

Minuchin, S. 1974. Families and family therapy. Cambridge, MA: Cambridge University Press.

Moore, I. M., Kramer, R. F., & Perin, G. (1986). Care of the family with a child with cancer: Diagnosis and early stages of treatment. Oncology Nursing Forum, 13, 60-66.

Morgan, D. L. (1988). Focus Groups as Qualitative Research. Newbury Park: Sage.

Morrow, G. R., Carpenter, P. J., & Hoagland, A. C. (1984). The role of social support in parental adjustment to paediatric cancer. Journal of Paediatric Psychology, 9, 317-329.

Morrow, G. R., Hoagland, A., & Carnrike, C. (1981). Social support and parental adjustment to paediatric cancer. Journal of Consulting and Clinical Psychology, 49, 763-765.

Morrow, G. R., Hoagland, A., & Morse I. (1982). Sources of support perceived by parents of children with cancer: Implications for counselling. Patient Counselling and Health Education, 4, 36-40.

Nugent, L. S. (1988). The social support requirements of family caregivers of terminal cancer patients. The Canadian Journal of Nursing Research, 20, 45-58.

Nunnally, J. (1967). Psychometric theory. New York: McGraw-Hill.

Nunnally, J. (1978). Psychometric Theory (2nd ed.). New York: McGraw-Hill.

Petrillo, M., & Sanger, S. (1980). Emotional Care of Hospitalized Children: An Environmental Approach. Philadelphia, PA: Lippincott.

Polit, D. F., & Hungler, B. P. (1991). Nursing research: Principles and methods (4th ed.). Philadelphia, PA: Lippincott.

Powzeck, M., Payne, J. S., Goff, J. R., Paulson, M. A., & Stagner, S. (1980). Psychological

ramifications of childhood leukaemia: One year post diagnosis. In J. L. Schulman & M. J. Kupst (Eds.). The child with cancer. Springfield, Ill: Charles C. Thomas.

Schulman, J. L. (1983). Coping with Major Disease: Child, family, pediatrician. The Journal of Pediatrics, 102, 988-991.

Shapiro, J. (1983). Family reactions and coping strategies in response to the physically ill or handicapped child: a review. Social Science and Medicine, 17, 913-928.

Thorne, S. (1985). The family cancer experience. Cancer Nursing, 8, 285-291.

Tringali, C. A. (1986). The needs of family members of cancer patients. Oncology Nursing Forum, 13, 65-70.

Walker, C. L. (1988). Stress and coping in siblings of childhood cancer patients. Nursing Research, 37, 208-212.

Walker, C. L. (1990). Siblings of children with cancer. Oncology Nursing Forum, 17, 355-360.

Wallace, M. H., Bakke, K., Hubbard, A., & Pendergrass, T. W. (1984). Coping with childhood cancer: an educational program for parents of children with cancer. Oncology Nursing Forum, 11, 30-35.

Wallace, M. H., Reiter, P. B., & Pendergrass, T. W. (1987). Parents of longterm survivors of childhood cancer: A preliminary survey to characterize concerns and needs. Oncology Nursing Forum, 14, 39-43.

Williams, H. (1988). Social support and social networks: A review of the literature. Journal of the Association of Paediatric Oncology Nursing 5, 6-10.

Williams, H. (1992). Comparing the perception of support by parents of children with cancer and by health professionals. Journal of Paediatric Oncology Nursing, 9, 180-186.

Wingate, A. L., & Lackey, N. R. (1989). A description of the needs of noninstitutionalized cancer patients and their care givers. Cancer Nursing, 12, 216-225.

**APPENDIX A**

**PILOT TESTING REQUEST**

Hello,

This is Pat Pruden calling. I am calling on behalf of Marilyn Whiteley a graduate student in nursing at the University of Manitoba. Marilyn is conducting a research study to develop an instrument to assess the needs of mothers of children with cancer. This study is part of her Masters of Nursing degree.

The paediatric oncology team at the Manitoba Cancer and Treatment Research Foundation and the Ethical Review Committee at the Faculty of Nursing, University of Manitoba have given Marilyn their approval to conduct this study. In order to begin this study Marilyn needs a panel of six mothers to review the questionnaire for her and tell her if the questions are clear and useful. I am calling to see if you would be willing to be one of the mothers to review the questionnaire.

Participation in this review will take about 45 minutes of your time. Your participation is voluntary and will in no way interfere with the care you and your child receive. If you choose not to participate in the pilot test, your decision will kept confidential. The information obtained from you is strictly confidential because your name will not be associated with the information you provide. If you agree I will give Marilyn your name and she can contact you about a time and place to get together and review the study.

If you have any further questions about the study you can contact Marilyn at 489-9437.

THANK YOU FOR YOUR TIME



**APPENDIX B**  
**Pilot Testing Information**

Hello,

This is Marilyn Whiteley calling. Pat Pruden gave me your name regarding participation in a pilot test for my study looking at the needs of mothers of children with cancer. If you are still willing to participate, and have the time to talk now, I would like to tell you more about the study, answer any questions you have about the pilot testing and the study, and also to arrange a time for us to get together. Pause, wait for yes or no and questions.

I am conducting a nursing research study titled: "Reliability and Validity of the FIN-PED: An Instrument to Measure Care Needs of Mothers of Children With Cancer" for my Master of Nursing thesis. This instrument is intended for use in future by mothers whose children have cancer to learn more about their needs. This is not meant to ignore father's or significant other's needs, but to recognize that mothers usually are the caregivers at the hospital, and that parents may have different needs at different times during a child's illness.

Participation would involve reviewing the needs instrument with me and rating the questions to see if they are clear and useful. The questions include needs that have been reported in articles and books, or needs that have been suggested by health care workers who work with children who have cancer. You would also be asked to list any other needs that you can think of that are missing from the questionnaire. Your help on this questionnaire will take approximately 45 minutes.

Your participation is voluntary. You may withdraw from the pilot testing at any time by simply telling me you choose to do so. Your withdrawal will in no way effect the care your child receives. The information obtained from you will be strictly confidential because your name will not be recorded with the information you provide. Any information provided during the study will be for the sole purpose of improving the needs questionnaire.

Do you have any further questions about the study or about your participation in the pilot testing? A time will then be set for participation in the pilot testing.

**APPENDIX C**  
**Pilot Testing Consent Form**

Reliability and Validity of the FIN-PED: An Instrument to Measure Care Needs of Mothers of Children With Cancer.

A nursing research study titled " Reliability and Validity of the FIN-PED: An Instrument to Measure Care Needs of Mothers of Children With Cancer" is being conducted by me, Marilyn Whiteley, a paediatric nurse, for my Master of Nursing thesis. The instrument is intended to improve the care of the child and mothers whose children have cancer.

Participation will involve completing three short questionnaires about the needs instrument itself. The items in the instrument have been reported in earlier studies or are concerns identified by health care professionals working with children with cancer. You would also be asked to list any other needs you may identify that are not listed in the questionnaire. It is expected to take about 45 minutes to complete all aspects of the pilot test.

Your participation is voluntary and will in no way affect the care you and your child receive. You may withdraw from the study at any time by simply telling me you wish to do so. The information obtained from you will be strictly confidential because your name will not be associated with the information you provide. Any information provided during the study will be for the sole purpose of testing the needs instrument and the results of the study will be presented in a manner that no one individual response could be identified.

If you have any questions about the study or about your participation in this study you may contact me at 489-9437, or contact my advisor Dr. Linda Kristjanson at or 474-8937. This project has been approved by the Ethical Review Committee, Faculty of Nursing and the paediatric oncology team at Manitoba Cancer Treatment and Research Foundation.

Principal Investigator:

---

**APPENDIX D**  
**CLARITY**

Instructions

This questionnaire is based on needs identified in previous studies and also those needs identified by health care workers working with children with cancer. You are being asked to rate a) the instructions on the questionnaire and b) each item in the questionnaire on its clarity since you are familiar with this content.

(a) Are the instructions on the questionnaire clear? Circle either the yes or no on your right. YES NO.

(b) Read each need on the instrument separately and respond to the same number on the response sheet. Beside each item number on the response sheet circle C (clear) or U (unclear) to indicate whether the item is clear or unclear to you.

(b) Write any comments in the space provided below each response.

(c) After you finish you may discuss your comments with the researcher.

Thank you for your assistance.

LIST OF ITEMS  
CLARITY

RESPONSE SHEET:

I NEED TO:

- |   |   |   |
|---|---|---|
| 1. have my questions answered honestly                    | C | U |
| Comments _____  |   |   |
| _____   |   |   |
| 2. know specific facts concerning my child's outcome.     | C | U |
| Comments _____  |   |   |
| _____   |   |   |
| 3. feel that the health professionals care about my child | C | U |
| Comments _____  |   |   |
| _____   |   |   |

**APPENDIX E**  
**APPARENT INTERNAL CONSISTENCY**

Instructions:

In this section, you are being asked to look at the items of the instrument and decide if you think they seem to belong together.

Read the entire questionnaire first. After you finish reading the questionnaire, answer question (A) at the top of the response sheet. Y (yes) N (no). Then answer question (B) for each item in the questionnaire. Answer by circling the response you choose under question (B). Add any comments you want to explain your answers.

Thank you for your assistance.

LIST OF ITEMS

I NEED TO:

1. have my questions answered honestly.
2. know specific facts concerning my child's outcome.
3. feel that the health professionals care about my child.

RESPONSE SHEET: CONSISTENCY

A. Do these items generally belong together?

Y                      N

B. Does each item belong in the questionnaire?

Circle one

Comments

- |    |   |   |       |
|----|---|---|-------|
| 1. | Y | N | <hr/> |
| 2. | Y | N | <hr/> |
| 3. | Y | N | <hr/> |

**APPENDIX F**  
**CONTENT VALIDITY**

Instructions:

In this section, you are asked to look at the items of the instrument and tell me if they measure the needs of mother's of children with cancer. In this study when we refer to a need we mean "judgments made by a family member about whether or not his or her perceived needs have been satisfied by health care professionals."

You will be given the questionnaire and a response sheet with a label and definition. Four questions will be asked about each item. The four questions are:

(a) In general, does the label and definition fit the questionnaire?

(b) Does each question belong to the label and definition?

Please answer Y (Yes) N (No) next to each question number on the response sheet.

(c) Save this question until you finish (A) and (B). Is each question unique (i.e. not repetitious)? Answer Y (Yes) or N (No) next to each question on the response sheet.

(d) Are there needs left off the list you think should be on the questionnaire?

e.g.

LIST OF ITEMS

I NEED TO:

1. have my questions answered honestly
2. know specific facts concerning my child's outcome.
3. feel that the health professionals care about my child

RESPONSE SHEET: CONTENT VALIDITYLabel: Family Inventory of Needs - PaediatricsDefinition: Instrument intended in this study to measure the needs of mothers of children with cancer.

a) In general, does the label and definition fit the whole set of items? Answer once for the whole questionnaire by circling Y for Yes or N for No.

Y

N

b) Does each question fit the label and definition?

Circle One

Comments

1. Y N

2. Y N

3. Y N

c) Is the question unique (not repetitious)?

Circle One

Comments

1. Y N

2. Y N

3. Y N

d) Are there needs left off the list you think should be on the questionnaire?

---

THANK YOU FOR YOUR PARTICIPATION

**APPENDIX G**  
**PILOT FAMILY INVENTORY OF NEEDS - PAEDIATRICS**

Below is a list of needs identified by some family members who have a child with cancer. Please rate how important each item is from 1 to 5 as it relates to your present situation. If an item is not at all important to you, give it a 1. If it is very important to you, give it a 5. If it is somewhere in between, give it a score between 1 and 5 which reflects how important it is for you. If you rated a need greater than (1) then check whether each need is currently met, partially met, or unmet.

IF YOU RATED  
AN ITEM HIGHER  
THAN 1, CHECK IF NEED WAS  
MET, PARTLY MET, OR UNMET

	RATINGS FROM <u>1-5</u>	<u>MET</u>	<u>PARTLY MET</u>	<u>UNMET</u>
<u>I NEED TO:</u>				
1. have my questions answered honestly	_____	_____	_____	_____
2. know I can ask questions anytime.	_____	_____	_____	_____
3. know to whom I should direct my questions.	_____	_____	_____	_____
4. have explanations given in terms that are understandable to me.	_____	_____	_____	_____
5. have explanations given to my child in terms that are understandable to him/her	_____	_____	_____	_____
6. know the probable outcome of my child's illness.	_____	_____	_____	_____
7. know what my child's stay in the hospital will be like.	_____	_____	_____	_____
8. know why things are done to my child.	_____	_____	_____	_____
9. know what treatment my child is receiving.	_____	_____	_____	_____
10. know what situations I can and can not control while my child is in hospital.	_____	_____	_____	_____
11. be told when and why changes are being made in my child's treatment plans.	_____	_____	_____	_____

<u>I NEED TO:</u>	RATINGS FROM			
	<u>1-5</u>	<u>MET</u>	<u>PARTLY MET</u>	<u>UNMET</u>
12. be assured that the best possible care is being given to my child.	_____	_____	_____	_____
13. know what symptoms the treatment can cause.	_____	_____	_____	_____
14. know when to expect symptoms to occur.	_____	_____	_____	_____
15. feel there is hope.	_____	_____	_____	_____
16. be allowed to discuss the terminal stage of my child's illness.	_____	_____	_____	_____
17. be informed of changes in my child's condition.	_____	_____	_____	_____
18. be involved in decisions about my child's care.	_____	_____	_____	_____
19. know how much time I can take in making my decisions.	_____	_____	_____	_____
20. know how I can help care for my child in the hospital.	_____	_____	_____	_____
21. know <u>what</u> information to give to my child with cancer	_____	_____	_____	_____
22. know <u>how</u> to give information to my child with cancer.	_____	_____	_____	_____
23. have information about how to care for my child at home.	_____	_____	_____	_____
24. feel that the health professionals care about my child.	_____	_____	_____	_____
25. believe that the health care professionals caring for my child are competent.	_____	_____	_____	_____
26. know the names of the health care professionals involved in my child's care.	_____	_____	_____	_____



<u>I NEED TO:</u>	RATINGS FROM			
	<u>1-5</u>	<u>MET</u>	<u>PARTLY MET</u>	<u>UNMET</u>
27. know how to contact the health professionals involved in my child's care.	_____	_____	_____	_____
28. know that health care professionals offer me the opportunity to participate equally in my child's care.	_____	_____	_____	_____
29. have a respectful relationship with the health care professionals caring for my child.	_____	_____	_____	_____
30. have my child feel trust in the health care professionals caring for him/her.	_____	_____	_____	_____
31. have health care professionals guide me in setting limits for my child.	_____	_____	_____	_____
32. feel that health care professionals accept me even if I am angry or upset.	_____	_____	_____	_____
33. feel encouraged by health care professionals to maintain a normal lifestyle.	_____	_____	_____	_____
34. have trust in the health care system.	_____	_____	_____	_____
35. meet with other mothers/parents dealing with similar issues.	_____	_____	_____	_____
36. be involved with a support group.	_____	_____	_____	_____
37. have someone be concerned with my health.	_____	_____	_____	_____
38. be told about people who could help with my concerns.	_____	_____	_____	_____

If you have children in addition to your child with cancer please answer the following two questions (#39 and 40). If you do not have other children please put an X in this space \_\_\_\_\_

	RATINGS FROM <u>1-5</u>	<u>MET</u>	<u>PARTLY MET</u>	<u>UNMET</u>
39. know <u>what</u> information to give to my other children.	_____	_____	_____	_____
40. know <u>how</u> to give information to my other children.	_____	_____	_____	=_____

Please tell me anything else health care providers could do to improve the care for you and your child:

Please tell me anything you would like to about the questions I have asked you. If you need more pages for your responses, please feel free to add them.

THANK YOU FOR YOUR PARTICIPATION.

c Whiteley/Kristjanson. 1995

## APPENDIX H

## Cover Letter to Mothers Explaining Study

Dear Mother,

My name is Marilyn Whiteley and I am conducting a research study, for my Master of Nursing thesis, looking at the "Needs of Mothers of Children With Cancer." This letter is being mailed for me by staff of the Manitoba Cancer and Treatment Foundation. I believe that if health care providers understand your needs, they can give better care to you and your child. This is not meant to ignore father's or significant other's needs, but to recognize that mother's usually are the caregivers at the hospital, and that parents may have different needs at different times during a child's illness.

If you wish to be part of this study you can answer the two questionnaires enclosed and mail them back in the self addressed envelopes also enclosed. One questionnaire asks for information about yourself and your family such as the ages of your children and how far you may have to travel to obtain care for your child. The other questionnaire is about your needs and how well health care providers met them while caring for your child with cancer. This information will help to identify individual supports families may need.

Your participation in this study is voluntary and will in no way affect the care you and your child receive. The information obtained from you will be strictly confidential because your name will not be associated with the information you provide. Any information provided by you is for this research study only. You could experience an emotional response to some of the questions. If concerns do arise during the completion of this questionnaire you could discuss them with your physician or a nurse clinician.

This study has received the approval of the paediatric oncology team at the Manitoba Cancer Treatment and Research Foundation and the Ethical Review Committee of the Faculty of Nursing, University of Manitoba. I am working under the direction of my advisor Dr. Linda Kristjanson, University of Manitoba, Faculty of Nursing. Only Dr. Kristjanson and I will have access to the questionnaire. Although Dr. R. Yanofsky is a member of my thesis committee she will not know who participated in the study and will not have access to the questionnaires. If you have any questions about the study you can reach me at 489-9437, or my advisor, Dr. Kristjanson at or 474- 8937. If you would like, a report of the final results of this study can be sent to you. I look forward to receiving your responses.

Yours Sincerely,

APPENDIX I  
DEMOGRAPHIC QUESTIONNAIRE

#\_\_\_\_\_

Please answer the following questions to the best of your ability.

1. How old is your son/daughter who has cancer?

\_\_\_\_\_

2. When was your child diagnosed with cancer?

month\_\_\_\_\_ year\_\_\_\_\_

3. What kind of cancer does your child have?

\_\_\_\_\_

4. (a) How often has your child been admitted to the hospital?

\_\_\_\_\_

(b) What were the reasons for admission? How long was he/she in the hospital? \_\_\_\_\_

5. Is your child receiving chemotherapy now?

Yes\_\_\_\_\_ No\_\_\_\_\_

6. Is your child receiving radiotherapy now?

Yes\_\_\_\_\_ No\_\_\_\_\_

7. If you said no to #5 or #6, what date did your child complete their course of treatment for cancer?

8. Has your child had any recurrences or relapses?

Yes \_\_\_\_\_ No\_\_\_\_\_

9. If you answered yes to #8 could you tell me when \_\_\_\_\_

10. Does your child with cancer have any brothers or sisters?

Yes\_\_\_ No\_\_\_

11. If you answered yes to #10 please indicate the age and gender of the brothers and sisters and if they live with the child who has cancer.

\_\_\_\_\_  
\_\_\_\_\_

12. What is your marital status? Please X one response only.

married\_\_\_\_\_

common law\_\_\_\_\_

never married\_\_\_\_\_

separated\_\_\_\_\_

widowed\_\_\_\_\_

divorced\_\_\_\_\_

13. What is your age? Please X one response only.

under 20 years\_\_\_\_\_

21 to 30 years\_\_\_\_\_

31 to 40 years\_\_\_\_\_

41 to 50 years\_\_\_\_\_

over 50 years\_\_\_\_\_

14. Could you tell me what is the highest schooling you have?

Less than high school diploma\_\_\_\_\_

High school diploma\_\_\_\_\_

Community college/technical/vocational diploma\_\_\_\_\_

University undergraduate degree\_\_\_\_\_

Graduate degree\_\_\_\_\_

Other\_\_\_\_\_

15. Do you live in Winnipeg? Yes\_\_\_ No\_\_\_

16. If you live outside of Winnipeg, how far away from  
Winnipeg do you live?\_\_\_\_\_

17. Do you work outside the home? Yes\_\_\_ No\_\_\_. If yes  
what do you do? \_\_\_\_\_

\_\_\_\_\_

Full time\_\_\_\_\_ Part time\_\_\_\_\_

APPENDIX J  
FAMILY INVENTORY OF NEEDS - PAEDIATRICS

Below is a list of needs identified by some family members who have a child with cancer. Please rate how important each item is from 1 to 5 as it relates to your present situation. If an item is not at all important to you, give it a 1. If it is very important to you, give it a 5. If it is somewhere in between, give it a score between 1 and 5 which reflects how important it is for you. If you rated a need greater than (1) then check whether each need is currently met, partially met, or unmet.

IF YOU RATED  
AN ITEM HIGHER  
THAN 1, CHECK IF NEED WAS  
MET, PARTLY MET, OR UNMET

	RATINGS FROM <u>1-5</u>	<u>MET</u>	<u>PARTLY MET</u>	<u>UNMET</u>
<u>I NEED TO:</u>				
1. have my questions answered honestly	_____	_____	_____	_____
2. believe that the health care professionals caring for my child are competent.	_____	_____	_____	_____
3. know that the knowledgs of health care workers fit my child's needs.	_____	_____	_____	_____
4. know I can ask questions anytime.	_____	_____	_____	_____
5. know to whom I should direct my questions.	_____	_____	_____	_____
6. have explanations given in terms that are understandable to me.	_____	_____	_____	_____
7. where appropriate have explanations given to my child in terms that are understandable to him/her	_____	_____	_____	_____
8. know the probable outcome of my child's illness.	_____	_____	_____	_____
9. know what my child's stay in the hospital will be like.	_____	_____	_____	_____
10. know how to handle my child's feelings	_____	_____	_____	_____
11. know why things are done to my child.	_____	_____	_____	_____

<u>I NEED TO:</u>	RATINGS FROM			
	<u>1-5</u>	<u>MET</u>	<u>PARTLY MET</u>	<u>UNMET</u>
12. know what treatment my child is receiving.	_____	_____	_____	_____
13. know what situations I can and can not control while my child is in hospital.	_____	_____	_____	_____
14. be told when and why changes are being made in my child's treatment plans.	_____	_____	_____	_____
15. be assured that the best possible care is being given to my child.	_____	_____	_____	_____
16. know <u>what</u> side effects the treatment can cause.	_____	_____	_____	_____
17. know <u>when</u> to expect side effects to occur.	_____	_____	_____	_____
18. feel there is hope.	_____	_____	_____	_____
19. be informed of changes in my child's condition.	_____	_____	_____	_____
20. be involved in decisions about my child's care.	_____	_____	_____	_____
21. where possible, know how much time I can take in making my decisions.	_____	_____	_____	_____
22. know how I can help care for my child in the hospital.	_____	_____	_____	_____
23. know <u>what</u> information to give to my child with cancer (appropriate to his/her age)	_____	_____	_____	_____
24. know <u>how</u> to give information to my child with cancer. (appropriate to his/her age)	_____	_____	_____	_____
25. have thorough information about how to care for my child at home.	_____	_____	_____	_____
26. feel that the health care professionals are sincere in caring about my child.	_____	_____	_____	_____
(see next page)				



<u>I NEED TO:</u>	RATINGS FROM			
	<u>1-5</u>	<u>MET</u>	<u>PARTLY MET</u>	<u>UNMET</u>
27. know that health care professionals accept my child even when he/she is angry or upset.	_____	_____	_____	_____
28. know the names of the health care professionals involved in my child's care.	_____	_____	_____	_____
29. know how to contact the health professionals involved in my child's care.	_____	_____	_____	_____
30. know that health care professionals offer me the opportunity to participate equally in my child's care.	_____	_____	_____	_____
31. have a respectful relationship with the health care professionals caring for my child.	_____	_____	_____	_____
32. know to whom to turn if conflict situations arise.	_____	_____	_____	_____
33. have my child feel trust in the health care professionals caring for him/her.	_____	_____	_____	_____
34. have my child participate in decisions about his/her care. (appropriate to his/her age)	_____	_____	_____	_____
35. know that where appropriate health care professionals will ask my child's permission to do things to my child.	_____	_____	_____	_____
36. have health care professionals guide me in setting limits for my child's behaviour.	_____	_____	_____	_____
37. know health care professionals will respect my family values regarding my child's behaviour.	_____	_____	_____	_____
38. feel that health care professionals accept me even if I am angry or upset.	_____	_____	_____	_____

(see next page)

## Care Needs of Mothers

133

<u>I NEED TO:</u>	RATINGS FROM <u>1-5</u>	<u>MET</u>	<u>PARTLY MET</u>	<u>UNMET</u>
39. feel encouraged by health care professionals to maintain a normal lifestyle.	_____	_____	_____	_____
40. have trust in the health care system.	_____	_____	_____	_____
41. meet with other mothers/parents dealing with similar issues.	_____	_____	_____	_____
42. be involved with a support group.	_____	_____	_____	_____
43. have someone be concerned with my health.	_____	_____	_____	_____
44. be told about people who could help with my concerns.	_____	_____	_____	_____
45. know where to park when at the hospital/clinic.	_____	_____	_____	_____
46. know where things are in the hospital.	_____	_____	_____	_____
47. know where things are in the city.	_____	_____	_____	_____
48. have financial assistance to help cope with the costs of my child's illness (e.g. parking, food, transportation, medicine).	_____	_____	_____	_____

The following question is sensitive in nature, but your response would be helpful to us

I NEED TO:

49. be allowed to discuss the terminal stage of my child's illness, if necessary.	_____	_____	_____	_____
---	-------	-------	-------	-------

(see next page)

If you have children in addition to your child with cancer please answer the following three questions (#50, 51 and 52). If you do not have other children please put an X in this space \_\_\_\_\_

	RATINGS FROM 1-5	<u>MET</u>	<u>PARTLY MET</u>	<u>UNMET</u>
50. know <u>what</u> information to give to my other children (appropriate to his/her age).	_____	_____	_____	_____
51. know <u>how</u> to give information to my other children (appropriate to his/her age).	_____	_____	_____	_____
52. how to handle the feelings of my other children.	_____	_____	_____	_____

Please tell me anything else health care providers could do to improve the care for you and your child:

Please tell me anything you would like to about the questions I have asked you. If you need more pages for your responses, please feel free to add them.

THANK YOU FOR YOUR PARTICIPATION.

c Whiteley/Kristjanson. 1995

**APPENDIX K****Followup Letter to Mothers**

Dear Mother,

One week ago you received a questionnaire from me looking at "the needs of mother's of children with cancer". This second questionnaire is meant to test the reliability of the questionnaire over time. If you have returned your first questionnaire I thank you for your participation. I would appreciate very much if you could complete this second questionnaire and return it as you did the first questionnaire.

If you have not returned your first questionnaire but could do so now I would appreciate it very much. You could then if you are able complete this second questionnaire and return it to me also within a week.

As stated in the first letter your responses are confidential because your name will not be associated with the information you provide. Any information provided by you is for this research study only. You could experience an emotional response to some of the questions. If concerns do arise during the completion of the questionnaire you could explored them with your child's physician or a nurse clinician.

This study has received the approval of the paediatric oncology team at the Manitoba Cancer Treatment and Research Foundation and the Ethical Review Committee of the Faculty of Nursing, University of Manitoba. If you have any questions about the study you can reach me at 489-9437 or my research advisor Dr. Linda Kristjanson, Faculty of Nursing at 235-3481 or 474-8937. I look forward to receiving your responses.

Yours Sincerely,