# INFORMATION RETRIEVAL OF SELF-CARE AND DEPENDENT-CARE AGENTS USING NETWELLNESS®, A CONSUMER HEALTH INFORMATION NETWORK

A Dissertation submitted to the

Division of Research and Advanced Studies of the University of Cincinnati

in partial fulfillment of the requirements for the degree of

DOCTORATE OF PHILOSOPHY (Ph.D.)

of the College of Nursing

2000

by

Linda Coyle Rieg

R.N., Diploma Burge Hospital School of Nursing, 1965

B.S.N., Edgecliff College, 1980

M.B.A., Xavier University, 1982

M.S.N., University of Cincinnati, 1985

Committee Chair: Elizabeth Weiner Ph.D., R.N., FAAN

# UNIVERSITY OF CINCINNATI

# July 14,2000

I, Lin	da Coyle Rieg ,
herel	by submit this as part of the
requi	irements for the degree of:
	Doctorate of Philosophy (Ph.D.)
in_1	Nursing
It is	entitled_ Information Retrieval of Self-Care And
De	pendent Care Agents Using NetWellness®, A Consumer Health
Inf	ormation Network

	Appro	ved by:	
20-22			

#### Abstract

Since the earliest times a major focus of nursing has been to provide health care information to those in their care. The purpose of this exploratory study was to investigate information retrieval of consumers using NetWellness<sup>®</sup>, a community health information network. Using Orem's Self-Care Deficit Nursing Theory, six research questions were developed. These questions were designed to determine if there were any differences in information retrieval based on whether the participants were self-care agents or dependent-care agents, or whether differences were based on basic conditioning factors identified as age, gender, race, household income and educational levels. In addition questions were included to determine the consumers' satisfaction with NetWellness<sup>®</sup> and to identify specific topics directed to experts. A convenience sample of 307 participants completed the on-line questionnaire; of these participants 215 were identified as either self-care or dependent care agents.

There was a statistically significant finding at the .05 level ( $\chi^2$  =8.708; p=.033) for Ask an Expert as the first selected category by basic conditioning factor: age. A significant difference at the .05 level was also calculated using a Chi-Square analysis for Condition Specific as the first selected category by race ( $\chi^2$ =3.857; p=.05). Although not statistically significant there were additional findings of importance to note from this study. The purpose for obtaining information tended to identify the type of information obtained by the participants. In addition questions directed to Ask an Expert demonstrated that specific information was sought related to self-care or dependent care needs. A major finding related to this study was that regardless of

any of the variables such as care agents or basic conditioning factors the mean number of categories participants accessed to obtain information ranged from 3.2 – 4.9 with the average being 3.7. Within Orem's supportive-educative nursing system, consumers indicated satisfaction with NetWellness® as a method of obtaining health care information. Recommendations were made for nurses to conduct further studies within Orem's supportive-educative nursing system utilizing the Internet for providing health care information to consumers. Additional recommendations were made for developing standards for rigor when conducting on-line surveys.

Copyright 2000

by Linda Coyle Rieg

All rights reserved

#### **Dedication and Acknowledgments**

Dedicated to Helen Virginia Coyle December 10, 1921 – July 20, 2000

This special dedication is in honor of my late mother, Helen Coyle. Although my mother was never able to attend college she was the most informed and wisest woman I ever knew. She always kept her priorities in the proper perspective and there was never any doubt of her absolute love for God, her husband, and family. In addition to her family, her life touched countless others as she served God through the many years as "Pastor Coyle's wife". She was truly a virtuous woman.

"Her children rise up and call her blessed; Her husband also and he praises her" Proverbs 31:28

I also want to express my love and appreciation to my wonderful family – they make everything worthwhile:

To my husband, Dan, his ever-present support, encouragement, and love made this accomplishment possible.

To my children – Jennifer, Julie, Jodi, Dan and step-daughter Karen – they have each been very special to me and have been understanding beyond measure of the time I have had to steal from them to complete this project.

To my grandchildren, Nicholas, Megan, Lauren, and Kierstin who I'm sure have no idea why "Granny Lin" is still going to school.

To my wonderful father – whose values, love and support I could always count on and my sisters Rebecca and Betty for their humor, encouragement, and love.

I would like to acknowledge the members of my dissertation committee for their support and encouragement. Each member contributed to this study in her own unique way. More specifically I would like to acknowledge:

Dr. Elizabeth Weiner, Chairperson, whose leadership in the field of nursing informatics stirred my initial interests. Her enthusiasm and guidance through my doctoral program will always be remembered.

Dr. Patricia Trangenstein contributed her extensive theoretical knowledge. The challenges she presented helped to shape and improve the study.

Dr. Kimberly Downing contributed her expertise in survey research, provided rapid responses to every e-mail and continuous words of encouragement. These contributions made the journey a little easier.

I would like to express a special note of appreciation to Dr. Jeanette Spero. Prior to her illness and eventual death she gave many hours to me for just talking. Many of these conversations were related to the study, however other times she provided fun, humor, and a challenge to keep things in balance.

I would also like to express thanks to some special people that assisted me throughout the study: Stephanie Amlung, for her friendship and statistical assistance; Ted Morris, for his rapid responses and assistance throughout the years; and Carole Kenner who provided editorial assistance.

In a project such as NetWellness® there are many people responsible for the initial ideas and on-going development. I would like to acknowledge some specific groups that contributed to the project and this study. Specifically these are:

The team that developed the Demonstration Grant Proposal and received the NTIA/TIIAP Award No. 39-40-94081

Principal Investigator: J. Roger Guard, M.L.S., Director, Medical Center Libraries, University of Cincinnati

Co-Principal Investigators: Anne S. Goss, M.L.S, Assistant Dean of Libraries and Director, Health Sciences Library, Ohio University; Richard C. Howe, PhD., Associate Senior Vice President and Associate Director, University Hospital Computing Services, University of Cincinnati; John R. Kues, Ph.D., Assistant Dean for Continuing Medical Education, College of Medicine, University of Cincinnati; Stephen A. Marine, M.L.S., Associate Director, Medical Center Libraries, University of Cincinnati; Leslie C. Schick, M.S.L.S., Associate Director, Medical Center Libraries, University of Cincinnati; Gaylene Tsipsis, M.S., RPh, Associate Director, Drug and Poison Information Center, University of Cincinnati

Collaborators: Jack M. Cook, CEO, University Hospital, University of Cincinnati; Donald C. Harrison, M.D., Senior Vice President and Provost for Health Education, University of Cincinnati; John Hutton, M.D., Dean, College of Medicine, University of Cincinnati; Andrea Lindell, D.N.Sc., Dean, College of Nursing and Health, University of Cincinnati; Nancy M. Lorenzi, Ph.D., Associate Senior Vice President, University of Cincinnati; Steve Shoemaker, TriState Online; Leonard T. Sigell, Ph.D., Director Drug and Poison Information Center, University of Cincinnati; Victor D. Warner, PhD., College of Pharmacy, University of Cincinnati; David G. Whitten, M.B.A., President, University of Cincinnati Medical Associates

NetWellness<sup>®</sup> Project Evaluation Committee: Chris Auffrey, PhD, Carol Deets, EdD, RN; Kim Downing, PhD; J. Roger Guard, MLS; Doris Haag, MSLS; Stephen Marine, MLS; Theodore A. Morris, MLS; Josette Riep; Leslie Schick, MSLS; Steve Shoemaker; Gaylene Tsipis, MS, RPh; Elizabeth Weiner, PhD, RN, FAAN

Ask an Expert Consultants: Thomas deHoop, MD; Marcia Hern, EdD, RN; Jennie McCowan, R.PH; Janet Trigg, EdD, RN; Gaylene Tsipis, MS, RPh; Tina Weitkamp, MSN, RN

Sigma Theta Tau -Beta Iota Chapter for the research award that partially funded this study

# Table of Contents

Abstract	ii.
Acknowledgments	v.
Table Of Contents	1.
List Of Tables	4.
Chapter One	
Overview	6.
Statement of the Problem	7.
Purpose	8.
Theoretical Framework: Orem Self-Care Nursing Theory	9.
Research Questions	15.
Conceptual and Operational Definitions	16.
Assumptions	18.
Limitations of the Study	19.
Significance for Nursing	20.
Chapter Two Review Of The Literature	22.
Orem's Self-Care Nursing Theory	22.
Orem's Theory: An Accepted Model In Nursing	24.
Research on Self-Care	26.
Research on Self-Care Actions	30.
Assessment of Self-Care Ability	33.
Research on Dependent Care and Dependent Care Agency	36.
Basic Conditioning Factors and Their Relationships to Self-Care, Self-Care Agency, Dependent-Care and Dependent-Care	41.
Agency	41.
Age	44.
Gender	45.
Race	46.
Education	47.
Household Income	- / •
Research on the Supportive Educative Nursing System	49.

Information Technology: Self-Care	53.
Information Technology and Self-Care	55.
Orem's Theory: Information Technology	61.
Cyber-Research Issues	63.
Synthesis	66.
Chapter Three Methodology	68.
Research Design	68.
Sample	68.
Methods of Measurement	69.
Human Subjects	70.
Data Collection.	70.
Methods for Analysis	71.
Limitations of Design	75.
Chapter Four Findings And Discussion	76.
Sample	76.
Findings:	
Research Question 1	80.
Research Question 2	84.
Research Question 3	101.
Research Question 4	105.
Research Question 5	106.
Research Question 6.	108.
Discussion	
Results Related to Theoretical Relationships	110.
Propositions from the Self-care, Self-care Deficit,	
and Nursing System Theories	111.
Self-care and Dependent-care Information Retrieval	112.
Information Retrieval and Basic Conditioning Factors	
Age	114.
Gender	116.
Race	117.
Household Income	118.
Educational Level	118.
Information Retrieval and Purpose	122.
Individual Variables of Consumers Who Took Action	124.
Type of Care Agent and Level of Satisfaction	127.
Ask an Expert Categories	131.
Summary	132.

Chapter Five Summary, Recommendations Conclusions		136.
Summary		136.
Theor	etical Framework	136.
Overv	riew of Study	138.
	eations for Nursing	148.
-	Theory	148.
	Practice	151.
Recommenda	tions for Further Study	152.
		154.
References		157.
Appendices		189.
Appendix A:	NetWellness® Questionnaire	190.
Appendix B:	Summary of Participants Who Took Action After	
	Retrieving Information on NetWellness <sup>®</sup>	195.
Appendix C:	Categories of Questions Directed to Experts;	
11	Pharmacy and Medications	196.
Appendix D:	Categories of Questions Directed to Experts;	
11	Children's Development and Health	197.
Appendix E:	Categories of Questions Directed to Experts;	
11	Breastfeeding and Newborn Care	198.
Appendix F:	Categories of Questions Directed to Experts;	
11	Gynecology	199.
Appendix G:	Categories of Questions Directed to Experts;	
rr	Pregnancy	200.
Appendix H:	Categories of Questions Directed to Experts;	
11	Infertility	201.
	J	

# List Of Tables

Table		Page
1	Summary of Care Agents by Basic Conditioning Factor	78.
2	Ranking for First Selected Category and Percentages By Care Agents	81.
3	Percentage of Self-care Agents and Dependent-care Agents by First Selected NetWellness Categories ®	83.
4	Ranking for Most Frequently Selected Categories By Care Agents	83.
5	Ranking for First Selected Category and Percentages By Age Groups	85.
6	Percentage of Participants that Selected Various NetWellness® Categories First by Basic Conditioning Factor – Age	87.
7	Ranking for Most Frequently Selected Categories by Basic Conditioning Factor – Age	88.
8	Ranking for First Selected Category By Gender Groups	89.
9	Percentage of Participants that Selected Various NetWellness® Categories First by Basic Conditioning Factor – Gender	89.
10	Ranking for Most Frequently Selected Categories by Basic Conditioning Factor – Gender	90.
11	Ranking for First Selected Category and Percentages By Basic Conditioning Factor - Race	91.
12	Percentage of Participants That Selected Various NetWellness® Categories First by Basic Conditioning Factor – Race	92.
13	Ranking for Most Frequently Selected Categories by Basic Conditioning Factor – Race	93.
14	Ranking for First Selected Category and Percentages By Basic Conditioning Factor – Household Income	95.
15	Percentage of Participants That Selected Various NetWellness® Categories First by Basic Conditioning Factor – Household Income	96.

16	Ranking for Most Frequently Selected Categories by Basic Conditioning Factor – Household Income	97.
17	Ranking for First Selected Category and Percentages Within Level of Education Groups	99.
18	Percentage of Participants That Selected Various NetWellness® Categories First by Basic Conditioning Factor – Educational Level	99.
19	Ranking for Most Frequently Selected Categories by Basic Conditioning Factor – Educational Level	100.
20	Ranking for First Selected Category by Purpose of Information Retrieval from NetWellness®	102.
21	Ranking for Most Frequently Selected Categories by Purpose of Information Retrieval from NetWellness®	104.
22	Ranking of Behavioral Actions Taken by Participants After Obtaining Information on NetWellness® Use	106.
23	Satisfaction With NetWellness® by Self-care Agents and Dependent care Agents	107.
24	Differences in Level of Satisfaction with NetWellness® by Self-care Agents and Dependent-care Agents	107.
25	Summary of Ouestions Directed to Experts on NetWellness®	109.

#### Chapter I

#### Overview

Nursing has long been a proponent of providing preventative and health promotion information for the client to make better self-care decisions. Over the last few years, however, there has been a growing public interest in health and wellness information as well as more emphasis on self-care and self-responsibility. These changes were the result of many different factors, including consumers' rights and economic changes brought about by the managed health care revolution. In the 1990s, legislators demanded more self-care responsibility as evidenced by the inclusion of self-care in most of the health care reform proposals. At the same time, consumers became more interested in exercising their right to participate in their health care decisions. Recently consumers sought easily accessed healthcare information to make better health care choices.

During this same period information technology was evolving and the World Wide Web (WWW) was becoming a consumers' resource in a wide variety of areas. The information "superhighway" was proposed as a means for consumers to obtain information about their own health care conditions, empowering them to take better care of themselves (Amtmann & Johnson, 1998; Brennan, 1996; Brennan & Strombom, 1998; Ehrenberger & Brennan, 1998). NetWellness®, an electronic consumer health information network, was initially designed to provide consumer health information to socioeconomically and geographically diverse populations in southern Ohio, northern Kentucky, and southeastern Indiana. In June of 1995 this tri-state region became a virtual community with placement of NetWellness® on the WWW. To provide information that consumers identified as necessary

for meeting their self-care needs, it was important to understand the characteristics of the participants within this virtual community. One way to find out about the nature of this community was to collect data that would identify characteristics about the people using NetWellness<sup>®</sup>, the patterns of information they selected, and the reasons they were searching for health care information.

Since the meaning of data is dependent on the theoretical model used to frame data gathering and analysis, Orem's Self-Care Nursing Theory, was used for this exploratory study. To provide easily accessible and meaningful information, the consumer was included as a major participant for using and continuously improving NetWellness<sup>®</sup>. An on-line questionnaire was used to obtain self-reported data to describe the users (see Appendix A). In addition, a software product (Interse Market Focus<sup>®</sup>) was used to interpret the information retrieval patterns of each subject. Using data from both of these sources, this study was designed to evaluate patterns of information retrieval of consumers using NetWellness<sup>®</sup>. Evaluation of specific variables and groups of variables was done to determine if there were differences in the pattern of information retrieval. In addition, satisfaction with NetWellness<sup>®</sup> as a means for obtaining health related information, and the use of information previously obtained from NetWellness<sup>®</sup> was evaluated.

#### Statement of the Problem

In the past, people reported they accessed consumer health information networks for a variety of reasons. The desire to provide better self-care or dependent care to persons such as family or friends was one reason to use this resource. However, several factors impacted the

usage and effectiveness of on-line health care information. Ease of use and obtaining information that was perceived as beneficial were two of these factors.

Although many studies have been conducted related to computer technology and its use in health care (Brennan, Moore, & Smyth, 1991, 1992, 1995; Brennan, Ripich, & Moore, 1991; Cohen, 1981; Kruckenber-Schofer & Ward, 1990; Ripich, Moore, & Brennan, 1992; Smyth & Harris, 1993;), these studies were directed toward a pre-selected category of clients or were designed to only evaluate a specific aspect of the information system. In addition, many systems have been designed to only collect or transfer data without use of a theoretical framework to guide the development or utilization of the system (Bliss-Holtz, Taylor, McLaughlin, Sayer, & Nickle, 1992; Ozbolt & Graves, 1993).

Orem's Self-Care Theory was used by an author group to develop one nursing information system (Bliss-Holtz, McLaughlin, & Taylor, 1990; Bliss-Holtz, Taylor, & McLaughlin, 1990; Bliss-Holtz, et al., 1992). However, very little was found in the literature that included the consumers in the community as partners in identifying what information was needed for their self-care. No reports were found that specifically evaluated a community health information network using Orem's Self-Care Nursing Theory. This study addressed this lack of knowledge.

#### Purpose

The purpose of this descriptive study was to identify, through an on line questionnaire, who and why individuals were seeking health care information from NetWellness<sup>®</sup>. The objectives of the study were to determine what variables impacted the information sought and the pattern in which the information was retrieved, satisfaction with NetWellness<sup>®</sup>, on-line

information sought from experts on NetWellness<sup>®</sup>, and if a differentiation could be made between information seeking patterns of self-care and dependent care agents. The essence of this exploratory study was to differentiate the information seeking patterns of self-care and dependent care agents, as identified by Orem (1995).

## Theoretical Framework: Orem's Self-Care Deficit Nursing Theory

The theoretical framework for this study was Orem's Self-Care Deficit Nursing
Theory. One of the most well developed concepts in nursing theory has been self-care.

Virginia Henderson first formally, though not directly, introduced the idea of self-care in
nursing in 1955. Henderson stated that "nursing is primarily assisting the individual (sick or
well) in the performance of those activities contributing to health, or its recovery (or a
peaceful death) that he would perform unaided if he had the necessary strength, will or
knowledge" (Henderson, 1966, p. 15). In the late 1950s and early 1960s Lydia Hall (1963)
developed and implemented a concept of nursing based on needs and interpersonal relations at
the Loeb Center for Nursing and Rehabilitation.

Orem began developing her theory in 1958 and it was first published in 1959. The theory was based around her core philosophy that man has an innate ability to care for himself. Orem's general theory of nursing was developed with three sub-theories: (a) self-care, (b) self-care deficit – or the inability to provide adequate self-care, and (c) nursing systems – the activities used by nurses to assist someone in meeting their self care needs. Orem defined self-care as the production of actions directed to self or to the environment in order to regulate one's functioning in the interests of one's life, integrated functioning, and well being. The provider of self-care was identified as the self-care agent. If the individual

was a child or a dependent adult, the provider of care was called the dependent-care agent. (Orem, 1991, 1995).

Orem's Theory of Self-Care included three constructs that were key to the present study: self-care, therapeutic self-care demand, and self-care agency. "Self-care is the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" Self-care is initiated to meet self-care requisites of a universal, developmental, and health-deviation nature. (Orem, 1991, p. 117). Orem defined therapeutic self-care demand as "a time-specific calculation of the sets of actions judged to have validity and reliability in controlling factors that affect human functioning" (p. 135).

Orem (1991) referred to self-care agency as the human capability to perform self-care for one's self. She defined self-care agency as "the complex acquired ability to meet one's continuing requirements for care" (p. 145). Furthermore, she proposed that self-care agency varied with the individual's age, health state, ability to learn and resources. According to Orem (1991, 1995) self-care agency regulates life processes and promotes integrity of one's structure, functioning, development, and well being. Becoming knowledgeable about self-care requisites was considered an important part of maintaining the adequacy of the individual's self-care agency. She stated that new self-care requisites necessitated additional knowledge, adjustments in some skills, and willingness to perform these new requisites (Orem, 1991, 1995).

Orem considered self-care a learned behavior (Orem, 1995). In addition, she stated that self-care was a deliberate action. This behavior included a self-initiated, self-directed,

purposeful, results producing activity. Experience, intellectual curiosity, and instruction and supervision from others were considered aids for the development of self-care agency.

The Self-Care Deficit Theory referred to the relationship between the self-care agency and the therapeutic self-care demand in which the self-care agency was not adequate to meet the known therapeutic self-care demand (Orem, 1991, 1995). The therapeutic self-care demand included all actions required to maintain life and promote health, development, and well being. Thus, a self-care deficit existed when the therapeutic self-care demand was greater than the self-care agency. When therapeutic self-care demand exceeded the individuals' self-care capabilities (self-care agency) deficits occurred and nursing intervention was legitimized.

The delivery of nursing care was guided by use of one or more of Orem's three types of nursing systems. The nursing systems identified were the wholly compensatory, partially compensatory, or supportive-educative. Within the wholly compensatory system, the client's ability to provide self-care is considered nonexistent or limited and the nurse is the major provider of self-care for the client. The client must be cared for and protected by the nurse. Both the client and the nurse perform patient self-care actions in the partially compensatory system. The responsibility for performing self-care actions varies according to the client's limitations, the knowledge and skills required to perform the self-care actions, and the client's ability to perform or readiness to learn to perform the specific self-care activities. The client requiring the supportive-educative nursing system is one who is able to perform self-care or is able to learn and does learn to perform the needed self-care actions from the nurse (Orem, 1995).

A number of factors, called basic conditioning factors (BCFs), were identified by Orem (1995) as those that influenced or modified self-care agency, therapeutic self-care requisites, and self-care. These factors included age, gender, years of education, health state, sociocultural orientation, healthcare system factors (e.g., treatment modalities), health state, family system factors, pattern of living (including activities regularly performed), environmental factors, health care system factors, and resource availability and adequacy. Orem submitted that BCFs collectively influenced the person's therapeutic self-care demand or particularized requirement for specific self-care action.

Orem proposed that changes in basic conditioning factors occur as various transitions happen in one's life. These changes in basic conditioning factors may impact one's self-care requisites and self-care agency. When this occurs actual or anticipated self-care deficits can result. When actual or anticipated self-care deficits occur there is an increased need to access health related information, in order to maintain one's self-care agency.

Information about relationships among health, self-care agency, self-care, and basic conditioning factors provided direction for using Orem's model for health promotion.

Propositions in Orem's theories of self-care deficit and self-care, state that basic conditioning factors, such as age, gender, educational level and available resources, and health state, can influence self-care agency which is necessary for self-care. Self-care agency of individuals varies over a range with respect to development from childhood through old age. It also varies with health state; with factors that influence educability, and with life experiences as they are enabling for learning, exposure to cultural influences, and for use of resources in daily living. The description of self-care, as the actions that persons perform in the interest of

maintaining life, health, and well being, suggests that health is a process as well as an outcome of self-care.

As actual or anticipated self-care deficits occur, knowledge is required in order to maintain self-care. Estimative operations is the time of obtaining knowledge and reflecting before making decisions (transitional operations) and making behavioral changes (productive operations). An increase in information during the estimative phase is required and impacts decision making during the transitional operations. (Orem, 1995).

The supportive educative system is the nursing system accessed for information seeking and guidance to better provide for self-care/dependent-care for preventative health and health promotion (Orem, 1995). There are various means within the supportive educative system available for obtaining information necessary to provide for self-care/dependent care. Information technology is one method that has been successfully used within the supportive educative system for providing information to individuals in order to support self-care and dependent care abilities (Brennan, Moore, et al., 1991, 1992, 1995; Brennan, Ripich, et al., 1991).

Health care information may be obtained from a variety of sources. However some researchers have argued that supportive-educative nursing systems must be developed from a theoretical perspective if they are to be useful for nursing practice and the discipline.

McLaughlin, Taylor, Bliss-Holtz, Sayers, and Nickle (1990) used Orem's Self-Care Deficit Nursing Theory in the development of an information processing model for use in a computerized nursing information system. The theoretical underpinnings of self-care provided the direction for data collection and data relationships that provided meaning for

nurses. This study used Orem's Self-care Deficit Nursing Theory for developing questions for the on-line survey.

Although Orem's theory had as its objective focus the self-care needs and abilities of individuals, these individuals were recipients of nursing care as members of various units of care. Orem stated that persons are served as individuals, in dependent-care units, as families, as households, as small groups, and as large groups such as communities (Orem, 1995). The consumers in this study were considered members in a virtual community.

Using Orem's theory data, collected through the NetWellness® on-line questionnaire, were examined to determine the relationships among various basic conditioning factors of care agents and patterns of information retrieval. This study of a virtual community, as a unit of service, was of value to nursing as an essential step for using and developing supportive-educative health information systems to meet self-care or dependent-care needs.

## **Research Questions:**

- 1. What was the difference between the pattern of information retrieval on NetWellness® and the type of care agents, identified as: self-care agent and dependent care agents?
- 2. What was the difference between the pattern of information retrieval on NetWellness® and basic conditioning factors, identified as: age, gender, race, household income, and educational level?
- 3. What was the difference between the pattern of information retrieval and the purpose identified by the care agent for accessing NetWellness®, identified as curiosity/browsing, chronic health problem, recent illness/injury, medications, healthy lifestyle, Ask an Expert, or a student's educational assignment?
- 4. What variables/groups of variables best described those individuals who took action as a result of information obtained on NetWellness®?
- 5. What was the difference between self-care agents' and dependent-care agents' level of satisfaction with information retrieval on NetWellness®?
  - 6. What were the categories of questions directed to the experts on NetWellness®?

## Conceptual and Operational Definitions

<u>Basic conditioning factors</u> were internal and external factors that affected the individual's ability to engage in self-care or dependent care as determined by the on-line survey of NetWellness<sup>®</sup>. These factors included age, gender, race, household income, and educational level.

<u>Deliberate action</u> was self-initiated, self-directed, purposeful, result seeking activity as identified by utilizing NetWellness<sup>®</sup> and indicated by the on-line survey whether this action was self-initiated or initiated by another (e.g. an educational assignment).

Estimative operations was the act of accessing and utilizing NetWellness® as a means for obtaining health information; utilization of system, satisfaction with information located, and information needed but not located to be retrieved through online questionnaire and system software.

Pattern of information retrieval was the health information-seeking behavior as identified through the analyses of the usage of individuals that sought information on NetWellness®. Specific information retrieval patterns were determined for self-care versus dependent-care agents, the purpose of information retrieval (curiosity/browsing, chronic health problem, recent illness/injury, medications, healthy lifestyle, Ask an Expert, educational assignment), basic conditioning factors (age, gender, race, household income, and educational level), and actions taken.

Self-care was the practice of one activity- health information seeking through the use of NetWellness® for the purpose of accomplishing self-care or dependent care or regulating the exercise and development of self-care or dependent care agency. Self-initiated, self-directed, purposeful, result seeking activity initiated by those individuals that have utilized NetWellness® once, or more than once was indicated by the self-reported on-line survey.

<u>Dependent-care</u> was the action of health information seeking by individuals to contribute to the health and well being of other persons. These individuals were identified as family member - child or family member - adult by the NetWellness<sup>®</sup> on-line survey.

<u>Care agents</u> were the group of individuals who provide health-related care to themselves or others. Self-care agents were identified as obtaining information for themselves through the on-line survey of NetWellness<sup>®</sup>. Dependent-care agents were identified as obtaining information for others, specifically family member-child and family member-adult.

<u>Supportive-educative health information system</u> was the health care system in which the self-care agent or dependent-care agent acquired knowledge in order to enhance their decision-making ability related to self-care and dependent care.

NetWellness<sup>®</sup> was the community-based, publicly and privately funded demonstration project developed to deliver health information through the WWW. This computerized health information resource was a tool within the supportive-educative health information system for obtaining health information by consumers.

#### <u>Assumptions</u>

- The following were the assumptions of this study:
- (1) Individuals initiate and perform self-care activities to maintain life, health, and well being.
- (2) Individuals perform dependent care activities on behalf of persons they consider socially dependent on them to maintain life, health and well being.
- (3) Self-care/dependent care is initiated to meet universal, developmental, or health-deviation requisites.
- (4) Becoming knowledgeable about self-care/dependent care requisites is an important part of maintaining the adequacy of the individual's self-care/dependent care agency.
- (5) New self-care/dependent care requisites necessitate additional knowledge, adjustments in skills, and willingness to perform these new requisites.
- (6) As actual or anticipated self-care/dependent care deficits occur, knowledge is required to maintain self-care/dependent care.
- (7) The supportive educative system is the nursing system accessed by consumers for information seeking and guidance in order to better provide for self-care/dependent-care and preventative health and health promotion.
- (8) Increased access to health care information is valued by consumers and society for more informed decisions about self-care/dependent care.
- (9) Computer technology is an important means of delivering current healthcare information.

(10) Nurses are essential partners in developing community health information for consumers.

# <u>Limitations of the Study</u>

Several design issues, common to survey research, were also limitations of this study. All individuals that utilized NetWellness® during this period and elected to participate in the on-line questionnaire were included. Although directions were provided to only participate one time in the survey, there was no way to control if someone participated once or several times. In addition, reasonable methods were not available to determine how many individuals used NetWellness® but chose not to participate in the survey.

As with all questionnaires, this study was dependent upon self-reporting. This particular questionnaire was developed specifically for this project and was not previously used or tested for validity and reliability in other populations. Relationships that were seen can only be applied to the people using NetWellness® during the data collection period who chose to complete the on-line survey.

Although no major technical difficulties were known to have occurred one limitation may be technical difficulties such as periods of down time, difficulties linking from one question to the next, or slow response times that could have been experienced by the user.

This situation may have impacted the ability of some participants to use NetWellness® and/or complete the questionnaire.

Another limitation to consider was the dynamic aspect of the system. A commitment was made to use a continuous quality improvement approach to NetWellness<sup>®</sup>. As feedback was received from consumers or other users, modifications were made to improve

NetWellness<sup>®</sup>. The potential for differences related to the subjects' satisfaction and their ability to find information may have changed from the earliest person to complete the questionnaire to the final subject.

A final consideration regarding limitations had to do with the rapidly changing environment of the World Wide Web. Although the latest technological capabilities were used at the time of this study, this was limited to linking the on-line survey with the pattern of information through the use of time stamps and IP numbers. The current capabilities on the WWW such as the use of cookies that can recall sites visited, or the Pentium III serial code ID chip were not available at the time of this study. However, due to the NetWellness® project coordinators' commitment to consumer privacy these tracking methods would not have been permitted - even if technologically possible.

## Significance for Nursing

The results of this study elucidated the supportive-educative nursing system for health information, the utilization patterns of such systems, and specific self-care informational needs for specific subgroups, as identified through basic conditioning factors. In addition, information regarding knowledge needs and how individuals utilized information to provide self-care was identified.

A contribution to the science of nursing was realized by these findings. It expanded the supportive-educative nursing system of Orem's theory from a nursing system that generally has dealt with individual client or small group of clients, to a nursing system that included local, national, and international communities. In addition, a better understanding of information needs identified by self-care and dependent care agents was obtained.

Historically, nurses have been associated with efforts that emphasize health promotion and prevention. With scarce health care dollars, efforts toward increasing consumer awareness of health care needs along with including them as partners in identifying what their informational needs are, was significant in supporting their self-care needs. The NetWellness® project intended to have the consumer involved in identifying their needs, as well as providing information needed for modifying the system to increase its effectiveness. Nurses were the predominant contributors for "Ask an Expert" during this study and they proved to be excellent sources of expert information. However, during this study they did not indicate that any theoretical framework was used for providing educative care to consumers. This study demonstrated the value of providing on-line supportive-educative care using Orem's Self-Care Theory as a theoretical framework. The need for nurses to become more involved as essential partners in developing and maintaining theoretically based electronic health care information resources for consumers was identified.

The NetWellness® project has evolved since this initial study to include multi-site partnerships and specific information projects, such as smoking cessation, minority, and adolescent health. The development of these projects and expansion of topics in Ask an Expert have potential for influencing health care policies and initiating changes in the health care delivery system in Ohio, as well as impacting the health of people in this new virtual community (Marine, et al., (1998).

#### Chapter II

#### Review of the Literature

The purpose of this chapter is to review the current level of knowledge about the access of electronic information by consumers in order to meet their self-care and dependent care needs. Empirical research is presented related to Orem's Self-Care Deficit Nursing Theory and information technology as a means for consumers to obtain health care information. The review is divided into three major sections. The first section focuses on Orem's Self-Care Deficit Nursing Theory; it provides an overview of the extensive literature and applications of Orem in research, education, and practice. This section includes research on self-care, self-care actions, and self-care ability followed by literature related to dependent care and dependent care agency. Research on the relationship of the basic conditioning factors of age, gender, race, socioeconomic status, and education to self-care, self-care agency, dependent care and dependent care agency is presented next. Studies that focus on the supportive-educative nursing system complete the first section. The second section provides an overview of the current literature related to information technology and self-care. The final section addresses cyber-research issues.

#### Orem's Self-Care Nursing Theory

Self-care is not a new concept in health care. In fact ancient literature validated that health care provided by self or the family was the norm. Self-care has continued to be the most consistent form of health care in existence today. The literature indicated that in the United States as well as the rest of the world individuals relied on self-care and care given by family members (dependent care) as their primary source of health care. In Healthy People

2000 (Department of Health and Human Services [DHHS], 2000a) and Healthy People 2010 (DHHS, 2000b) self-care was reported to account for 85% of all health care in the world. There was also evidence that self-care was valued by individuals, families, and society. Studies conducted in industrialized nations demonstrated that self-care was used in the majority of health care situations (DeFriese, Sehnert, & Barry, 1982; Levin, 1976). A variety of factors have been identified as important contributors to the rebirth and interest in self-care; these included inadequacies in the health care system, the nature of available health care organizations and medical economics, growing discontent with dehumanism and excessive technology, and mistrust of the medical establishment (Levin, 1978; Levin & Idler, 1983; Padula, 1992; Steiger & Lipson, 1985; Woods, 1989).

The self-care, self-management, self-help movement has become big business with enormous profits being made. Targeted consumers were the lay public, healthy people or those with an illness, and healthcare providers. Not-for-profit organizations have also taken an interest in self-care. Under a Robert Wood Johnson Foundation grant, the Healthwise Communities Project provided education and support to 250,000 residents of four Idaho counties who received the HEALTHWISE Handbook: A Self-Care Manual for You (Dodd, 1997). With self-care so widely used, interest in the outcomes of this type of care increased.

Several patient outcome studies linked a greater ability to provide for self-care to increased health outcomes, such as knowledge, symptom management and activities of daily living, with decreased cost (Dodd, 1997; Hegyvary, 1992; Lang, & Marek, 1992). In addition, several authors suggested that society demanded increased individual responsibility

for self-care and dependent care (DeFriese & Woomert, 1983; Hickey, Dean, & Holstein, 1986; Relman, 1988).

#### Orem's Theory: An Accepted Model In Nursing

Orem's Self-Care Deficit Nursing Theory (1971; 1980; 1985; 1991; 1995) was chosen for this study because it has been one of the most widely used conceptual models across settings, health states, and with individuals and groups. The International Orem Society (<a href="www.muhealth.org/~nursing/scdnt/">www.muhealth.org/~nursing/scdnt/</a>) listed eighty-one schools of nursing that exclusively used Orem as a conceptual framework for the curriculum or to guide clinical practice. In 1999, a literature search with the name Orem resulted in 821 articles. When Orem was combined with research the articles still numbered 321. Meleis (1997) stated that Orem had the widest circle of contagiousness of all theories in practice.

The use of Orem's Self-Care Deficit Theory of Nursing for nursing practice was well documented in the literature. Orem's Self-Care Deficit Theory of Nursing has been used to organize patient care in many inpatient settings. It was used in critical care units (Fawcett, Cariello, Davis, Farley, Zimmaro, & Watts, 1987; Jacobs, 1990; James, 1992; Tolentino, 1990), acute care units (Mullin, 1980; Robichand-Ekstrand, 1990; Weis, 1988), obstetrical units (Fields, 1987; Woolery, 1983), psychiatric units and institutions (Davidhizar & Cosgray, 1990; Duffy, Miller, & Parlocha, 1993; Lacey, 1993; Moscovitz, 1984), rehabilitation settings (Bracher, 1989; Orem, 1985; Smith, 1977), and pediatric units (Titus & Porter, 1989). The theory has also been used in a variety of outpatient settings including Hospices (Murphy, 1981; Walborn, 1980), ambulatory clinics (Allison, 1973; Backscheider, 1974; Vasquez,

1992), emergency departments (Hughes, 1983), a college student health program (Hedahl, 1983), and nursing homes (Anna, Christensen, Hohon, Ord, and Wells, 1978).

The theory served as a framework to provide care for patients with varying health states. Examples of specific diseases or patient conditions have included: diabetes (Allison, 1973; Backscheider, 1974; Fitzgerald, 1980; Frey & Denyes, 1989; Petrlik, 1976; Zach, 1982), cancer (Dodd & Dibble, 1993; Foltz, Gaines, & Gullatte, 1996; Richardson, 1992), adolescents with chronic disease (McCracken, 1985), alcoholics (Williams, 1979), head and neck surgery (Dropkin, 1981), multiple sclerosis (MacLellan, 1989), end-stage renal disease (Perras and Zappacosta, 1982; Turner, 1989), hypertension (Galli, 1984), myocardial infarction (Garrett, 1985) and rheumatoid arthritis (Ailinger & Dear, 1993, 1997; Smith, 1989).

Many nursing educational programs have adopted Orem's Self-Care Theory as foundation for the curriculum. The University of Missouri developed and maintained the International Orem Society's web page (<a href="www.muhealth.org/~nursing/scdnt/">www.muhealth.org/~nursing/scdnt/</a>). Orem's work inspired individuals and groups of faculty to work with her ideas and to encourage masters and doctoral students to develop studies based on the major concepts in the theory. At Wayne State University, there was a post-doctoral program developed for this purpose.

The Self-Care Deficit Theory was used with families (Haas, 1990; Orem 1983a, 1983b, 1983c; Tadych, 1985; Taylor, 1989). It was also expanded for use in communities (Dahlen, 1997; Hanchett, 1988, 1990; Orem 1995; Taylor & McLaughlin, 1991).

Wide use of Orem's Self-care Deficit Theory served as a stimulus for research. The large number of studies and articles that have used Orem as a theoretical foundation

contributed to the extensive use of the theory in practice and educational settings. For this study research on self-care, self-care actions, self-care abilities and the relationship of basic conditioning factors to self-care agents and dependent care agents were addressed.

In summary, Orem's theory has had extensive use in a variety of settings. As an accepted model within nursing a large circle of educational programs' curricula have been based on the theory and research programs devoted to theory testing and testing of specific concepts within the theory. A theory with such broad acceptance within nursing was necessary for this web-based study since the study's consumers came from local as well as international locations.

#### Research on Self-Care

Of more specific concern to this study was Orem's concept of self-care agency. Orem (1991) described self-care agency as being comprised of three substantive components: (1) capabilities to perform self-care operations; (2) enabling capabilities or power components; and (3) foundational capabilities and dispositions as they articulate with the more specific capabilities. This particular concept was the focus of several instrument developers.

The first instrument found in the literature to measure self-care agency was the Exercise of Self-Care Agency Instrument (ESCAI) by Kearney and Fleischer (1979). Based on Orem's conceptualization of self-care, the scale was designed to measure an individual's perception of his or her self-care actions. An expert panel and the application of two parallel tests established content and construct validity. McBride (1987) examined the reliability and construct validity of Kearney and Fleischer's (1979) ESCAI. The Self-Directed Learning Readiness Scale (SDLRS) (Guglielmino, 1977) was used to test construct validity between

two groups (basic nursing students and adult diabetic patients). The results showed significant correlations between the scales for both groups.

The Denyes Self-care Agency Instrument (DSCAI) was developed to measure self-care agency in adolescents. In the initial instrument, evidence of internal consistency, test-retest, and alternate forms of reliability were demonstrated (Denyes, 1980; 1982; 1988).

Construct validity was established initially by the positive relationship between self-care performance and health-state. Gast, Denyes, Campbell, Hartweg, Schott-Baer and Isenberg (1989) and McBride (1991) followed with factor and content analyses and agreed that the DSCAI reflected foundational capabilities and dispositions, as well as elements of the power components, defined as "enabling capabilities" for performing self-care operations. These power components linked foundational capabilities and dispositions with abilities for self-care operations.

Hanson and Bickel (1985) developed the Perceived Self-Care Agency Questionnaire (PSCAQ). Reliability and construct validity were well established in the original format when it was applied to samples of two different populations.

McBride (1991) examined the latent traits associated with three instruments designed to measure self-care agency. These instruments included Kearney and Fleischer's ESCAI (1979). Denyes' DSCAI, (1980), and Hanson and Bickel's (1985) PSCAQ. The findings supported the multidimensionality of the concept self-care agency, but found that the use of one instrument did not adequately reflect the multidimensionality.

The Appraisal of SCA (ASA), was developed to measure the operability of self-care agency. The scale assessed whether a person could actually meet his or her general self-care

needs. Validity and reliability of this Scale was confirmed in studies conducted in North America and other countries (Achterberg, Lorensen, Isenberg, Evers, Levin, & Philipsen, 1991; Evers, 1989; Evers, Isenberg, Philipsen, Senten, & Brouns, 1993; Soderhamn, Evers, & Hamrin, 1996). Soderhamn et. al (1996) recommended further testing for both validity and reliability if the ASA Scales were to be used in the Swedish population.

Many of the concepts of Orem's model were studied and instruments designed and tested to measure some concepts in this model. Therapeutic self-care demand (Kubricht, 1984), self-care actions (Mapanga & Andrews, 1995), nursing agency (Chang, 1980), nursing systems (Hartley, 1988), and dependent care (Gaffney & Moore, 1996; Villarreul, 1995) have been investigated. Several scholars developed programs of research to further the development of her theory. Dodd (1984; 1987; & 1988) completed several studies related to cancer patients. Moore (1987; 1993; & 1995), and Moore and Gaffney (1989) developed a program of study for investigating self-care in children.

West (1993) developed the Mental Health Self-Care Agency Scale (MH-SCA) to examine the relationship between selected basic conditioning factors, including level of depression and the substantive components of women's self-care agency. Findings in West's (1993) study showed a significant relationship between the foundational capabilities and dispositions and self-care agency, which meant that the three subconcepts of self-care agency were correlated, including a significant correlation with mental health self-care agency (MH-SCA), a specialized self-care ability. West and Isenberg (1997) in a study, using a sample of depressed and non-depressed young women, supported the MH-SCA as a reliable and valid instrument for theory-testing research.

Self-care agency was conceptualized as including: the ability to attend to specific things and to understand their characteristics and meaning; the ability to apprehend, the need to change, or regulate the things observed; the ability to acquire knowledge of appropriate courses of action for regulation; the ability to decide what to do; and the ability to act to achieve change or regulation (Orem, 1995). This study focused on the consumers' acquisition of knowledge for performing self-care or dependent care through the use of NetWellness<sup>®</sup>. The development and testing of these instruments since 1979 have contributed to the refinement of self-care agency by identifying some of the components necessary for self-care.

## Research on Self-Care Actions

Although some studies were conducted to develop valid and reliable instruments for self-care agency, other research studies on self-care used open-ended questionnaires, personal diaries, or semi-structured interviews for collecting data related to self-care actions. Three studies (Hartweg, 1991; 1993; Woods, 1985) identified the type of self-care actions performed by well women to satisfy universal and developmental self-care requisites. In Woods's and Hartweg's studies, the actions reported by the women were explicitly recognized as deliberate actions carried out to improve or maintain their health and well being. Their activities were classified according to the particular element of universal self-care requisites they represented. Activities undertaken to satisfy developmental self-care requisites were frequently associated with changes due to aging. In Woods's (1985) study few nonmedical self-care practices, such as nutrition and exercise, were identified. Woods proposed that the open-ended data collection procedure and the Western emphasis on

medication might have contributed to the limited number of nonmedical self-care practices reported.

Allan (1988) explored the self-care actions taken by women to maintain their optimal weight as an aspect of self-care. The ethnographic research showed that women most often avoided obesity by exercising and dieting for the purpose of preventing illness and improving their self-image.

Investigations with cancer patients showed self-care actions were mainly directed to alleviate symptoms and the side effects of treatment (Dodd, 1984; 1988; Dodd & Dibble, 1993; Hanucharurnkul, 1989). The data collection instruments used to collect data from cancer patients consisted of check lists, diaries, and structured questionnaires. Clients were asked to list the actions they performed and how effectively an action eased symptoms and side effects of their treatment. In Dodd and Dibble's study (1993) multiple regression techniques were used to obtain four significant predictors of self-care, which accounted for 47% of the variance. Subjects with lower performance status, higher anxiety, less social support, and more education performed more self-care.

Foltz, et al. (1996) studied 59 adult patients with cancer who received at least one prior cycle of chemotherapy as inpatients. Subjects were asked to complete the Nail's Self-Care Diary (SCD) (Nail, Jones, Greene, Schipper, & Jensen, 1991), recalling side effects and self-care actions since their last hospitalization for chemotherapy, as well as patient demographic forms and evaluations of the SCD. The Nail's SCD was found to be useful in collecting data retrospectively and provided a basis for proactive patient teaching regarding management of side effects.

Clients that had chronic diseases were also the focus of some self-care research (Aish & Isenberg, 1996; Harper, 1984; Harris, 1991). Qualitative and quantitative instruments and methods were used to determine the type of self-care actions performed by adult and elderly patients with diabetes, hypertension, and schizophrenia. The Food Habits Questionnaire, the Self-care Behaviors Rating Scale, and personal interviews were used by the investigators, who reported in their results that self-care was guided by the type of illness experienced by the patient and its effect on maintaining function and integrity in the life of the individual. Utz and Ramos (1993) presented a focused program of research studies that described the self-care needs of people with symptomatic mitral valve prolapse. In these four completed studies which described those subjects' needs for nursing assistance, Orem's theory was used as a framework.

Conn (1991) interviewed a convenience sample of elderly adults to identify the type and frequency of self-care actions taken to meet universal, developmental, and illness derived requisites when suffering from a cold or influenza. The self-care actions of the ill subjects changed as the illness derived symptoms were relieved.

Children and adolescents have also been a focus of self-care research. Samples of diabetic and asthmatic patients revealed that self-care actions among children and adolescents included actions directed at coping with symptoms, monitoring the day to day course of the illness, and identifying the side effects of diagnostic procedures and treatments. In addition self-care actions that were taken to meet universal and developmental self-care requisites were identified (Frey & Denyes, 1989; Gaut & Kieckhefer, 1988; Rew, 1987; Saucier, 1984). Instruments used to measure self-care included specific items related to actions required by

the particular chronic conditions studied: Examples were the Diabetic Self-care Practice Instrument (Frey & Denyes, 1989) and the Self-care Behavior Scale designed for children with asthma (Rew, 1987). McCaleb (1991) and McCaleb and Edgil (1994) described the self-care practices of healthy adolescents and the relationship between self-care practices and the covariates of self-concept and selected conditioning factors. The influence of sociocultural characteristics on self-care activities was supported.

James (1991) studied a sample of obese adolescents using the Personal Lifestyle Questionnaire to identify factors that influenced performance of self-care actions performed related to exercise, use of drugs, and the practice of health promoting activities. Conclusions drawn from the findings indicated that obese adolescents with higher perceived self-efficacy tended to be more effective self-care agents and those with higher perceived health status, perceived self efficacy and self-care agency tended to engage in more self care practices.

In this section many studies were described that explicated the self-care actions of a variety of persons serving as self-care agents. The types of self-care actions taken were generally described as those deliberate actions taken to improve health and well being or alleviate symptoms related to disease or treatments. Essential to these deliberate actions was knowledge for providing self-care. This study was based on the need to identify the type of information needed by consumers in order to meet their self-care needs.

#### Assessment of Self Care Ability

Some studies used quantitative scales for measuring universal and health related self-care with healthy and ill samples. The Self-As-Carer Inventory was designed to permit individuals to express their perceived capacity to care for self. A 44-item questionnaire was developed and tested in a college population by Geden and Taylor (1988). After the instrument was revised, a second study was conducted with a more heterogeneous population (Geden & Taylor, 1991). The age range of the respondents was broadened and the variability of health state and ethnicity was increased. Significant positive correlations were found between total scores on the Self-As-Carer Inventory and ratings of health in general, health at this moment, and an estimate of the amount of their own self-care provided. No differences were found in total scores across health state, defined as respondents' reports of being sick-at-home (n = 130), hospitalized (n = 259), or well (n = 200).

The Health Promoting Lifestyle Profile was another structured scale used to measure self-care related to health promotion (Simmons, 1990). The scale questioned respondents about the type and frequency of their performance in ten categories of health behaviors similar to the universal self-care requisites defined by Orem.

A methodological study was conducted by Moore (1995) to develop an instrument for measuring the self-care practices of children and adolescents. The study of 471 students ages nine through eighteen involved item development and testing the instrument for reliability, readability, and construct validity. It was determined that The Child and Adolescent Self-Care Practice Questionnaire could be used in further research to determine how children and adolescents performed as self-care agents.

Dellesaga (1995) reported on the development and preliminary testing of the Self-Care of Older Persons Evaluation (SCOPE) instrument, which was derived from Orem's model of self-care. SCOPE was designed to provide nurses with a structured but brief format for assessing the actual self-care abilities of institutionalized older adults. Initial testing of SCOPE confirmed that it was a reliable and valid instrument for use in clinical settings.

Horsburgh (1994) used the Self-Care Inventory with chronically ill and well adults to study the satisfaction of the eight universal self-care requisites described by Orem. The mean scores obtained were higher for the well adults than for those identified as ill. For subjects recuperating following surgery, the relevant self-care action was the maintenance of balance between activity and rest.

Hanucharurnkul and Vinya-nguag (1990) reported on the effectiveness of clients' participation in self-care of forty adult clients undergoing pyelolithotomy and nephrolithotomy. The experimental group participated in their self-care through nurse-patient interaction in addition to the usual care received in the setting. Results of the study indicated that patients in the experimental group had significantly less pain sensation and distress, used fewer analgesics, ambulated more, had fewer complications, and had higher satisfaction with care than patients in the control group.

The review of relevant studies on self-care showed that actions differed greatly according to health or illness states, and the age and life circumstances of the subjects. The well adult performed self-care actions directed toward meeting universal self-care requisites; whereas the pattern for ill subjects described actions more often oriented toward satisfying needs emerging from the particular disease, and fewer actions to cope with universal and

developmental self-care requisites. These findings supported Orem's assertion that therapeutic self-care demand of persons with health states within the prescribed norms was composed of universal and developmental components. On the other hand, when this was not the case and illness was present, health state and health care system factors provoked new requisites or modifications of the existing ones (Orem, 1995).

#### Research on Dependent Care and Dependent Care Agency

Orem stated that the concept of dependent-care agency (DCA) was in the process of formalization. Like self-care agency its broad conceptual structure was formed by capabilities to perform estimative, transitional, and productive operations in knowing and meeting the therapeutic self-care demand of another. Dependent-care agency was defined as the complex, acquired ability of mature or maturing persons to know and meet some or all of the self-care requisites of adolescents or adults who have health-derived or health-associated limitations of self-care agency, which places them in socially dependent relationships for care (Orem, 1995).

Moore and Gaffney (1989) recognized that attempts to study mothers' performance of self-care activities for children were hampered due to the lack of an instrument to measure dependent care agent performance. This study presented the development of The Dependent Care Agent (DCA) questionnaire, which was a 39-item instrument that examined dependent-care practices, related to nutrition, safety, and sleep. Analysis of the instrument indicated that it was reliable and could be used to measure dependent care agent performance for mothers. A study that followed (Moore, 1993) examined relationships between basic conditioning factors, self-care agency, and dependent-care agent performance in 414 children ages 9-18

years. A correlational analysis showed a moderate relationship between a child's self-care performance and her or his mother's dependent-care agent performance.

Gaffney and Moore (1996) tested the relationship between dependent care performance and basic conditioning factors. They found that basic conditioning factors influenced dependent care agent performance. Dependent care agent performance for children was defined as health promotion and self-care activities provided by a responsible adult on behalf of the child. The Dependent Care Agent Questionnaire was used with a sample of 380 mothers of children from ages 1 to 16 years. In a study by Moore and Mosher (1997) children completed two questionnaires - the Children's Self-Care Performance Questionnaire (Moore, 1995) and the Children's State-Trait Anxiety Inventory (Spielberger, Edwards, Lushene, Montuori, & Platzek, 1973). Mothers completed the Dependent Care Agent Performance Questionnaire, the State-Trait Anxiety Inventory and a demographic form. The purpose of the study was to examine childrens' and their mothers' adjustment responses (self-care and anxiety) to cancer. Basic conditioning factors (age, gender, healthstate, and sociocultural orientation) significantly predicted childrens' self-care practices and state and trait anxiety as well as mothers' dependent-care and state anxiety. A significant canonical correlation surfaced between the set of childrens' adjustment responses and the set of mothers' adjustment responses.

Haas (1990) tested the theoretical relationships between coping dispositions, and power components of dependent-care agency in 230 parents of children with special health care needs. Results of this study provided support for several elements of Orem's self or dependent-care deficit theory. A positive relationship between coping dispositions and power

components of dependent care agency was found. Basic conditioning factors accounted for a significant proportion of the variance in both power components and coping dispositions.

A causal model of relationships among self-care agency, basic prenatal care actions, foundations for dependent-care agency, and selected pregnancy outcomes was studied by Hart (1995). Self-care agency was significantly and directly related to basic prenatal care actions and foundations for dependent-care agency. Humphreys (1995) used open-ended, semi-structured interviews with mothers (N=50) at battered women's shelters in a metropolitan area in the Midwest. The women demonstrated deliberate, creative, and diverse dependent-care. Caring action and timing provided the basis for patterns of dependent-care.

In addition to studies that focused on the parent as the dependent care agent, research on dependent care for spouses was also conducted. Schott-Baer (1989) examined the relationship between the self-care agency of caregivers providing dependent-care to a spouse with cancer and a set of variables assessing the family system. Spouses (N = 119) of cancer patients that received radiation or chemotherapy treatments at a Midwest hospital comprised the sample for the study. Another study by Schott-Baer (1993) examined the relationships between dependent care, caregiver burden, and self-care agency of 113 spouse caregivers of radiation oncology or chemotherapy patients in a large metropolitan hospital. The Denyes Self-Care Agency Instrument (1980; 1982) was used to measure self-care agency. The Task Scale, (Montgomery, Gonyea, & Hooyman, 1985) was used to operationalize dependent care. This scale was a 27-item instrument used to collect information about the amount of time caregivers spent in assisting family members in four areas: body or personal care, meals, financial assistance, and transportation. The Burden Scales (Montgomery et. al, 1985) were

used to measure objective and subjective caregiver burden. Objective burden was defined as the disruption or change in the caregiver's life and household; subjective burden focused on the feelings, attitudes, and emotions expressed about care giving. Demographic data were collected on the number of weeks in the caregiver role, presence of health problems in the caregiver, gender, age, income, and education. In the total sample, subjective burden was negatively and significantly related to self-care agency and objective burden. Women as care givers were specifically susceptible to a decrease in their self-care agency.

Schott-Baer, Fisher, and Gregory (1995) conducted a partial replication of the 1993 study. Data from this replication were compared with those of the previously reported study. Data were collected from a home health agency and a radiation-oncology unit. A moderate significant negative correlation was found between objective burden and dependent care. Moderate significant positive correlations were found between self-care agency scores and the commitment/challenge and control subscales of health-related hardiness scores. The major difference between this study and the previous one was in the level of subjective burden. Even though caregivers reported greater levels of subjective burden, the correlation with self-care agency and hardiness was nonexistent. The small subsample of male caregivers (n=14) prevented a statistical comparison with the previous data; however, in the pooled sample previous findings were supported.

Baiardi (1997) examined the relationship between dependent-care agency and self-care agency in caregivers of cognitively impaired elderly and the influence of selected basic conditioning factors on the dependent-care agency and self-care agency in caregivers. Results indicated that there was a significant positive relationship between self-care agency and

dependent-care agency. Health status of the caregiver and burden were more associated with self-care agency while degree of cognitive impairment and living arrangements were more related to dependent-care agency.

Villarruel (1995) conducted an ethnographic investigation to discover MexicanAmerican meanings and expressions of pain and to describe associated self-care and
dependent-care actions. Four themes concerned with pain meanings expressions, care of self,
others, and by others were identified. One of the emergent themes was the primacy of caring
for others, which was the essence of the family. This obligation and willingness to care for
others in the family were viewed as characteristic of Mexican culture. Major gender
differences were identified in the care of self and care of others within the family context.

Both men and women indicated that men tended to rely on others in caring for self and others
within the context of the family. Villarruel and Denyes (1997) examined the previous study
using ten theory-verification criteria developed by Silva and Sorrel (1992) for inductive
methods of inquiry. They concluded that these criteria provided a systematic way to evaluate
the adequacy of an inductive verification of nursing theory. The findings also provided a
basis for further development of Orem's theory for use with an ethnic minority group.

The studies described in this section focused on two groups of dependent care agents - mothers or parents of children or adolescents and spouses of ill partners. Although the concept of dependent-care agency was still in the process of formalization, most of the studies focused not only on the actions performed, but also the attitudes, responsibilities, and burdens that were identified by the dependent care agents. This study focused on identifying the type of information sought by dependent-care agents.

# Basic Conditioning Factors and Their Relationship to Self- Care, Self-Care Agency, Dependent-Care and Dependent Care Agency

Orem recognized that as transitions occur in life, different patterns of self-care and dependent care emerge according to the self-care or dependent care requisites brought about by these transitions. Basic conditioning factors have been defined as the conditions or events in a time-place matrix that affect the values or ways of meeting persons' existent self-care requisites, or affect the development, operability, or adequacy of persons' capabilities to care for themselves or their dependents (Orem, 1995). For this study the basic conditioning factors associated with the core concepts included age, gender, race, education level, and household income. Research on self-care, self-care agency, dependent care, and dependent care agency showed a diversity of ways through which basic conditioning factors affected the specific populations studied. An overview of some of the research related to these basic conditioning factors was summarized in the following paragraphs.

Age. Age was a variable that indicated a certain level of biological and psychosocial growth and development. Certain self-care requisites and capabilities were assumed in the healthy individual dependent on the developmental state reflected by age.

The literature outlined how the theory has been used to provide care for patients of various ages. It was used for providing care to the elderly (Ailinger & Dear, 1997; Alford, 1985; Bower & Patterson, 1986; Dellesga, 1995; Eliopoulos, 1984; Hankes, 1984; Hewes & Hannigan, 1985; Sullivan & Monroe, 1986). It was also used in the care of children and adolescents (Baker, 1991; Eichelberger, Kauffman, Rundahl, & Schwartz, 1980; Facteau,

1980; Frey & Denyes, 1989; Gaut & Kieckhefer, 1988; Hurst, 1991; Jesek-Hale, 1994; Koster, 1983; Moore, 1995; Neuman, 1996; Rew, 1987, 1990; Saucier, 1984)

In several studies age was significantly correlated with self-care agency. O'Connor (1995) found age to be a significant predictor of the level of self-care agency as measured by the ASA scale. This relationship held true in a healthy adult population of both sexes and ages ranging from 18 to 70; the same correlation held true in three different populations. Vannoy (1989) reported an inverse relationship between self-care agency and age with a sample of overweight adults (18 to 68) enrolled in a weight loss program. West (1993) reported similar findings in a study of young women suffering from depression. Ailinger and Dear (1997) reported that older clients reported more changes associated with universal self-care requisites than younger clients with rheumatoid arthritis. In a study of pregnant adolescents, Jesek-Hale (1994) reported that younger adolescents (14 and 15) had higher self-care agency scores than older adolescents (16 through 19). However, Canty (1993), did not find a significant relationship between age and self-care agency in a group of adolescents from 13 to 19 years of age.

In several studies self-care actions were also correlated to age. Hartweg (1991) focused on universal self-care requisites of women (40 to 59 years). She described a number of self-care actions associated with age. Women identified 8,693 diverse self-care actions that promoted well being; one-fourth of the actions were categorized as self-care actions related to developmental changes experienced in middle age. When demographic variables were correlated with self-care actions, education, age, and number of children were significantly correlated with types of self-care actions. Allan (1988) found an inverse relation between

women's age (19 to 56 years) and self-care actions for managing weight. Conn (1991) found a negative correlation between age and the number of self-care actions used by individuals (65 to 94 years) with a cold or influenza. Moore (1993) studied children 9 to 18 years old and found a negative relationship between age and self-care as measured by the Self-care Performance Questionnaire (SCP). Frey and Denyes (1989) found an inverse correlation to age and self-care actions in diabetic children between the ages of 11 and 19 years of age. In a study of adolescents with cystic fibrosis, Baker (1991) reported that although none of the basic conditioning factors, including age, emerged as significant predictors of self-care, it suggested that age impacted self-care agency and therefore indirectly influenced self-care.

In a study by Aish and Isenberg (1996) the correlation of age and self-care agency was mixed in 104 men and women that had recently experienced a myocardial infarction.

Relationships among concepts were investigated by examining the 104 subjects as a group.

They found mixed results on self-care agency with age; younger men and older women increased their self-care agency while self-care agency of older men and younger women was decreased.

Spitzer, Bar-Tal, and Ziv (1996) found that age played an important role in the relations between self-care and others' care and self-care outcomes of women and men treated in the outpatient clinics of two large Israeli hospitals. They suggested that the theory of self-care might fit better with an older rather than younger population.

Gender. Gender, as a basic conditioning factor, reflected biological, social, and cultural characteristics that affected the person's self-care requisites as well as their

capabilities to care for themselves. Gender was also associated with various roles defined by the individual's culture associated with dependent care and dependent care agency.

In the study by Ailinger and Dear (1997) gender was not associated with the number or type of universal self-care requisites affected by rheumatoid arthritis. Aish (1996) also reported no significant differences between males and females regarding incidence of obesity or diabetes, their smoking pattern, or on measures of self-care agency or self-efficacy. However, men perceived higher levels of social support for healthy eating. In a study of the relationship between dependent-care agency and self-care agency in caregivers of cognitively impaired elderly, health status of the caregiver and burden were more associated with self-care agency while degree of cognitive impairment and living arrangements were more related to dependent-care agency. These findings indicated that capabilities for self-care subsumed capabilities for dependent-care. Caregivers were found to be dual agents and the findings supported the conditioning effect of self-care agency on dependent-care agency and articulation of these two systems (Baiardi, 1997). No significant differences were found between male and female caregivers on dependent care agency.

However Koster (1995) found significant relationships between self-care agency and gender (specifically female) in a study that compared the relationship of self-care agency, self-determinism, and absenteeism in two groups of school-age children. McDermott (1989) also found significant differences between men and women. Self-care agency of full-time working adults between the ages of 21 through 65 years was measured with the PSCAQ; when related to learned helplessness conceptualized as opposed to self-care capabilities, women's scores were significantly higher than men's. Whetstone and Reid (1991) studied the

perceptions of rural men and women ages 50 to 70 years of age regarding barriers to health promotion in the treatment of hypertension. Major findings indicated no relationship between health beliefs/values and self-care. The women scored somewhat higher than men did on all four health-value subscales. Average, appraised, and achievable ages for relative risk of dying from all causes were significant for men.

Race. Race was a basic conditioning factor suggested to have an influence that may or may not favor the development of self-care agency and the development and performance of self-care actions. Dashiff (1992) studied the self-care capabilities of black girls in preparation for menarche. Ladewig (1989), in a study of adult workers in a university program, found that black Americans scored higher than Hispanics in self-care agency. Jirovec and Kasno (1990) examined the relationship between environmental and personal factors on self-appraised self-care agency of nursing home residents. Race and previous occupation were related to self-care agency with residents who were black or previously self-employed evidencing higher scores in ASA than whites.

In a study of self-care practices of healthy adolescents by McCaleb and Edgil (1994), the influence of sociocultural characteristics on self-care activities was supported. Race, self-concept, church attendance and participation in the paid lunch program were the variables in the statistically significant four-variable regression model. This result suggested that sociocultural influences were important predictors of self-care agency and the actual self-care practices of the individual. McQuiston (1993) studied the basic conditioning factors and self-care agency of unmarried women at risk for sexually transmitted diseases. The strongest

predictor of general self-care agency was race, which was mediated by influence in decisionmaking.

Education. Self-care agency and self-care actions were learned during the years from childhood to adulthood. Formal education as a basic conditioning factor was reported to have a significant association between self-care agency and education. Ladewig (1989) reported higher scores in self-care agency with higher levels of education. West (1993) found similar findings when studying depressed women. Ailinger and Dear (1997) found education and duration of illness were related to self-care agency in a study of outpatients with rheumatoid arthritis. Dodd and Dibble (1993) found that subjects with cancer that had more education performed more self-care. In a study that described self-care actions in healthy middle-age women, Hartweg (1993) found a significant correlation between education and types of self-care actions. Robinson (1996) examined the relationships among selected basic conditioning factors and self-care agency and functional status in chronically ill adults; a significant relationship was found between educational level and self-care agency.

Allan (1988) and Hartweg (1991) studied two groups of women and identified that women with more education tended to perform a higher number of health promoting self-care actions. Hanucharurnkul (1989) also reported that high levels of education corresponded to high performance of self-care actions in a sample of cancer patients.

Household income. Socioeconomic (SES) status reflected the availability of resources and options available to individuals and families as they made self-care or dependent care decisions. Socioeconomic status was represented by a variety of factors that have often been correlated with each other. For example income, education, and type of occupation were

factors that were used to represent socioeconomic status. Level of education and type of occupation have usually been linked; income was generally represented by the combination of these factors.

Hanucharurnkul (1989) found that SES was a significant predictor of self-care behaviors performed by cancer patients. Socioeconomic status was operationalized as family income, occupational prestige, and years of formal education. Jirovec and Kasno (1990) studied the institutionalized elderly and found that previous occupation had a significant relationship with ASA Scale scores; occupation was considered the indicator of SES because the higher status occupations usually indicated more years of education and higher earned income. Caregivers of cancer patients studied by Schott-Baer (1993) had a positive relationship between level of education and income; yet only education had a significant association with self-care agency of the subjects. Income was thought to have an indirect affect on self-care due to its association with education.

In a study of specific self-care agency in women at risk for sexually transmitted diseases McQuiston (1993) found race to be the strongest predictor of general self-care agency. However when race was controlled socioeconomic status, health-state, and influence in decision making were significant predictors of attention to health. In this study a negative relationship was reported between SES and self-care agency; women with lower SES had more favorable attitudes toward condom use, which indicated a specific self-care agency.

Nicholas (1989) examined the relationship among hardiness, self-care practices, and perceived health status of the elderly. The illness index, income, and living circumstance accounted for 46% of the variance in perceived health status scores. In two studies of

adolescents Baker (1991) and Canty (1993) did not find income to be predictive of self-care behaviors or influence self-care agency. Dowd (1994) studied urinary incontinence in women and although the extent of urinary incontinence was not related to any of the demographic characteristics income was related to depressive symptoms.

The extensive literature explored in this section provided support for the basic conditioning factors selected for this study. Although some of the studies' findings conflicted with other studies, the basic conditioning factors of age, gender, race, educational levels and socioeconomic status have been suggested to influence self-care requisites as well as self-care agency. In other words differences in age, gender, race, educational levels, and socioeconomic status were found to be associated with some of the self-care needs and capabilities or self-care agency required to effectively respond to the needs.

### Research on the Supportive Educative Nursing System

Orem stated that "nursing systems may be produced for individuals; for persons who constitute a dependent-care unit; for groups whose members have therapeutic self-care demands with similar components or who have similar limitations for engagement in self-care or dependent-care; or for families or for other multiperson units" (Orem, 1995, p.176). Orem identified three nursing systems; "(a) the wholly compensatory system, in which the nurse compensates for the patient's total inability to engage in self-care activities; (b) the partially compensatory system, in which both the nurse and the patient perform care measures: and (c) the supportive-educative system, in which either the patient or the caregiver is able to perform or can learn to perform required care measures" (p. 306). This study focused on the supportive educative system. Orem outlined four variations within the supportive-educative

system: In the first, a patient can perform care measures, but needs guidance and support; teaching is required in the second variation; in the third, providing a developmental environment is the preferred method of helping; the fourth variation is in situations where the patient is competent in self-care but requires periodic guidance that he or she is able to seek; in this variation, the nurse's role is primarily consultative (Orem, 1995).

Research related to Orem's supportive-educative nursing system was found to be scarce compared to the number of studies related to instrument development and concepts such as self-care and dependent care. Many studies mentioned the value of patient education but did not specifically focus on the supportive-educative system. In studies that identified the supportive-educative nursing system as the focus, specific interventions rather than the nursing system were the research focus.

In one study, primary nurses that worked in a 58-bed rehabilitation unit located in a 1,700-bed tertiary care medical center implemented a follow-up telephone call program to support the patient's transition from acute rehabilitation nursing care to community living. The most frequently used helping interventions identified during the study were guiding and supporting (Closson, Mattingly, Finne, & Larson, 1994). Folden (1993) studied the effect of a specific supportive-educative nursing intervention (guided decision-making) on older adults' perceptions of self-care post stroke. The findings supported the effectiveness of using individually focused supportive-educative nursing interventions to improve older adult's perception of ability to care for self and to increase their use of self-care activities.

Fujita and Dungan (1994) presented a protocol study developed to evaluate the usefulness of the nursing diagnosis "high risk for ineffective management of therapeutic

regimen" among patients with congestive heart failure (CHF). Nursing interventions for increasing the CHF patient's abilities to perform therapeutic self-care for the promotion and maintenance of a prescribed medication regimen were evaluated based on predicted outcomes. Orem's supportive-educative nursing system was the approach used. Knowledge deficit was noted to be a major obstacle for maintaining the prescribed medication regimen among CHF patients. Comprehensive teaching of the patient was identified as the most important factor for the promotion and maintenance of a prescribed medication regimen among patients with CHF.

Graff, Thomas, Hollingsworth, Cohen, and Rubin, (1992) described the development of a postoperative self-assessment form based on concepts derived from Orem's supportive-educative nursing system. The client was taught how to assess these areas for normalcy and report deviations from normal to aid in recovery. Hagopian (1991) investigated the effects of a weekly newsletter on the knowledge, side effects, and self-care behaviors of clients with cancer who were undergoing radiation therapy. Although the subjects who read the newsletter scored significantly higher on the knowledge test, there were no significant differences in the helpfulness or number of self-care behaviors or in the severity of side effects experienced.

Hartley (1988) conducted a pilot study to test the proposition that a supportiveeducative nursing system influenced self-care behavior. The hypotheses relating congruence of teaching strategy and learning style to accuracy and frequency of performance of breast self-examination were not supported. In a descriptive case study, Hiromoto and Dungan (1991) included chemotherapy clients and their families in identifying self-care requisites for a learning needs assessment tool. Findings suggested that the protocol provided a systematic and comprehensive approach to patient's self-care deficits using adult learning principles

Kennedy (1990) conducted a pretest-posttest experimental study to determine if the application of a Self-Care Medication Education Protocol resulted in improved patient care outcomes for recently hospitalized elders. Results from this study supported the premise that elderly patients who participated in a Self-Care Medication Education Protocol achieved a greater increase in the home medication behaviors, of medication knowledge, and medication administration skills, and a decrease in medication error rate than those patients who received the traditional discharge medication instructions.

The Jopp, Carroll, and Waters (1993) study identified how older adults managed self-care activities at home following hospital discharge. Survey results indicated that 66% of the clients reported self-care deficits after discharge. Fifteen percent reported an inability to totally care for themselves after discharge. Further analysis revealed the lack of a supportive-educative system to promote self-care at home. The authors made recommendations for nurses to develop strategies that promoted partnerships with older adults in planning self-care activities after hospitalization.

The essence of the studies in this section provided support for the necessity of providing information to patients for providing self-care. However, most of the studies focused on a specific intervention for a narrowly defined group of patients, rather than the development of a supportive-educative system to address the information needs of many consumers. The author believed further investigation of supportive educative nursing systems

was necessary and development of creative methods - available through technology - were needed to provide information to consumers.

#### <u>Information Technology: Self-Care</u>

Computers have only recently been a vehicle for consumers to obtain health care information. Initially computers were introduced in hospitals and physician offices to help staff members manipulate large amounts of information, enhance communication, save time, and reduce the potential for errors. Secondarily, computers were used for teaching in the form of computer-assisted instruction. These programs were developed by and for health professionals and their clients (Hendrickson, Kelly, & Citrin, 1991).

Many studies were conducted related to information technology and its use in health care. Afrin, Kuppuswamy, Slater, and Stuart (1997) reported on an electronic method to distribute clinical trial protocols via the WWW. They reported that the Physicians Research Network (PRN) improved their ability to keep community physicians aware of available trials and referral mechanisms; in addition errors and costs were reduced. London, Morton, Marinucci, Cataloano, and Comis (1997) described a telemedicine project being used by physicians at member hospitals of the Jefferson Cancer Network (JCN) for consultations regarding the diagnosis and management of cancer patients. Evaluation of the project found that the WWW was an efficient means for communicating updated information on cancer clinical trials to community physicians. Similarly, the telemedicine consultations were useful with physician participants unanimously concurring that they were more effective than

traditional telephone consultations. In addition the consultations contributed to an increase in the number of clients enrolled in clinical trials from the JCN hospitals.

Murray (1995a; 1995b; 1996) described the use of messages to worldwide Internet Listserv discussions to recruit nurse interviewees and the storage and analysis of data from the list discussions. Lakeman (1997) examined nurses' use of electronic discussion forums.

Brennan (1988) however, envisioned the real potential for education and support of clients and consumers in her statement "computers will be as common in the home of the 1990s as VCRs are in the 1980s" (p. 806). Health care information specialists predicted that the general population would use information technology to access on-line health information and services from home; patient-focused informatics were discussed (Gassert, 1996, 1998).

Brennan (1997) stated that as health care moved into the community nurses and physicians would not be the only ones with new jobs; patients would have new and increasing responsibilities for self-care and disease management. She believed that information technologies provided the necessary tools to ensure that patients were well equipped to meet these challenges. The Agency for Healthcare Research and Quality (AHRQ) also recognized the importance of providing information to the consumers as well as their health care practitioners. The Consumer Health section (<a href="http://www.ahcpr.gov/consumer">http://www.ahcpr.gov/consumer</a>) placed on the WWW included consumer versions of AHRQ supported clinical practice guidelines - information to help consumers and their families make informed decisions about preventing or treating common health conditions. This information and data were central to AHRQ's mission to enhance the quality, cost-effectiveness, and delivery of health care services.

Nursing evolved within this societal context of shifting paradigms and pervasive technology. Ehrenberger and Brennan (1998) maintained that information technology offered real solutions to challenges in the delivery of healthcare service to people. They stated that computer networks linked patients and clinicians, and ensured that geographic or temporal limitations did not pose barriers to clinical care. Additionally, the capacity for comprehensive access to and integration of information and knowledge made feasible a holistic approach that transcended time, settings, and providers.

#### <u>Information Technology and Self-Care</u>

Many studies specifically focused on technology for self-care and caregiver support (Afrin, et al. 1997; London, et al. 1997). Lindberg (1997) described The Interactive Home Health Care Program, a demonstration project that provided full interactive video and audio capacity between elderly patients in their homes and a telemedicine nurse. Six months into the project 38 patients were being cared for at three sites in rural Kansas. Individual patient profiles showed improvement and project participants were encouraged by the daily successful use of telemedicine in the home. However, these initial results were limited to evaluation data for this ongoing project. Additional studies have been directed toward a preselected category of patients or were designed to evaluate a specific aspect of technology (Brennan, Moore, et al., 1991, 1992, 1995; Brennan, Ripich, et al., 1991; Cohen, 1981; Kruckenber-Schofer & Ward, 1990; Ripich, Moore, et al., 1992; Smyth & Harris, 1993).

In an innovative project known as ComputerLink, a team of nurses used an electronic network to provide information, communication, and decision support to homebound persons and their caregivers (Brennan, 1996). One ComputerLink project served people living with

AIDS (Brennan and Ripich, 1994). Positive findings of the study included: 1) individual control of time of participation and the amount of information given or received, 2) opportunity to participate without leaving home, 3) safety to discuss sensitive issues, and 4) ready availability of information and social support.

A second project by Brennan, Moore, et al. (1995) evaluated caregivers of persons with Alzheimer's disease. Although their decision-making skill was unaffected access to ComputerLink enhanced caregivers' decision-making confidence. ComputerLink access did not lead to changes in social isolation as measured by standard instruments and the decision-support function was used least often. Postings to ComputerLink's public bulletin board included both information-seeking and supportive messages. These findings were congruent with reports of other community-based interventions for caregivers and consistent with evaluations of computerized decision-support systems.

Fawcett and Buhle (1995) designed a questionnaire to collect information about the problems experienced by cancer survivors, strategies used to cope with these problems, and suggestions regarding what could be done and by whom to help cancer survivors cope more effectively. A request for demographic data and seven open-ended questions comprised the questionnaire. After the survey had been posted for three months 30 cancer survivors had responded. The researchers found the electronic survey to be a cost-effective and expedient method for collecting preliminary data. They acknowledged that some researchers have expressed concerns with this data collection method due to the lack of traditional face-to-face interactions and respondents that represented a self-selected sample of well-educated and literate computer users. These researchers noted that face-to-face interactions were also

absent in mailed questionnaires and surveys - both of which have been well-established and validated data-collection methods.

Klemm, Reppert, and Visich (1998) described categories or themes of information shared on an Internet cancer support group (ICSG). They determined how many people used the list, and how frequently they posted on it. Content analysis was conducted on the 300 messages posted on an ICSG and eight categories of responses were identified. These included information giving/seeking, personal opinions, encouragement/support, personal experience, thanks, humor, prayer, and miscellaneous. Gustafson, Wise, and McTavish (1993) reported positive features after studying a computer support group for women with breast cancer. The women evaluated the system highly in terms of information and support and reported that the system had empowered them.

Nurse researchers evaluated the usefulness and function of a specific discussion forum (CompuServe Information Service's Cancer Forum) by electronically posting a survey with 22 multiple-choice and Lickert-type responses (Fernsler and Manchester, 1997). Several items targeted the support functions of the forum (by asking how helpful discussions and participation had been) as well as the pragmatic issues (by asking what factors facilitated or limited participation in the forum). The survey was posted on the network and mailed to 12 members of the forum who had not recently posted messages. Data were collected for two months, and 54 responses were obtained. Seven of the 12 people who received the survey by mail responded. Of the respondents, 98% indicated that communicating electronically with people that had a similar experience moderately or greatly facilitated their participation in the

forum. Although the findings were informative, limitations included the small self-selected sample given the actual number of forum members.

Amtmann and Johnson (1998) described the benefits of using the Internet and information technologies for people with disabilities. Brief case studies were presented to illustrate how people with different functional limitations used electronic resources in their everyday lives. The authors strongly advocated that rehabilitation professionals should acquire expertise necessary to assist people with disabilities in gaining access to and effective use of information networks. They believed this would improve the disabled persons' quality of life, opportunities for employment, education and recreation.

Soetikno, Mrad, Pao, and Lenert (1997) conducted an on-line survey for clients with ulcerative colitis (UC) and patients whose UC had been treated with surgical procedures. They wanted to study the effects of disease on quality of life through self-administered questionnaires and also to understand how patients on the WWW might differ from those in practice. They concluded that it was feasible to conduct epidemiological research on the effects of UC on quality of life on the WWW. However systematic differences in disease activity between volunteer patients on the WWW and "in the clinic" was listed as a limitation for applicability of results.

McKay, Feil, Glasgow, and Brown (1998) evaluated the feasibility and use of an Internet support service for diabetes self-management. In their study, a web site for diabetes self-management that emphasized personalized goal setting, feedback, and social support was developed. Over a 10-week period, 111 persons logged onto D-NET for a total of 21,046 accesses. Users included persons across a broad age range (up to age 77 years) and duration

of diabetes. The most popular areas of the site were the Social Support Conference and the Diabetes Information Pages. User ratings revealed high satisfaction with the service.

Brennan and Strombom (1998) presented a strong case for the role of using computer technology to better understand patient preferences which would improve health care. When delivered via the WWW these programs facilitated patients' exploration of preferences in the privacy of their homes or away from an anxiety-producing health encounter. Examples of Computer Based Preference Assessment projects included The Stanford Center for the Study of Patient Preference and The Comprehensive Health Enhancement Support System (CHESS).

The Stanford Center for the Study of Patient Preference pioneered the use of computers and the Internet for low-cost elicitation of patient preferences for health care. Initially computerized surveys and instructional programs walked the patient through classic decision analytic methods to help them clarify their preferences (Lenert and Soetikno, 1997). The Comprehensive Health Enhancement Support System (CHESS) was a health promotion and support network application that operated as a module-based computer system for inhome or health care setting use (Gustafson, Hawkins, Boberg, Bricker, Pingree, & Chan, 1994). People with major illness or health concerns accessed information, decision support, social support, skill training, and a referral resource. Several of the CHESS services helped patients clarify their values as they prepared to make decisions that were consistent with their preferences.

Patient participation in contemporary health care also involved learning about health promotion strategies, disease and condition-specific etiology, treatment, and available health

care resources. One example, The Telephone Linked Computer (TLC) system (Friedman, Stollerman, Mahoney, & Rozenblyum, 1997) was reported as an interactive environment in which a patient at home was provided with information about a condition and obtained consumer information or help in designing an intervention.

McRoy, Liu-Perez, and Ali (1998) described their work on the Layman Education and Activation Form (LEAF). LEAF was designed to be an interactive, Internet-based system for collecting a patient's medical history. It was unique in that it gave patients access to educational information when it was most pertinent, while they were attempting to complete a form. The study showed that the users who had access to medical information while they were working on the form found it helpful.

Jenkinson, Wilson-Pauwels, Jewett, and Woolridge (1998) described The Prostate Centre, a hypermedia program that integrated CD-ROM and Internet technology. It was developed to assist patients with localized prostate cancer in making treatment decisions. Pilot testing elicited positive responses; the patients regarded the program as useful, relevant to their needs, and navigable. Although the sample size was small, the method of involving patients in the design process proved to be a major factor contributing to the success of the program.

#### Orem's Theory: Information Technology

For nursing, as with any discipline, the meaning of data is dependent on the theoretical or conceptual model that is used to frame data gathering and analysis. Using Orem's Self-Care Deficit Nursing Theory, a group of nurse theorists and practicing nurses derived an information process model for use in a computerized nursing information system. This gave

direction for defining variables of interest to nursing and their relationships. It also provided direction for defining each data item, a necessary precursor to retrieval. The theoretical elements that provided the framework for the computerized nursing information system content were the basic conditioning factors, the therapeutic self-care demand and associated self-care requisites, and self-care agency. (Bliss-Holtz, 1996; Bliss-Holtz, McLauglin, & Taylor, 1990; Bliss-Holtz, Taylor, McLaughlin, Sayer, et al., 1992; McLaughlin, Taylor, et al., 1990).

Nurses that worked to develop this clinical information system, demonstrated that by using the Self-Care Deficit Nursing Theory to construct an information processing model, it was possible to develop a user-friendly intuitive computerized information system which supported nursing practice. The user was not required to learn the language of the theory to use the system. The language of human action that was common to the user in their work was all that was needed. At the same time it was the very precision of the language of the theory, the scope of the theory, and ongoing activities in relation to theory development, that made the emergence of the information system possible (McLaughlin, Taylor, et al., 1990). Without using nursing theory as a framework, population reports have generally been categorized by medical diagnosis, medical treatment, or limited to demographic information of age, occupation, or residence.

Orem's framework provided an enumeration of goals that were fulfilled by computer-based nursing interventions, within the supportive educative system including guiding, teaching, and created an environment that supported development (Ehrenberger & Brennan, 1998). Several studies were not specifically designed from Orem's Self-Care Deficit Nursing

Theory, however computer technology was successfully used for providing information to individuals to support self-care and dependent care abilities (Brennan, Moore, et al., 1991, 1992, 1995; Brennan, Ripich, et al., 1991).

Although Orem's theory had as its objective focus the self-care needs and abilities of individuals, she recognized that these individuals were recipients of nursing as members of larger groups such as families and communities. Orem stated that nursing was delivered to individuals, dependent-care units, families, households, small groups, and large groups (Orem, 1995). The Self-Care Deficit Theory was expanded for use with families and communities (Haas, 1990; Hanchett, 1988; 1990; Orem, 1983a; 1983b; 1983c; 1991; 1995; Tadych, 1985; Taylor, 1989; and Taylor & McLaughlin, 1991). Taylor and McLaughlin (1991) proposed that Orem's Self-Care Deficit Nursing Theory could legitimately be viewed as having meaning for nursing when the community is viewed from any of the three models suggested by Kirkpatrick (1986). These three basic models of community included the atomistic/contractarian, organic/functional, and mutual/personal. The philosophical and theoretical perspectives of community were presented as the basis for developing a model for community nursing. Gomez, Dubois, and King (1998) also looked at the definition of community from a different perspective. They argued that the Internet as a network of computers was increasingly becoming a place for learning, entertainment, and networking. They stated that it created points of contact for people widely dispersed across space and time and has changed the way people communicate, interact, and define "community"

#### Cyber-Research Issues

A review of relevant research regarding important cyber-research issues was conducted and presented in this section. Studies that focused on physician/caregiver informatics and consumer-oriented informatics research were reviewed. The importance for nursing to include a theoretical perspective when conducting informatics research was supported.

The interface between nursing practice, nursing research, and nursing informatics has provided an opportunity to create new science and expand the boundaries of nursing knowledge. However, this new area of research has produced issues that require careful consideration. Unfortunately, a great deal of the information that focused on the use and types of interpersonal interactions occurring via computers was primarily anecdotal.

Research that examined nurses' or clients' use of computer networks or the ways in which formal and informal nurse-patient interactions occurred was scarce (Ehrenberger & Murray 1998).

Even though the potential for this research is innovative and important, many researchers have recognized that there are problems that must be addressed. Some of these issues have included the recruitment of research subjects, privacy and confidentiality of interactions, and the generalizability of results from field studies (Brennan, 1996; Ehrenberger & Murray 1998). Specific issues cited about recruitment of subjects included the fact that subjects obtained via this method may have a higher education or financial status because they have access to a computer, which may skew the socioeconomic characteristics of the sample. Conversely, others have argued that results obtained from studies conducted

electronically may increase the generalizability of study findings because the sample may represent a wide geographic distribution of online members (Wilmonth, 1995).

Privacy, confidentiality and informed consent procedures were other issues that have been addressed. All researchers argued that regardless of the method used to recruit subjects and conduct studies, ethical standards must be upheld. Waskul and Douglas (1996) addressed the nature of online interactions and proposed that for research purposes a distinction be made between "publicly accessible" and "publicly distributed" on the basis of the "publicly private" nature of online interactions. They also suggested that research on and in cyberspace will continue to present conceptual, theoretical, and methodologic challenges in the future, but they proposed that resolution of these issues will represent academic advancement. Privacy and confidentiality issues were addressed from the perspectives of technologies to ensure them and the ethical principles necessary to evaluate them. Disease management models that capitalized on technologies to assure privacy and confidentiality have also been discussed (Brennan, 1997).

Some controversies regarding the advantages and disadvantages of care and research via electronic methods have surfaced. Many nurses have expressed concerns about the lack of affective factors and non-verbal cues of face-to-face communications when conducted by computers. Walther (1992) was one researcher that has been critical of computer mediated communication. Jones (1995) however, was one of several researchers who have questioned the assumption that face-to-face communication is the "ideal" against which other forms are measured. Brennan (1996; 1997) showed that many times the messages do include content that is highly emotional and maintained that, despite challenges of depersonalization and

emotional distance, electronic communication appeared surprisingly affective, purposeful, and particularistic. Murray (1995a) also found that nurses on the NURSENET listserv felt safe and confident in presenting themselves to others and often exposed aspects of themselves that they might be less willing to do in face-to-face situations.

Additional arguments for the value of the Internet were related to several advantages that included availability 24-hours a day, low cost, and the capability of reaching thousands of people simultaneously. Advantages described included: the speed of e-mail communication; the fact that differing time zones or work schedules could be accommodated; and that the entire communication interaction already existed as electronic text eliminated the need for text to be transcribed for research purposes. Some have argued that the research itself will necessitate changes to existing research practices and the development of new and innovative methods for conducting and analyzing research and disseminating the results were needed (Murray 1995b; Skiba, 1993; Toler, 1997; Wilmonth, 1995; Woolery & Yensen, 1995).

These changes have been evolving as more studies are being conducted.

#### **Synthesis**

In this chapter, literature was presented that demonstrated the wide use and pertinent research of Orem's Self-Care Deficit Nursing Theory. The theory was used in many settings across North American and around the world and has been recognized as an acceptable model in nursing. Research studies were presented related to the many concepts of the theory and development of scales to measure these concepts. Self-care actions, self-care abilities and assessment of self-care abilities were presented for a variety of conditions and populations.

Specifically the basic conditioning factors, age, gender, race, educational level and household income were described. Based upon the literature these basic conditioning factors influenced the person's self-care requisites as well as their self-care agency. The supportive educative nursing system was described as the appropriate system to use for consumers to obtain information related to their self-care or dependent care needs.

Historically, information technology applications in health care were focused on acute care settings and physician-delivered patient care in hospitals. Little attention was directed toward population-based health care. Increasingly the field began to emphasize health informatics, which had a broader multidisciplinary focus on health services delivery. This focus also included community needs assessment, population health status indicators, health promotion, and disease prevention, in addition to the treatment of illness (Hannah, 1995; Henry, 1995; Morris, et al., 1997).

Few studies have been conducted that blended Orem's theory with the development of information systems (Bliss-Holtz, 1996; Bliss-Holtz et al., 1992; Bliss-Holtz, Taylor et al., 1990). Although not specifically designed from Orem's theory, information technology was successfully used to provide information, support and education for consumers in order to support self-care and dependent care abilities (Brennan, Moore, et al., 1991; 1992; 1995; Brennan, Ripich, et al., 1991).

Although research findings differed, Orem's theory appeared to be appropriate to use across a comprehensive population such as accessed by the WWW. Cyber-research was recognized as still in its infancy and standards of rigor were not well established, but evolving as this study took place. No studies were found that specifically addressed information

retrieval of consumers on the WWW with Orem as a theoretical framework. This study was conducted to investigate the information retrieval of consumers that used NetWellness<sup>®</sup>, a web based consumer health information network, within Orem's Self-care Deficit Nursing Theory. It was proposed that NetWellness<sup>®</sup> was an appropriate resource within the supportive educative nursing system to provide information to consumers related to their self-care needs.

# Chapter III

#### Methodology

The methods used for this research are presented in this chapter. The research design, description of the sample, methods of measurement, and data collection procedures are presented below. The chapter continues with a brief explanation of the analyses used to answer the research questions and concludes with a statement regarding human subjects.

#### Research Design

This descriptive study utilized a cross-sectional survey design to assess information retrieval patterns of individuals using NetWellness<sup>®</sup>. The purpose of the study was to determine if there were differences in information retrieval patterns associated with basic conditioning factors identified as age, gender, race, household income, and educational levels by self-care and dependent care agents.

# <u>Sample</u>

A convenience, self-selected sample of 307 participants accessed NetWellness® and completed the on-line questionnaire during a three-month period from September to December of 1996. The number of subjects in the analyses varied from 215 to 301 depending on how many participants completed the items being considered. Although the issue of randomly selecting respondents was discussed, a strategy for accomplishing randomization was not identified for this web-based research. Experts on the evaluation team determined that it would be more appropriate to include all participants within a specified time frame to assure that rapid changes within the web environment and changes that might occur within NetWellness® did not confound the survey results.

## Methods of Measurement

This study utilized the NetWellness® project evaluation database for secondary analyses of data. This database was created as part of the demonstration project evaluation plan for the NTIA/TIIAP Grant Award No. 39-40-94081 and was determined to be appropriate for this study. The investigator participated with the evaluation team and questions that reflected information necessary to answer the research questions for this study were included in the questionnaire.

An on-line self-selected survey (Appendix A) was presented to users, which queried about their information needs, their encounters with the system, and demographics. These data were compared with the transaction log analyses, provided by the Interse software, to obtain a picture of how various categories of participants used NetWellness® resources.

The on-line survey was developed by a multidisciplinary group composed of nurses with expertise in informatics and evaluation research, library science specialists, a survey specialist with expertise in public policy research, along with system and technical team members. For ease of completion several questions were designed to branch, depending on the previous answer, so the participant was presented only applicable questions.

Approximately 20-25 short multiple choice or fill-in-the-blank questions were presented, depending on the branching necessitated by higher level questions. An opportunity for openended suggestions was also included.

Content validity of the survey was based on the comparison of all items in the survey being evaluated against the purpose and intent of the survey on the a priori evaluation plan.

The multidisciplinary expertise on this project provided many years of previous experience in

developing similar surveys. Many revisions of the survey were made by the independent and group process of testing each question based on the intent of the evaluation plan and categories of responses needed in order to answer those questions.

# **Human Subjects:**

The primary source of data included a statement at the beginning of the on-line questionnaire, which indicated the confidentiality of data as well as the fact that completing the questionnaire would be considered implied consent. In addition, as an initial step to accessing NetWellness<sup>®</sup>, each individual read and acknowledged that information retrieved from NetWellness<sup>®</sup> was general in nature and not to take the place of consultation with their personal health care provider.

#### **Data Collection**

Participants accessed NetWellness<sup>®</sup> in three different ways: from the Internet, via the WWW protocol; through a regional community network (in many cases a Free-Net) such as Tri-State On-Line, or through one of 43 public access sites. When someone accessed NetWellness<sup>®</sup> they were informed of the survey by a banner requesting them to click on it if they were willing to complete the questionnaire (Appendix A). The NetWellness<sup>®</sup> questionnaire could also be self-selected at any major menu selection, or at the end of the session. Respondents were asked to complete the questionnaire only once.

During the data collection period there was not a method to determine the "start" and "stop" of a given user's session. Post hoc interpretation of potential patterns of usage was achieved through the use of a software product, Interse Market Focus. This on-line software (Interse) automatically collected data from the log files related to access, estimated time of

each session, applications accessed, and time spent on each application as well as the IP address and pattern of applications followed.

The survey file contained the user's responses to the online survey questions and a time and date stamp of when the survey was completed. After loading the web log file and the survey file into a Microsoft Access database, user access patterns were produced. Identifying the file names associated with each survey file generated access patterns. The survey was composed of several different web pages; each page was a different file on the web server. Structured Query Language (SQL) queries in Access joined the web log database table with the survey database table where the time the survey file was accessed was within the same hour of the web log table time stamp. In this same query, the accesses by IP address and time were grouped to reveal the user patterns. Capture of the IP address, survey file name, time and date stamps and survey results of all users who had taken the survey were grouped by IP address and time/date.

#### Methods for Analysis

After reviewing the initial data (questionnaires, log files, and linked log-questionnaire files) preparations were made for tabulating the data. Although the log files and surveys were linked, manual tallies were required to summarize the information retrieval utilization patterns.

Evaluation of these tallies required revising the categories that were included in the original information retrieval patterns. The information retrieval patterns originally included multiple disease specific categories. These multiple categories resulted in many cells having

very few or no responses. The data were then revised so that all individual disease specific categories were collapsed into a single category identified as Condition Specific.

Evaluation of the data required revisions or elimination of some of the proposed questions due to insufficient responses or changes in accessing the questionnaire from a local area network to the WWW. The original proposal for question one was to examine the relationship between the pattern of information retrieval on NetWellness® and the types of care agents, identified as self-care agent, dependent care agent, nursing agent and health care professional agent. Examination of the data revealed that very few participants identified themselves as health care professional agents and there were no nursing agents identified. Therefore, question one was revised to evaluate the differences between the pattern of information retrieval on NetWellness® and the types of care agents, identified as self-care agent and dependent care agents. These nominal level data were evaluated using frequency tables and chi square analysis.

The second question was to look at the differences between the pattern of information retrieval on NetWellness® and basic conditioning factors, identified as: age, gender, race, household income, and educational level. The intended analysis of these basic conditioning factors was modified due to the numbers represented in each category. The original groupings for age (12-17, 18-22, 23-29, 30-39, 40-49, 50-59, 60-69) were revised to include 12-17, 18-39, 40-59, and 60-89 years of age. The original categories for race (African-American, American Indian, Mexican, Asian, and Caucasian) were limited to two categories (Caucasian and other). This revision was made due to 261 of the total sample being Caucasian leaving only 40 participants as other; only a few subjects were represented in each

of the represented categories for race. Due to the number of responses in each category for educational level (<H.S., H.S., some college/associate degree, college, some graduate school, graduate degree) data were collapsed into three categories (H.S. graduate and below, some college/college degree, and some graduate school/graduate degree). The analysis of the basic conditioning factors identified in question two included frequency distributions and chi square analysis.

Due to the number of subjects in each cell question three was also revised to look at differences rather than relationships between the pattern of information retrieval and the purposes for accessing NetWellness<sup>®</sup>. The purposes were identified by the care agent as curiosity/browsing, healthy lifestyle, newly identified health concern/injury, chronic health concerns, or educational assignment. Frequency tables were created, with no further analyses, since subjects could select more than one category for this question.

Question four was designed to simply describe the action taken by individuals who had previously used NetWellness®. A frequency table was used to present this information.

Question five was designed to determine if there were differences between the type of care agents and level of satisfaction with information retrieval on NetWellness<sup>®</sup>. A frequency table was created to show frequencies and percentages by care agents. At test was also conducted to determine differences in level of satisfaction between self-care and dependent-care agents.

Question six was designed to identify categories of questions that were directed to the experts on NetWellness<sup>®</sup>. Although the original question was intended to identify self-care and dependent-care needs, links between the specific "Ask an Expert" questions and the

surveys were not possible. Analyses was then completed by reviewing all of the questions during the study time period and categorizing them according to the questions asked and if they were obtaining this information for their own use or for someone else. Although a question regarding whom the information was for was not specifically asked, essentially all of the questions began with statements that would categorize the individual as seeking information for themselves or others. Examples included statements such as - I have recently been diagnosed with, or my child is 14 months and isn't doing some type of behavior, or since my mother started taking some type of medication. Frequency tables were then created to present the findings by categories and if they were seeking the information for self or others.

A seventh question was eliminated due to the change created by accessing NetWellness<sup>®</sup> through the WWW. Originally, differences in the local geographic areas, categorized as urban, suburban, and rural identified through zip codes were to be considered and included in the analyses. However, when NetWellness<sup>®</sup> and the questionnaire were placed on the WWW, the categorization through zip codes was not meaningful.

## <u>Limitations of Design</u>

This research study was part of a much larger evaluation project and as such, it was not possible to design the survey specifically for the research questions of interest to the investigator. Although the investigator was part of the evaluation team and was able to influence the inclusion of some specific questions, the limitations often experienced in secondary analysis of data were still present.

This study had many of the known difficulties that are inherent when using convenience samples and self-selected surveys. In addition, the study was limited by the necessary time restrictions; this resulted in fewer subjects being represented in each of the categories than necessary for associations and relationships to be analyzed.

Research utilizing on-line questionnaires was very new; this created a major design limitation for this study. There were no established standards of rigor with regard to research using advance technology such as the WWW to gather data. In addition, due to the rapidly changing technological developments, better methods for retrieving and summarizing the collected data are currently available that were not possible at beginning of the study.

## Chapter IV

# Findings and Discussion

In this chapter results of the study are presented and discussed. The chapter begins with a description of the sample, and is followed with the presentation and analysis of the six research questions. The chapter concludes with a discussion of these findings.

# Sample

A total of 307 NetWellness® users elected to complete the survey questionnaire during the three-month data collection period. Of the 307 users, the number of subjects in the analysis differed depending on how many people responded to the specific items. The mean age of these respondents was 41 with a standard deviation of 15. The median age was 43 years and the mode was 49 years of age. The youngest was 12 and the oldest 85. Slightly more women (52.5%) than men (47.5%) completed the survey (NetWellness® Project Report, 1997).

More than 57% of the sample had completed college or had higher levels of education. Twelve percent (12%) of the participants had a high school education or less with 27% reporting some college or an associate degree. Eighteen and one-half percent (18.5%) had completed college; 10% reported some graduate school, and 29% had graduate or professional degrees. The remaining 3% reported did not specify (NetWellness® Project Report, 1997).

Income levels indicated that 44% had household incomes greater than \$45,000. The reported household income responses were: 20% reporting less than \$29,999, 14% with \$30-

44,999, 13% with \$45-59,999, and 31% reported an income of \$60,000 or more. Twenty-two percent (22%) did not respond to the item. (NetWellness® Project Report, 1997).

From the 307 participants, 215 were identified as self-care or dependent care agents.

Table 1 summarizes the characteristics of these 215 respondents by the basic conditioning factors that were studied.

Table 1: Summary of Care Agent by Basic Conditioning Factor

Basic Con	ditioning Factors	Self-Care Agent	Dependent Care Agent	Totals	Missing Data
		(N=156)	(N=59)	(N=215)	
Gender					
Male	(N=127)	70	13	83	44
Female	(N=145)	80	46	126	19
Missing Dat	ta (N= 35)	6			
Age					
12-17 Yr.	(N=17)	11	1	12	5
18-39 Yr.	(N=99)	55	21	76	23
40-59 Yr.	(N=129)	69	26	95	34
60-89 Yr.	(N=28)	17	5	22	6
Missing Dat	ta (N= 34)	4	6		
Race					
Caucasian	(N=261)	126	37	163	98
Other	(N=40)	20	3	23	17
Missing Dat	ta (N= 6)	10	19		
Household					
Income					
<\$15,000	(N=27)	13	5	18	9
	,999 (N=35)	24	5	29	6
\$30,000-44	,999 (N=45)	24	9	33	12
	,999 (N=39)	19	11	30	9
>\$60,000	(N=94)	54	20	74	20
Missing Dat	a (N=67)	22	9		
Education					
H.S. Grad &	Below (N=33)	23	3	26	7
Some Colle	ge/	68	32	100	18
College Deg					
Some Grad	School/	55	21	76	29
Grad Degree	e (N=105)				
Missing Dat	ta (N= 51)	10	3		

 $\underline{\text{Note}}$ : The numbers in parenthesis in the basic conditioning factor column represent the number of participants in the total sample

There were more women than men who participated in both care agent categories. Fifty-three percent of self-care agents were women and 47% of men were identified as self-care agents; 78% of dependent care agents were women and 22 % of men were identified as dependent care agents. A larger percentage of missing data was observed for males (35%) than for females (13%).

The age distributions for self-care agents approached a normal distribution (7% for 12-17, 36% for 18-39, 46% for 40-59 and 11% for the 60-89 years of age). The extremes were less represented in the dependent-care agents (2% for the 12-17, 40% for 18-39, 49% for 40-59, and 9% for 60-89 years of age). The majority of both self-care agents and dependent-care agents were between 18 –59 years. The percentage of missing data was comparable for all age groups.

A large percentage of respondents (86% for self-care agents and 93% for dependent care agents) identified themselves as Caucasian. The original questionnaire included the racial categories of African-American, American Indian, Mexican/Hispanic, and Asian.

However the individual numbers for each of these categories (African American, 9; American Indian, 5; Mexican/Hispanic, 5; and Asian, 11) in the total sample were too small to analyze individually and the data were collapsed into the other category. The highest group for missing data was in the race category - 38% for Caucasians and 42.5% of others.

As represented in Table 1, more than 50% of the self-care agents and dependent-care agents had household incomes of higher than \$45,000. In contrast 10% of both self-care and dependent care agents reported household incomes of less than \$15,000. Another 10% of the self-care agents and 18% of dependent care agents reported household incomes of \$15,000 to

\$29,999. Eighteen percent (18%) of self-care and dependent care agents reported household incomes of \$30,000 to \$44,999, and 14% of self-care agents and 22% of dependent care agents reported incomes of \$45,000 to \$59,999. Forty percent (40%) of self-care agents and (44%) of dependent-care agents had incomes of greater than \$60,000.

Educational levels corresponded with the income levels of the self-care and dependent care agents. Fifteen percent (15%) of the self-care agents listed high school graduation or below as the highest level of education compared to 5% of the dependent care agents. Forty-seven percent (47%) of self-care agents had some college or a college degree and 38% had graduate education or professional degree. Fifty-seven percent (57%) of the dependent-care agents had some college or a college degree and 38% had a graduate or professional degree.

#### Findings

## Research Question 1

What was the difference between the usage pattern of information retrieval on NetWellness® and the types of care agents, identified as self-care agent or dependent care agent? This question was answered by analyzing the usage pattern of information retrieval by the care agents in two ways. The first was to identify categories that were first selected by the care agents and the second was to evaluate the category most frequently selected. Three tables were used to present the analysis. Table 2 presents the ranking and percentage of the first selected category by care agents. Table 3 presents the percentage and chi square analysis of the first selected category by care agents, and Table 4 presents the most frequently selected categories and the means for the average number of categories the care agents selected.

Table 2: Ranking for First Selected Category and Percentages by Care Agents

			A	gents				
Category First Selected		f-Care (N = 15	_	Dependent Care Agent (N=59)			Totals (N=215)	
	Rank	f	%	Rank	f	%	f	%
Condition Specific	1	37	26%	1	19	34%	56	28%
PDR	2	33	23%	4	11	20%	44	22%
Hot Topics	3	29	20%	2.5	12	21%	41	20%
Ask an Expert	4	22	15%	2.5	12	21%	34	17%
Health Literature	5	15	10%	5	2	4%	17	9%
News	6	8	6%	6	0		8	4%
Missing Data		12			3		15	

<u>Note</u>: N in parentheses = Total number of self-care/dependent care agents

The category for Condition Specific included all sites that were associated with specific diseases or health care concerns, such as cancer, stroke, diabetes, and arthritis. As presented in Table 2, self-care agents (26%) and dependent-care agents (34%) selected Condition Specific first; PDR, Hot Topics, and Ask an Expert were ranked second, third or fourth for both categories. However, there were only four frequencies separating the first and second selected category by self-care agents; only four frequencies separated the second, third, and fourth categories for dependent care agents. Health Literature had few numbers in both categories, ranking fifth and News was last for self-care agents and was not selected first by any dependent care agent.

Self-care agents and dependent care agents had similar patterns of information retrieval for first selected categories with the exception of Health Literature and News.

Although they represented the fifth and sixth ranked categories for both types of agents, 16%

of self-care agents first selected these categories compared to only 4% of the dependent-care agents. As shown in Table 3, no statistically significant differences were found between the self-care agents and dependent care agents and the first categories selected on NetWellness<sup>®</sup>.

The pattern for most frequently selected categories by self-care and dependent care agents is presented in Table 4. The self-care agents' and dependent-care agents' rankings were the same with Condition Specific and Ask an Expert categories ranked first and second. For dependent-care agents, the rest of the categories had fewer frequencies with only a few numbers separating the categories; self-care agents were similar except for News, which had significantly fewer numbers. The average number of category pages selected was 3.4 for self-care agents and 3.9 for dependent care agents.

Table 3: Percentage of Self-care and Dependent Care Agents That First Selected NetWellness® Categories

Agents									
Category First Selected	SCA (N=156)	DCA (N=59)	$\chi^2$	ρ					
Condition Specific	26%	34%	1.600	.206					
PDR.	23%	20%	.166	.684					
Hot Topics	20%	21%	.085	.771					
Ask an Expert	15%	21%	1.251	.263					
Health Literature	10%	4%	2.279	.131					
News	6%		3.143	.076					

Table 4: Ranking for Most Frequently Selected Categories By Care Agents

		Age	ents	
	Self-Ca	are Agent	Dependent	Care Agent
Most Frequently Selected Category	(N =	= 156)	(N=	=59)
	Rank	f	Rank	f
Condition Specific	1.	159	1.	91
Ask an Expert	2.	88	2.	39
Hot Topics	3.	80	3.	29
Health Literature	4.	78	4.	25
PDR	5.	75	5.	24
News	6.	46	6.	20
Total		526		228
Mean		3.4		3.9

Note: N's in parentheses = total number of participants in agent category

Frequency for Condition Specific greater than N due to multiple Condition Specific categories selected by some self-care and dependent care agents

## Research Question 2

What was the difference between the usage pattern of information retrieval on NetWellness® and basic conditioning factors, identified as: age, gender, race, household income, and educational level? This research question was answered by analyzing the usage pattern of information retrieval by each of the basic conditioning factors in two ways. The first selected categories and most frequently selected categories were compared across basic condition factors.

Three types of tables were used to present the analysis for each of the basic conditioning factors - age, gender, race, household income, and educational level. Rankings and percentages for the first selected category by basic conditioning factors are presented in Tables 5 (age), 8 (gender), 11 (race), 14 (household income), and 17 (educational level). Percentages and chi square analysis are presented in Tables 6 (age), 9 (gender), 12 (race) 15 (household income) and 18 (educational level). Most frequently selected categories by basic conditioning are presented in Tables 7 (age), 10 (gender), 13 (race), 16 (household income), and 19 (educational levels).

Table 5: Ranking for First Selected Category and Percentages by Age Groups

						A	ge							
Category First Selected	12-17 Yr. (N=17)		18-39 Yr. (N=99)		40-59 Yr. (N=129)		60-89 Yr. (N-28)		Total (N=273)					
Sciected	Rank	f	%	Rank	f	%	Rank	f	%	Rank	f	%	f	%
Condition Specific	1.5	6	43%	1	24	26%	1	37	32%	1	9	32%	76	30%
Hot Topics	1.5	6	43%	4	15	16%	3	22	19%	4	4	14%	47	19%
News	3	2	14%	6	6	6%	6	6	5%	6	1	4%	15	6%
PDR		0	-	2.5	18	19%	2	25	22%	3	5	18%	48	19%
Health Literature		0		5	12	13%	5	12	10%	5	2	7%	26	10%
Ask An Expert		0	-	2.5	18	19%	4	13	11%	2	7	25%	38	15%
Total		14			93			115			28		250	

Note: N in parentheses = total number of participants in this category for age group

Difference between the number of categories selected and number of participants in age group reflects either missing data or participants did not first select any of the listed categories

It is important to note in Table 5 that the number of participants for the 12-17 years were low and may not be representative for this age range. Condition Specific was ranked first across all age ranges, except the 12-17 years; they had the same number for Condition Specific and Hot Topics and this group did not first select three categories – PDR, Health Literature and Ask an Expert. News was ranked last for all age groups. In the 18-39 year group, Ask an Expert and PDR had the same numbers and percentages, which put them at the same rank. However, only six numbers separated the second through the fifth rankings for this age category. In the 40-59 year group PDR was ranked second, followed by Hot Topics, Ask an Expert, Health Literature and News. In the 60-89 year group, 32% ranked Condition Specific first and 25% selected Ask an Expert second, however these percentages represented low numbers with only eight frequencies separating all six first selected categories.

There were some differences observed in pattern of information retrieval on NetWellness® by the different age groups. It is interesting to note that 25% of the 60-89 year group selected Ask an Expert first while none selected it first in the 12-17 year group. As seen in Table 6, there was a statistically significant finding at the .05 level ( $\chi^2$  =8.708; p=.033) for "Ask an Expert" as the first selected category by basic conditioning factor: age. However this result needs to be viewed cautiously due to the possibility of Type I error associated with multiple statistical tests.

Table 6: Percentage of Participants That Selected Various NetWellness® Categories First by Basic Conditioning Factor - Age

Age									
Category First Selected	Age (12-17 Yr.) (N=17)	Age (18-39 Yr.) (N=99)	Age (40-59 Yr.) (N=129)	Age (60-89 Yr.) (N=28)	$\chi^2$	ρ			
Condition Specific	43%	26%	32%	32%	1.412	.703			
Hot Topics	43%	16%	19%	14%	4.365	.225			
News	14%	6%	5%	4%	1.724	.632			
PDR	0%	19%	22%	18%	3.940	.268			
Health Literature	0%	13%	10%	7%	2.756	.431			
Ask an Expert	0%	19%	11%	25%	8.708	.033*			

Note: \* p < .05

The pattern of information retrieval represented by the most frequently selected categories across age groups is presented in Table 7. The first selected category across all age groups was Condition Specific. Ask an Expert was in second or third place across all categories; however in the 12-17 year group only six frequencies separated the second through sixth ranked categories. In the 18-39 year group larger differences in frequencies were seen between the second ranked Ask an Expert (60) and the third, fourth, and fifth ranked categories (Hot Topics, 47; Health Literature, 44; PDR, 40). In the 40-59 year group, the frequencies were closer between the second ranked Health Literature (71) and third place Ask an Expert (69). The fourth and fifth ranked categories, Hot Topics (60) and PDR (57), were also close in frequencies with News having few numbers and ranked last. For the 60-89

year group after the second ranked Ask an Expert (25), the rest of the categories most frequently selected had relatively few and close numbers. The average number of category pages selected by all age groups was 3.3 to 3.6 with the exception of the older group that selected an average of almost 5 categories.

Table 7: Ranking for Most Frequently Selected Categories By Basic Conditioning Factor – Age

				Aş	ge			
	12-17 Yr. (N=17)		18-	18-39		-59	60-8	39
			(N=99)		(N=	129)	(N=28)	
Most Frequently								
Selected Category	Rank	f	Rank	f	Rank	f	Rank	f
Conditions Specific	1.	27	1.	119	1.	173	1.	49
Hot Topics	2.	10	3.	47	4.	60	3.	19
Ask an Expert	3.	9	2.	60	3.	69	2.	25
News	4.	8	6.	29	6.	35	5.5	15
PDR	5.	7	5.	40	5.	57	5.5	15
Health Lit.	6.	4	4.	44	2.	71	4.	16
Total		65		339		465		139
Mean		3.8		3.4		3.6		4.9

N's in parentheses = total number of participants in age group

Frequency for Condition Specific greater than N due to multiple Condition Specific categories selected by some participants in age group

Table 8 represents the first selected category by gender. Both men and women ranked Condition Specific first and Ask an Expert, Health Literature, and News as fourth, fifth and sixth. Hot Topics was ranked second by men and third by women; PDR was ranked third by men and second by women.

Table 8: Ranking for First Selected Category by Basic Conditioning Factor - Gender

Gender								
Category First Selected	N (N:	Female (N=145)			Total (N=272)			
	Rank	f	%	Rank	f	%	f	%
Condition Specific	1	30	27%	1	43	31%	73	29%
Hot Topics	2	24	21%	3	23	17%	47	19%
PDR	3	21	19%	2	28	20%	49	20%
Ask an Expert	4	19	17%	4	21	16%	40	16%
Health Literature	5	14	12%	5	13	9%	27	11%
News	6	5	4%	6	9	6%	14	5%
Total		113			137		250	

Note: N in parentheses = total number of participants in this group for gender

Difference between the number of categories selected and number of participants in gender group reflects
either missing data or participants did not first select any of the listed categories

The pattern of information retrieval represented by the first selected category was similar for both men and women. As presented in Table 9, there were no statistically significant differences between men and women for the first selected category.

Categories First by Basic Conditioning Factor- Gender Gender  $\chi^2$ Male Female ρ Category First (N=127)(N=145)Selected Condition Specific 31% 1.255 .263 27% **Hot Topics** 21% 17% .436 .509 PDR 19% 20% .353 .552 17% .012 .912 Ask an Expert 16% Health Literature 12% 9% .321 .571 News 4% 6% .714 .398

Table 9: Percentage of Participants That Selected Various NetWellness®

The most frequently selected categories by both genders are presented in Table 10. Condition Specific was ranked first by both men and women; Ask an Expert was ranked second for women and third for men; Health Literature was ranked second for men and fourth for women; and Hot Topics was ranked fourth for men and third for women. PDR and News were ranked fifth and sixth by both genders. In both the male and female groups there was a large difference in frequencies between the first ranked Condition Specific and second ranked categories selected. For males the frequencies for second through fifth categories had a narrower distribution (78 through 63) while the female group was more evenly distributed (84 through 57). The average number of pages selected by men was 3.9 and women 3.5.

Table 10: Ranking for Most Frequently Selected Categories
By Basic Conditioning Factor - Gender

			Gender		
	M	ale		Fen	nale
Most Frequently Selected Category	(N=	127)		(N=	145)
	Rank	f		Rank	f
Conditions Specific	1.	174		1.	182
Health Lit.	2.	78		4.	68
Ask an Expert	3.	75		2.	84
Hot Topics	4.	69		3.	72
PDR	5.	63		5.	57
News	6.	39		6.	44
Total		498			507
Mean		3.9			3.5

Note: N's in parentheses = total number of participants in gender group

Frequency for Condition Specific greater than N due to multiple Condition Specific categories selected by some participants in gender group

Although Caucasians represented almost 87% of the total participants for the race category, Table 11 indicates that Condition Specific was the first selected category by both Caucasian and other (which included the racial categories of African-American, American Indian, Mexican/Hispanic, and Asian). There was a wide margin between the frequencies for first and second selected categories for Caucasian; only three frequencies separated the second through the fourth categories (PDR, Hot Topics, and Ask an Expert). There was also a wide margin between first selected and the next categories, for the other race group with four of the selections PDR, Hot Topics, Ask an Expert and News having the same frequencies. Health Literature was fifth for Caucasian and sixth for the other race group.

Table 11: Ranking for First Selected Category and Percentages by Basic Conditioning Factor-Race

			Ra	ice				
Category First Selected	Caucasian (N=261)			Other (N=40)			Total (N=301)	
	Rank	f	%	Rank	f	%	f	%
Condition Specific	1	77	31%	1	18	45.0%	95	33%
PDR	2	46	18%	3.5	5	12.5%	51	18%
Hot Topics	3	45	18%	3.5	5	12.5%	50	17%
Ask an Expert	4	43	17%	3.5	5	12.5%	48	17%
Health Literature	5	24	10%	6	2	5.0%	26	9%
News	6	14	5%	3.5	5	12.5%	19	6%
Total		249			40		289	

Note: N in parentheses = total number of participants that were Caucasian and other

Difference between the number of categories selected and number of participants in race group reflects either missing data or participants did not first select any of the listed categories

A chi-square analysis is presented in Table 12 that depicts the difference between the pattern of information retrieval on NetWellness® and the basic conditioning factor: race.

Although the actual frequencies are very different, the pattern of information retrieval by race

categories has some similarities. Forty-five percent of the other racial category and 31% of Caucasians first selected Condition Specific. A significant difference at the .05 level was calculated using a Chi-Square analysis for Condition Specific as the first selected category by race ( $\chi^2$ =3.857; p=.05). However, the uneven distribution between the two groups for race led to caution related to interpretation of these findings.

Table 12: Percentage of Participants That Selected Various NetWellness® Categories First by Basic Conditioning Factor – Race

	Rac	ce		
Category First Selected	Caucasian (N=261)	Other (N=40)	$\chi^2$	ρ
Condition Specific	31%	45.0%	3.857	.050*
PDR	18%	12.5%	.647	.421
Hot Topics	18%	12.5%	.563	.453
Ask an Expert	17%	12.5%	.409	.523
Health Literature News	10% 5%	5.0%	.774 2.987	.379
Tiews	5 70	12.5/0	2.701	.004

<u>Note</u>: \* p < .05

Table 13 presents the most frequently selected category by race; Condition Specific again ranked first in both groups. In the Caucasian group, Ask an Expert was clearly the second choice with Hot Topics and Health Literature closely ranked for third and fourth categories. In the other group by race second place was Hot Topics however there was only one frequency separating the categories of Ask an Expert, Hot Topics, and Health Literature. PDR and News ranked fifth and sixth for most frequently selected in both categories. The

average number of category pages selected was 3.2 for Caucasian and 3.7 for the other race group.

Table 13: Ranking for Most Frequently Selected Categories By Basic Conditioning Factor – Race

		Race	<b>;</b>		
Most Frequently Selected Category	Cauc (N=2	Otl (N=		Total (N=301)	
Selected Category	Rank	f	Rank	f	f
Condition Specific	1	302	1.0	52	354
Ask an Expert	2	131	3.5	21	152
Hot Topics	3	116	2.0	22	138
Health Literature	4	118	3.5	21	139
PDR	5	100	5.0	16	116
News	6	65	6.0	14	79
Total		832		146	978
Mean		3.2		3.7	3.2

Note: N's in parentheses = total number of participants in race group

Frequency for Condition Specific greater than N due to multiple Condition Specific categories selected by some participants in race group

Table 14 presents the pattern of information retrieval, represented as the first selected category, by household income. Condition Specific was ranked first for all income groups except the greater than \$60,000 group which ranked PDR first. However, these rankings may be misleading since there are small differences within several of the income groups. In the less than \$15,000 first ranked Condition Specific and second ranked Hot Topics were

separated by only one frequency. First ranked Condition Specific and second ranked Ask an Expert were also separated by only one frequency for the \$45,000-59,999 income group; first ranked PDR and second ranked Condition Specific were also separated by only one frequency for the greater than \$60,000 income group. After the first and second frequencies in the greater than \$60,000 group, the third place numbers dropped off significantly. Clearer differences between first and second place were also seen in the \$15,000-29,999 and \$30,000-44,999 groups. Many of the frequencies from third to sixth place categories in all except the two highest income groups were very close.

As seen in Table 15, there were no significant differences found between household income groups and the pattern of information retrieval represented by first selected categories. Table 16 presents the most frequently selected categories by income groups. Many more people were represented in the greater than \$60,000 income group, and had substantially more total categories selected than any other group. Condition Specific was clearly the first choice among all income groups with a large difference between the first and second ranked categories in all income groups. Ask an Expert was ranked second by the less than \$15,000 and \$45,000-59,999 groups with close frequencies for the third through sixth ranked categories. Hot Topics was ranked second for the \$15,000-29,999 group with the third through sixth ranked numbers close together. Second ranked categories for the \$30,000 – 44,999 and greater than \$60,000 income groups were not clearly defined since the numbers for the second through fifth ranked categories were so close. The average number of pages selected by all income groups ranged from 3.5 to 4.0.

Table 14: Ranking for First Selected Category and Percentages by Household Income Groups

Category	(	\$15,0 (N=27			000-29 (N=35)	*	\$30,	ehold Ir ,000-44 (N=45)	,999		000-59 (N=39)	*		\$60,00 (N=94		) Total (N=240)	
First Selected	i Rank	f	%	Rank	f	%	Rank	F	%	Rank	f	%	Rank	f	%	f	%
Condition Specific	1	8	33%	1	11	35%	1	15	36%	1	10	28%	2	23	27%	67	31%
Hot Topics	2	7	29%	2	6	19%	4	6	14%	3.5	7	19%	3	16	19%	42	19%
Ask an	3	4	17%	6	2	6%	2	7	17%	2	9	25%	4	13	15%	35	16%
Expert PDR	4.5	2	8%	3	5	16%	4	6	14%	3.5	7	19%	1	24	28%	44	20%
Health	4.5	2	8%	4	4	13%	4	6	14%	6	1	3%	5	7	8%	20	9%
Literature News	6	1	4%	5	3	10%	6	2	5%	5	2	5%	6	4	4%	12	5%
Total		24			31			42			36			85		218	

Note: N in parentheses = total number in this household income category

Difference between the number of categories selected and number of participants in household income group reflects either missing data or participants did not first select any of the listed categories

Table 15: Percentage of Participants That Selected Various NetWellness® Categories First by Basic Conditioning Factor - Household Income

	2						
First Category	<\$15,000	\$15,000- 29,999	\$30,000- 44,999	\$45,000 59,999	>\$60,000	$\chi^2$	ρ
Selected	(N=27)	(N=35)	(N=45)	(N=39)	(N=94)		
Condition Specific	33%	35%	36%	28%	27%	1.566	.815
Hot Topics	29%	19%	14%	19%	19%	1.892	.756
Ask an Expert	17%	6%	17%	25%	15%	4.547	.337
PDR	8%	16%	14%	19%	28%	6.544	.162
Health Literature	8%	13%	14%	3%	8%	3.738	.443
News	4%	10%	5%	5%	4%	1.176	.882

Table 16: Ranking for Most Frequently Selected Categories By Basic Conditioning Factor - Household Income

					]	Household	Income				
Most Frequently Selected Category	<\$15,000 (N=27)		\$15,000 - 29,999 (N=35)		\$30,000-44,999 (N=45)		\$45,000-59,999 (N=39)		>\$60,000 (N=94)		Total (N=240)
, and the second of the second	Rank	Freq.	Rank	Freq.	Rank	Freq.	Rank	Freq.	Rank	Freq.	Freq.
Condition Specific	1.0	42	1.0	52	1	62	1	50	1	114	320
Ask an Expert	2.0	17	4.5	16	3	24	2	26	3	53	136
Health Literature	3.5	13	3.0	17	2	27	5	14	4	48	119
Hot Topics	3.5	13	2.0	24	4	23	3	18	2	54	132
News	5.0	11	4.5	16	6	0	6	12	6	25	64
PDR	6.0	6	6.0	15	5	21	4	17	5	45	104
Total		102		140		157		137		339	875
Mean		3.8		4.0		3.5		3.5		3.6	3.6

Note: N's in parentheses = total number of participants in household income group

Frequency for Condition Specific greater than N due to multiple Condition Specific categories selected by some participants in household income group

Pattern of information retrieval, represented by first selected categories, by level of education is presented in Table 17. Condition Specific as the first selected category was ranked first for all educational groups. Hot Topics was ranked second by the high school or below educational group, however it is important to note that the difference in first and second place was represented by only one frequency. PDR was ranked second by the college and grad degree groups. Small numerical differences were represented in the third and fourth ranked positions in these groups. News or Health Literature was in fifth or sixth place in all three groups. Educational levels were similar in the pattern of information retrieval represented by the first selected category. None of the differences between the level of education and the choice of first selected category were found to be statistically significant, as seen in Table 18.

Table 17: Ranking for First Selected Category and Percentages by Level of Education

Category First Selected	HS Grad & Below (N=33)			Educational Level Some College/ College Degree (N=118)			Gr	Grad ad Deg N=10	Total (N=256)		
	Rank	f	%	Rank	f	%	Rank	F	%	f	%
Condition Specific	1	9	28%	1	30	27%	1	28	29%	67	28%
Hot Topics	2	8	25%	3.5	21	19%	3	16	17%	45	19%
Ask an Expert	3.5	5	16%	3.5	21	19%	4	15	16%	41	17%
PDR	3.5	5	16%	2	23	21%	2	22	23%	50	21%
News	5	3	9%	6	6	5%	6	7	7%	16	7%
Health Literature	6	2	6%	5	10	9%	5	8	8%	20	8%
Total		32			111			96		239	

Note: N in parentheses = total number in this educational level

Difference between the number of categories selected and number of participants in level of education group reflects either missing data or participants did not first select any of the listed categories

Table 18: Percentage of Participants That Selected Various NetWellness® Categories First by Basic Conditioning Factor – Educational Level

		Educational Lev	vel		
First Category Selected	HS Grad & Below (N=33)	Some College/ College Degree (N=118)	Some Grad School /Grad Degree (N=105)	$\chi^2$	ρ
Condition Specific	28%	27%	29%	.068	.966
Hot Topics	25%	19%	17%	1.412	.494
Ask an Expert	16%	19%	16%	.530	.767
PDR	16%	21%	23%	.538	.764
News	9%	5%	7%	.759	.685
Health Literature	6%	9%	8%	.218	.897

Most frequently selected category by educational level is presented in Table 19. All educational groups ranked Condition Specific first. Ask an Expert was second for the college and graduate degree groups and third by the high school and below group. However, in the high school graduate and less than high school group there was only a difference of four frequencies between the second and fifth ranked categories. In the graduate group the second ranked Ask an Expert and third ranked Health Literature represented only one selection. The frequencies were more evenly distributed in the college group with Hot Topics third, Health Literature fourth, PDR fifth and News sixth. The average number of categories selected by each of the educational level groups ranged from 3.4 to 4.4 pages.

Table 19: Ranking for Most Frequently Selected Categories by Basic Conditioning Factor - Educational Level

Educational Level										
Most Frequently Selected Category	HS Grad & Below (N=33)		Some College/ College Degree (N=118)		Grad	ad School/ Degree =105)	Total (N=256)			
	Rank	Freq.	Rank	Freq.	Rank	Freq.	Rank	Freq.		
Condition	1	57	1	139	1	129	1	325		
Specific										
Hot Topics	2	21	3	62	4	54	3	137		
Ask an Expert	3	20	2	71	2	60	2	151		
PDR	4	19	5	48	5	48	5	115		
Health Literature	5	17	4	51	3	59	4	127		
News	6	13	6	35	6	31	6	79		
		147		406		381		934		
Total										
Mean		4.4		3.4		3.6		3.6		

Note: N's in parentheses = total number of participants in level of education group
Frequency for Condition Specific greater than N due to multiple Condition Specific
categories selected by some participants in level of education group

## Research Question 3

What was the difference between the usage pattern of information retrieval and the purpose identified by the care agent for accessing NetWellness®, identified as curiosity/browsing, healthy lifestyle, recent illness/injury, chronic health concerns, medication, Ask an Expert, or educational/work assignment? Table 20 presents the ranking, and percentages for the category first selected by purpose of information retrieval. The most frequently selected purpose for accessing NetWellness<sup>®</sup> was browsing with chronic problems, recent illness and medication in the middle. Healthy living and Ask an Expert were next with education/work assignments having the fewest numbers. Condition Specific was ranked first for the purposes of browsing (29%), chronic problem (48%), recent illness/injury (46%), and education/work assignment (50%). However PDR (40%) was ranked first for medication. Of the participants that indicated their purpose for accessing NetWellness® was to obtain information from Ask an Expert, 65% selected this category first. Hot Topics was ranked first (29%) for those who listed Healthy Living as their purpose for seeking information. The News or Health Literature categories were ranked last across all purposes. It is important to note that after the first or second ranked category the frequencies for the rest of the categories within the purposes were very close and had few numbers. For example in education/work assignment there were only one or two frequencies for all categories after the first ranked Condition Specific; Ask an Expert had only one or two frequencies for the third, fourth and fifth ranked categories, with none in Health Literature.

Table 20: Ranking for First Selected Category By Purpose of Information Retrieval from NetWellness®

								F	Purpose	es for In	nforma	ation Re	etrieval								
Category First Selected	Browsing (N=104)			Chronic Problem (N=59)			Recent Illness/Injury (N=76)		Medication (N=83)		Healthy Living (N=46)		Ask An Expert (N=36)		Ed/Work Assignment (N=33)						
	Rank	f	%	Rank	f	%	Rank	f	%	Rank	f	%	Rank	f	%	Rank	f	%	Rank	f	%
Condition Specific	1	22	29%	1	23	48%	1	27	46%	2.5	9	19%	2	5	18%	2	6	19%	1	8	50.0%
Ask an Expert	3	14	18%	2	9	19%	4	7	12%	4.5	4	9%	4.5	4	14%	1	20	65%	4	1	6.0%
Hot Topics	3	14	18%	4	4	8%	2	8	14%	2.5	9	19%	1	8	29%	4.5	2	6%	2	2	12.5%
PDR	3	14	18%	3	6	12%	3	8	14%	1	19	40%	4.5	3	11%	4.5	2	6%	3	2	12.5%
News	5	7	9%	5.5	3	6%	6	4	6%	6.0	2	4%	4.5	4	14%	5	1	3%	5.5	1	6.0%
Health Literature	6	5	7%	5.5	3	6%	5	5	8%	4.5	4	9%	4.5	4	14%	6			5.5	2	12.5%
Total		76			48			59			47			28			31			16	

Note: N in parentheses = total number in this category for purpose

Difference between the number of categories selected and number of participants in purpose group reflects either missing data or participants did not first select any of the listed categories

Table 21 presents the ranking, frequencies, and means for most frequently selected categories by purposes. Condition Specific was most frequently selected across all purposes identified and News was ranked last or next to last for all categories. There was a substantial difference in frequencies between Condition Specific and the second ranked categories which were Ask an Expert for chronic problem, recent illness/injury, healthy living, and Ask an Expert. Health Literature was ranked second in the browsing category however there were only two frequencies separating Health Literature and third ranked Ask an Expert for browsing. Although Ask an Expert was ranked second for the purpose Chronic Problem, there were differences of only four frequencies between this category and third and fourth ranked Health Literature and Hot Topics. After the first and second ranked categories for Recent Illness/Injury, the third and fourth ranked categories Hot Topics and Health Literature again had frequencies that were very close. As one might expect, PDR was ranked second for those accessing NetWellness® for the purpose of medication; third, fourth and fifth ranked categories within medication were Ask an Expert, Health Literature, and Hot Topics, however there was only a difference of six frequencies between these three categories. After the first and second ranked categories of Condition Specific and Ask an Expert (for the purposes of Healthy Living and Ask an Expert) the rest of the categories had very close frequencies. The means presented indicate that for all purposes of seeking information on NetWellness<sup>®</sup>, the average number of categories selected ranged between 2.7 and 4.2. with 3.4 as the average for all purposes.

Table 21: Ranking for Most Frequently Selected Categories by Purposes of Information Retrieval on NetWellness®

				Purp	oses For S	Seeking I	nformatio	on on Ne	tWellness	S <sup>®</sup>						
Categories Most Frequently Selected	Browsing (N=104)		Chronic Problem (N=59)		Recent Illness/ Injury (N=76)		Medication (N=83)		Healthy Living (N=46)		Ask The Expert (N=36)		Educational Assignment (N=33)		Total (N=437)	
Selected	Rank	f	Rank	f	Rank	f	Rank	f	Rank	f	Rank	f	Rank	f	Rank	f
Condition	1	151	1.0	103	1	98	1	66	1.0	44	1	37	1	47	1	546
Specific Health Literature	2	54	3.5	33	4	31	4	34	3.0	19	4	14	4	15	3	200
Ask an Expert	3	52	2.0	37	2	40	3	36	2.0	21	2	31	3	16	2	233
Hot Topics	4	47	3.5	33	3	35	5	30	4.0	17	4	14	2	20	4	196
PDR	5	37	5.0	22	5	26	2	49	5.5	11	4	14	6	10	5	169
News	6	34	6.0	19	6	18	6	19	5.5	11	6	9	5	12	6	122
Totals		375		247		248		234		123		119		120		1466
Mean		3.6		4.2		3.3		2.8		2.7		3.3		3.6		3.4

Note: N's in parentheses = total number of participants in purpose group

Frequency for Condition Specific greater than N due to multiple Condition Specific categories selected by some participants in purpose group

## Research Question 4

What variables/groups of variables best described those individuals who took action as a result of information obtained on NetWellness<sup>®</sup>? Fifty-two people indicated they had previously obtained information from NetWellness<sup>®</sup>. Of these, forty-six - almost 90%, indicated they had taken some behavioral actions as a result of visiting NetWellness®. Table 22 lists the frequencies and percentages of the behavioral actions taken as a result of information they had previously obtained from NetWellness®. Fifty-nine percent of the participants' actions were related to reinforced beliefs and better communication. Even though the other reported actions (making an appointment with their health care provider, seeking a second opinion, providing information to their health care provider and making lifestyle changes) had lower percentages, the potential benefit of each of these actions could be extremely important to the individual's health. Due to the small number of participants, and the instructions to check all actions that applied, along with the multiple categories included in the basic conditioning factors, no conclusions could be made regarding those individuals most likely to take actions. A summary of the actions taken by the participants, categorized by basic conditioning factors (age, gender, race, household income and educational level), is presented in Appendix B. In this summary a higher percentage of participants within the higher education and income categories took action.

Table 22: Ranking of Behavioral Actions Taken by Participants After Obtaining Information on NetWellness® (N=46)

Action	Rank	F	Percent
Reinforced Beliefs	1	17	37%
Better Communication	2	10	22%
Changed Lifestyle	3	7	15%
Gave Information To Health	4	6	13%
Care Provider			
Made An Appointment With	5	4	9%
Health Care Provider			
Sought Second Opinion	6	2	4%

# Research Question 5

What was the difference between the type of care agent and level of satisfaction with information retrieval on NetWellness®? Table 23 presents the frequencies and percentages for satisfaction, by type of care agents. Similar findings were found for both self-care and dependent care agents. Eighty-one percent of all self-care agents and 77% of dependent care agents indicated they were satisfied or extremely satisfied with NetWellness®; only 4% of all self-care and dependent-care agents indicated they were dissatisfied with NetWellness®. The groups means and SDs and the t-test results are shown in Table 24. The mean score (SD) for self-care agents was 4.21 (.875) and 4.04 (.86) for dependent care agents; there were no significant differences between self-care agents and dependent care agents and their level of satisfaction with information retrieved on NetWellness®.

25

		re Agents 156)	-	Care Agents 59)	Total (215)		
	f	%	f	%	f	%	
Extremely Satisfied	62	45%	15	29%	77	41%	
Satisfied	50	36%	25	48%	75	39%	
Neutral	20	14%	10	19%	30	16%	
Dissatisfied	5	4%	1	2%	6	3%	
Extremely Dissatisfied	1	<1%	1	2%	2	1%	

7

 $\label{eq:Note:Note} \frac{Note}{N \text{ in parentheses}} = total \text{ number of self-care or dependent care agents} \\ Difference \text{ between N and total due to missing data}$ 

18

Table 24: t Test for Differences in Level of Satisfaction with NetWellness® by Self-Care and Dependent Care Agents M M SCA SD DCA SD t p Level of .875 4.04 .86 1.251 .212 4.21 Satisfaction\*\*

Note: df = 191

Missing Data

<sup>\*\*</sup>Satisfaction was rated from 1 (extremely dissatisfied) to 5 (extremely satisfied)

# Research question 6

What care needs were identified for individuals seeking information for their own or some other person's use? Table 25 presents a summary of the major categories of questions directed to the various experts on NetWellness®. Eighty-eight percent (88%) of the participants obtained information for themselves and 12% obtained information for others. Drug information was specific to side effects and drug disease/indications for use. Questions related to breastfeeding, newborn care, gynecology, pregnancy, and infertility were mainly (92%) requested for the individual's use. However, child development questions were geared toward others (97%) indicating the dependent nature of individuals within this category. Detailed information for each of the Ask an Expert categories is presented in Appendixes C-G. It is important to note that different categories of experts were brought on-line at different times during the study. Therefore, comparisons regarding the relative use of expert sites would have limited value.

Table 25: Summary of Questions Directed to Experts on NetWellness®									
Category	Category Totals	Information Obtained For Self	Information Obtained For Someone Else						
Pharmacy and Medications	228	88%	12%						
Major Categories: Side Effects/Adverse Effects(65) Drug Indications (59) Drug/Disease (34) Other (70)									
Women's Health	100	92%	8%						
Gynecology (N=43) Pregnancy (N=21) Infertility (N=2) Breastfeeding & Newborn Care (N=34)									
Child Development and Health	73	3%	97%						
Total	401								

Note: Numbers in parentheses represent number of questions in this category directed to this expert.

#### Discussion

The purpose of this research was to investigate the theoretical relationships between self-care and dependent-care agents, basic conditioning factors, and the supportive-educative nursing system proposed by Orem (1995). As established in the research problem, a better understanding of the people that chose to use NetWellness® along with their information retrieval patterns for self-care or dependent care needs would be useful for further expansion of Orem's supportive-educative nursing system.

The results of this investigation are discussed in this section. The underlying theoretical propositions from which the questions were derived and the support for the results will be discussed.

# Results Related to Theoretical Relationships

This exploratory study has statistical as well as practical value and lends support to three of Orem's propositions that are described below. These propositions focus on the relationships between self-care or dependent care agency, basic conditioning factors, and the supportive-educative nursing system. The most salient findings related to the propositions are presented followed by a discussion of additional findings.

# <u>Propositions from the Self-care, Self Care Deficit, and Nursing System Theories</u>

The following three propositions served to establish the relationships between the concepts of self-care, self-care agency, dependent care, dependent care agency, basic conditioning factors and nursing systems. Orem stated (1995):

Engagement in self-care or dependent-care involves performance of operations to estimate or establish what can and should be done, to decide what will be done and the operations to produce care. *Note*: These operations conform to the estimative or intentional and the production phases of deliberate action (p. 173).

Individuals' abilities to engage in self-care or dependent-care are conditioned by age, developmental state, life experience, sociocultural orientation, health and available resources (p. 175).

In the design and production of the nursing system, nurses seek and confirm information needed to make judgments about the components (some or all) of therapeutic self-care demand and powers of self-care agency or dependent care agency of persons under their care (p. 176).

These propositions formed the basis for the study's research questions. All six questions investigated the theoretical relationships between these three propositions. Questions two and four specifically focused on the second proposition listed, to determine the basic conditioning factors that influenced information retrieval and productive operations. These six questions were:

- 1. What was the difference between the pattern of information retrieval on NetWellness® and the type of care agents, identified as: self-care agent and dependent care agents?
- 2. What was the difference between the pattern of information retrieval on NetWellness® and basic conditioning factors, identified as: age, gender, race, household income, and educational level?

- 3. What was the difference between the pattern of information retrieval and the purpose identified by the care agent for accessing NetWellness<sup>®</sup>, identified as curiosity/browsing, chronic health problem, recent illness/injury, medications, healthy lifestyle, Ask an Expert, or a student's educational assignment?
- 4. What variables/groups of variables best described those individuals who took action as a result of information obtained on NetWellness®?
- 5. What was the difference between self-care agents' and dependent-care agents' level of satisfaction with information retrieval on NetWellness®?
- 6. What were the categories of questions directed to the experts on NetWellness®?

# Self-care and Dependent-care Information Retrieval

The first research question was to determine if there were differences between the information retrieval on NetWellness® and the types of care agents, identified as self-care agent or dependent care agent. Although not statistically significant, the Condition Specific category was ranked first by both the self-care and dependent care agents for the site first selected as well as the most frequently selected site. The Condition Specific category included all sites that were associated with specific diseases. Some may argue that combining these sites into one category increased the opportunities for Condition Specific to be the highest ranked due to the large number of potential sites the care agent could select.

However, another possibility could be the type of content included in the various categories. With a more thorough examination, clustering of categories by

related content is possible. Two of the categories (Condition Specific and Ask an Expert) had content related to specific self-care or dependent care information. Two of the categories (PDR and Health Literature) provided reference materials that may or may not be related to a specific self-care or dependent care need. Hot Topics and News were both general information sites that most likely would be unrelated to a specific health care related need for seeking information on NetWellness<sup>®</sup>. However, the home web page was designed with feature buttons that made it possible to jump to one of these features and then return to the home page with relative ease.

The combined categories of Condition Specific and Ask an Expert were most frequently selected by both self-care and dependent care agents. Almost 45% of the self-care agents and greater than 50% of the dependent care agents first selected Ask an Expert and Condition Specific indicating that they were seeking specific self-care or dependent care information. These results indicated that both care agents were most interested in sites that could provide information about their specific self-care of dependent care needs.

These findings were consistent with Orem's first proposition; that engagement in self-care or dependent-care involves performance of operations to estimate or establish what can and should be done. That is, the deliberate action of information seeking was performed in order to gain more knowledge related to the specific purposes identified by self-care or dependent-care agents. Within the broad structure of self-care agency this information seeking was in the phase of estimative

operations (obtaining information); the content of information obtained was derived from the purpose for which it was directed (Orem, 1995, p.173, 212-213).

## Information Retrieval and Basic Conditioning Factors

The second research question was to determine if there were differences between information retrieval on NetWellness<sup>®</sup> and basic conditioning factors, identified as: age, gender, race, household income, and educational level. The results are first presented followed by a discussion of these findings in relationship to previous research studies.

Age. For age, Condition Specific was ranked highest for first selected across all age categories and News was ranked the lowest for all age groups. Condition Specific was also the highest ranked for all age groups for the most frequently selected.

In the 12-17 year age group, the number of participants was only 14. With these few numbers findings would not necessarily be representative of this age group and should be considered cautiously. Over 43% (n=6) of this group first selected Condition Specific and another 43% (n=6) first selected Hot Topics. Two participants (14%) first selected News for third place and no one in this age group first selected Ask an Expert, PDR, or Health Literature. For most frequently selected categories Condition Specific was clearly first with the rest of the category numbers aggregated together. Although the numbers are few, these findings may be related to the developmental characteristics of this age group. It is quite possible that most participants in this age group would not know the names of these healthcare and

medical texts, or specifically seek information found in them. However, one could argue that these survey participants would be interested in checking out a site to seek specific information about a disease or ask questions of an "expert". Visiting sites such as Hot Topics or News may have also appealed to this age group as they "surfed" the site.

In the 18-39 year group Condition Specific was also ranked first and Ask an Expert and PDR received the same number of hits for second place; News for this group was last. The combined categories of Condition Specific and Ask an Expert accounted for over 45% of the first selected categories. PDR and Health Literature accounted for 32% of the first selected categories and 22% first selected Hot Topics and News. Rankings for most frequently selected were the same as first selected for this age group. This possibly represented a change in focus from the younger age group. These participants quite possibly visited NetWellness® for a specific purpose and went to content specific or reference material areas to meet their informational needs.

In the 40-59 year group, 43% first selected the combined Condition Specific and Ask an Expert; PDR and Health Literature accounted for 32%; and Hot Topics and News represented 24%. For most frequently selected Condition Specific was clearly ranked first and Health Literature was ranked second. However Health Literature and third ranked Ask an Expert were separated by only two frequencies.

In the 60-89 year group Condition Specific and Ask an Expert accounted for over 57% of the first selected categories, 25% selected PDR and Health Literature and Hot Topics and News totaled 17.9%. For most frequently selected, after

Conditions Specific and Ask an Expert, Hot Topics, PDR, Health Literature and News were very closely ranked.

Individuals in the middle and older age groups tended to select the combined categories of Condition Specific and Ask an Expert first with PDR and Health Literature next. It may be that participants in these age groups were more knowledgeable about health care literature and reference materials. In addition, more self-care and dependent care needs related to specific conditions may have been present in the older age groups.

Statistically significant findings ( $\chi^2$  =8.708; p=.033) were calculated for the difference between the pattern of information retrieval on NetWellness® and the basic conditioning factor of age. "Ask an Expert" was the first selected category by age groups. Although some caution is recommended related to these findings, there are some important observations that should be considered from both a statistical and practical standpoint. Most important is the fact that no one in the 12-17 year age group first selected Ask an Expert. However, it should also be noted that the "Ask an Expert" categories present during this study focused on topics that would not routinely be considered of interest or important to most participants in the 12-17 age group for meeting their self-care needs. In contrast 25% of those 60-89 years selected "Ask an Expert" as the first category.

<u>Gender.</u> For gender, Condition Specific was ranked first for both males and females. All other categories for first selected were ranked in the same order with the exception of Hot Topics and PDR. Males ranked Hot Topics second and PDR third, while females ranked PDR second and Hot Topics third. The combined

categories for most frequently selected by both genders were Condition Specific and Ask an Expert (44% for males and 47% for females) first, Health Literature and PDR (31% males and 29% females) - second with Hot Topics and News (25% males and 23% females) third. These results were based on broad categories and may initially indicate that there were not any differences in information retrieval between genders. However gender specific topics were identified when Ask an Expert question topics were analyzed. For example when information was sought for a female specific topic, such as pregnancy or breastfeeding, this information was obtained for self.

Race. Condition Specific and Ask an Expert were ranked as the first selected and most frequently selected categories for Caucasians. Health Literature and PDR second, and Hot Topics and News, third . For other races, the combined Condition Specific and Ask an Expert, was also first, with Hot Topics and News second and Health Literature and PDR third. Although the pattern of information retrieval was significant ( $\chi^2$  =3.857; p=.05) for Condition Specific by race, the large differences in the number of participants between the two categories led to some caution in making any inferences related to these findings. A major observation is the difference in the number of participants between Caucasian and other race categories. This difference may represent the "digital marginalization" often cited as a concern related to consumers health information networks (Ehrenberger & Murray, 1998). However, the large percentage that chose Condition Specific first by both races may indeed indicate that many conditions that have a predominant occurrence within certain

racial groups are of particular importance, and should be considered when designing on-line systems.

Household income. Condition Specific was ranked first for the first selected category in all household income groups except for the greater than \$60,000 group. In this group PDR was ranked first but the difference in first and second represented only one person. Hot Topics was ranked second for participants in the <\$15,000 and \$15,000-29,999 group. Ask an Expert was ranked second for the \$30,000-44,999 and \$45,000-59,999 group.

For most frequently selected by household income, the combined Condition Specific and Ask an Expert categories were ranked first for all groups. PDR and Health Literature combined was second for the three higher income groups, however Hot Topics and News was ranked second for the two lower income groups. These results may be interpreted with several considerations in mind. A large number of participants indicated they had professional or graduate degrees. In addition persons in health care often have particular interest in on-line health information systems. It is possible that these results reflect the type of occupation (for example physicians, nurses, or researchers) or purpose for obtaining information rather than it being specifically related to household income. Another consideration would be that those persons in higher income and with more education may be more familiar with the literature available for meeting information needs related to health and medications.

<u>Educational level.</u> For first selected, all groups (HS graduate and below, some college/college degree, and some graduate school or graduate degree) ranked the combined categories of Condition Specific and Ask an Expert first. Hot Topics,

and News was second and Health Literature combined with PDR was ranked third for HS graduates and below. PDR and Health Literature was ranked second and Hot Topics combined with News ranked third for the college and graduate school categories. For most frequently selected all three groups ranked Condition Specific combined with Ask an Expert first, PDR and Health Literature as second and Hot Topics and News third.

This second research question was based on Orem's (1995) second proposition listed as significant for this study; individuals' abilities to engage in self-care or dependent-care are conditioned by age, developmental state, life experience, sociocultural orientation, health and available resources (p.175). The Self-care Deficit Theory of Nursing is a synthesis of knowledge about the theoretical entities self-care (and dependent-care), self-care agency (and dependent care agency), therapeutic self-care demand, the relational entity self-care deficit, and nursing agency (p 170).

Self-care agency is the complex acquired capability to meet one's continuing requirements for care of self that regulates life processes, maintains or promotes integrity of human structure and functioning and human development, and promotes well-being. "Self-care agency of individuals varies over a range with respect to its development from childhood through old age. It varies with health state, with factors that influence educability, and with life experiences as they are enabling for learning, for exposure to cultural influences, and for use of resources in daily living" (Orem, 1995, p 203). Orem describes 10 factors that influence an individual's self-care agency. These basic conditioning factors are "factors internal or external to

individuals that affect their abilities to engage in self-care or affect the kind and amount of self-care requires" (p 203). These basic conditioning factors may act individually or in combination. A large number of studies have been conducted that focused on these relationships between core concepts of Orem's Self-care Deficit Theory and the effect of basic conditioning factors.

Other studies examining relationships between selected basic conditioning factors and self-care agency have been performed with a variety of populations. In a study of chronically ill adults, educational level was found to have a statistically significant relationship with self-care agency (Robinson, 1996). A study of well elderly adults showed that self-concept was correlated with self-care agency, but there were no significant differences in self-care agency scores when comparing them by the basic conditioning factors of age, income, gender and employment status (Smits and Kee, 1992). Self-care agency in a sample of individuals with arthritis was above average, meaning a greater ability for self-care, for 83% of the subjects (Ailinger & Dear, 1993). Education and duration of illness were related to self-care agency in this group, but age was not. In another study no association was found between subjects gender and number or type of affected universal self-care requisites; only age was related to promotion normalcy (Ailinger & Dear, 1997). In a group of nursing home residents, those who were black or previously self employed had higher self-care agency scores (Jirovec & Kasno, 1990). Dodd and Dibble (1993) found that the basic conditioning factors, age and gender, had no effect on self-care agency scores. In research investigating levels of self-care agency and learned helplessness with a sample of well working adults, McDermott (1993)

also reported that neither age, nor gender was related to self-care agency for that group. Mosher and Moore (1998) found a relationship between children's self-concept and age, gender, sociocultural orientation, and health state was partially supported; age was the only significant predictor of self-concept.

In summary, all of the basic conditioning factors have been investigated to some degree but with mixed results. These results bear out Orem's (1995) statement that "different basic conditioning factors influence self-care agency at different times" (p. 83).

For this study age, gender, race, household income, and education were the basic conditioning factors that were believed to have a relationship to the information retrieval of participants using NetWellness®. There were statistically significant findings between age groups and the first selected category Ask an Expert ( $\chi^2$ =8.708; p=.033) and also between race and the first selected category Condition Specific ( $\chi^2$ =3.857; p=.05). Various observations as previously described may also have additional practical value.

There appeared to be an association in the combined basic conditioning factors of race, age, educational level and household income. As presented in Tables 1, 5, 8, 11, 14, and 17 there were greater numbers of Caucasian and older participants, with college or graduate degrees and household incomes of more than \$45,000 in this study.

### <u>Information Retrieval and Purpose</u>

The third research question was to determine if there were differences between information retrieval and the purpose identified by the care agents for accessing NetWellness®. The purposes were identified as curiosity/browsing, healthy lifestyle, recent illness/injury, chronic health concerns, medication, Ask an Expert, or educational/work assignment.

Due to the multiple purposes the survey was intended to fulfill for the evaluation of NetWellness<sup>®</sup>, the participants were instructed to identify all categories that applied for this question. The frequency data presented in Tables 20 and 21, although not statistically significant demonstrate some interesting findings. As might be expected, first selected for browsing was fairly evenly distributed across various categories. For chronic problems 48% selected Condition Specific first with Ask an Expert second and PDR third. For recent illness/injury 46% selected Condition Specific first with PDR, Hot Topics and Ask an Expert following close together. When individuals indicated the purpose of seeking information was for medications, 40% selected PDR first. Surprisingly, Ask an Expert was tied with Health Literature for last place for first selected by this same group. Healthy living was distributed fairly evenly, after Hot Topics, which ranked first for first selected. Not surprising, Ask an Expert was selected first for 65% of the participants who indicated the purpose for their information seeking was Ask an Expert; Condition Specific ranked second. For education/work assignment, 50 % of the participants selected Condition Specific first. Most frequently selected categories by purpose

presented similar findings. Although participants could select more than one category for most frequently selected categories, the consistent findings with first selected strengthened the argument that the purpose of accessing NetWellness® influenced the information they retrieved.

These results are consistent with Orem's concept of deliberate action within the theory of self-care. This finding is demonstrated by the association that the first selected category had with the purpose identified for information retrieval on NetWellness<sup>®</sup>. Inherent in this theory is that self-care is a form of conscious, deliberate action and is a behavior that is not inborn, but is learned though culture and habit. This means that it is a purposeful goal - or result-seeking activity that operates on the assumption that each human has a need to care for himself or herself. For this study, deliberate action was seeking information on NetWellness<sup>®</sup> for an identified purpose. The purpose can then be considered as the motivation to seek information, or in other words motivation to act.

Two recent studies supported the proposition that self-care agency, as demonstrated by deliberate action, was influenced by motivation to act. Hart and Foster, (1998) investigated Orem's self-care agency concept in two different populations of pregnant women, a childbirth education group and a clinic group. The fact that self-care agency scores were, in general, high in both the prenatal care clinic group and the childbirth education class group suggested to health care providers that during the prenatal period women may be highly motivated to care for themselves and their unborn babies. They indicated that nurses and physicians should use this time for teaching and health promotion, since this is a time that

motivation to obtain knowledge for better decision-making may be at a peak.

Lukkarinen and Hentinen (1997) conducted a study to assess the self-care agency and factors related to this agency among 250 patients with coronary heart disease.

They identified that the most significant precondition for self-care was "appreciation and motivation to self-care". The findings from these studies support the potential for on-line health care information systems since the self-care or dependent care agent has identified a need and has then demonstrated their motivation to self-care by seeking information.

#### Individual Variables of Consumers Who Took Action

The fourth research question was to determine what variables or groups of variables best described those individuals who took action as a result of information obtained on NetWellness<sup>®</sup>. The broad structure of the concept self-care agency is understood in relation to and modeled on operations specific to the phases of deliberate action, namely, estimative operations, transitional operations of reflection, critical judgment and decision making, and production operations. Estimative self-care operations are operations of inquiry that seek both empirical and technical knowledge for purposes of knowing and understanding what is, what can, and what should be brought about with respect to taking care of self. The transitional operations of reflecting, judging, and deciding with respect to self-care matters are grounded in what individuals know about the self-care situation, their experiences and their knowledge about self-care requisites and measures for meeting them, as well as their values, self-concepts, and their willingness. Productive operations are

doing operations to achieve practical results demanding preparation for and performance of self-care measures, monitoring performance as well as their effects and results, and making judgments and decisions about subsequent actions (Orem, 1995, p. 221).

Table 22 presents the ranked behavioral actions taken as a result of information obtained from NetWellness<sup>®</sup>. A detailed summary of actions the 46 subjects took is presented in Appendix B. For basic conditioning factor, age, only one participant in the 12-17 age category responded, and indicated that the information they previously received helped them reinforce their beliefs. However, 32% of the people in the 60-89 age group category identified a variety of actions taken as a result of getting information from NetWellness<sup>®</sup>. Similar responses for actions taken were identified for both genders and racial groups. The greater than \$60,000 household income group as well as the higher education group listed more actions taken than those with lower incomes and less education. Reinforced beliefs was the most frequently cited response across all of the basic conditioning factors, age, gender, race, household income and education.

For this study, information seeking could be considered in the phase that Orem identified as estimative operations. During and after the 46 participants' previous information seeking experience on NetWellness<sup>®</sup>, transitional operations occurred. Reinforced beliefs, listed by 37% of the participants, may be included in this category. Productive operations included using the information for better communication (22%), making a lifestyle change (15%), giving information to their

health care provider (13%), making an appointment with their health care provider (9%), and seeking a second opinion (4%).

Nursing system refers to the design and organization of an action plan that bridges the identified gap between self-care agency and therapeutic self-care demand (Whitener, Cox, & Maglich, 1998). Nursing systems are formed (designed and produced) by nurses to compensate for or overcome known or emerging health-derived or health associated limitations of the recipients' powers of self-care agency.

The nursing system appropriate for this study was the supportive-educative system. It was the only system where a patient's requirements for help are confined to decision making, behavior control, and acquiring knowledge and skills. Within the supportive-educative system, Orem listed five nursing interventions classified as valid helping techniques: (a) acting or doing for, (b) guiding, (c) supporting (physically or psychologically), (d) providing a developmental environment, and (e) teaching (Orem, 1995). One of the variations of this system that was appropriate for this study, is in situations where the patient is competent in self-care but requires periodic guidance that he or she is able to seek; in this variation, the nurse's role is primarily consultative (Orem, 1995)

Many studies have been conducted that focused on the relationships between supportive-educative systems, self-care agency, and basic conditioning factors of subjects as predictors of productive operations. Folden (1993) found that a guided decision-making intervention used with older adults after a stroke increased their self-care abilities. Comprehensive teaching was found to be the most important factor in the promotion and maintenance of a prescribed medication regimen among

patients with congestive heart failure (Fujita & Dungan, 1994). Guiding and supporting were the most frequently used helping interventions in follow-up telephone calls (Closson, et al., 1994).

Specific studies that evaluated computer technology with the supportive-educative system of Orem as a framework were not found. Several articles were reviewed that discussed the importance of using Orem as a theoretical framework for designing computer systems (Bliss-Holtz, Taylor, et al. 1990; 1992) but these were not specifically directed at the supportive-educative nursing system.

### Type of Care Agent and Level of Satisfaction

The fifth research question was to determine if there were differences between the type of care agent and level of satisfaction, identified as ease of use and ability to find the information needed, with information retrieval on NetWellness<sup>®</sup>? Level of satisfaction was presented in Table 23, however, the specifics regarding ease of use and ability to find information could not be linked to only the self-care or dependent care agents.

Findings related to consumer satisfaction, including ease of use and ability to find information needed was presented in the NetWellness® Report (1997). One item specifically addressed for the total group was if the information was easily found. Sixty-five percent indicated that they agreed or strongly agreed that information was easily found. For first time users, 80% agreed or strongly agreed. The percent that strongly disagreed was higher for first time user. First time users tended to have either positive or negative reactions with the total group having more

than twice as many indicating neutral rather than first time users. This could have implications for how subsequent interface and training efforts might be structured, but will required more investigation to determine what factors prompted bipolar reactions. When asked if they would use NetWellness® again, 90% were positive they would.

A six-item, Likert-type, attitude scale was developed to measure attitude toward NetWellness<sup>®</sup>. Items were responded to in terms of a five-point scale from strongly agree to strongly disagree. The most positive score on the Attitude toward NetWellness<sup>®</sup> scale was 30 and the least was six. The mean for the total score on the Attitude toward NetWellness<sup>®</sup> scale was 21.92 with a standard deviation of 6.81. The reliability of this scale was high (internal consistency estimate for reliability using Cronbach's alpha - .92). Clearly, the respondents' attitudes were positive towards NetWellness<sup>®</sup> since the neutral point on the Attitude toward NetWellness<sup>®</sup> scale was 18.

The possibility of other variables influencing the degree of positiveness toward NetWellness<sup>®</sup> was assessed using one-way analysis of variance (ANOVA). The number of times people had used NetWellness<sup>®</sup> was recategorized into one time and more than once. Significant differences were found: first time users were less positive than more than one-time users (P<.01). The data suggested that the more one uses NetWellness<sup>®</sup> the more positive one becomes towards it. (NetWellness<sup>®</sup> Report, 1997)

The level of satisfaction by self-care and dependent care agents as presented in Tables 23 and 24 was consistent with the report for the total sample as described

above. Self-care agents (81%) and dependent care agents (77%) were satisfied or extremely satisfied with NetWellness® as a source of health care information. There were no statistically significant differences between type of care agents and level of satisfaction. These results were comparable to other studies that focused on computer mediated care delivery.

Specific studies that linked satisfaction with the various non-computer based interventions within supportive-educative systems were not found. Productive operations or self-care behaviors were evaluated, but few statements were found that specifically evaluated the method of information delivery. One exception to this was the study by Whitener, et al. (1998). In this study a follow up evaluation of a child's health fair was completed to determine retention and recall of meaningful health messages for children to learn self-care. They concluded that nurses needed to blend cognitive development theories with foundational knowledge and dispositions from Orem's Self-Care Deficit Nursing Theory to design developmentally appropriate health messages. However, the level of satisfaction by participants to this type of informational intervention was not reported.

In contrast, consumer satisfaction was discussed in the majority of studies that addressed healthcare information delivery through computer technologies. Fernsler and Manchester (1997) evaluated the usefulness and function of an electronic discussion forum for people with cancer. In this study comments were overwhelmingly positive. Respondents reported using the network for contacting others in a similar situation, obtaining information and emotional support. These comments make the criticism often cited, that delivering health care information

electronically is too impersonal, questionable. McKay et al. (1998) evaluated the feasibility and use of an Internet support service for diabetes self-management. User ratings revealed high satisfaction with the service. McRoy et al. (1998) reported that users responded favorably to the Layman Education and Activation Form (LEAF), an interactive computerized health care education system. In a study conducted for the purpose of developing a computer-based system for the parents of children diagnosed with acute lymphocytic leukemia, parents responses were overall positive, with mothers tending to be more enthusiastic (Tetzlaff, 1997).

These differences in evaluation focus were probably related to the aspect that innovative systems are frequently challenged by traditionalists. In contrast, researchers may have made assumptions related to benefits and satisfaction for users of the "tried and true" systems that were unwarranted.

These results support the importance of the third proposition, that nurses design and produce nursing systems to seek and confirm information needed to increase the powers of self-care agency and dependent care agency of persons under their care. The power of the evolving information superhighway is an important method for providing needed information to consumers for their self-care and dependent care needs. In this study there were not enough nurses - or other health care providers - identified as users of NetWellness® to include them in the analysis of data. However some of the first expert consultants to participate in the Ask an Expert site were nurses.

# Ask an Expert Categories

The sixth research question was to determine the care needs that were identified for individuals seeking information for their own or some other person's use through questions directed to the experts on NetWellness<sup>®</sup>. Prior to the study, focus groups in the local community identified information about medications as a high priority for NetWellness<sup>®</sup>. The first category to come on-line was Pharmacy/Medications; the next three brought online were Pregnancy, Breast Feeding and Newborn Care; and Children's Development and Health.

A summary of the Ask an Expert questions is presented in Table 25.

Information most frequently obtained by individuals for themselves included pharmacy and medications (88%) and women's health (92%). As one might expect, 97% of the questions directed to the Ask an Expert for children's development and health were asked to obtain information for someone else. More detailed information related to the questions directed to the various experts is found in Appendixes C through H.

Ask an Expert experienced many changes due to the types of questions received and attempts to get the consumer to the most appropriate expert site as early in the session as possible. As questions and consumer feedback came in, continuing revisions occurred that improved the navigation to appropriate experts and resulted in the addition of new expert categories. The separation by some of the experts into specific categories for infertility, pregnancy, and gynecology was one attempt to

more easily guide consumers to the appropriate site as well as ensuring that questions would get to the appropriate expert.

#### **Summary**

In this chapter findings were presented followed by a discussion of the results. Two statistically significant findings were presented along with descriptive findings that have practical value and can serve as a foundation for further research.

In summary, questions one, two, and three were seeking information related to the usage pattern of care agents, basic conditioning factors (age, gender, race, household income and educational levels) and purpose for obtaining information (curiosity/browsing, healthy lifestyle, recent illness/injury, chronic health concerns, medication, Ask an Expert or educational/work assignment). These three questions were answered by the analysis of first selected and most frequently selected categories. Condition Specific was ranked first for the first selected category for self-care as well as dependent care agents and across all age, race, gender, income, and educational groups. One observation was made regarding the type of content of the selected categories. Two of the categories (Condition Specific and Ask an Expert) had content related to specific self-care or dependent-care information. Two of the categories (PDR and Health Literature) were references that may or may not be related to specific self-care or dependent-care needs and two categories (Hot Topics and News) were general information regarding health care issues.

When analyzed from this perspective almost 45% of self-care agents, and greater than 50% of dependent-care agents first selected the combined categories of Condition Specific and Ask an Expert. Similar findings were seen for the basic

conditioning factors for age, with the exception of the 12-17 year group. Forty-five percent (45%) in the 18-39, 43% in the 40-59, and 57% in the 60-89 age groups selected the combined Condition Specific and Ask an Expert sites first. Although the numbers were small, 57% in the 12-17 year group selected Hot Topics and News first. The combined categories of Condition Specific and Ask an Expert were also selected first by both genders (44% for males and 47% for females); race (48% Caucasian and 57.5% other); household income (50% for <\$15,000, 41% for \$15,000-29,000, 53% for \$30,000-44,999, 53% for \$45,000-59,999, and 42% for >\$60,000); and educational levels (44% for HS and below, 46% for college and 45% for graduate degrees).

For the combined categories of PDR and Health Literature both self-care and dependent care agents ranked this second (36% SCA and 41% DCA). Similar findings were found in all age groups except for the 12-17 year group; no one in this group selected PDR or Health Literature first. For the other age groups (32% for 18-39, 32% for 40-59, and 25% for the 60-89) PDR and Health Literature were ranked second for first selected. Males and females also selected this combined category second (31% for males and 29% for females), Caucasians ranked it second with 28% however other races ranked it third for 17.5%. Some differences in the second place ranking for the combined category of PDR and Health Literature were observed in income levels. In all categories except the \$30,000-44,999 and >\$60,000 categories Hot Topics and News ranked second with PDR and Health Literature third. However, the actual frequencies of numbers were low and percentages very close. In the high school graduate and below, the combined categories of PDR and Health

Literature ranked the same as for Hot Topics and News. Persons holding a college or graduate degree placed PDR and Health Literature second and Hot Topics and News third.

Rankings related to purpose of information retrieval revealed some important findings. The combined categories of Condition Specific and Ask an Expert were ranked first for browsing (47%), with the other combined categories close together (27% for Hot Topics and News and 27% for PDR and Health Literature). However, those seeking information for chronic problems ranked Condition Specific and Ask an Expert first at 67%. Fifty-eight percent (58%) ranked the combined categories first if purpose was recent Illness/Injury and 56% if purpose was Education/Work Assignment. In contrast, for purposes such as medication PDR and Health Literature were ranked first with 49% and the purpose of Healthy Living ranked Hot Topics and News first at 43%. When Ask an Expert was identified as the purpose for seeking information, 65% first selected the Ask an Expert site with the combined categories of Ask an Expert and Condition Specific capturing 84% of the first selected frequencies.

Another important finding observed in this study was related to the average number of categories selected by self-care and dependent-care agents, basic conditioning factors, and purpose. The average number of pages selected ranged from a low of 2.7 to a high of 4.9 with a total averaging between 3 and 4 for any category of user. Although it wasn't known how much time was spent at each of the locations, it was clear that attention in designing these on-line systems is important.

These findings indicated that categories of information must be accessed within a few pages to keep the consumers' interest.

# Chapter V

#### Summary, Recommendations and Conclusions

#### **Summary**

#### Theoretical Framework

The development of this research study and interpretation of findings were established through the theoretical framework of Orem's Self-care Deficit Nursing Theory. Orem defines self-care as the deliberate action that individuals take to provide care for themselves (self-care practices) or for others (dependent-care practices). Within the self-care deficit theory of nursing, 10 personal characteristics or internal and external factors called basic conditioning factors (BCFs) are described. BCFs collectively influence the person's therapeutic self-care demand or particularized requirement for specific self-care action. In addition, BCFs influence or modify the person's self-care agency at any level within its structure. The BCFs included for this study were age, gender, race, household income and level of education (Orem, 1995). Gast et al. (1989) were the first to describe self-care agency as a complex, three-tiered, hierarchical structure consisting of foundational capabilities and dispositions as its base, mediated by power components and leading to capabilities for self-care operations.

Most foundational capabilities consist of basic abilities pertaining to sensation, perception, memory, and orientation. The power components, found in the middle tier of self-care agency's hierarchical structure, consist of 10 enabling or empowering capabilities necessary to perform self-care. Orem summarized the power components as knowledge, attitudes, and skills that enable engagement in

self-care (Orem, 1995, p.221). The top tier of self-care agency's hierarchical structure comprises the capabilities for self-care operations or self-care actions. These capabilities can be viewed as a two-phase process. The first phase, estimative and transitional operations, entails looking at what needs to be done, becoming knowledgeable, and then making a decision in relation to self-care action. The decision about the course of action to be followed begins the second phase or the productive operations, when goal setting occurs and the kind of action to be taken is specified (Orem, 1995).

The theory of nursing system attributes to nurses the power of nursing agency, the exercise of which results in produced action sequences toward accomplishment of nursing's' purposes that are contributory to the life, health and well-being of those in their care. The supportive-educative system is the only system where a person's requirements for help are confined to decision-making, behavior control, and acquiring knowledge and skills (Orem, 1995, p 310). The supportive-educative system was the appropriate nursing system and the focus of investigation for this study.

Three related propositions within this theory were the focus of this study. The first, engagement in self-care or dependent-care involves performance of operations to estimate or establish what can and should be done, to decide what will be done and the operations to produce care (Orem, 1995, p. 173). Second, individuals' abilities to engage in self-care or dependent-care are conditioned by age, developmental state, life experience, sociocultural orientation, health and available resources (p.175). The third proposition "in the design and production of nursing

systems, nurses seek and confirm information needed to make judgments about the components (some or all) of therapeutic self-care demand and powers of self-care agency or dependent care agency of persons under their care" (p. 176).

# Overview of Study

This study began with the usual unstructured questions within the mind of every researcher that needed time and additional discovery to bring into a proposal format. The early ideas stemmed from the resurgence of the idea that consumers needed and wanted to take more responsibility for their own self-care. This need was made evident through the government as health care reform and managed care movements started recognizing that keeping people healthy through self-care responsibility was economically wise.

Consumers also expressed their desire to have more control in all areas of their life, including health care. No longer were they satisfied accepting authorities (until recent history seen as their physicians) as the director of their health care decisions.

Relationships were changing; consumers and members within the health care delivery system were talking about collaboration and consumers as partners with more responsibility for self-care. However, in order to be active participants in self-care consumers as well as the other partners recognized the need for easily accessible health care information to make better decisions.

Nurses have historically been advocates for preventative care and providing "patient education" to those in their care. In fact, the major focus of community health nursing was based on keeping people healthy or improving their health. One

of the major interventions these nurses provided was delivery of information in areas identified as currently being a problem in the community (or sub-group of the community). In addition, potential problems were identified and health care information was provided for prevention. As with any other intervention, nurses sought new and better methods for providing this information and evaluated the success or failure of their interventions.

The capability for providing information was also taking a dramatic turn due to changes in technology and the emergence of the WWW. Business, industry, and various organizations, as well as consumers started recognizing the value of this "just in time" anywhere, anytime, and any type of information resource. Health care information also became available; however the quality and credibility of the source could not always be guaranteed since there were no gatekeepers that established what could be published on the WWW.

The early developers of NetWellness®, originally called the Ohio Valley

Consumer Health Information Network (OVCHIN), also recognized the importance
of using this new technology to provide healthcare information to consumers. In
1994, the University of Cincinnati received a Telecommunications and Information
Infrastructure Assistance Program (TIIAP) grant from the U.S. Department of
Commerce National Telecommunications and Information Administration – and
NetWellness® began.

Evaluation of the project was not only expected from the funding agents, but also as a fundamental desire of the developers to establish the effectiveness of this

information resource. As a result a multidisciplinary evaluation team was created that included this researcher as a doctoral candidate.

From the beginning the project took on a continuous quality improvement approach that required knowledge of the successes and failures from a technical and marketing standpoint, as well as the successful inclusion of partnerships that included consumers. One of the earliest changes - although a technology change - also changed the composition of the consumer community. Originally NetWellness® was viewed as a regional resource for the greater Cincinnati area; in 1995 it became apparent that the WWW offered a more effective mechanism for widely disseminating health care information to the global community.

The evaluation team established a twelve-point research plan to guide the evaluation and establish rationale for changes. Two sources of data collection were identified as important for the evaluation project; (1) an on-line survey and (2) passive collection of information usage patterns through Interse software.

As part of the evaluation team, and thinking through the perspective of Orem's Self-Care Deficit Theory, questions for the survey were proposed by the researcher that would be helpful in determining the self-care and dependent care agents information needs. These questions included data regarding why people were accessing NetWellness® who they were getting information for and other questions that would reveal some of the basic conditioning factors identified by Orem (1995). Ask an Expert, one of the unique services offered by NetWellness®, permitted interaction between the consumers and health care experts through on-line questions and answers. There was special interest in evaluation of this site.

The purpose of this exploratory study was to identify the characteristics of individuals accessing NetWellness® in relationship to the type of information they were seeking in order to determine if self-care or dependent-care needs could be identified. This study was believed to have importance for establishing if this was an effective way to provide health care information to consumers as well as establishing a profile of the community of users that would be useful for further development of information sites to meet their self-care information needs.

The researcher also believed that questions consumers ask (or don't ask) may actually provide more information about the users than a single survey. Ask an Expert provided an excellent method to analyze these users.

In brief, consumers accessed NetWellness®, a consumer health information network, and an example of one method of providing information within Orem's supportive-educative nursing system. Their information retrieval patterns were evaluated to determine if there were any differences based on the basic condition factors, or purpose of their information retrieval, and actions as a result of their seeking information.

The results of this study provided information regarding the characteristics of the individuals that were identified as self-care or dependent care agents through a survey on NetWellness® during this study period. Analysis of the information retrieval was completed; the results are summarized in the following paragraphs.

An overview of the participants showed that more women (52.5%) than men (47.5%) participated in the survey. Fifty three percent of the self-care agents were women compared to 47% of men, however 78% of the dependent care agents were

women compared to 22% of men. Ages of participants ranged from 12 to 85, with the largest number of self care and dependent care agents being in the 40-59 age group, followed closely by the 18-39 age group. Eighty six percent of self-care agents and 97% of dependent care agents were Caucasians. Fifty four percent of the participants indicated their household incomes were greater than \$45,000, with 40% being in the greater than \$60,000 category. Educational levels were comparable to the household incomes, with college or graduate degrees representing over 84% of self-care agents and 95% of dependent care agents. Predominantly white, middle to upper middle-class, educated men and women made up the participants in this study. More women than men were identified as dependent care agents.

The first three questions were designed to determine the differences in first selected sites and most frequently selected sites by type of care agents, basic conditioning factors (age, gender, race, household incomes, and educational levels) and purpose of accessing information. The findings were somewhat consistent across the first two questions. Condition Specific (which incorporated all specific disease/illness sites) was ranked first by self-care agents, dependent care agents, all age groups, both genders, Caucasian and others, educational levels and all income categories except for the > \$60,000 which selected PDR first more frequently. However, the difference between PDR and Conditions Specific was only one frequency.

Some variations occurred in the rankings of the rest of the categories for first selected. However, for the self-care and dependent care agents, the most frequently

selected was the same – Conditions Specific first, Ask an Expert second, followed by Hot Topics, Health Literature, PDR and News.

After Condition Specific, rankings for first selected by gender were fairly evenly distributed, with the exception of News – which was last. For most frequently selected Ask an Expert was again second, for women and third for men.

There was a statistically significant difference between age groups and the first selected category of Ask an Expert ( $\chi^2$  =8.708; p=.033). For the 12-17 age group, no participant chose PDR, Health Literature or Ask an Expert for first selected. Rankings for the rest of the categories across age groups revealed that Ask an Expert was ranked second or third for all age groups.

A statistically significant difference was identified between race, identified as Caucasian and other, and the first selected category of Condition Specific ( $\chi^2$ =3.857; p=.05). Even though there were a relatively large number in the Caucasian group and fairly equal distribution of the categories after Condition Specific, Ask an Expert was ranked second by both groups for most frequently selected. For Household Income, and Educational Level, the rankings once again were distributed in much the same manner for first selected, but for most frequently selected Ask an Expert was second or third across all groups.

Although the question for this study specifically asked for race, additional considerations such as culture, language, and ethnicity are major factors related to self-care that have been studied. International studies in a variety of cultures have been conducted. Two studies of perceived self-care agency were carried out in East Germany (Whetstone, 1987) and Sweden (Whetstone & Hansson, 1989). In both

studies the authors noted a need for more cultural focus in self-care research and more analysis of culturally related behavioral characteristics of people engaging in self-care and more refining of instruments for cultural relevancy. Collaborative efforts for cross-cultural testing of the Appraisal of Self-Care Agency Scale have been conducted (Lorensen, Holter, Evers, Isenberg & Achtrerberg, 1993; Evers, Isenberg, Philipsen, et al., 1993). Dahlen (1997) studied older residents in an Eastern Norwegian community to determine the problems people 67 years and older had in meeting their self-care requisites. Factors in living arrangements associated with meeting self-care requisites were explored and it was found that the elderly living alone or with a family member had greater problems than the elderly living with a spouse. Lukkarinen and Hentinen (1997) assessed the self-care agency and factors related to this agency among patients with coronary heart disease in Finland using the Self-As-Carer Inventory (SCI). They found that the SCI inventory seemed to cover the self-care requirements, but the clinical use of the SCI was considered too difficult for many patients due to the abstractness of the items.

Morales-Mann and Jiang (1993) indicated cross-cultural applicability of Orem's conceptual framework in Chinese nursing practice. The appropriateness of Orem's nursing theory for application in Chinese nursing practice was determined through an examination of its completeness, compatibility, practicality and feasibility. Wang (1997) also indicated applicability of Orem's Theory of Self-Care in a Chinese population with diabetes. A significant correlation was found between the educational level and the universal self-care behaviors. There were significant correlations among the universal self-care behaviors and diabetes-related self-care;

between the universal self-care behaviors and the perception of health and between the diabetes related self-care behaviors and the perception of health.

Hildebrandt and Robertson (1995) studied self-care practices of older black adults in a South African community. They stated that Orem's Self-Care Nursing Theory and the concept of community involvement in health (CIH) promoted by the World Health Organization (WHO) were useful for addressing challenges posed by global growth in the aging population. Esterhuysen (1997) also evaluated Orem's theory in community health practice in South Africa and found it to be useful to evaluate self-care abilities and guide the nurse in identifying deficiencies and planning nursing care.

Chammaro (1985) examined the usefulness of self-care in a Puerto Rican community, and concluded that self-care was a viable theoretical framework if cultural elements were considered. However, Ortiz-Martinez (1994) conducted a cross-cultural study comparing the attitudes, beliefs, and reported behaviors of two samples of subjects with respect to self-care; one from Puerto Rico and the other from the United States (South Carolina and Illinois). Eight dimensions were found to have significant differences between Puerto Ricans and Americans and recommendations were made for defining a nursing model more appropriate to the context of Puerto Rico.

Yamishita (1998) examined the perceptions of the exercise of self-care in nursing students in Japan. The results confirmed Orem's (1980; 1991; 1995) propositions that cultural factors influence one's self-care activities in terms of health seeking behaviors. The construct of self-care, however, was not well understood and

practiced by students in Japan compared to their counterparts in the United States or Europe. It was recommended that major concepts such as self-care agency, self-care agent, and self-care deficits be closely examined and operationally defined first to make them acceptable to practitioners and clients in the Japanese culture.

There are obvious challenges and opportunities for nurses within the international community to develop meaningful theories, conduct collaborative research, and improve practice. The technological advances available through the WWW should be recognized as an essential tool that can facilitate progress in these areas.

For the third question, information retrieval by purpose: identified as curiosity/browsing, healthy lifestyle, recent illness/injury, chronic health concerns, Ask an Expert, or educational work assignment, there were some differences noted. For the category, browsing, condition specific was ranked first, but then a relatively even distribution was evident. For the two illness categories, Condition Specific was almost 50% of the first selected category. For medication as purpose, the PDR was the most frequently selected category; healthy living ranked Hot Topics first, and then Condition Specific; for Ask an Expert, that site was selected first by 65% of the participants. Education/Work Assignment, ranked Condition Specific 50% of the time first. Ask an Expert, however, was again ranked second or third for the most frequently selected site.

First selected and most frequently selected sites were established as the way to look at the patterns of information retrieval because the researcher believed these two patterns represented different ways of viewing the relative importance of the sites. It was originally believed that first selected would represent the most important to the participant. However, this logic may not be accurate. First selected may not have much value, since web pages are designed to link easily from one site to another and back again. In addition she believed identifying the numbers of times sites were visited by categories of participants would reveal overall interest in the site and give a different perspective.

One interesting observation regarding the categories was the type of content contained in each of the sites. Condition Specific and Ask an Expert contained information that could be considered to deal with specific self-care or dependent care needs. The PDR and Health Literature sites contained reference materials that may have some relationship to the self-care or dependent care needs. The News and Hot Topics sites contained general interest information, but not necessarily related to any specific self-care or dependent-care needs. When combined in this manner, Condition Specific and Ask an Expert were consistently ranked first, with the reference sites, PDR and Health Literature, second and the general content site third.

Question four was directed at those participants who had visited NetWellness® previously. Fifty-two participants answered the question regarding what action (or productive operations) they took as a result of receiving information on NetWellness®. The most frequently cited answers were reinforced beliefs (33%) and better communication (19%). Fourteen percent claimed to have made some lifestyle change followed by giving information to a health care provider (12%). Eight percent made an appointment with their health care provider, and 4% sought a

second opinion. Only 6% said they did nothing the final 6% said the information wasn't useful or did not apply.

Question five was asked to determine if the self-care and dependent care agents were satisfied with NetWellness®, in particular with the ease of use and ability to find information needed. Eighty one percent of self-care agents and 77% of dependent care agents indicated they were satisfied or extremely satisfied.

The sixth question was included to simply evaluate the type of information being sought at the Ask an Expert sites. Frequency charts were developed, grouping question categories asked from the various experts, with a summary analysis. A connection may be made to the number of women designated as dependent care agents and the Ask an Expert site for children's health and development and the category for medication

## <u>Implications for Nursing</u>

The results of this research have several implications for nursing theory, practice, and research. The following sections will present specific implications for each area.

Theory. Meleis (1997) would place this study in the theory-research strategy for theory development. In this strategy support is provided for existing propositions and for clinical actions. Three propositions were identified as important for this study. Support for the first proposition (engagement in self-care or dependent-care involves performance of operations to estimate or establish what can and should be done, to decide what will be done and the operations to produce care), was provided

from research questions one, three, four and six. Information was obtained in categories that would be considered self-care or dependent-care directed. Consumers explained the purposes for retrieving information, which in general was specifically for a self-care or dependent-care need and they also identified the actions taken as a result of the information received from NetWellness<sup>®</sup>.

Support for the second proposition (individuals' abilities to engage in self-care or dependent-care are conditioned by age, developmental state, life experience, sociocultural orientation, health and available resources) was provided in question two. Basic conditioning factors (age, educational level, and household income) were somewhat consistent in the categories of information most frequently retrieved.

Differences observed for various age groups were noted.

Support for the third proposition (in the design and production of the nursing systems, nurses seek and confirm information needed to make judgments about the components [some or all] or therapeutic self-care demand and powers of self-care agency or dependent care agency of persons under their care), was provided in question five and six. Consultative care was provided through Ask an Expert; consumers were satisfied or very satisfied with information obtained. Analysis of categories revealed the type of information needed; inferences related to self-care and dependent care needs were made. These multiperson care self-care and dependent-care groups could be considered nursing populations.

Geden (1986) proposed that theory-based research and defining nursing populations were two highly and intimately related concepts. Defining one's nursing population is possible through theory-based practice which gives rise to theory-based

research. Defining your nursing population is a critical process for knowledge development. A nursing population is a description of a subgroup or class in need of nursing. It's defining who you nurse by the way you think nursing, not the site or place where you nurse. Having defined your nursing population, you are free to roam around your world and describe the kinds of people you nurse, the kinds of systems you design, the technologies you find successful and those you find not successful. It is the frame wherein you conduct your nursing research; it is theory-based research.

Therefore, if you are thinking of your population within Orem's Self-care Deficit Theory of Nursing – nursing systems and technologies are designed and evaluated for success through this self-care lens. NetWellness®, as a supportive-educative nursing system to provide consultative nursing care to a global community, is one such technology.

Another implication for nursing that evolved from this study was the need to continue expansion of the concept of "community" within Orem's Self-care Deficit Theory. Historically, nurses have interacted with the individual as the focus of care or unit of service, that is, an individual with a self-care deficit within the context of family. Taylor and Renpenning (1995) extended the model proposed by Orem to describe features of nursing practice situations when the unit of service is greater than one, that is, a multiperson unit such as a family. They described multiperson care systems as comprising action systems serving the following purposes (a) to meet the therapeutic self-care demands of members, (b) to facilitate the development and exercise of self-care agency of all members of the group, and (c) to establish

and/or maintain the welfare of the unit. The existent individual care systems were conceptualized as subsystems of the multiperson care system (Taylor & Renpenning, 1995; Geden & Taylor, 1999).

A general model for the community as a unit of service, congruent with Orem's theory, is presented by Taylor and McLaughlin, (1991). There are various ways of conceptualizing community including a conditioning-factor, as an aggregate, a functional entity or system. Community may be viewed as an aggregate or collection of individuals essentially independent and isolated, with a limited agreedupon common purpose. With this view, the outcome of the nursing diagnostic and prescription operations is identification of the nature of the relationship between the therapeutic self-care demand and self-care agency of members of the community and specification of how nursing can assist in developing the self-care agency of the individual or group of individuals and /or in meeting the self-care demand. Data collection may occur at the individual and community level and prescription may address either or both levels (Orem, 1995 p 376). Understanding the "community" is possible by having a better understanding of the consumers (their BCFs) along with identifying their self-care and dependent-care needs and then sharing information with the individual and community. NetWellness® is changing the definition of community as well as community resources.

<u>Practice.</u> The results of this study have implications for practice in two major ways. First, these findings will increase the awareness of clinicians to incorporate web-based information as part of their supportive-educative nursing system. The second implication is to encourage more nurses to become essential partners in

developing high quality consultative systems that are designed and developed from a theoretical perspective in order to contribute to the knowledge base of nurses.

Understanding factors influencing the utilization of a web based supportive-educative nursing system in self-care agency and self-care actions is critical to determining their therapeutic self-care demand and for designing systems of nursing care for consumers. Collaborative efforts are consistent within Orem's theory. She states that nursing systems may be for the specific purpose of providing nursing. On the other hand, the nursing system may be a system, which is a part of a larger interdisciplinary system concerned with the overall health and welfare of the community (Orem, 1995).

Nurses must recognize the importance of collaboration for developing consumer focused supportive-educative nursing systems. At the same time it is imperative for nurses to recognize the value added by developing these systems within a theoretical framework for consumers' self-care as well as building knowledge for nursing practice and research.

#### Recommendations for Future Research

Recommendations for future research are based on the findings and limitations of this study. Two types of studies are recommended. The first would be directed toward continuously upgrading the system through evaluative research. The second would be specific research designed to better understand, respond to, and evaluate consultative care for consumers with self-care and dependent-care needs in the NetWellness® community.

Replication studies that would expand the population profiles, such as increasing the number of non-Caucasians and people with lower educational levels and incomes should be conducted. Studies should also be conducted that would compare the learning and behavioral outcomes of groups, that use NetWellness® with those that do not. One major need is the creation and evaluation of developmentally appropriate sites for influencing healthy lifestyles in the child and adolescent population.

Nurses need to conduct research that would lead to expansion of on-line supportive-educative nursing systems. Part of this research effort should be to collaborate with others for establishing a "gold standard" for web based health care delivery systems. Another research effort should include participating with others to establish specific standards for rigor of research related to on-line studies. Of particular interest for nurses should be the need for building the knowledge base through assuring that accepted nursing language systems are adhered to and further developed to facilitate theory development.

One of the limitations of this research was in the construction of some of the questions, due to the multiple uses the survey was expected to address. As a result, clear identification of participants that were truly dependent care agents, as defined by Orem, was difficult. Future studies focusing on specific information needs of dependent care agents should be completed. Specific studies are needed that investigate the roles women fulfill as dependent-care agents in culturally diverse areas.

A web-based supportive-educative nursing system provides an excellent opportunity for collaborative international research. This "global community" would facilitate international research efforts that could clarify various concepts within a culturally sensitive perspective. Many studies had conflicting results as to the usefulness of Orem's Self-care Deficit Nursing Theory within other cultures (Yamishita, 1998; Ortiz-Martinez, 1994; Roberson & Kelley, 1996; Morales-Mann and Jiang 1993; Porter, Youssef, Shaaban, & Ibrahim 1992; Hildebrandt, 1996). However, multisite studies for concept clarification within various cultures would have major benefit for further development of Orem's SCDNT theory.

## Conclusions

Several important conclusions, as a result of this study, are presented in the following discussion. They include the appropriateness of Orem's Self-Care Deficit Nursing Theory for on-line information retrieval, the importance of purpose related to information retrieval patterns, the number of pages subjects will visit prior to leaving the web site, and the challenges associated with on-line research.

The overall results of this research demonstrated that Orem's Self-Care

Deficit Nursing Theory was an appropriate framework for this study. Consumers

used the supportive-educative nursing system, NetWellness<sup>®</sup>, to obtain information

regarding their self-care and dependent care needs. Productive operations were

listed as a result of information obtained on NetWellness<sup>®</sup>. Differences in obtaining

information were identified related to basic conditioning factors and the purpose for

obtaining information on NetWellness<sup>®</sup>. In addition, there was specific interest in

interactive systems such as "Ask an Expert". Analysis of consumers that participated in this survey revealed that women were most frequently listed as dependent care agents.

The purpose for seeking information seemed to drive the pattern of information retrieval. These findings supported Orem's central idea of the theory that self-care must be learned and it must be deliberately performed in association with factors such as stages of growth and development, states of health, specific features of health or developmental states, environmental factors and levels of energy (Orem, 1995, p 173). These factors would be considered by Meleis (1997) as developmental, situational or health/illness transitions.

Meleis and Trangenstein (1994, p 257) defined nursing as being concerned with the process and the experiences of human beings undergoing transitions; therefore nursing is defined as "facilitating transitions to enhance a sense of well-being". This definition focused on the nature of transitions, responses and consequences of transition, and the different strategies by which nurses can enhance healthy transitions (1997, p 118). This study described one strategy, information retrieval for estimative operations, on NetWellness®, for the consumer to make better decisions. Nurses can enhance healthy transitions through development of better supportive –educative nursing systems such as NetWellness®.

Clients come to the health care system "either with their consciousness raised about their rights for information for care and for participation in decision making, or if they do not come with such expectations, the caring encounter may then include opportunities for consciousness raising" (Meleis, 1997, p. 413). NetWellness®

provides an excellent vehicle for increasing awareness and participation of consumers.

Meleis (1997) stated that theories of the future would be profoundly influenced by the nature of technological development and by how technology is used in practice, research, teaching, and administration. "We are moving steadfastly into an era where there will be client-centered information systems, organized data sets, where many aspects of people's lives will be dominated by computers, and increasing availability of health care information to the public will be disseminated through network systems. Our challenge is to address ways by which theoretical frameworks and informatics will interface, especially while nurses continue to adopt pluralistic philosophies in defining, connecting, and using data for nursing practice, research, and policy development" (p. 417). The challenge to face in the future is in the development of processes to integrate the development of informatic and theoretical nursing and to guide and develop informatics within the mission, the goals, and theories that reflect the discipline and the goals of health care (Hays, Norris, Martin, and Androwich, 1994). Orem's theory shows promise in helping us better understand how people, as members of a virtual community, seek and retrieve information. This finding is even more important since this theory was presented well before the explosion of the information age of the Internet.

A major finding that was not part of the original study questions was the fact that users selected only three to four choices before leaving the site. This has major implications for the way information is categorized by way of initial choices on the web page. Designing web pages that take into consideration basic conditioning

factors such as age, race, culture, educational level - including language and reading abilities – and health status is essential to assure that information resources needed for self-care and dependent-care are available without multi-level searching.

A final conclusion is related to the evaluation challenge of on-line research.

Traditional evaluation methods are difficult to use due to the dynamic nature of web sites and the inability to conform to accepted standards for randomization and control. However the potential benefit from good studies related to web based health care information is obvious and will demand that new methods and standards for quality research emerge.

This study was conducted to evaluate NetWellness® as a supportive-educative nursing system for providing care to a global community. Perhaps in the future nurses will be explaining what they do in terms such as "I care for individuals around the world with self-care needs related to" - instead of 'I work in Pediatrics, ICU or ambulatory care".

REFERENCES

## References

Achterberg, T., Lorensen, M., Isenberg, M. A., Evers, G. C. M., Levin, E., & Philipsen, H. (1991). The Norwegian, Danish and Dutch version of the Appraisal of Self-care Agency scale; comparing reliability aspects. <u>Scandinavian Journal of Caring Sciences</u>, 5 (2), 101-108.

Afrin, L. B., Kuppuswamy, V., Slater, B., & Stuart, R. K. (1997). Electronic clinical trial protocol distribution via the WorldWide Web: A prototype for reducing costs and errors, improving accrual, and saving trees. <u>Journal of the American</u>

Medical Informatics Association, 4(1), 25-35.

Ailinger, R. L., & Dear, M. R. (1993). Self-care agency in persons with rheumatoid arthritis. Arthritis Care and Research, 6(3), 134-140.

Ailinger, R. L., & Dear, M. R. (1997). An examination of clients with rheumatoid arthritis. <u>Rehabilitation Nursing</u>, 22 (3), 135-140.

Aish, A. (1996). A comparison of female and male cardiac patient's responses to nursing care promoting self-care. <u>Canadian-Journal-of Cardiovascular-Nursing</u>, 7 (3), 4-13.

Aish, A. E., & Isenberg, M. (1996). Effects of Orem-based nursing intervention on nutritional self-care of myocardial infarction patients. <u>International Journal of Nursing Studies</u>, 33 (3), 259-270.

Alford, D. M. (1985) Self-care practices in ambulatory nursing clinics for older adults. In J. Riehl-Sisca. <u>The science and art of self-care</u> (pp. 253-261). Norwalk, CT: Appleton-Century-Crofts.

Allan, J. D. (1988). Knowing what to weigh: women's self-care activities related to weight. Advances in Nursing Science, 11 (1), 47-60.

Allison, S. E. (1973). A framework for nursing action in a nurse-conducted diabetic management clinic. <u>Journal of Nursing Administration</u>, 3 (4), 53-73.

Amtmann, D., & Johnson, K.L. (1998). The Internet and information technologies and consumer empowerment. <u>Technology and Disability</u>, 8 (3), 107-113.

Anna, C. J., Christensen, D. G., Hohon, S. A., Ord, L., & Wells, S. R. (1978). Implementing Orem's conceptual framework. <u>Journal of Nursing Administration</u>, 8(11), 8-11.

Backscheider, J. E. (1974). Self-care requirements, self-care capabilities and nursing systems in the diabetic nurse managed clinic. <u>American Journal of Public Health 64</u>(12), 1138-1146.

Baiardi, J. M. (1997). The influence of health status, burden, and degree of cognitive impairment on the self-care agency and dependent-care agency of caregivers of elders. (Doctoral dissertation, Wayne State University, Detroit).

<u>Dissertation Abstracts International-B 58(11)</u>, 5885. (University Microfilms No. AAT 9815269).

Baker, L. K. (1991). <u>Predictors of self-care in adolescents with cystic fibrosis: a test and explication of Orem's theories of self-care and self-care deficit.</u> (Doctoral dissertation, Wayne State University, Detroit). <u>Dissertation Abstracts International-B</u> 53(03), 1290. (University Microfilms No. AAT 9215059).

Bliss-Holtz, J. (1996). Using Orem's theory to generate nursing diagnosis for electronic documentation. <u>Nursing Science Quarterly</u>, 9 (3), 121-125.

Bliss-Holtz, J., McLauglin, K., & Taylor, S. G. (1990). Validating nursing theory for use within a computerized nursing information system. <u>Advances in Nursing Science</u>, 13 (2), 46-52.

Bliss-Holtz, J., Taylor, S. G., & McLauglin, K. (1990). Nursing theory as a base for a computerized nursing information system. <u>Nursing Science Quarterly</u>, 5 (3), 124-128.

Bliss-Holtz, J., Taylor, S. G., McLaughlin, K., Sayer, P., & Nickle, L. (1992).

Development of a computerized information system based on self-care deficit nursing theory. In J. M. Arnold, & G. A. Pearson, (Eds.). Computer Applications in Nursing Education and Practice. New York: NLN Pub. No. 14-2406

Bower, F. N., & Patterson, J. (1986). A theory-based nursing assessment of the aged. Topics in Clinical Nursing, 8(1), 22-32.

Bracher, E. (1989). A model approach. <u>Nursing Times</u>, <u>85</u> (43), 42-43.

Brennan, P. F. (1988). Home care nursing via computer networks: justification and design specifications. <u>Proceedings of Twelfth Annual Symposium Computer</u>

<u>Applications in Medical Care</u>. 805-809.

Brennan, P. F. (1996). The future of clinical communication in an electronic environment. <u>Holistic Nursing Practice</u>, <u>11</u> (1), 97-104.

Brennan, P. F. (1997). Information technology in the community: The right tools for the job. <u>Journal of the American Medical Informatics Association</u>, 4 (6), 522-523.

Brennan, P. F., Moore, S. M., & Smyth, K. A. (1991) ComputerLink: Electronic support for the home caregiver. <u>Advances in Nursing Science</u>, 13 (4), 14-27.

Brennan, P. F., Moore, S. M., & Smyth, K. A. (1992). Alzheimer's disease caregivers uses of a computer network. Western Journal of Nursing Research. 14 (5), 662-673.

Brennan, P. F., Moore, S. M., & Smyth, K. A. (1995). The effects of a special computer network on caregivers of persons with Alzheimer's disease. <a href="Nursing Research">Nursing</a> Research, 44 (3), 166-172.

Brennan, P.F., & Ripich, S.R. (1994). Use of a home-care computer network by persons with AIDS. <u>International Journal of Technology Assessment in Health Care</u>, <u>10</u>(2), 258-272.

Brennan, P. F., Ripich, S. R., & Moore, S. M. (1991). The use of home-based computers to support persons living with AIDS. <u>Journal of Community Health</u>, 8 (1), 3-14.

Brennan, P.F., & Strombom, I. (1998). Improving health care by understanding patient preferences: The role of computer technology. <u>Journal of the American</u>
Medical Informatics Association, 5 (3), 257-262.

Canty, J. L. (1993). An investigation of life change events, hope and self-care agency in inner city adolescents. (Doctoral dissertation, University of Miami, Miami). Dissertation Abstracts International-B 54(06), 2992. (University Microfilms No. AAT 9331482).

Chammaro, L. (1985). Self-care in the Puerto Rican community. In J. Riehl-Sisca (Ed.), <u>The science and art of self-care (189-195)</u>. Norwalk, CT: Appleton-Century-Crofts.

Chang, B. (1980). Evaluation of health care professionals in facilitating self-care: Review of the literature and a conceptual model. <u>Advances in Nursing Science</u>, 3(1), 43-58.

Closson, B.L., Mattingly, L.J., Finne, K.M., & Larson, J.A. (1994). Telephone follow-up program evaluation: Application of Orem's self-care model. <u>Rehabilitation</u>
Nursing, 19, 287-297.

Cohen, S. (1981). Experience with a computerized medical history system in private practice. In S. Hefferman, (Ed.), <u>Proceedings of the Fifth Annual Symposium</u> on Computer Applications in Medical Care (121-123). New York: IEEE.

Conn, V. (1991). Self-care actions taken by older adults for influenza and colds. Nursing Research, 40(3), 176-181.

Dahlen, A. (1997). Health status of elderly—67 years and older in a community—and their need of nursing care. A survey. <u>Vard I Norden –Nursing Science and Research in the Nordic Countries 17</u>(3), 36-42.

Dashiff, C. J. (1992). Self-care capabilities in Black girls in anticipation of menarche. <u>Health Care for Women International</u>. 13(1), 67-76.

Davidhizar, R., & Cosgray, R. (1990). The use of Orem's model in psychiatric rehabilitation assessment. Rehabilitation Nursing, 15 (1), 39-41.

DeFriese, G., Sehnert, K., & Barry, P. (1982). Medical self-care instruction for laypersons: A new agenda for health science continuing education. Mobius, 2 (1), 42-48.

DeFriese, G., & Woomert, A. (1983). Self-care among U.S. elderly. Research on Aging, 5 (1), 3-23.

Dellesaga, C. (1995). A practical method for assessing the self-care status of elderly persons. <u>Rehabilitation Nursing Research</u>, 4 (4), 128-135.

Denyes, M. J. (1980). Development of an instrument to measure self-care agency in adolescents. (Doctoral dissertation, University of Michigan, Ann Arbor, Mich.). Dissertation Abstracts International 41; 1716-B.

Denyes, M. J. (1982). Measurement of self-care agency in adolescents. <u>Nursing</u>
Research, 31, 63.

Denyes, M. J. (1988). Orem's model used for health promotion: Directions from research. Advances in Nursing Science, 11 (1), 13-21.

Department of Health and Human Services. (2000a). Healthy People 2000, Office of Disease Prevention and Health Promotion. <u>Healthy People 2000</u>: [fact sheet on-line]. Retrieved: May 22, 2000 from the WWW:

Department of health and Human Services. (2000b). Office of Disease

http://ophp.osophs.dhhs.gov/pubs/hp2000

Prevention and Health Promotion. <u>Healthy People 2010:</u> [fact sheet on-line].

Retrieved: May 22, 2000 from the WWW: <a href="www.health.gov/healthypeople">www.health.gov/healthypeople</a>

Dodd, M. J. (1984). Measuring informational intervention for chemotherapy knowledge and self-care behavior. <u>Research in Nursing and Health 7</u>, 43-50.

Dodd, M. J. (1987). Efficacy of proactive information of self-care or radiation therapy patients. Patient Education, 16(5), 538-544.

Dodd, M. J. (1988). Patterns of self-care in patients with breast cancer. Western Journal of Nursing Research, 10, 7-24.

Dodd, M. J. (1997). Self care: ready or not! Oncology Nursing Forum, 24(6), 983-990.

Dodd, M. J., & Dibble, S. L. (1993). Predictors of self-care: A test of Orem's model. <u>Oncology Nursing Forum</u>, <u>20</u> (6), 895-901.

Dowd, T. T. (1994). <u>Relationship among health state factors, foundational capabilities and urinary incontinence self-care in women</u>. (Doctoral dissertation, Wayne State University) <u>Dissertation Abstracts International-B 55</u>(04), 1376. (University Microfilms No. AAT 9423704).

Dropkin, M. J. (1981). Development of a self-care teaching program for postoperative head and neck patients. <u>Cancer Nursing</u>, 4, 103-106.

Duffy, J., Miller, M. P., & Parlocha, P. (1993). Psychiatric home care: A framework for assessment and intervention. <u>Home Healthcare Nurse</u>, <u>11</u> (2), 22-28.

Ehrenberger, H., & Brennan, P. F. (1998). Nursing informatics as a support function for oncology nursing research. <u>Oncology Nursing Forum 25, (10)</u> (Suppl.), 21-26.

Ehrenberger, H., & Murray, P. J. (1998). Issues in the use of communications technologies in nursing research. <u>Oncology Nursing Forum 25</u>, (10) (Suppl.), 11-15.

Eichelberger, K. M., Kaufman, D. N., Rundahl, M. E., & Schwartz, N. E. (1980). Self-care nursing plan: Helping children to help themselves. <u>Pediatric Nursing</u>, *6*(3), 9-13.

Eliopoulos, C. (1984). A self-care model for gerontological nursing. <u>Geriatric</u> Nursing 4, 366-369.

Esterhuysen, A.E.C. (1997). Orem's theory applied in the community health practice. (Masters thesis, University of South Africa, South Africa, 1998). <u>Masters Abstracts International</u>, 36(03), 781.

Evers, G.C.M. (1989). <u>Appraisal of self-care agency: ASA Scale.</u>
Ashen/Mastricht, The Netherlands: VanGorcum.

Evers, G. C. M., Isenberg, M. A., Philipsen, H., Senten, M., & Brouns, G. (1993). Validity testing of the Dutch translation of the appraisal of the self-care agency A.S.A. - scale. <u>International Journal of Nursing Studies</u>, 30, 331-342.

Facteau, L. M. (1980). Self-care concepts and the care of the hospitalized child.

Nursing Clinics of North America, 15 (1), 145-155.

Fawcett, J., & Buhle, E. L. (1995). Using the Internet for data collection. An innovative electronic strategy. <u>Computers in Nursing</u>, 13 (6), 273-279.

Fawcett, J., Cariello, F. P., Davis, D. A., Farley, J., Zimmaro, D. D., & Watts, R. J. (1987). Conceptual models for nursing: Application to critical care nursing practice. <u>Dimensions of Critical Care Nursing</u>, *6*, 202-213.

Fernsler, J. I., & Manchester, L. J. (1997). Evaluation of a computer-based cancer support network. <u>Cancer Practice</u>, 5 (1), 46-51.

Fields, L. M. (1987). A clinical application of the Orem nursing model in labor and delivery. <u>Emphasis: Nursing, 2</u>, 102-108.

Fitzgerald, S. (1980). Utilizing Orem's self-care nursing model in designing an educational program for the diabetic. <u>Topics in Clinical Nursing</u>, 2(2), 57-65.

Folden, S. F. (1993). Effect of a supportive-educative nursing intervention on older adults' perceptions of self-care after a stroke. <u>Rehabilitation Nursing</u>, 18, 162-167.

Foltz, A. T., Gaines, G., & Gullatte, M. (1996). Recalled side effects and self-care actions of patients receiving inpatient chemotherapy. <u>Oncology Nursing Forum</u>, <u>23</u> (4), 679-683.

Frey, M. A., & Denyes, M. J. (1989). Health and illness self-care in adolescents with IDDM: A test of Orem's theory. <u>Advances in Nursing Science</u>, 12, (1), 67-75.

Friedman, R. H., Stollerman, J. E., Mahoney, D. M., & Rozenblyum, L. (1997). The virtual visit: using telecommunications technology to take care of patients.

Journal of the American Medical Association, (4), 413-425.

Fujita, L.Y., & Dungan, J. (1994). High risk for ineffective management of therapeutic regimen: A protocol study. <u>Rehabilitation Nursing</u>, 19, 75-79.

Gaffney, K. F., & Moore, J. B. (1996). Testing Orem's theory of self-care deficit: Dependent care agency performance for children. Nursing Science Quarterly, 9(4), 160-164.

Galli, M. (1984). Promoting self-care in hypertensive clients through patient education. <u>Home Healthcare Nurse</u>, March-April, 43-45.

Garrett, A. P. (1985). A nursing system design for a patient with myocardial infarction. In J. Riehl-Sisca, <u>The science and art of self-care</u> (pp. 142-160). Norwalk, CT: Appleton-Century-Crofts.

Gassert, C. A. (1996). Defining information requirements using holistic models: Introduction to a case study. <u>Holistic Nursing Practice</u>, 11 (1), 64-74.

Gassert, C. A. (1998). The challenge of meeting patients' needs with a national nursing informatics agenda. <u>Journal of the American Medical Informatics</u>

<u>Association</u>, <u>5</u> (3), 263-268.

Gast, H. L., Denyes, M. J., Campbell, J. J., Hartweg, D. L., Shott-Baer, D. & Isenberg, M. (1989). Self-care agency: Conceptualizations and operationalizations.

Advances in Nursing Science, 12 (1), 26-38.

Gaut, D. A., & Kieckhefer, G. M. (1988) Assessment of self-care agency in chronically ill adolescents. Journal of Adolescent Health Care, 9, 55-60.

Geden, E. (1986). Theory based research and defining populations. Paper presented at the Fifth Annual Self-Care Deficit Theory Conference University of Missouri-Columbia, November 6-7, 1986 St Louis, MO. <u>International Orem Society Newsletter 5</u> (2). Retrieved April 22, 2000 from the World Wide Web: <a href="http://www.muhealth.org/~nurising/scdnt/geden497.html">http://www.muhealth.org/~nurising/scdnt/geden497.html</a>

Geden, E., & Taylor, S. (1988). Self-as carer: A preliminary evaluation. In <a href="Proceedings of seventh annual nursing research conference">Proceedings of seventh annual nursing research conference</a>, (abstract, p.7). Columbia MO: University of Missouri-Columbia School of Nursing.

Geden, E., & Taylor, S. (1991). Construct and empirical validity of the Self-As-Carer Inventory. Nursing Research, 40 (1), 47-50. Geden, E., & Taylor, S.G. (1999). Theoretical and empirical description of adult couples' collaborative self-care systems. <u>Nursing Science Quarterly</u>, 12 (4), 329-334.

Gomez, E. G., Dubois, K., & King, C. R. (1998) Improving oncology nursing practice through understanding and exploring the Internet. <u>Oncology Nursing Forum</u>, <u>25</u>(10) (Suppl.), 4-10.

Graff, B. M., Thomas, J. S., Hollingsworth, A. O., Cohen, S. M., & Rubin, M. M. (1992). Development of a postoperative self-assessment form. <u>Clinical Nurse</u>

<u>Specialist</u>, 6 (1), 47-50.

Guglielmino, L. S. (1977). <u>Self-Directed Learning Readiness Scale (SDLRS)</u>. Boca Raton, Florida: Guglielmino and Associates.

Gustafson, D. H., Hawkins, R. P., Boberg, E. W., Bricker, E., Pingree, S., & Chan, C. L. (1994). The use and impact of a computer-based support system for people living with AIDS and HIV infection. <u>Proceedings of 18<sup>th</sup> Annual Symposium of Computer Applications in Medical Care</u>, 604-608.

Gustafson, D. H., Wise, M., & McTavish, P. (1993). Development and pilot evaluation of a computer-based support system for women with breast cancer.

Journal of Psychosocial Oncology, (11), 69-93.

Haas, D. L. (1990). Application of Orem's self-care deficit theory to the pediatric chronically ill population. <u>Issues in Comprehensive Pediatric Nursing</u>, 13, 253-264.

Hagopian, G. A. (1991). The effects of a weekly radiation therapy newsletter on patients. Oncology Nursing Forum, 18 (7), 1199-1203.

Hall, L.E. (1963). Center for nursing. Nursing Outlook, 11, 805-806

Hanchett, E. S. (1988). Nursing theory and public health science: is synthesis possible? <u>Public Health Nursing</u>, 5 (1), 2-6.

Hanchett, E. S. (1990). Nursing models and community as client. <u>Nursing Science Quarterly</u>, 3 (2), 67-72.

Hankes, D. D. (1984). Self-care: Assessing the aged client's need for independence. Journal of Gerontological Nursing, 10 (5), 27-31.

Hannah, K. J. (1995). Transforming information: data management support of health care reorganization. <u>Journal of the American Medical Informatics Association</u>, <u>2 (3)</u>, 147-155.

Hanson, B. R., & Bickel, L. (1985). Development and testing of the questionnaire on perception of self-care agency. In Riehl-Sisca (Ed.), <u>The science</u> and art of self-care (pp.271-278). Norwalk, CT: Appleton-Century-Crofts.

Hanucharurnkul, S (1989) Predictors of self-care in cancer patients receiving radiotherapy. <u>Cancer Nursing</u>, 12, 21-27.

Hanucharurnkul, S. & Vinya-nguag, P. (1990). Effects of promoting patients' participation in self-care on postoperative recovery and satisfaction with care.

Nursing Science Quarterly, 4 (1), 14-20.

Harper, D. C. (1984). Application of Orem's theoretical constructs to self-medication behaviors in the elderly. <u>Advances in Nursing Science</u>, <u>6</u>(1), 29-46.

Harris, M. D. (1991). Clinical and financial outcomes in patient care in a home health care agency. <u>Journal of Nursing Quality Assurance</u>, 5(2), 41-49.

Hart, M. A. (1995). Orem's self-care deficit theory: Research with pregnant women. <u>Nursing Science Quarterly</u>, 8 (3), 120-126.

Hart, M. A., & Foster, S. N. (1998). Self-care agency in two groups of pregnant women. <u>Nursing Science Quarterly</u>, <u>11</u> (4), 167-171.

Hartley, L. A. (1988). Congruence between teaching and learning self-care, A pilot study. Nursing Science Quarterly, 1 (4), 161-167.

Hartweg, D. L. (1991). Health promotion self-care actions of healthy, middle-aged women. (Doctoral dissertation, Wayne State University, Detroit). <u>Dissertation</u>
Abstracts International-B 52(12), 6316. (University Microfilms No. AAT 9215094).

Hartweg, D. L. (1993). Self-care actions of healthy middle-aged women to promote well-being. Nursing Research, 42 (4), 221-227.

Hedahl, K. (1983). Assisting the adolescent with physical disabilities through a college health program. <u>Nursing Clinics of North America</u>, 18, 257-274.

Hegyvary, S. T. (1992). Outcomes research: Integrating nursing practice into the world view. In <u>Patient outcomes research</u>, examining the effectiveness of nursing <u>practice proceedings of the state of the science conference</u>. (NIH Pub No. 93-3411) 17-24.

Henderson, V. (1966). Nature of nursing. New York: Macmillan.

Hendrickson, G., Kelly, J. B., & Citrin, L., (1991). Computers in oncology nursing; present use and future potential. <u>Oncology Nursing Forum</u>, 18 (4), 715-723.

Henry, S. B., (1995). Informatics: Essential infrastructure for quality assessment and improvement in nursing. <u>Journal of the American Medical Informatics</u>

<u>Association</u>, 2 (3), 169-182.

Hewes, C. J., & Hannigan, E. P. (1985). Self-care model and the geriatric patient. In J. Riehl-Sisca, <u>The science and art of self-care</u> (pp. 161-167). Norwalk, CT: Appleton-Century-Crofts.

Hickey, T., Dean, K, & Holstein, B. E. (1986). Emerging trends in gerontology and geriatrics: implications for the self-care of the elderly. <u>Social Science and Medicine</u>, 23 (12), 1363-1369.

Hildebrandt, E. (1996). Building community participation in health care: A model and example from South Africa. <u>Image: Journal of Nursing Scholarship, 28</u> (2). 155-159.

Hildebrandt, E. & Robertson, B. (1995). Self-Care of older black adults in a South African community. <u>Nursing & Health Care: Perspectives on Community</u>, 16, 136-143.

Hiromoto, B. M., & Dungan, J. (1991). Contract learning for self-care activities: a protocol study among chemotherapy outpatients. <u>Cancer Nursing</u>, 14 (3), 83-89.

Horsburgh, M. E. (1994). The contribution of personality to adult well-being: A test and explication of Orem's theory of self-care (Dorothea E. Orem). (Doctoral dissertation, Wayne State University, Detroit). <u>Dissertation Abstracts International-B</u> 56(03), 1346. (University Microfilms No. AAT 9519902).

Hughes, M. M. (1983) Aftercare instruction: seizure disorders. <u>Journal of Emergency Nursing</u>, 9 (3), 154-155.

Humphreys, J. C. (1995). Dependent-care by battered women: protecting their children. <u>Health Care for Women International</u>, 16 (1), 9-20.

Hurst, J. D. (1991), The relationship among self-care agency, risk-taking, and health risks in adolescents. (Doctoral dissertation, University of Alabama, Birmingham). <u>Dissertation Abstracts International-B</u>, 52(03), 1352. (University Microfilms No. AAT9123887).

Jacobs, C. J. (1990). Orem's self-care model: Is it relevant to patients in intensive care? <u>Intensive Care Nursing</u>, 6, 100-103.

James, K. S., (1991). Factors related to self-care agency and self-care practices of obese adolescents. (Doctoral dissertation, University of San Diego) <u>Dissertation</u>

<u>Abstracts International-B, 52</u>(04), 1955. (University Microfilms No. AAT 9125236).

James, L. A. (1992). Nursing theory made practical. <u>Journal of Nursing</u>

Education, 31 (1), 42-44.

Jenkinson, J., Wilson-Pauwels, L., Jewett, M. A., & Woolridge, N. (1998).

Development of a hypermedia program designed to assist patients with localized prostate cancer in making treatment decisions. <u>Journal of Biomedical</u>

Communication, 25 (2), 2-11.

Jesek-Hale, S. R. (1994). Self-care agency and self-care in pregnant adolescents:

A test of Orem's theory. (Doctoral dissertation, Rush University, Chicago).

<u>Dissertation Abstracts International-B 56(1)</u>, p.173. (University Microfilms No.

AAT 9514321).

Jirovec, M. M., & Kasno, J. (1990). Self-care agency as a function of patient-environmental factors among nursing home residents. Research in Nursing and Health, 13, (5), 303-309.

Jones, S. G., (1995). Understanding community in the information age. In S.G. Jones (Ed.), <a href="Cybersociety: Computer-mediated communication and community.">Cybersociety: Computer-mediated communication and community.</a>
Thousand Oaks, CA: Sage.

Jopp, M., Carroll, M. C., & Waters, L. (1993). Using Self-care theory to guide nursing management of the older adult after hospitalization. <u>Rehabilitation Nursing</u>, <u>18 (2)</u>, 91-94.

Kearney, B. Y., & Fleischer, B. J. (1979). Development of an instrument to measure the exercise of self-care agency. Research in Nursing and Health, 2, 24-34.

Kennedy, L. M. (1990). The effectiveness of a self-care medication education protocol on the home medication behaviors of recently hospitalized elderly.

(Doctoral dissertation, University of Texas, Austin). <u>Dissertation Abstracts</u>

<u>International-B 51</u>(08), 3779. (University Microfilms No. AAT 9031613).

Kirkpatrick, F. G. (1986). <u>Community: A trinity of models.</u> Washington, DC: Georgetown University Press.

Klemm, P.; Reppert, K.; & Visich, L. (1998). A nontraditional cancer support group, The Internet. <u>Computers In Nursing</u>, 16 (1), 31-36.

Koster, M. K. (1983). Self-care: Health behavior for the school-age child. Topics in Clinical Nursing, 5, 29-40.

Koster, M. K. (1995). A comparison of the relationship among self-care agency, self-determinism, and absenteeism in two groups of school-age children. (Doctoral dissertation, University of Texas, Austin). <u>Dissertation Abstracts International-B</u> 56(10), 5418. (University Microfilms No. AAT 9603886).

Kruckenber-Schofer, K. & Ward, C. (1990). The computerization of the patient education process. <u>Comprehensive Nursing</u>, 8, 116-122.

Kubricht, D. W. (1984). Therapeutic self-care demands expressed by outpatients receiving external radiation therapy. <u>Cancer Nursing</u>, 7, 43-52.

Lacey, D. (1993). Using Orem's model in psychiatric nursing. Nursing Standard, 7, (29), 28-30.

Ladewig, P.W. (1989). Relationships among locus-of-control, self-care agency and degree of autonomous decision-making about health care. (Doctoral dissertation, University of Denver). <u>Dissertation Abstracts International-B 50</u>(09), 3922. (University Microfilms No AAT 9004067).

Lakeman, R. (1997). Using the Internet for data collection in nursing research.

Computers in Nursing, 15, 269-275.

Lang, N.M., & Marek, K.D. (1992) Outcomes that reflect clinical practice. In <a href="Patient Outcomes Research">Patient Outcomes Research</a>, Examining the Effectiveness of Nursing Practice</a>
Proceedings of the State of the Science Conference. (NIH Pub No. 93-3411) 27-38.

Lenert, L. A., & Soetikno, R. M. (1997). Automated computer interviews to elicit utilities: potential applications in the treatment of deep venous thrombosis.

Journal of the American Medical Informatics Association, 4 (1), 49-56.

Levin, L. (1976). Self-care: An international perspective. <u>Social Policy</u>, 7 (2), 70-75.

Levin, L. (1978). Patient education and self-care: how do they differ? <u>Nursing</u> Outlook, 78, 170-175.

Levin, L. & Idler, E. (1983). Self-care in health. <u>Annual Review of Public Health</u>, 4, 181-201.

Lindberg, C. C. S. (1997). Implementation of in-home telemedicine in rural Kansas: Answering an elderly patient's needs. <u>Journal of the American Medical Informatics Association</u>, 4 (1), 14-17.

London, J. W., Morton, D. E., Marinucci, D., Cataloano, R. & Comis, R. L. (1997). The implementation of telemedicine within a community cancer network.

Journal of the American Medical Informatics Association, 4 (1), 18-24.

Lorensen, M., Holter, I. M., Evers, G. C., Isenberg, M. A., & Achterberg, T. V. (1993). Cross-cultural testing of the "appraisal of self-care agency: ASA scale" in Norway. International Journal of Nursing Studies, 30 (1), 15-23.

Lukkarinen, H., & Hentinen, M. (1997). Self-care agency and factors related to this agency among patients with coronary heart disease. <u>International Journal of Nursing Studies</u>, 34 (4), 295-304.

MacLellan, M. (1989). Community care of a patient with multiple sclerosis.

Nursing (London): The Journal of Clinical Practice, Education and Management, 3

(33), 28-32.

Mapanga, K. G., & Andrews, C. M. (1995). The influence of family and friends' basic conditioning factors on unmarried teenage primipara's engagement in contraceptive practice. <u>Journal of Community Health Nursing</u>, 12 (2), 89-100.

Marine, S., Guard, R., Morris T., Haag, D., Kaya, B., Rieg, J., Schick, L., Tsipis, G., & Shoemaker, S. (1998). A model for enhancing worldwide personal health and wellness. In Cesnik, B., McCray, A.T., Scherrer, J-R, (eds.), Medinfo '98, Proceedings, World Congress on Medical Informatics, 9th, Seoul, Korea, August 18-22, 1998. (pp1265-1268). Amsterdam: IOS Press.

McBride, S. (1987). Validation of an instrument of measure exercise of self-care agency. Research in Nursing and Health, 10, 311-316.

McBride, S. (1991). Comparative analysis of three instruments designed to measure self-care agency. Nursing Research, 40 (1), 12-16.

McCaleb, A. (1991). Self-concept and self-care practices of healthy adolescents. (Doctoral dissertation, University of Alabama, Birmingham) <u>Dissertation Abstracts</u>
International-B 52(07), 3529. (University Microfilms No AAT 9134234).

McCaleb, A., & Edgil, A. (1994). Self-concept and self-care practices of healthy adolescents. <u>Journal of Pediatric Nursing</u>, 9 (4), 233-238.

McCracken, M. J. (1985). A self-care approach to pediatric chronic illness. In J. Riehl-Sisca, <u>The science and art of self-care</u> (pp. 91-104). Norwalk, CT: Appleton-Century-Crofts.

McDermott, M. A. N. (1989). The relationship between learned helplessness and self-care agency in adults as a function of gender and age. (Doctoral dissertation, New York University). <u>Dissertation Abstracts International</u>, 50(08), 3403. (University Microfilms No. AAT 8916029).

McDermott, M.A.N. (1993). Learned helplessness as an interacting variable with self-care agency: testing a theoretical model. <u>Nursing Science Quarterly</u>, 6 (1), 28-38.

McKay, H. G., Feil, E.G., Glasgow, R. E., & Brown, J.E. (1998). Feasibility and use of an Internet support service for diabetes self-management. <u>Diabetes Educator</u>, <u>24</u> (2), 174-179.

McLaughlin, K., Taylor, S., Bliss-Holtz, J., Sayers, P., & Nickle, L. (1990). Shaping the future: The marriage of nursing theory and informatics. <u>Computers in Nursing</u>, (4), 174-179.

McQuiston, C. M. (1993). Basic conditioning factors and self-care agency of unmarried women at risk for sexually transmitted disease. (Doctoral Dissertation, Wayne State University, Detroit) <u>Dissertation Abstracts International-B 55</u>(02), 368. (University Microfilms No. AAT 9418209).

McRoy, S. W., Liu-Perez, A., & Ali, S. S. (1998). Interactive computerized health care education. <u>Journal of the American Medical Informatics Association</u>. 5 (4), 347-356.

Meleis, A. I. (1997). <u>Theoretical nursing: Development and progress</u> (3<sup>rd.</sup> ed.): Philadelphia: Lippincott.

Meleis, A.I., & Trangenstein, P. (1994). Facilitating transitions: Redefinition of the nursing mission. <u>Nursing Outlook</u>, 42, 255-259.

Montgomery, R., Gonyea, J., & Hooyman, N. (1985). Caregiving and the experience of subjective and objective burden. Research Aging, 7, 137-152.

Moore, J. B. (1987). Effects of assertion training and first aid instruction on children's autonomy and self-care agency. Research in Nursing and Health, 10, 101-109.

Moore, J. B., (1993). Predictors of children's self-care performance: testing the theory of self-care deficit. <u>Scholarly Journal for Nursing Practice</u>, 7 (3), 199-217.

Moore, J. B., (1995). Measuring the self-care practice of children and adolescents: instrument development. <u>Maternal-Child Nursing Journal</u>, 23 (3), 101-108.

Moore, J. B., & Gaffney, K. F. (1989). Development of an instrument to measure mothers' performance of self-care activities for children. <u>Advances in</u> Nursing Science, 12 (1), 76-83.

Moore, J. B., & Mosher, R. B., (1997). Adjustment responses of children and their mothers to cancer: self-care and anxiety. <u>Oncology Nursing Forum, 24 (3)</u>, 519-525.

Morales-Mann, E. T., & Jiang, S. L., (1993). Applicability of Orem's conceptual framework: A cross-cultural point of view. <u>Journal of Advanced Nursing</u>, 18, (5) 737-741.

Morris, R. A., Guard, J. R., Marine, S. A., Schick, L., Haag, D. Tsipis, G., Kaya, B., & Shoemaker, S. (1997). Approaching equity in consumer health information delivery: NetWellness. <u>Journal of the American Medical Informatics Association</u>, 4, 6-13.

Moscovitz, A. O., (1984). Orem's theory as applied to psychiatric nursing. Perspectives in Psychiatric Care, 22 (1), 36-38.

Mosher, R. B. & Moore, J. B. (1998). The relationship of self-concept and self-care in children with cancer. <u>Nursing Science Quarterly</u>, <u>11</u> (3), 116-122.

Mullin, V. I. (1980). Implementing the self-care concept in the acute care setting. Nursing Clinics of North America, 15 (1), 177-190.

Murphy, P. P. (1981). A hospice model and self-care theory. <u>Oncology Nursing</u>
<u>Forum, 8 (2)</u>, 19-21.

Murray, P. J. (1995a). Nursing the Internet: A case study of nurses' use of computer-mediated communications. [Unpublished master's thesis], University of Wales Colleges of Medicine, Cardiff, Wales. Retrieved: October 21, 1998 from the WWW: http://www.lemmus.demon.co.uk/diss01.htm

Murray, P. J. (1995b). Research data from cyberspace: Interviewing nurses by email. Health Informatics, 1 (2), 73-76.

Murray, P.J. (1996). Nurses' computer-mediated communications on NURSENET: A case study. <u>Computers in Nursing</u>, 14, 227-234.

Nail, L., Jones, L., Greene, D., Schipper, D. & Jensen, R. (1991). Use and perceived efficacy of self-care activities in patients receiving chemotherapy.

Oncology Nursing Forum, 18 (4), 883-887.

NetWellness Final Project Report. (1997). (Tech. Rep. NTIA/TIIAP Grant Award No. 39-40-94081) Cincinnati, Ohio: University of Cincinnati Medical Center, Department of Academic Information Technology and Libraries.

Neuman, B. M., (1996). Relationships between children's descriptions of pain, self-care and dependent-care, and basic conditioning factors of development, gender, and ethnicity: "bears in my throat". (Doctoral dissertation, Wayne State University, Detroit). <u>Dissertation Abstracts International-B</u>, 57(04), p. 2482. (University Microfilms No. AAT 9628925).

Nicholas, P. K. (1989). Hardiness, self-care practices, and perceived health status in the elderly. (Doctoral dissertation, Boston University, Boston). <u>Dissertation</u>

<u>Abstracts International</u>, 52(04), 1957. (University Microfilms No. AAT 9120027).

O'Connor, N. A. (1995). Maieutic dimensions of self-care agency: instrument development. (Doctoral dissertation, Wayne State University, Detroit) <u>Dissertation</u>

<u>Abstracts International-B 56(05)</u>, 2563. (University Microfilms No. AAT 9503573).

Orem, D. E. (1971). Nursing: Concepts of practice. New York: McGraw Hill.

Orem, D. E. (1980). Nursing: Concepts of practice. (2<sup>nd</sup> ed.). New York:

McGraw Hill.

Orem, D. E. (1983a). Analysis and application of Orem's theory. In I. W. Clements & F. B. Roberts (Eds.). Family health: A theoretical approach to nursing care (pp. 205-217). New York: John Wiley.

Orem, D. E. (1983b). The family coping with a medical illness. Analysis and application of Orem's self-care theory. In I. W. Clements & F. B. Roberts (Eds.). Family health: A theoretical approach to nursing care (pp. 385-386). New York: John Wiley.

Orem, D. E. (1983c). The family experiencing emotional crisis. Analysis and application of Orem's self-care theory. In I. W. Clements & F. B. Roberts (Eds.), Family health: A theoretical approach to nursing care (pp. 367-368). New York: John Wiley.

Orem, D. E. (1985). <u>Nursing: concepts of practice</u> (3<sup>rd</sup> ed.). New York: McGraw Hill.

Orem, D. E. (1991). <u>Nursing: concepts of practice</u> (4<sup>th</sup> ed.). St. Louis: C. V. Mosby.

Orem, D. E. (1995). <u>Nursing: concepts of practice</u> (5<sup>th</sup> ed.). St. Louis: C. V. Mosby.

Ortiz-Martinez, M. A. (1994). The self-care model for nursing in Puerto Rico: A cross-cultural study of the implementation of change. (Doctoral dissertation, Walden University,) <u>Dissertation Abstracts International-B</u>, 56(7), p 3696. (University Microfilms No. 9536769).

Ozbolt, J., & Graves, J. (1993). Clinical nursing informatics: Developing tools for knowledge workers. <u>Nursing Clinics of North America</u>, 28, 407-425.

Padula, C. A. (1992). Self-care and the elderly: Review and implications. <u>Public Health Nursing</u>, 9 (1), 22-28.

Perras, S. T., & Zappacosta, A. (1982). The application of Orem's theory in promoting self-care in a peritoneal dialysis facility. <u>AANNT Journal</u>, 9 (3), 37-39.

Petrlik, J. C. (1976). Diabetic peripheral neuropathy. American Journal of Nursing, 76, 1794-1797.

Porter, L., Youssef, M., Shaaba, I., & Ibrahim, W. (1992). Parenting and enhancement among Egyptian mothers in a tertiary care setting. <u>Pediatric Nursing</u>, <u>18</u>, 329-336, 386.

Relman, A. (1988), Assessment and accountability, the third revolution in medical care. New England Journal of Medicine, 319, 1220-1222.

Rew, L. (1987). The relationship between self-care behaviors and selected psychosocial variables in children with asthma. <u>Journal of Pediatric Nursing</u>, 2 (5), 333-341.

Rew, L. (1990). Childhood sexual abuse: Toward a self-care framework for nursing intervention and research. <u>Archives of Psychiatric Nursing</u>, 4 (3), 147-153.

Richardson, A. (1992). Studies exploring self-care for the person coping with cancer 17 treatment: a review. <u>International Journal of Nursing Studies</u>, 29 (2), 191-204.

Ripich, S., Moore, S. M., & Brennan, P. F. (1992). A new nursing medium: computer networks for group intervention. <u>Journal of Psychosocial Nursing</u>, <u>30</u>(7), 15-20.

Roberson, M.R., & Kelley, J.H. (1996). Using Orem's theory in transcultural settings: A critique. Nursing Forum, 31, (3), 22-28.

Robichaud-Ekstrand, S. (1990). Orem in medical-surgical nursing. The Canadian Nurse, 86 (5), 42-47.

Robinson, M. K. (1996). Determinants of functional status in chronically ill adults. (Doctoral dissertation, University of Alabama, Birmingham). <u>Dissertation</u>

<u>Abstracts International-B 56</u>(10), 5424. (University Microfilms No. AAT 9606050).

Saucier, C. P., (1984). Self-concept and self-care management in school-age children with diabetes. <u>Pediatric Nursing</u>, 10, 135-138.

Schott-Baer, D. (1989). Family culture, family resources, dependent-care, caregiver burden and self-care agency of spouses of cancer patients (Doctoral dissertation, Wayne State University, Detroit). <u>Dissertation Abstracts International-B</u> 51(07), 3327. (University Microfilms No. AAT 9022448).

Schott-Baer, D. (1993) Dependent care, caregiver burden, and self-care agency of spouse caregivers. <u>Cancer Nursing</u>, 16, 230-236.

Schott-Baer, D., Fisher, L., & Gregory, C. (1995). Dependent care, caregiver burden, hardiness, and self-care agency of caregivers. <u>Cancer Nursing</u>, 18 (4), 299-305.

Silva, M. C., & Sorrel, J. M. (1992) Testing of nursing theory: Critique and philosophical expansion. <u>Advances in Nursing Science</u>, 14 (4), 12-23.

Simmons, S. J., (1990). The Health-Promoting Self-Care System Model: directions for nursing research and practice. <u>Journal of Advanced Nursing</u>, <u>15</u> (10), 1162-1166.

Skiba, D. (1993). Collaborative tools. Reflections, 19 (1), 10-12.

Smith, M. C. (1977). Self-care: A conceptual framework for rehabilitation nursing. <u>Rehabilitation Nursing</u>, 2 (2), 159-161.

Smith, M. C. (1989). An application of Orem's theory in nursing practice.

Nursing Science Quarterly, 2 (4), 159-161.

Smits, M. W., & Kee, C. C. (1992). Correlates of self-care among the independent elderly: self-concept affects well-being. <u>Journal of Gerontological Nursing</u>, 18 (9), 13-18.

Smyth, K. A., & Harris, P. B. (1993). Using telecomputing to provide information and support to caregivers of persons with dementia. <u>The Gerontologist</u>, 33, 123-127.

Soderhamn, O., Evers, G., & Hamrin, E. (1996). A Swedish Version of the Appraisal of Self-care Agency (ASA) Scale. <u>Scandinavian Journal of Caring Sciences</u>, 10(1), 3-9.

Soetikno, R. M., Mrad, R., Pao, V., & Lenert, L. A. (1997). Quality of life research on the Internet: feasibility and potential biases in patients with ulcerative colitis. Journal of the American Medical Informatics Association, (4), 426-435.

Spielberger, C. D., Edwards, C. D., Lushene, R. E., Montuori, J., & Platzek, D. (1973). <u>STAIC preliminary manual for the state trait anxiety inventory for children.</u>
Palo Alto, CA. Consulting Psychologists Press.

Spitzer A., Bar-Tal, Y., & Ziv, L. (1996) The moderating effect of age on self-care. Western Journal of Nursing Research, 18 (2), 136-148.

Steiger, N. J. & Lipson, J. G. (1985). <u>Self-Care Nursing: Theory and Practice.</u>
Bowie, MD: Brady Communications.

Sullivan, T., & Monroe, D. (1986). A self-care practice theory of nursing the elderly. Educational Gerontology, 12, 13-26.

Tadych, R. (1985). Nursing in multiperson units: The family. In J. Riehl-Sisca, The science and art of self-care (pp. 49-55). Norwalk, CT: Appleton-Century-Crofts.

Taylor, S. G. (1989). An interpretation of family within Orem's general theory of nursing. <u>Nursing Science Quarterly</u>, 2 (3), 131-137.

Taylor, S. G., & McLaughlin, K. (1991). Orem's general theory of nursing and community nursing. <u>Nursing Science Quarterly</u>, 4 (4), 153-160.

Taylor, S.G. & Renpenning, K. (1995). Nursing in multiperson situations: family and community. In <u>Orem, D. E. Nursing: Concepts of Practice</u>, 5th ed., St. Louis: Mosby Yearbook.

Tetzlaff, L. (1997). Consumer informatics in chronic illness. <u>Journal of the</u>

American Medical Informatics Association, 4, 285-300.

Titus, S., & Porter, P. (1989). Orem's theory applied to pediatric residential treatment. <u>Pediatric Nursing</u>, 15 (5), 465-468, 470-471, 556.

Tolentino, M. B. (1990). The use of Orem's self-care model in the neonatal intensive care unit. <u>Journal of Obstetric, Gynecologic and Neonatal Nursing, 19</u> (6), 496-500.

Toler, J. C., (1997). Telemedicine and telehealth programs: Reaching into patients' homes. <u>Proceedings of the 1997 Partnerships for Networked Consumer Health Information Conference</u> [Online]. Available:

http://clinquery.bidmc.harvard.edu//cme/cybermed.htm [October 1, 1998].

Turner, K. (1989). Orem's model and patient teaching. <u>Nursing Standard</u>, 50 (3), 32-33.

Utz, S. W., & Ramos, M. C., (1993). Mitral valve prolapse and its effects: a program of inquiry within Orem's self-care deficit theory of nursing. <u>Journal of Advanced Nursing</u>, 18 (5), 742-751.

Vannoy, B. E. (1989). Relationships among basic conditioning factors, motivational dispositions, and the power element of self-care agency in people beginning a weight loss program. (Doctoral dissertation, Wayne State University, Detroit), <u>Dissertation Abstracts International-B 51</u>(03), 1197. (University Microfilms No. AAT 9022462).

Vasquez, M. A. (1992). From theory to practice: Orem's self-care nursing model and ambulatory care. <u>Journal of Post Anesthesia Nursing</u>, 7 (4), 251-155.

Villarruel, A. M. (1995). Mexican-American cultural meanings, expressions, self-care and dependent care actions associated with experiences of pain. Research in Nursing and Health, 18, 427-436.

Villarruel, A.M. & Denyes, M.J. (1997). International scholarship. Testing

Orem's theory with Mexican Americans. <u>Image Journal of Nursing Scholarship</u>, 29

(3): 283-288.

Walborn, K. A. (1980). A nursing model for the hospice: Primary and self-care nursing. <u>Nursing Clinics of North America</u>, 15, 205-207.

Walther, J. B., (1992). Interpersonal effects in computer-mediated interaction: A relational perspective. <u>Communication Research</u>, 19 (1), 52-90.

Wang, C. (1997). The cross-cultural applicability of Orem's conceptual framework. <u>Journal of Nursing diversity</u>, 4 (2), 44-48.

Waskul, D., & Douglas, M. (1996). Considering the electronic participant: Some polemical observations on the ethics of online research. <u>The Information Society</u>, 12, 129-139.

Weis, A. (1988). Cooperative care and an application of Orem's self-care theory. Patient Education Counselor, 11 (2), 141-146.

West, P. P., (1993). The relationship between depression and self-care agency in young adult women. (Doctoral dissertation, Wayne State University, Detroit).

<u>Dissertation Abstracts International-B 55(02)</u>, 372. (University Microfilms No. AAT 9418272).

West, P. & Isenberg, M. (1997). Instrument development: The mental health-related self-care agency scale. <u>Archives of Psychiatric Nursing</u>, 6 (3), 126-132

Whetstone, W. R. (1987). Perceptions of self-care in East Germany: A cross-cultural empirical investigation. <u>Journal of Advanced Nursing</u>, 12 (2), 167-176.

Whetstone, W.R., & Hansson, A.M.O. (1989). Perceptions of self-care in Sweden: a cross-cultural replication. <u>Journal of Advanced Nursing</u>, <u>14</u> (11), 962-969.

Whetstone, W. R. & Reid, J. C. (1991) Health promotion of older adults: perceived barriers. <u>Journal of Advanced Nursing</u>. <u>16</u> (11), 1343-1349.

Whitener, L. M., Cox, K. R., & Maglich, S. A., (1998). Use of theory to guide nurses in the design of health messages in children. <u>Advances in Nursing Science</u>, 20 (3), 21-35.

Williams, A. (1979). The student and the alcoholic patient. <u>Nursing Outlook, 17,</u> 470-472.

Wilmonth, M. (1995). Computer networks as a source of research subjects.

Western Journal of Nursing Research, 17, 335-338.

Woods, N. (1989). Conceptualizations of self-care: Toward health-oriented models. <u>Advances in Nursing Science</u>, 12 (1), 1-13.

Woods, N. F. (1985). Self-care practices among young adult married women.

Research in Nursing and Health, 8 (3), 227-233.

Woolery, L. (1983). Self-care for the obstetrical patient. <u>Journal of Obstetrical</u>, <u>Gynecologic</u>, and <u>Neonatal Nursing</u>, 12, 33-37.

Woolery, L. & Yenson, J. (1995). Nursing collaboratory development via the Internet. Medinfo, 8, 1349-1352.

Yamishita, M. (1998). The exercise of self-care agency scale. West-J-Nurs-Res., 20 (3), 370-381.

Zach, P. (1982). Self-care agency in diabetic ocular sequelae. <u>Journal of</u>

<u>Ophthalmic Nursing Techniques</u>, 1 (2), 21-31.

Appendices

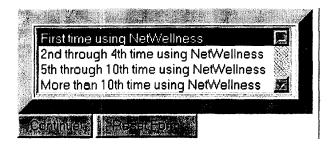
#### Appendix A



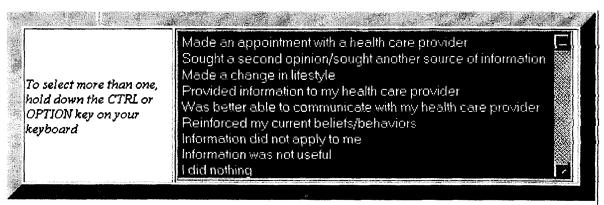
#### **NetWellness Feedback Survey**

Instructions: We would like to have your feedback regarding your experience using NetWellness. Please take a few moments to answer these questions. Your answers will be confidential. Please answer the survey only once. Thank you for participating.

How many times have you used NetWellness?



If you have used NetWellness before, how did you make use of the information you gained? (Select all that apply)



Have you received training on the use of NetWellness?

O Yes O No O No Response

How did you receive training? (Select All that Apply)



Have you used printed guides 10 help you use NetWellness?

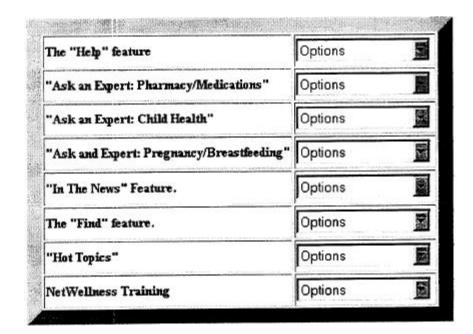
O Yes, O No, O No Response

Please tell us how much you agree with each statement about NetWellness

NetWellness is easy to use	Options	
I easily found the information I was seeking.	Options	
The information I found was useful	Options	2
For health information I prefer using NetWellness compared to using books or brochures	Options	
I am able to find the information I need quicker on NetWellness compared to other print information sources	Options	
NetWellness is more useful than other print information sources.	Options	8

#### Options

Strongly Agree Agree Somewhat Neutral Disagree Somewhat Strongly Disagree Please tell us how useful you found each of the following features of NetWellness.



# Options Very Useful Somewhat Useful Not Useful Not At All Useful Did Not Use

Who were you seeking information for:

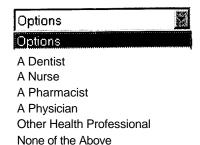
Options

Resembled

Options

Self
A Friend
A Family Member: Adult
A Family Member: Child
A Patient or Client
Other

#### Are you:



If you did not use

the feature,

please say so.

Did you print information or save information on a disk to take with you?

0 Yes, 0 No, 0 No Response

Will you use NetWellness again to find health-related information?

0 Yes, 0 No, 0 No Response

location?	etWellness at another Options
0 Yes, 0 No, 0 No Response	
	Newspaper Article
Where did you first h	On Television
NetWellness?	Tribught the internet (computer on line)
ret weilless.	Saw a NetWellness Computer
Ontions	A Friend or Family Member
Options	A Health Care Professional
	Other
	Don't Remember/Don't Know
How Much experience would y	you say you have in using computers?
	~
Options	A Lot
_	Some
The following is important for the	overall evaluation of NetWellness Very Little
Are you:	
0 Male, 0 Female, 0 No Res	ponse
How old are you?	_
	Options
	Less Than High School Graduate
What is your highest level of ed	lucation? High School Graduate
Options	Some College or Associate Degree
Options	College Graduate
	Some Graduate School
What type of education?	Graduate or Professional Degree
	Other
Racial background: Are you	
Racial background: Are you Options	Options
Options	Black/African-American
	Black/African-American White
Options	Black/African-American White Chicano/Puerto-Rican/Mexican/or Spanish-American
Options	Black/African-American White Chicano/Puerto-Rican/Mexican/or Spanish-American American Indian
Options	Black/African-American White Chicano/Puerto-Rican/Mexican/or Spanish-American American Indian Asian
Options	Black/African-American White Chicano/Puerto-Rican/Mexican/or Spanish-American American Indian
Options  If Other Please Specify	Black/African-American White Chicano/Puerto-Rican/Mexican/or Spanish-American American Indian Asian
Options  If Other Please Specify	Black/African-American White Chicano/Puerto-Rican/Mexican/or Spanish-American American Indian Asian
Options  If Other Please Specify	Black/African-American White Chicano/Puerto-Rican/Mexican/or Spanish-American American Indian Asian
Options  If Other Please Specify	Black/African-American White Chicano/Puerto-Rican/Mexican/or Spanish-American American Indian Asian Other
Options  If Other Please Specify  Please Enter your Zip Code:	Black/African-American White Chicano/Puerto-Rican/Mexican/or Spanish-American American Indian Asian Other
Options  If Other Please Specify  Please Enter your Zip Code:  Your total household income for	Black/African-American White Chicano/Puerto-Rican/Mexican/or Spanish-American American Indian Asian Other  Coptions Less than \$15.000
Options  If Other Please Specify  Please Enter your Zip Code:	Black/African-American White Chicano/Puerto-Rican/Mexican/or Spanish-American American Indian Asian Other

\$60.000 or more

If you are sitting at a NetWellness workstation and there is a number on the side or front of the computer you are using, please enter that number now



This was the last question on the survey. The survey questions were spread across several screens. At the bottom of each screen, one could modify responses before proceeding:



## Appendix B

Appendix B: Summary of 46 Participants Who Took Actions As A Result of Retrieving Information From NetWellness®Categorized by Basic Conditioning Factors, Age, Gender, Race, Household Income and Education

Basic Condition Factors	Reinforced Beliefs (n=17)	Better Comm. (n=10)	Changed Lifestyle (n=7)	Gave Info. To HCP (n=6)	Made Appt. With HCP (n=4)	Sought 2nd. Opinion (n=2)	Total
Age							f %
(12-17) (n=17)	1						1 (6%)
(18-39) (n=99)	8	2	3	1	1	1	15 (15%)
(40-59) (n=129)	5	5	2	4	2	1	18 (14%)
(60-89) (n=28)	2	3	2	1	1		9 (32%)
Gender							
Male(n=127)	7	4	3	4	2	1	20 (16%)
Female (n=145)	10	7	4	2	2	1	25 (17%)
D							
Race	12	9	6	5	4	1	26 (140/)
Caucasian (n=261) Other (n=40)	4	9 1	6 1	3 1	4	1 1	36 (14%) 7 (18%)
Household	4	1	1	1		1	7 (18%)
Income							
<\$15,000			2	1			3 (11%)
(n=27)			_	•			3 (1170)
\$15,000-29,999	2	1		1			4 (11%)
(n=35)							
\$30,000-44,999	4	2	2	1	1	1	10 (22%)
(n=45)	2			2			4 (100/)
\$45,000-59,999 (n=39)	2			2			4 (10%)
>\$60,000	5	7	3	1	3	1	19 (20%)
(n=94)	-	·		_		_	-> (-0,0)
Education							
H.S. Grad & <	1	1		1			3 (9%)
(n=33)							- ( )
Some College/	6	3	2	2		1	13 (11%)
College Degree							
(n=118)	0	7	2	2	4	1	26 (25%)
Some Grad Sch/	9	7	3	3	4	1	26 (25%)
Graduate Degree (n=105)							
(11-100)							

Appendix C

Appendix C: Categories of Questions Directed To Experts on NetWellness®

Pharmacy and Medications (N=228)						
Question Category		obtained self		tained for one else	Total	%
	(N=200)	%	(N=28)	%	(N=228)	%
Dose Administration	6	3	3	10	9	4
Side Effects	48	24	2	7	50	22
Drug Indications	59	30	5	18	64	28
Drug Interactions	12	6			12	5
Adverse Effects	17	9	4	14	21	9
Drug/Disease	34	17	7	25	41	18
Drug/Pregnancy	5	2	2	7	7	3
Overdose/Abuse			2	7	2	1
Manufacture/Pricing	4	2	1	4	5	2
Not Within Scope of Expert	15	8	2	7	17	7
Total	200		28		228	

## Appendix D

Appendix D: Categories of Questions Directed To Experts on NetWellness®

Children's Development and Health (N=73)					
Question Category	Info. obtained for self		tained for one else Total		
	(N=2)	(N=71)	(N=73)		
Musculo-Skeletal		10	10		
Communicable Diseases		9	9		
Upper Respiratory		6	6		
Cardiac		5	5		
Ear/Nose/Throat		5	5		
ADD/ADHD		4	4		
Genitourinary		4	4		
Toddler		4	4		
Digestive Tract		3	3		
Dietary		3	3		
HSP		3	3		
Psychological	2	2	4		
Restless/Sleep Disorders		2	2		
Nervous System		2	2		
Integumentary		2	2		
Genetic		2	2		
Not Within Scope of Expert		5	5		
Total	2	71	73		

## Appendix E

Appendix E: Categories of Questions Directed To Experts on NetWellness®

Breastfeedi	ing and Newborn Care	(N=34)	
Question Category	Info. obtained for self	Info. Obtained for someone else  Total	
	(N=30)	(N=4)	(N=34)
Neonate Care	4		4
Pregnancy Risks	4		4
Conception & Breastfeeding	3		3
Fertility	2		2
Breastfeeding Risks	1	1	2
Ovarian Cysts	1		1
Pregnancy	1		1
Nipple Care	1		1
Referred To Another Expert	11	1	12
Not Within Scope of Expert	2	1	3
	•		
Total	30	3	33

## Appendix F

Appendix F: Categories of Questions Directed To Experts on NetWellness®

	G 1 07 10)		
	Gynecology (N=43)		
Question Category	Info. obtained for self	Info. Obtained for someone else	Total
	(N=40)	(N=3)	
Hormones/Birth Control	7		7
Milestones & Healthcare	5		5
Endometriosis/ Abnormalities of Reproductive Tract	4		4
Cancer	3	3	6
Bowel/Bladder	3		3
Pregnancy	3		3
Infections	2		2
Surgical Procedures	2		2
Consult Your Own HCP	6		6
Not Appropriate for Expert	5		5
Total	40	3	43

## Appendix G

Appendix G: Categories of Questions Directed To Experts on NetWellness®

Pregnancy (N=21)				
Question Category	Info. obtained for self	Info. Obtained for someone else		
	(N=20)	(N=1)	Total	
Risks to Fetus	6		6	
Fertility	4		4	
Ovarian Cysts	3		3	
Medications During Pregnancy	2		2	
Pregnancy Test	2		2	
Pregnancy / Side	2	1	3	
Effects				
Neonate	1		1	
Total	20	1	21	

## Appendix H

## Appendix H: Categories of Questions Directed To Experts on NetWellness®

To Experts on Net Werniess				
Infertility (N=2)				
Question Category	Information			
	Obtained For Self			
	(N=2)			
Thyroid	1			
Fibroid	1			
Total	2			