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Loss Associated with Chronic Illness: Application of the Roy Adaptation Model

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LOSS ASSOCIATED WITH CHRONIC ILLNESS:
APPLICATION OF THE ROY ADAPTATION MODEL

By

Linda M. DeHaan

A THESIS

Submitted to
Grand Valley State University
in partial fulfillment of the requirements for the
degree of

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ABSTRACT

The Roy Adaptation Model guided this pretest-posttest quasi-experimental study to test an intervention addressing loss associated with chronic illness. Differences in adaptation and well-being were evaluated between control (n=20) and experimental groups (n=20) 30 days after intervention. Adaptation was measured by PAIS-SR scores and analyzed using ANCOVA to adjust for pretest differences. T-test and Mann-Whitney U was used to evaluate well-being as measured by the Global Well-being Scale. Changes in adaptation were not significantly different between groups, but well-being improved 12.8% in the experimental group as compared with 1.4% in the control group. Inconsistency of results with RAM concepts raised questions regarding the accuracy of the PAIS-SR as a measurement of adaptation. Results of the study lend support to the application of nursing theory to nursing practice as a means of improving health outcomes.

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CHAPTER ONE

Chronic illness affects the lives of more than 300 million persons in the United States (Statistical Abstract, 1991). Twelve percent of our population is age 65 or older, 86% of whom suffer from one or more chronic conditions. As the baby boom generation ages, the number of older Americans will nearly double, significantly adding to the chronically ill population (Harper, 1990).

Chronic illness is an altered state of health that cannot be cured (Miller, 1983). Reif (1975) described three common features of chronic illness:

1. The disease symptoms interfere with many normal activities and routines.
2. The medical regimen is limited in its effectiveness.
3. Treatment contributes substantially to the disruption of usual patterns of living.

Chronic illness permanently changes the lives of those affected. Departure from what was represents loss. The person's sense of self may be altered in numerous ways: physical ability, body image, self-esteem, role performance, socioeconomic status, relationships. Dealing effectively with these losses requires reorganization and acceptance of self on a level that transcends the illness, thereby enabling the person to preserve a sense of personal integrity. (Feldman, 1974; Miller, 1983).

Because chronic illness affects so many individuals, and because treatment is focused not on cure but on management of a life-long

condition, it is an important area for nursing practice. Care designed to effectively meet the complex needs of the chronically ill must focus not only on the illness, but on the person as an integrated whole. Within this context, loss and interventions to address it become integral components of the plan of care.

Problem

The Roy Adaptation Model (Roy & Andrews, 1991) provides a theoretical framework to guide nursing care. Although conceptual models have become widespread, Fawcett (1990, p. 1418) observed " . . . little evidence of the influence of these models on nursing care." She warned that in order for conceptual models to gain credibility, their effect on client health status must be demonstrated (Fawcett, 1989). Tolley (1995) supported the importance of increasing the utility of nursing theory as a means of bridging the theory-practice gap, citing the separation between the academic world of nursing theory and the "real world" of nursing practice. Literature in the realm of nursing theory tested theory tenets and described application of theory concepts to various practice settings, but offered little evidence that intervention based on nursing theory is more effective than standard nursing practice.

Purpose

The purpose of this study was to link theory to practice by comparing the effectiveness of a theory-based nursing intervention with that of standard nursing practice. An intervention to address loss, guided by the Roy Adaptation Model, was tested for its effect on health outcomes among persons with chronic illness.

CHAPTER TWO

Conceptual Framework and Literature Review

The Roy Adaptation Model

The theory of person as an adaptive system (Roy & McLeod, 1981), derived from the Roy Adaptation Model (RAM), provides a conceptual framework to guide nursing intervention. Within the model, *person* is viewed as an integrated, whole, and adaptive system which is in constant interaction with the environment. The person is engaged in a continual and purposeful process of achieving wholeness, integrity, and fulfillment of maximum potential (Andrews & Roy, 1991). This process, defined as adaptation, is dynamic and self-generating, fueled by stimuli from the environment (Lutjens, 1991).

The *environment* consists of all factors within and surrounding the person which affect the person's development and behavior (Roy & Andrews, 1991). The environment is dynamic and constantly changing. Stimuli from the environment prompt the person to respond, and that response in turn affects and changes the environment.

Environmental stimuli are categorized as focal, contextual, and residual. The focal stimulus is the primary demand or stressor provoking the person to respond. Contextual stimuli are all other factors which influence the person's response to the primary stressor. Residual stimuli are those factors suspected to have bearing upon the person's response, but which have not been confirmed or verified (Lutjens, 1991; Andrews & Roy, 1991).

The combined effect of the focal, contextual, and residual stimuli serve as input to internal coping mechanisms classified as the regulator and the cognator. The regulator consists of autonomic neural, chemical, and endocrine processes; the cognator involves psychological processes such as perception, judgment, learning, and emotion. Coping mechanisms are both innate and acquired through learning. Action of the coping mechanisms is manifested through behavioral responses which are either adaptive or ineffective. An adaptive response promotes a sense of integrity and harmony with the purpose and goals of existence; an ineffective response does not (Andrews & Roy, 1991).

When an adaptive response is achieved, energy used in the adaptation process is freed, enabling the person to respond to other stimuli (Roy, 1984). In this manner, adaptation is an active and self-propelled process which promotes ongoing achievement of life goals. These goals are defined as survival, growth, reproduction, and mastery (Roy & McLeod, 1981). Ineffective responses bind up energy and inhibit the achievement of life goals.

The response to a particular stimulus will be adaptive or ineffective depending upon the person's adaptation level. The adaptation level is determined by the combination of all factors which influence the person's ability to respond in an adaptive manner. If the focal stimulus falls outside this range, the person will be unable to respond effectively. The adaptation level can be altered by either modifying the focal stimulus in such a way that it falls within the adaptation zone, or by modifying contextual stimuli in such a way that

the zone is expanded to permit an adaptive response (Andrews & Roy, 1991).

Nursing activity is directed toward maintaining and strengthening adaptive behaviors, and changing ineffective behaviors (Andrews & Roy, 1991). This is accomplished by management of environmental stimuli to reinforce or modify the person's adaptation level so that an adaptive response is possible.

Nursing activity is planned by evaluating behavior manifested in each of four adaptive modes: physiological, self-concept, role function, and interdependence. Behavior is categorized in modes to facilitate assessment and evaluation of responses (Andrews & Roy, 1991). Operationally, the modes are dynamically interrelated; behavior in any single mode affects the others. The composite of behavior in the four adaptive modes represents the person's adaptation at a particular point in time. In this sense, adaptation is a state or end-product of the adaptation process (Lutjens, 1991).

The *goal of nursing*, according to RAM, is to promote adaptation and thereby contribute to the person's ability to achieve "healing and high-level wellness" (Roy & Roberts, 1981, p. 45). Roy defines *health* as "a state and a process of being and becoming an integrated and whole person" (Andrews & Roy, 1991, p. 4). Health represents integrated function and the process of a person's striving to achieve maximum potential (Lutjens, 1991). Adaptation is the means by which that process occurs. Health is a reflection of adaptation. In promoting adaptation, nursing activity influences health.

Concepts of Roy's theory of the person as an adaptive system are illustrated in Figure 1.

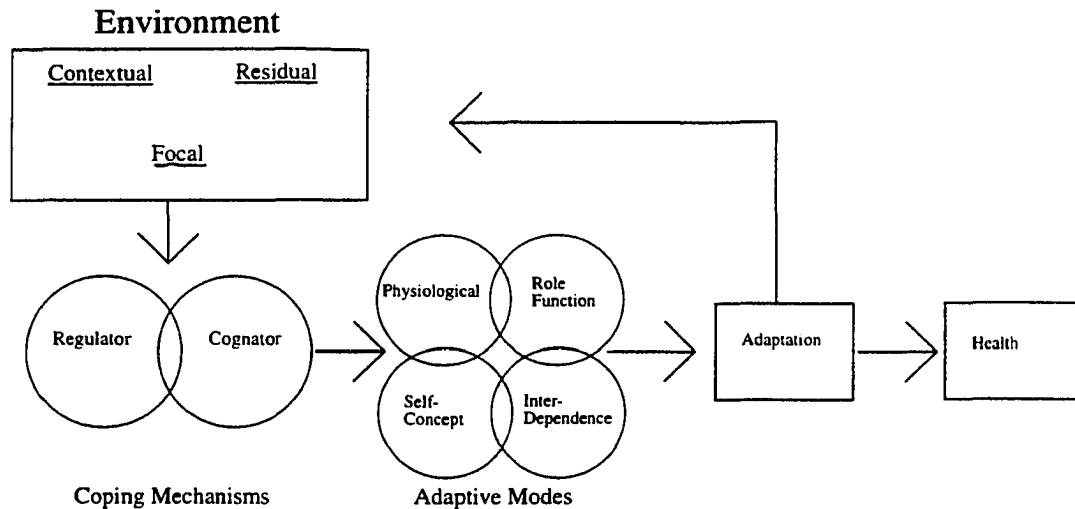


Figure 1. Theory of the person as an adaptive system (adapted from Roy & McLeod, 1981).

Application of RAM Concepts to Variables of Interest

In the Roy Adaptation Model, *person* refers to the recipient of nursing activity. In this study, recipients of nursing activity were persons with chronic illness.

Chronic illness represented the *focal stimulus*, or the primary environmental stressor to which the person must respond. *Contextual stimuli* which influenced the person's response to illness might have included such factors as degree of illness/disability, health care knowledge, endurance, nutritional status, social support, financial resources, etc. Loss was identified as a contextual stimulus of particular interest in this study.

Nursing activity is directed toward management of environmental stimuli. The focal stimulus in this study, chronic illness, could not

be eliminated. However, intervention may be directed toward contextual stimuli to expand the adaptation level and thereby facilitate adaptation. Through management of environmental stimuli, nursing activity influences the *coping mechanisms*. For instance, management of physical symptoms promotes regulator function, and knowledge about health maintenance promotes cognator function. These activities are consistent with standard nursing practice.

Outcomes of the coping mechanisms are manifested in each of the adaptive modes. Examples of adaptive responses might include physiological patterns consistent with the person's maximum potential (physiological mode); a sense of personal value and self-consistency (self-concept mode); satisfying vocational, social, and leisure role activities (role function mode); and the ability to give and receive nurturance and affection (interdependence mode). Ineffective responses might include exacerbation of physiological conditions or inability to care for one's health needs, shame or disillusionment with oneself, inability to enjoy or participate in role activities, social/emotional isolation.

The contextual stimulus "loss" as processed by the regulator might manifest in the physiological mode with responses such as alterations in heart rate, insomnia, fatigue, and gastrointestinal disorders (Joffrion & Douglas, 1994). Grief, the process by which a person copes with loss (Buck, 1984; Marticchio, 1985; Rando, 1984), is a function of the cognator. Although cognator effects may be manifested across all four modes, loss ultimately affects the person's sense of self, which is observed in the self-concept mode (Buck, 1984). Self-concept guides and

directs behavior in all modes (Andrews & Roy, 1991) and is therefore central to adaptation. The experimental intervention in this study, implemented in conjunction with standard nursing care, addressed loss by facilitating the grief process.

The combined behavior in all four modes represents the state of adaptation. *Adaptation* was measured using a modified Psychosocial Adjustment to Illness Scale–Self Report (PAIS-SR) developed by Derogatis (1978). The scale is comprised of seven domains, four of which were used in this study. The first domain represents elements of the cognator which in turn influences behavior in all four adaptive modes. The other three domains correspond to the psychosocial modes: self-concept, role function, interdependence. The total score reflects adaptation to illness. Although there was no specific measure of physiological function, because the RAM indicates that behavior in all four modes is interrelated and integrally associated with adaptation, it was believed the total PAIS-SR score would reflect adaptation across modes.

The process of adaptation promotes *health*, which was represented by the person's sense of global well-being (Andrews & Withey, 1976). Roy's definition of health as a state of wholeness and integrated function and the process of achieving maximum potential (Lutjens, 1991; Andrews & Roy, 1991) is consistent with well-being as conceptualized by Andrews and Withey. Figure 2 represents the variables of interest in relation to RAM concepts.

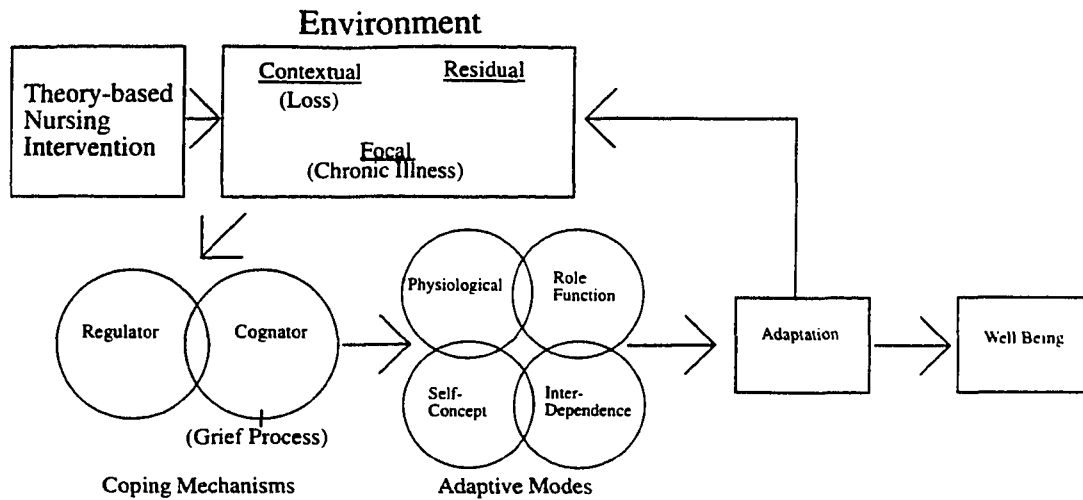


Figure 2. Theory of the person as an adaptive system specified for variables of interest.

Definitions

Definition of variables derived from the Roy Adaptation Model relevant to this study are as follows:

Theory-based Nursing Intervention: A set of nursing activities directed toward promoting adaptation and well-being among persons with chronic illness by facilitating the grief process. The RAM guided development of the intervention; specific nursing activities used in the intervention were derived from a model of grief resolution developed by Joffrion & Douglas (1994).

Adaptation: The end product of the adaptation process which represents the person's overall adjustment to chronic illness.

Well-being: A person's sense of satisfaction with life as a whole; a state of wholeness and integrated function and the process of achieving maximum potential.

Hypotheses

Guided by concepts of the Roy Adaptation Model, this study tested the following hypotheses:

1. When a theory-based nursing intervention is used in conjunction with standard care, persons with chronic illness achieve higher levels of adaptation than persons who receive standard care alone.

2. When a theory-based nursing intervention is used in conjunction with standard care, persons with chronic illness achieve higher levels of well-being than persons who receive standard care alone.

3. Adaptation and well-being are positively correlated.

Significance to Nursing

This study contributed to nursing science by demonstrating that health outcomes are improved when theory-based nursing intervention is used. The literature contains very little experimental research in this area. This knowledge may influence increased application of theory to practice and ultimately contribute to improved quality of nursing care. More specifically, the experimental intervention may provide a useful guide to nurses caring for persons with chronic illness.

Literature Review

A review of literature addressing the variables of interest was conducted. Studies were sought which might provide models for the experimental intervention and evaluating its relationship to RAM concepts.

Loss. Literature pertaining to loss was descriptive in nature and primarily discussed loss related to death, although some authors acknowledged other forms of loss, including the on-going loss associated with chronic illness (Buck, 1984; Rando, 1984; Schaefer, 1995; Schwalb & Zahr, 1985; Stephenson & Murphy, 1986). Loss was defined as "any situation in which a valued object is rendered inaccessible . . . or is altered in such a way that it no longer has qualities that render it valuable" (Gruendemann, 1986, p. 193). Loss of any valued item affects the person's sense of personal identity (Buck, 1984). Persons with chronic illness "mourn the loss of their identity as healthy individuals" (Schwalb & Zahr, 1985, p. 74). Loss of identity is ultimately equated with death of self (Buck, 1984; Rubin, 1968). Schaefer (1995) identified a paradoxical theme of loss and discovery as part of the ongoing life experience of women with chronic illness. These works support the assumption that loss is an issue facing the person with chronic illness and is therefore an appropriate area for nursing intervention.

Grief was identified as the process by which a person copes with loss, allowing the person to heal and resume life with a renewed sense of integrity (Buck, 1984; Marticchio, 1985; Rando, 1984). Studies described the grief process and the various behaviors and tasks associated with it (Haylor, 1987; Rando, 1984; Schaefer, 1995; Schwalb & Zahr, 1985). Several treatment models to facilitate the grief process were offered, with considerable consistency among the described interventions (Attig, 1991; Engel, 1964; Joffrion & Douglas, 1994; Kubler-Ross, 1969; Marticchio, 1985; Rando, 1984). These models were

applied to loss associated with death rather than the on-going loss associated with chronic illness. Although some implied that the process of resolution was the same, none of the studies tested this assumption.

Adaptation. Much work has been done by Roy and associates in developing and testing concepts derived from the Roy Adaptation Model. Other researchers (e.g., Barnfather, Swain, & Erickson, 1989; Farkas, 1981; Fawcett & Tulman, 1990; Mastal, Hammond, & Roberts, 1982; Smith, 1988; Pollock, Christian, & Sands, 1990) have used concepts of RAM to guide program development, nursing assessment and intervention, and to test relationships among theory concepts.

One such study, conducted by Frederickson, Jackson, Strauman, and Strauman (1991), set out to examine the holistic nature of the person as proposed by Roy, by demonstrating the relationship among modes and testing the predictive relationships within the model, specifically the role of perception related to adaptation. This was a non-experimental study using a one-time cross sectional design. Forty-five cancer patients completed instruments to measure actual physiological status (APACHE II), perceived physiological distress (Symptom Distress Profile), and psychosocial adaptation to illness (Sickness Impact Scale). Results were analyzed using Pearson correlations and revealed the following: a weak relationship between actual and perceived physiological status (.13); a weak relationship between actual physiological status and psychosocial adaptation (.17); a moderate relationship between perceived physiological status and psychosocial adaptation (.60). Additional results revealed that survival of subjects (more than 6 months compared with less than 6 months) was linked to

adaptation in physiological and psychosocial modes but not to actual physiological status.

Results of this study supported concepts of the Roy Adaptation Model and the ability to predict relationships based on the model. Implications for nursing derived from this study include the use of RAM concepts to guide and direct care and development of interventions to focus on perception and adaptation.

Because these results were based on a small sample size, replication would be necessary to support these findings. It would be useful to learn what other factors besides perception may have influenced subjects' adaptation to illness. It would be helpful to learn how adaptation in each mode is affected, as this study reported on the physiological mode alone. And finally, experimental research would be necessary to compare the effectiveness of intervention based on these findings with standard practice.

Fawcett (1990) is involved in an ongoing research program designed to test the application of a RAM-based nursing intervention in her work with Caesarian-birth parents. Based on findings from a preliminary retrospective study (N=24), a nursing intervention based on RAM concepts was designed to address the identified need for more information prior to delivery. This intervention was delivered in a clinical field test study of 81 couples, 18 of whom experienced unexpected Caesarian birth. Those couples received a questionnaire, to which 15 responded. Content analysis revealed higher levels of adaptation in each of the four adaptive modes than respondents in the preliminary study. A third study was conducted, incorporating a modified version of the intervention into

standard childbirth preparation classes. Questionnaires were sent to 105 class participants; of the 86 respondents, 71 found the intervention helpful. No information was reported relative to the adaptation levels of this group.

Well-being. Andrews and Withey (1976) conducted extensive research examining indicators of quality of life. Four national surveys and two supplemental surveys were conducted using probability sampling; the six surveys included 5,422 respondents. Interviews were conducted using a 60-page questionnaire. Results were calculated using Multiple Classification Analysis with R^2 values ranging from .50-.62 (95% confidence level).

The authors found that a global evaluation based on combined feelings about a person's perceived well-being was the means by which persons ultimately defined the quality of their lives. Factors that people weigh most heavily in this evaluation were found to include personal enjoyment, satisfaction, accomplishments, relationships, and ability to meet basic needs. These factors are consistent with the concept of health as defined within the Roy Adaptation Model (Andrews & Roy, 1991).

Andersen, Smereck, and Braunstein (1993) have tested the effects of an intervention to promote well-being on high risk behaviors of intravenous drug users. Using a quasi-experimental pretest-posttest design, data were gathered from 995 participants. Following completion of the pretest, subjects returned for two counselling sessions in which they received theory-based nursing intervention designed to improve overall well-being as measured by the Global Well-being Scale (Andrews &

Withey, 1976). The intervention was delivered according to the LIGHT Model based on concepts of nursing theory (Andersen & Smereck, 1989). Subjects returned after 3 months and again after 6 months to complete posttests. Results showed that the intervention was effective in increasing the overall well-being of subjects ($t=-11.77$, $p<.001$) with a mean increase of 29%. In addition, using the Wilcoxon Matched Pair Signed Rank Test (significance set at .01), results showed that subjects reduced high-risk behavior in four categories: 76% reduced IV heroin use ($z=-18.4$, $p<.001$), with 45% reporting no use; 73% reduced IV cocaine use ($z=-16.0$, $p<.001$), with 53% reporting no use; 71% reduced speedball use (cocaine and heroin mixed) ($z=-14.3$, $p<.001$), with 54% reporting no use; and 69% reduced frequency of sharing drug equipment ($z=-13.8$, $p<.001$). Posttest results after 6 months were unchanged.

The study by Andersen et al. (1993) demonstrated the relationship of intervention promoting well-being on other health behaviors and supported the effectiveness of theory-based nursing practice. Limitations of the study included the transient nature of the subjects and the use of self-report data which could not be verified. Corroborating information from well-being scores and nursing observation supported the data. Another limitation was the lack of a control group. An experimental project has been initiated to compare the results of the intervention with those of a control group (M. D. Andersen, personal communication, April, 1994).

Summary

Literature supported concepts of nursing theory and the value of theory-based nursing practice. However, there was a lack of

experimental research comparing the effectiveness of theory-based practice with standard practice.

Loss was acknowledged as an experience associated with chronic illness, but was almost exclusively studied in association with death. As a result, grief responses experienced by persons with chronic illness may not be recognized or understood by family members, caregivers, or the persons themselves. Intervention models designed to assist persons experiencing loss associated with death were not examined for effectiveness in loss associated with chronic illness. This study was designed to address these gaps in the literature.

CHAPTER THREE

Methodology

Research Design

A pretest-posttest, non-synchronized groups, quasi-experimental design was used to evaluate the effectiveness of a theory-based nursing intervention on adaptation and well-being among persons with chronic illness. Subjects in the control group were recipients of standard nursing care; subjects in the experimental group received the theory-based intervention in conjunction with standard care. Both standard care and the experimental intervention were delivered by the same nurses during two distinct phases of the study, each lasting approximately 30 days. Upon completion of the control phase, instruction was provided concerning the experimental intervention, after which the experimental phase of the study was conducted. Convenience sampling was used to recruit eligible subjects from the caseloads of each nurse.

Advantages and Disadvantages

A disadvantage of a longitudinal design is attrition. A significant number of subjects (38%) failed to complete the study due to weakness, declining health, hospitalization, and death. Replacing these subjects was time-consuming because control and experimental portions of the study were not conducted simultaneously. Delays of several weeks often occurred before new subjects could be entered into the appropriate study group.

Threats to Internal Validity

Potential threats to internal validity included variations related to individual intervention styles among participating nurses. This was managed by using the same nurses during both the control and experimental phases of the study. Using the same nurses raised the potential threat of treatment diffusion, which was controlled by operating the control and experimental phases of the study separately and sequentially. This method significantly increased the length of the data collection period.

Reliability of treatment implementation was a threat as different nurses might implement the experimental intervention in varying ways and there also might be differences from visit to visit when the same nurse implemented the experimental intervention (Cook & Campbell, 1979). To minimize this threat, the researcher conducted a training session focusing on the concepts of loss, the grief process, and application of the test intervention (see Appendix A). To prevent contamination, this training did not occur until after the control portion of the study had been completed. Throughout the experimental phase, the researcher met with the nurses to discuss implementation questions and assist with problem solving to promote consistency.

Maturation presented a threat. In a longitudinal study, time and historical events intervene, and persons adapt to situations over time independent of any intervention. Use of a control group minimized the effects of this threat. And finally, the individual adaptation levels (Andrews & Roy, 1991) of each subject could influence outcomes. The difference in adaptation levels among subjects in each group was

controlled statistically using analysis of covariance (ANCOVA).

Threats to External Validity

This study included a conveniently selected small sample size taken from one treatment setting. Therefore, results cannot be generalized to a broader population.

Convenience sampling was necessary due to the limited number of eligible subjects available at a given time who were able and willing to participate in the study. Lack of random sampling restricts the generalizability of the results. This threat was minimized by using a pretest-posttest design which allowed the researcher to identify pre-existing differences in variables of interest between groups. However, administration of the pretest presented the disadvantage of a possible testing effect in that familiarity with the test might have influenced performance on the posttest (Cook & Campbell, 1979).

Setting

The setting for this study was a home-care nursing organization which provides care to persons during acute phases of illness. The agency employs 250 health care workers who provide approximately 100,000 visits annually to persons living in both rural and urban areas. Approximately 90% of service is provided to persons aged 65 years or older.

Sampling

The target population consisted of persons with chronic illness. Each participating nurse submitted names of clients on his or her caseload who met the following eligibility criteria:

1. a medical diagnosis of a chronic illness

2. alteration in one or more of the following areas within the past year: self-care, body image, mobility, role behavior, socialization, leisure activities

3. able to respond to a questionnaire either verbally or in writing

4. anticipated to remain under care at the treatment site for the duration of the test period

5. receiving at least one nursing visit per week

Eligible subjects were contacted by the researcher, and those willing to participate in the study were assigned to the control group. Upon completion of the control phase, the same sampling method was used to select subjects for the experimental group. Separate sampling periods were necessary because the two groups would not be tested simultaneously and the caseloads would change over time. Any subjects who failed to complete the study were replaced using the same process until each group contained 20 subjects, for a total sample size of 40.

Human Subjects Consideration

Risk to subjects involved in this study were minimal because the test intervention used neither invasive procedures nor omissions from standard care and because data were obtained from questionnaires. However, it was anticipated that the questions might be tiring for some subjects, or that some items might evoke a degree of anxiety. Subjects were encouraged to discuss any problems or concerns with their nurse or the researcher. Participation by subjects and nurses was voluntary.

Prior to conducting this study, permission was obtained from the Human Research Review Committee of Grand Valley State University and

from the research committee at the treatment site. Confidentiality was protected with the exception of coding to permit matching of tests.

Sample Characteristics

The sample consisted of 27 females and 13 males ranging in age from 46-98 years, with a mean of 76.6 years. Fifty-seven percent were unmarried (5% single, 15% divorced, 37% widowed); 92% were Caucasian and 8% African-American. Eight subjects (20%) indicated race as Native American, but, based on other observations, this was believed to represent unfamiliarity with the terminology rather than racial identity. These subjects were re-classified as Caucasian in the tabulations.

All subjects were experiencing acute illness episodes in conjunction with chronic disease. Ninety-two percent reported that their health interfered at least moderately with daily activities and 85% had experienced this interference for longer than 6 months. Spiritual beliefs were helpful in coping with the effects of illness among 82% of subjects. Diagnostic categories included cardiavascular, pain, neurological, poor endurance, arthritis, diabetes, cancer, orthopedic, renal, respiratory, and gastrointestinal.

Comparison tests were conducted to evaluate similarity between control and experimental groups based on demographics variables. No significant differences were found, although marital status ($p=.11$) approached significance (see Table 1).

Table 1
Sample Characteristics

Variable	Group			Statistics	
	Sample	Control	Experimental	Test	p-Value
Age: years mean	46-98 76.6	52-87 74.8	46-98 78.3	t-test t=-1 df=38	.32
Gender: female male	67.5% 32.5%	60% 40%	75% 25%	chi ² $\chi^2=1.03$.31
Race: Afr-Am Caucasian	7.7% 92.3%	10% 90%	5% 95%	chi ² $\chi^2=0.31$.58
Status: married unmarried	42.5% 57.5%	55% 45%	30% 70%	chi ² $\chi^2=2.56$.11
Interferes ^a : not at all a little quite a bit severely completely	2.5% 5.0% 37.5% 32.5% 22.5%	5% 5% 40% 20% 30%	0% 5% 35% 45% 15%	Mann-Whitney U=197.5	.95
How Long ^b : <3 mos 3-6 mos 6 mos- 1 yr 1-5 yrs >5 yrs	7.5% 7.5% 22.5% 40.0% 22.5%	5% 5% 15% 45% 30%	10% 10% 30% 35% 15%	Mann-Whitney U=142.5	.12
Beliefs ^c : yes somewhat no	57.5% 25.0% 17.5%	50% 25% 25%	65% 25% 10%	Mann-Whitney U=162.5	.25
Diagnosis: cardiac pain neuro endurance arthritis cancer diabetes ortho renal resp GI	36% 13% 10% 8% 5% 5% 5% 5% 5% 5% 3%	37% 16% 10% 5% 5% 5% 0% 5% 5% 5% 0%	35% 10% 10% 10% 5% 5% 10% 5% 5% 0% 5%	chi ² $\chi^2=5.51$.85

^aHow much do you feel your medical condition interferes with your daily activities? ^bHow long has your health interfered with activities? ^cDo your religious/spiritual beliefs help you cope with your illness?

Experimental Intervention

The independent variable was a theory-based nursing intervention guided by the Roy Adaptation Model which was tested for its effect on adaptation and well-being among subjects in the experimental group. The test intervention addressed loss as a contextual stimulus affecting the person's adaptation to the focal stimulus, chronic illness. This intervention (see Appendix B) was implemented as an addendum to the standard plan of care (see Appendix C).

Instruments

The first dependent variable, adaptation, was measured by the total score on a 26-item modified Psychosocial Adjustment to Illness Scale (PAIS-SR) (Derogatis, 1986). The PAIS-SR is a 46-item self-report tool designed to measure a person's psychosocial adjustment to illness in seven domains: health care orientation, vocational environment, domestic environment, sexual relationships, extended family relationships, social environment, and psychological distress. Numerical values of 0-3 points are assigned to each response; scoring is reversed on even-numbered items within each domain to reduce position-bias. Higher scores represent lower levels of adjustment, resulting in an inverse relationship between PAIS-SR scores and adaptation.

Adjustment was conceptualized as consisting of seven domains. Factor analysis supported seven factors accounting for 63% of the variance in the matrix (Derogatis, 1986). Intercorrelations among the domains were low with a mean of .28, while correlations with the total score resulted in a mean of .61. Thus construct validity was supported. As a result, each domain score can be used independently as a measure of

adjustment within that domain, as well as a component of the total adjustment score.

Derogatis has established reliability coefficients for each domain in studies with three diagnostic groups. Reliabilities for domains used in this study were calculated using Cronbach's alpha and ranged from .71-.89 (see Table 2).

Table 2
Reliability Coefficients for PAIS-SR

PAIS-SR Domain	Current Study	Renal Dialysis ^a	Lung Cancer ^a	Cardiac ^a
Hlth Orient	.71	.63	.83	.47
Ext. Family	.78	.66	.12	.62
Social Env	.80	.78	.93	.80
Psych Dist	.84	.80	.93	.80
Total Score	.89			

^a(Derogatis, 1986, p. 82). Derogatis did not calculate reliability for total scores.

The instrument used in this study was modified after the first 12 months of data collection, in response to a sustained poor completion rate (38%) with the PAIS-SR. In addition to general complaints about the length of the tool, questions in the domains of vocational environment, domestic environment, and sexual relationship were frequently the focus of critical comments by subjects or left unanswered. Characteristics of this sample included retired status, widowed status, frail health with decreased energy and often failing vision, as well as generational values about privacy. These factors were not well-addressed in the style and content of the PAIS-SR. A modified version of the PAIS-SR, printed in bolder, standard-size type

and which omitted the domains identified above, was used for the remainder of the study (see Appendix D). Completion rate with the modified tool rose to 86%. Domains included in the final instrument were health care orientation, extended family relationships, social environment, and psychosocial distress, representing each of the psychosocial modes. Subscores for these domains were used to calculate total PAIS-SR scores.

The second dependent variable, well-being, was measured by the Global Well-being Scale (Andrews & Withey, 1976). Subjects were asked to respond to the question "How do you feel about your life as a whole?" Their responses were rated on a single item seven-point scale ranging from Terrible (1) to Delighted (7) (see Appendix G). Andrews and Withey reported a reliability coefficient of .70 and construct validity of .82 based on Pearson's *r* analysis.

Data Collection Procedures

Data were gathered from June, 1994 to October, 1995. Subjects were contacted by the researcher by telephone to obtain their permission to be included in the study. From a prepared script (see Appendix E), they were informed about the purpose of the study, methods to be used, potential risks, and were given the opportunity to ask questions. After obtaining verbal consent, the researcher provided a consent form and pretest to the subject's nurse, who delivered the materials and obtained written consent (see Appendices F & G). The pretest included the demographics questionnaire, Global Well-being Scale, and PAIS-SR (modified). Subjects were asked to complete the pretest materials and place them in the included envelope prior to the next nursing visit.

The nurse submitted the completed questionnaire to the researcher.

Approximately 30 days later, a posttest consisting of the Global Well-being Scale, PAIS-SR (modified), and a letter of appreciation was delivered to the subjects and returned to the researcher in the same manner (see Appendix H). In the event of substantial missing data, subjects were contacted by the researcher by telephone to obtain the deleted items when possible.

CHAPTER 4

Data Analysis

Results

Adaptation was measured based on the total PAIS-SR (modified) scores. Raw scores were used in the analysis rather than t-test conversions because normative scores have not been established for this sample (Derogatis, 1986). Possible scores ranged from 78-0, with higher scores representing lower levels of adaptation. Ten missing items were replaced with imputed scores based on the subjects' subscale means. There was no more than one imputed score per subscale per group. Two tests, one from each group, were eliminated from analysis due to the amount of data missing. Analysis was computed on the remaining 38 tests (see Table 3).

Table 3
Pretest and Posttest PAIS-SR Scores for Control (n=19) and Experimental (n=19) Groups

Domain (max. score)	Control Group			Experimental Group		
	Pre	Post	Change	Pre	Post	Change
Health Orientation (24)						
<u>M</u>	8.8	7.1	-1.7	6.0	5.6	-0.4
<u>SD</u>	4.1	3.7		3.7	2.7	
Family Relationships (15)						
<u>M</u>	3.5	3.0	-0.5	1.9	2.2	+0.3
<u>SD</u>	3.5	2.7		2.3	2.4	
Social Environment (18)						
<u>M</u>	12.7	11.2	-1.5	9.8	8.8	-1.0
<u>SD</u>	4.8	6.0		4.9	5.2	
Psychological (21)						
<u>M</u>	8.4	8.8	+0.4	8.0	6.8	-1.2
<u>SD</u>	5.0	5.6		3.6	4.4	
Total Score (78)						
<u>M</u>	34.38	31.56	-2.8	25.68	23.49	-2.2
<u>SD</u>	12.38	13.26		13.26	10.82	

Note. Lower scores represent higher levels of adjustment.

T-tests were performed on pretest total scores, showing a significant difference in baseline adaptation levels between groups ($t=2.17$, $df=36$, $p=.04$). With pretest adaptation scores as the covariate, changes in adaptation were calculated using ANCOVA. The difference in posttest scores between groups was not significant ($F=.35$, $df=1$, one-tailed $p=.28$). These findings do not support Hypothesis 1. Based on these measures, persons with chronic illness receiving the test intervention did not achieve higher levels of adaptation than persons receiving standard care.

Well-being was measured based on Global Well-being Scores (refer to Table 4). Comparison of scores between groups using Mann-Whitney U showed no significant difference at pretest ($U= 195.5$, $p=.90$) but a

significant difference between groups at posttest ($U=117$, one-tailed $p=.01$). The degree of change in well-being scores between groups was analyzed using t-test and found to be significant ($t=-2$, $df=38$, one-tailed $p=.03$). Posttest scores showed a 1.4% improvement in well-being among the control group compared with a 12.8% improvement among the experimental group. Based on these results, Hypothesis 2 was supported. When the test intervention was used, persons with chronic illness achieved higher levels of well-being than persons who received standard care alone.

Table 4
Pretest and Posttest Global Well-being Scores for Control (n=20) and Experimental (n=20) Groups

Group	Global Well-being Score		
	Pretest	Posttest	Change
Control			
<u>M</u>	3.75	3.85	+.10
<u>SD</u>	1.33	1.49	
Experimental			
<u>M</u>	3.90	4.85	+.95
<u>SD</u>	1.02	1.09	

Pearson's r was used to test the correlation between adaptation and well-being based on PAIS-SR and Global Well-being scores. (There is an inverse relationship between adaptation scores and adaptation). Correlations ranged from low ($-.37$) to high ($-.86$), with the highest correlation occurring among the control group pretest scores (see Table 5). These results support Hypothesis 3, demonstrating a positive correlation between adaptation and well-being.

Table 5
Intercorrelations between Adaptation and Well-being Scores by Group and Time

Group	Correlation Coefficients	
	Pretest	Posttest
Control (n=19)	-.37 (p=.12)	-.86 (p<.0005)
Experimental (n=19)	-.44 (p=.06)	-.58 (p=.01)

Note. Adaptation scores and adaptation are inversely related. A positive correlation is indicated by a negative correlation coefficient.

Summary

Following intervention, subjects in the experimental group achieved significantly higher levels of well-being than the control group, but there was no significant difference in adjusted levels of adaptation between groups. A positive correlation was demonstrated between adaptation and well-being, although the degree of correlation varied widely.

CHAPTER 5

DISCUSSION

Relationship of the Findings to the Conceptual Framework

Because the study included a sample of only 40 subjects, the findings must be interpreted cautiously. Loss was found to be a relevant area for nursing intervention and fit within the conceptual model as a contextual stimulus. Behavior associated with loss is observed in all four adaptive modes, but is primarily linked with self-concept. This was supported by PAIS-SR subscale scores in the Psychological Distress domain, which showed a greater degree of change on this measure of self-concept among subjects who received the test intervention. The self-concept mode drives behavior and is considered central to adaptation. According to the RAM, adaptation promotes health. The test intervention was associated with significantly higher well-being scores, the measure by which health was evaluated. These findings support the association of improved health outcomes among persons with chronic illness with intervention promoting adaptation to loss.

While both groups experienced improvement in adaptation and well-being following nursing intervention, the adjusted levels of adaptation were not significantly different between groups, but well-being was significantly higher among the test group. These findings present some difficulty in terms of the conceptual framework. The RAM does not examine health directly, but instead focuses on adaptation as the means of promoting health and views health as a reflection of adaptation. It is implied that as adaptation improves, so does health, and that

improvement in health indicates higher levels of adaptation. This relationship was not supported by the results of this study.

While Roy continues to develop the concept of health (Andrews & Roy, 1991), it is possible that health, as defined within the RAM and as measured in this study, is comprised of components beyond the scope of the model. Consistent with Roy's view of the person as a holistic being that is more than the sum of its parts, it is possible that a person's well-being or state of health reflects something more than behavior in the four adaptive modes. However, a more likely explanation for the incongruity between adaptation and health in this study lies in the means by which adaptation was measured.

The PAIS-SR measures adjustment to illness in seven domains which can be associated with the three psychosocial modes. There is some question regarding the congruence between what constitutes adjustment according to PAIS-SR scores and what would be considered adaptation according to the RAM. For instance, persons experiencing physical limitations associated with chronic illness may not be able or interested in participating in previous role or leisure activities (scored as 3 points or least amount of adjustment), but may have adapted to these conditions through alternate activities or interests. Another question concerns "ceiling effects". While norms have been established for several diagnostic groups, no norms have been developed for the mixed group of diagnoses represented in this study. It is likely that among a group of persons with chronic illness, a point would be reached in which no further change in behavior could be achieved, so that responses from pretest to posttest may be limited in the amount of

change possible. This would be more likely among members of the experimental group whose pretest mean score was significantly lower (i.e., higher level of adjustment) than the control group. It is possible that the experimental group had approached the ceiling for change, resulting in a more narrow range for possible improvement than the control group.

Because the PAIS-SR was not easily adaptable to the living situations of retired, unmarried/unpartnered persons living alone, it was not well-received by nearly two-thirds of the subjects included in the initial portion of this study. Lack of response rate necessitated revisions which may have reduced the sensitivity of the instrument. The modified tool eliminated three domains which would have contained information relative to adaptation in the role function and interdependence modes. Although each of the psychosocial modes was represented in the modified tool, the domains which were eliminated contained information in the areas of domestic role, domestic environment, and intimacy, which may have been significant measures of adaptation influenced by the self-concept mode. It is also noteworthy that the only measure of intimacy was associated with sexual behavior. The sample included persons who were not sexually active or who preferred not to respond to those questions, but who may have achieved adaptive behavior in the area of intimate relationships.

Relationship of the Findings to the Literature

There was little in the literature directly related to the findings of this study. No studies examining the Roy Adaptation Model were found which compared differences in adaptation between control and

test groups and none were found that related changes in adaptation with changes in health. Therefore, it is difficult to compare these findings with other research.

Concepts related to loss and facilitation of the grief process, particularly the model described by Joffrion and Douglas (1994), although generally associated with death, were found to be meaningful when applied in the experimental intervention addressing loss associated with chronic illness. Lack of any comparison studies raises questions regarding how these concepts may differ in the case of on-going loss and how the intervention may be refined for maximum effectiveness with this population.

Limitations and Recommendations

Persons of a predominately elderly age group, experiencing acute health problems in conjunction with chronic illness, are dealing with a multitude of extraneous situations which make follow-through with a longitudinal research project problematic. These factors contributed to the small sample size in this study. Characteristics of the sample were specific to a home care setting and did not represent the larger population of persons with chronic illness. Replication with larger samples from different settings is necessary to substantiate any conclusions drawn from this limited study.

Because of the small sample, incomplete data presented a significant problem. An interview style might have been more productive than self-report and might have allowed for interpretation of content subjects did not understand.

Lack of an adequate measure of adaptation has already been

discussed and limits examination of the results with RAM concepts and other studies testing adaptation. It is suggested that another instrument more accommodating to characteristics of this population be used in future studies.

Implications

In supporting the relationship of theory-based practice to improved health outcomes, this study has potential significance to both nursing education and nursing practice. As suggested by Fawcett (1989), it is only in demonstrating the effectiveness of conceptual models that they will gain the credibility necessary for application in practice. By bridging the gap between the academic world of theory and the "real world" of practice (Tolley, 1995), this study and others which may follow provide a practical means of linking theoretical concepts to the planning and delivery of nursing intervention in specific health care situations. The Roy Adaptation Model can be applied in practice to improve health outcomes of persons with chronic illness and intervention addressing loss is a valuable adjunct to plans of care.

This study also may have significance to nursing administration. Results may support the adoption of a theoretical model to guide nursing care delivery and to evaluate the effectiveness of care within an organization.

Implications for nursing research include further development of the RAM concept of health and its relationship to other concepts within the model. Development of instruments to measure adaptation consistent with model definitions would be beneficial to further research testing model concepts and their application. Other areas for further study

might include examination of the significance of improved well-being with other aspects of adaptation, such as the effects of perceived well-being on adaptation across modes (Frederickson et al., 1991) and the effects of well-being on health behaviors (Andersen et al., 1993).

It would be helpful to know what effects adaptation to loss may have on the physiological mode, which was not included in this study, and to examine the effects of improved well-being over time. Demonstrating the effects of improved levels of well-being on specific aspects of the physiological mode, such as symptom exacerbation and hospitalization, would be most beneficial in substantiating not only the relevance but also the cost-effectiveness of intervention to promote well-being.

Conclusions

Results of this study suggest that although a person may experience limitations imposed by illness which cannot be significantly altered, nursing intervention can influence improvement in well-being, thus contributing to quality of life. The experimental intervention designed to promote adaptation to loss among persons with chronic illness was appropriate and beneficial. The concepts of loss and grief, primarily studied when related to death, were found to be applicable to loss associated with chronic illness.

The PAIS-SR was not found to be a satisfactory measure of adaptation among this sample. Based on these inconclusive results, a measure of well-being was not found to be indicative of adaptation. Further work is needed to explain the inconsistencies of these results with RAM concepts.

Both standard nursing intervention and the theory-based intervention were associated with improved adaptation to illness, with no significant difference in the amount of improvement between groups. However, subjects who received the theory-based intervention achieved significantly higher levels of well-being. Therefore, intervention guided by the Roy Adaptation Model was associated with improved health outcomes when compared with standard intervention. The findings supported the purpose of the study, which was to link theory to practice by demonstrating the effectiveness of a theory-based intervention.

APPENDICES

APPENDIX A

LOSS ASSOCIATED WITH CHRONIC ILLNESS

Nursing Intervention Guide

I. Loss

- A. Definition: Any situation in which a valued object is rendered inaccessible or is altered in such a way that it is no longer has qualities that render it as valuable.
- B. Loss associated with chronic illness
 - a. on-going
 - b. loss of identity as a healthy individual
 - c. loss of who one was: death of self
 - *appearance
 - *function
 - *role
 - *status
- C. Any loss alters the sense of personal identity and requires change and reintegration of a new identity.

II. Grief

- A. Definition: The process by which a person copes with loss, allowing the person to heal and resume life with a new sense of integrity.
- B. Phases of the Grief Process
 - 1. Denial - refusal to believe the loss is real; unable to deal with practical matters associated with the loss; self-protective; "shock"
 - 2. Anger - an effort to regain some control; may be directed at self/others/God
 - 3. Bargaining - struggle to come to terms with the loss and make it go away; ambivalence; mood changes; guilt
 - 4. Depression - reality sinking in; permanence of the loss; deep sorrow; inability to envision a happy future; may be verbal or may withdraw
 - 5. Acceptance - coming to terms with the loss and making peace; begins to make plans; may become more isolated in the process
 - 6. Transcendence - reaching out to others; sharing;

making a difference; creating something good from the experience

C. Significance to Health

1. Inability to invest energy into physical healing until later phases of grieving
2. Teaching health care behavior too early will be ineffective
3. Dysfunctional or blocked grief ties up energy and may contribute to negative health outcomes

III. Nursing Intervention

A. Grief is a natural and dynamic process which occurs independently of any intervention and takes time to complete

B. Others may facilitate the process

1. support
2. opportunity to talk
3. knowledge
4. promote coping and planning

C. Careplan Guide

1. Assess Emotional Status and Well-being

"How are you doing?"

"It must be hard at times."

"How are you handling all the changes in your life?"

2. Facilitate Grief Work

- a. support the person at the stage they are at; listen; provide opportunity to talk; gentle guidance toward realistic view
- b. reinforce acceptance and value for the person both verbally and nonverbally
- c. increase knowledge about what is happening; help the person recognize loss and grief; instruct about the grief process and the phases they are going through

- d. help the person identify how they have coped in the past and are coping now
- e. offer hope: there is meaning and purpose to the person and what they are going through; this is a healing process and gets better over time; support of others who have been through this
- f. use referrals for complicated grief responses

APPENDIX B

Experimental Intervention: Addendum to Standard Plan of Care

NURSING DIAGNOSIS: (POTENTIAL FOR) UNRESOLVED GRIEF

RVT Loss associated with chronic illness: _____

Expected Outcomes

Interventions

Resolution of loss.

-verbalization of feelings\concerns

-active involvement in treatment

-maximum independent function in self-care and role activities

ASSESS:

Emotional Status\Well-being:

- response to loss\life-style changes
- signs of active or blocked grief work
- coping strategies

FACILITATE GRIEF WORK:

Encourage verbalization of feelings associated with health status and life-style changes

Assist to identify loss and its significance; encourage reminiscence.

Instruct re: grief process phases and purpose.

Instruct and support utilization of effective coping strategies

Assist to identify necessary life-style modifications

Encourage utilization of strengths and talents; reaching out to others and giving of self.

Refer as appropriate:

- MHRN\MSW
- Rehab services
- Chaplain
- Community resources

NURSING DIAGNOSIS: ALTERATION IN CARDIAC OUTPUT: CHF CHF clinical pathway

R/T: [] Ineffective pumping mechanism [] _____
[] Knowledge deficit [] _____

Expected Outcomes

Interventions

- C
1. improved cardiac output as evidenced by:
. B/P within range of:
. free from s/s CHF
. pulse within range of:
. palpable peripheral pulses
. minimal orthostatic changes
. denial of syncope
. usual mental status
. decrease in peripheral edema
. stable weight pattern
. unlabored respirations of 16-20/min.
. clear breath sounds
. minimal drug side effects
. stable lab values

- d/c
Assess and monitor:
1. T,P,r, b/p qv q
2. Orthostatic Bp qv q
3. PEripheral pulses qv q
4. LUNg sounds qv q
5. WEight qv q
6. SKIn color/temp/texture qv q
7. BOWel/urinary status qv q
8. Mental/EMotional status qv q
9. SYNcope/vertigo qv q
10. ENdurance qv q
11. CHEst pain qv q
12. Edema (1-4+) qv q
13. MEDication response/se qv q
14. REferrals/coordination qv q
(ot, pt, msw, hha, mh)
15. qv q

date achieved rehab pot.
Good
Fair
GUarded
not achieved at discharge
reason:

- tX:
20. call MD if wt gain > 2 lbs, increased sob, edema, or rales, or if bp, pulse is +/-20 of pt. normal range and symptomatic (chf path)
21. Draw labs per Venipuncture Central line

(tests and dates/freq)

- CT
2. client/caregiver is able to perform care, verbalize disease process related to CHF and s/s that require medical intervention

- start res
Teach:
30. S/S that require medical intervention and emergency plan
31. Disease process, s/s complication
32. MEDication use and se
33. BOWel management
34. DIET/fluid regime:
35. ENergy conservation
36. EXercise as ordered:
37. Avoidance of Caffeine, etoh intake, smoking
38. Fluid retention, s/s
39. PULSE monitoring
40. WEight monitoring
41.

date achieved rehab pot.
Good
Fair
GUarded
not achieved at discharge
reason:

Date Initiated - - -

RN signature _____

Pt (last) (first) (mi) DOB - - -

APPENDIX D

PAIS-SR MODIFIED

INSTRUCTIONS: In answering each question, please put a mark in the box alongside the answer that best describes your experience. Please answer all the questions and try not to skip any. If none of the answers to a question match your experience exactly, please choose the answer that comes closest to the experience you have had.

The time we would like you to refer to is the past 30 days, including today. Answer each question in terms of what your experience has been like during this time.

If you have any questions, please ask. Please return the questionnaire to your nurse as soon as you have completed it.

Thank you.

SECTION I

1. Which of the following statements best describes your usual attitude about taking care of your health?
 - a. I am very concerned and pay close attention to my personal health.
 - b. Most of the time I pay attention to my health care needs.
 - c. Usually, I try to take care of health matters but sometimes I just don't get around to it.
 - d. Health care is something that I just don't worry too much about.

2. Your present illness probably requires some special attention and care on your part. Would you please select the statement below that best describes your reaction.
 - a. I do things pretty much the way I always have done them and I don't worry or take any special considerations for my illness.
 - b. I try to do all the things I am supposed to do to take care of myself, but lots of times I forget or I am too tired or busy.
 - c. I do a pretty good job taking care of my present illness.
 - d. I pay close attention to all the needs of my present illness and do everything I can to take care of myself.

3. In general, how do you feel about the quality of medical care available today and the doctors who provide it?
 - a. Medical care has never been better, and the doctors who give it are doing an excellent job.
 - b. The quality of medical care available is very good, but there are some areas that could stand improvement.
 - c. Medical care and doctors are just not of the same quality they once were.
 - d. I don't have much faith in doctors and medical care today.

4. During your present illness, you have received treatment from both doctors and medical staff. How do you feel about them and the treatment you have received from them?
- a. I am very unhappy with the treatment I have received and don't think the staff has done all they could have for me.
 - b. I have not been impressed with the treatment I have received, but I think it is probably the best they can do.
 - c. The treatment has been pretty good on the whole, although there have been a few problems.
 - d. The treatment and the treatment staff have been excellent.
5. When they are ill, different people expect different things about their illness, and have different attitudes about being ill. Could you please check the statement below which comes closest to describing your feelings.
- a. I am sure that I am going to overcome the illness and its problems quickly and get back to being my old self.
 - b. My illness has caused some problems for me, but I feel I will overcome them fairly soon, and get back to the way I was before.
 - c. My illness has really put a great strain on me, both physically and mentally, but I am trying very hard to overcome it, and feel sure that I will be back to my old self one of these days.
 - d. I feel worn out and very weak from my illness, and there are times when I don't know if I am really ever going to be able to overcome it.
6. Being ill can be a confusing experience, and some patients feel that they do not receive enough information and detail from their doctors and the medical staff about their illness. Please select a statement below which best describes your feelings about this matter.
- a. My doctor and the medical staff have told me very little about my illness even though I have asked more than once.
 - b. I do have some information about my illness but I feel I would like to know more.
 - c. I have a pretty fair understanding about my illness and feel that if I want to know more I can always get the information.
 - d. I have been given a very complete picture of my illness, and my doctor and the medical staff have given me all the details I wish to have.
7. In an illness such as yours, people have different ideas about their treatment and what to expect from it. Please select one of the statements below which best describes what you expect about your treatment.
- a. I believe my doctors and medical staff are quite able to direct my treatment and feel it is the best treatment I could receive.
 - b. I have trust in my doctor's direction of my treatment; however, sometimes I have doubts about it.
 - c. I don't like certain parts of my treatment which are very unpleasant, but my doctors tell me I should go through it anyway.
 - d. In many ways I think my treatment is worse than the illness, and I am not sure it is worth going through it.

8. In an illness such as yours, patients are given different amounts of information about their treatment. Please select a statement from those below which best describes information you have been given about your treatment.
- a. I have been told almost nothing about my treatment and feel left out about it.
 - b. I have some information about my treatment, but not as much as I would like to have.
 - c. My information concerning treatment is pretty complete, but there are one or two things I still want to know.
 - d. I feel my information concerning treatment is very complete and up-to-date.

SECTION V

1. Have you had as much contact as usual (either personally or by telephone) with members of your family outside your household since your illness?
- a. Contact is the same or greater since illness
 - b. Contact is slightly less
 - c. Contact is markedly less
 - d. No contact since illness
2. Have you remained as interested in getting together with these members of your family since your illness?
- a. Little or no interest in getting together with them
 - b. Interest is a lot less than before
 - c. Interest is slightly less
 - d. Interest is the same or greater since illness
3. Sometimes, when people are ill, they are forced to depend on members of the family outside their household for physical help. Do you need physical help from them, and do they supply the help you need?
- a. I need no help, or they give me all the help I need
 - b. Their help is enough, except for some minor things
 - c. They give me some help but not enough
 - d. They give me little or no help even though I need a great deal
4. Some people socialize a great deal with members of their family outside their immediate household. Do you do much socializing with these family members, and has your illness reduced such socializing?
- a. Socializing with them has been pretty much eliminated
 - b. Socializing with them has been reduced significantly
 - c. Socializing with them has been reduced somewhat
 - d. Socializing with them has been pretty much unaffected, or (I have never done much socializing of this kind)

5. In general, how have you been getting along with these members of your family recently?

- a. Good
- b. Fair
- c. Poor
- d. Very poor

SECTION VI

1. Are you still as interested in your leisure time activities and hobbies as you were prior to your illness?

- a. Same level of interest as previously
- b. Slightly less interest than before
- c. Significantly less interest than before
- d. Little or no interest remaining

2. How about actual participation? Are you still actively involved in doing these activities?

- a. Little or no participation at present
- b. Participation reduced significantly
- c. Participation reduced slightly
- d. Participation remains unchanged

3. Are you as interested in leisure time activities with your family (i.e., playing cards and games, taking trips, going swimming, etc.) as you were prior to your illness?

- a. Same level of interest as previously
- b. Slightly less interest than before
- c. Significantly less interest than before
- d. Little or no interest remaining

4. Do you still participate in those activities to the same degree you once did?

- a. Little or no participation at present
- b. Participation reduced significantly
- c. Participation reduced slightly
- d. Participation remains unchanged

5. Have you maintained your interest in social activities since your illness (e.g., social clubs, church groups, going to the movies, etc.)?

- a. Same level of interest as previously
- b. Slightly less interest than before
- c. Significantly less interest than before
- d. Little or no interest remaining

6. How about participation? Do you still go out with your friends and do those things?

- a. Little or no participation at present
- b. Participation reduced significantly
- c. Participation reduced slightly
- d. Participation remains unchanged

SECTION VII

1. Recently, have you felt afraid, tense, nervous, or anxious?
 a. Not at all
 b. A little bit
 c. Quite a bit
 d. Extremely

2. Recently, have you felt sad, depressed, lost interest in things, or felt hopeless?
 a. Extremely
 b. Quite a bit
 c. A little bit
 d. Not at all

3. Recently, have you felt angry, irritable, or had difficulty controlling your temper?
 a. Not at all
 b. A little bit
 c. Quite a bit
 d. Extremely

4. Recently, have you blamed yourself for things, felt guilty, or felt like you have let people down?
 a. Extremely
 b. Quite a bit
 c. A little bit
 d. Not at all

5. Recently, have you worried much about your illness or other matters?
 a. Not at all
 b. A little bit
 c. Quite a bit
 d. Extremely

6. Recently, have you been feeling down on yourself or less valuable as a person?
 a. Extremely
 b. Quite a bit
 c. A little bit
 d. Not at all

7. Recently, have you been concerned that your illness has caused changes in the way you look that make you less attractive?
 a. Not at all
 b. A little bit
 c. Quite a bit
 d. Extremely

APPENDIX E

Verbal Script

Hello _____. My name is Linda DeHaan. I am a student completing my Masters Degree in Nursing at Grand Valley State University. I am conducting a research project to evaluate the effectiveness of care and ways to improve the care provided to persons living with a chronic illness. I am calling to see if you would be willing to participate in this project.

Participants will be asked to complete a questionnaire now and again in 30 days. The questions will take about 20-30 minutes to complete and will deal with the effects of illness on the person's everyday life and the way he or she feels emotionally.

The study involves no risks to participants, but some persons may experience fatigue from answering the questions. We encourage the person to rest if this occurs, and go back to it later. Some of the questions may make participants more aware of their feelings. If this should cause any discomfort or difficulty, participants are encouraged to contact myself or discuss their concerns with their nurse.

Participation in this project is completely voluntary and will not affect the care that you receive. You may change your mind at any time. If you agree to participate, all information you provide will be strictly confidential. Your name will not be included on any of the material, and none of the answers can be associated with you specifically. Your answers will go into an envelope which will be opened by no one but myself. Your participation will be greatly appreciated, as it will help us learn better ways to assist people adjust to life with a chronic illness such as yours. Results of this study may be published in professional literature so others can learn from our research.

Do you have any questions about this study? Would you be interested in participating? (If no:) Thank you for your time. (If yes:) The first questionnaire will be delivered with an envelope by your nurse. Please complete it and return it to the envelope prior to the next time your nurse visits. The second questionnaire will be delivered in one month. You will be asked to complete it in the same manner. Each time, answer the questions as honestly as you can based on your experience during the preceeding 30 days. If some questons don't apply to you, just skip them and go to the next one. If you have any questions, please feel free to contact me at any time. My name and phone number will be included with the questionnaire.

Do you have any further questions? Thank you very much.

APPENDIX F

Informed Consent for Participation in Nursing Research

The purpose and procedure for this research project has been explained to me as follows:

1. This project will evaluate the effectiveness of care and ways to improve the care provided to persons living with a chronic illness.
2. I will complete a questionnaire now and again in 30 days. The questions concern effects of illness on my everyday life and the way I feel emotionally. They will take about 20-30 minutes to complete.
3. Participation in this project is completely voluntary. Refusal to participate will not affect my care in any way.
4. All test information will be confidential. My name will not be recorded on any of the forms, and none of the information I provide can be linked specifically with me.

Risks to myself are minimal, but may include fatigue or mild anxiety related to the test questions. I understand that I may speak with the researcher, Linda DeHaan, if I experience any difficulty associated with this project. She may be reached at 343-1396.

Knowledge gained from this project will have no direct benefit to myself, but may be of value to others. Results of the project may be included in professional literature. Information provided by me will remain confidential and my identity will not be revealed in any way.

The above information has been explained to me and I have had the opportunity to ask any questions. I give my consent freely and may withdraw consent at any time.

Signature_____

Date_____

Witness_____

Date_____

I am interested in receiving a summary of the study results.

APPENDIX G

Pretest (Include with PAIS-SR-modified)

Dear Participant,

Please answer the following questions and complete the enclosed test booklet. Do not write your name on any of the forms. When you are finished, place this paper and the booklet in the envelope and return them to your nurse at the next visit.

Please answer all of the questions in the booklet based on your experience during the last 30 days. If some questions do not apply to your situation, they may be omitted. Section II asks about job performance. If you are retired or have never held a job outside your home, please answer those questions as if your household activities or hobbies were your job.

If you have any questions or difficulty related to the study, please contact me at 343-1396. Thank you for your participation in this research project.

Sincerely,

Linda DeHaan, MSNc, RN

APPENDIX H

POSTTEST (Include with PAIS-SR-modified)

Dear Participant,

At this time you are asked to respond to the questions below and complete the enclosed test booklet. Base your answers on your experience during the past 30 days.

Do not write your name on any of the documents. When you are finished, place this paper and the booklet in the envelope and return them to your nurse at the next visit.

Thank you for your participation in this project.

1. How do you feel about your life as a whole these days?

— 1 ——— 2 ——— 3 ——— 4 ——— 5 ——— 6 ——— 7 ———
terrible unhappy mostly mixed mostly pleased delighted
 dissatisfied satisfied

2. Do you have any questions or comments about your involvement in this project?

3. Do you have any questions or comments about the care you have received?

APPENDIX 1

PERMISSION NOTIFICATIONS

February 4, 1994

Gwen Maes
Institute for Social Research
University of Michigan
Room 6130
426 Thompson Street
Ann Arbor, Michigan 48106-1248

Dear Ms. Maes,

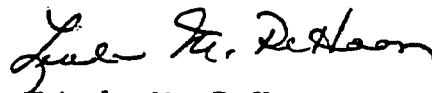
I am a graduate student at Grand Valley State University completing my Masters in Nursing. I am interested in administering the Global Well-being Scale developed by Frank Andrews and Stephen Withey as a pre-test\post-test for my research.

I am requesting permission to administer the test and wish to order copies of the instrument. I will need 120 copies, or will make copies from an original, whichever is most acceptable.

If more information is required, I am available during the day at (616) 343-1396. My Fax number is (616) 382-8686.

Thank you.

Sincerely,



Linda M. DeHaan

Request for Approval

Signature



Date

2/7/94

Librarian
(313) 764-8573

QUALIFICATION FORM

The majority of the tests and rating scales described in this catalogue are selectively available to qualified professionals in accordance with the principles represented in the Ethical Standards for Psychologists published by the American Psychological Association. Eligibility to purchase these instruments is established on the basis of professional training and experience. This form should be completed and submitted with your first order from this catalogue.

Name/Degree Linda M. DeHaan,

Licensed Profession Registered Nurse License Number 4704096484

Address _____

Organization _____ Job Title _____

Please describe the activities in which these instruments will be used.

Pre-test / Post-test as part of Master's Thesis - studying effects of loss on adaptation to chronic illness & effectiveness of intervention to address loss

Within your organization, who is responsible for supervising the use of these materials?

Name Louette R. J. Lutjens PhD RN Title Associate Professor

Academic Training Degree	Year	Institution	Major Field
<u>PhD</u>	<u>1990</u>	<u>Wayne State Univ.</u>	<u>Nursing Science</u>

I hereby certify that I and/or individuals under my supervision possess a knowledge of the basic principles of psychological measurement and of the limitations on valid interpretations as represented in the APA standards for education and psychological tests. I further certify that I am qualified to utilize the instruments purchased in a manner consistent with APA recommended standards.

Signature _____ Date 1/4/94

If a graduate student check here.

Professor/Supervisor:

I agree to supervise this student in the use of the test materials ordered.

Professor's Name Louette R. J. Lutjens PhD RN Date Jan. 10, 1994

Signature _____

Department Kerkhof School of Nursing Institution Grand Valley State Univ



May 16, 1994

Linda DeHaan
10107 Woodlawn
Portage, MI 49002

Dear Linda:

I am writing to express the intent of the Visiting Nurse Association of Southwest Michigan to cooperate in the implementation of your study regarding loss associated with chronic illness. VNA staff nurses who agree to participate in the inservice, nursing intervention, and measurement requirements of the study may do so as a component of their staff responsibilities. Patients who meet the selection criteria for the study may be given the opportunity to participate and must sign an informed consent form which meets agency requirements.

Congratulations on your progress to date. All of us on the Research Committee are enthusiastic about your study and look forward to working with you. Please let me know when you are ready to begin implementation of the study so we can set forth a schedule of activities. I will serve as your liaison to the Committee and will be glad to help with any problem solving needed to facilitate your progress with data collection.

Sincerely,

Terry Hluchyj
Vice President, Planning and Research

GRAND VALLEY STATE UNIVERSITY
HUMAN RESEARCH REVIEW COMMITTEE

Principal Investigator: Linda M. DeHaan

Department of School: Nursing

Address and Telephone: _____

Title of the Project: Loss associated with Chronic Illness

Summary of the Project: Subjects will be persons with chronic illness receiving care by a home-based nursing organization. Subjects in the control group will receive nursing care according to a standard plan of care. Subjects in the experimental group will receive standard care plus an intervention to address loss. Subjects in both groups will complete a pretest/posttest questionnaire. Items will be scored and evaluated for changes in adaptation and well-being.

In what capacity does this project involve human subject? (E.g., surveys, interviews, clinical trial, use of medical records, etc.)

- 1) application of a non-invasive intervention consistent with professional nursing practice.
- 2) completion of questionnaires which will maintain participant confidentiality.

Check one:

- This is a report on research on human subjects which is exempted by 46.101 of the Federal Register 46(16):8336, January 26, 1981. (Refer to instructions on the reverse of this form.)
- This is a request for expedited review as described in 46.110 of the Federal Register 46(16):8336, January 26, 1981. (Refer to instructions on the reverse of this form.)
- This is a request for full review. (Refer to instructions on the reverse of this form.)

Principal Investigator

Department Chair or Advisor

Date

Date

Loss associated with Chronic Illness:
Application of the Roy Adaptation Model

Basis for Expedited Review

Research activities involve no more than minimal risk to subjects. The study involves the use of non-invasive procedures routinely employed in clinical practice. The experimental intervention consists of standard care used at the research site plus an intervention addressing loss. The test intervention activities are consistent with nursing practice and are documented in nursing literature.

Data will be obtained from responses on pretest and posttest questionnaires which will consist of a demographics profile, Global Well-being Scale, and Psychosocial Adjustment to Illness Scale. Questionnaires will be coded to permit matching. The researcher will have the only record linking subjects' names with the codes. This list will be maintained by the researcher to protect confidentiality and will be destroyed when data collection is completed. Participation in the study is voluntary. Informed consent will be obtained.

Permission to use the Global Well-being Scale was obtained from the University of Michigan. The Psychosocial Adjustment to Illness Scale (Self-Report) is a published instrument available for purchase. The instrument and scoring sheets were purchased for use in this study. Permission to conduct the project was obtained from the research committee at the study site.

LIST OF REFERENCES

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- Andersen, M. D., & Smereck, G. A. D. (1989). Personalized nursing: LIGHT model. Nursing Science Quarterly, 2, 120-130.
- Andersen, M. D., Smereck, G. A. D., & Braunstein, M. S. (1993). LIGHT model: An effective intervention model to change high-risk AIDS behaviors among hard-to-reach urban drug users. American Journal of Drug & Alcohol Abuse, 19, 309-325.
- Andrews, F. M., & Withey, S. B. (1976). Social indicators of well-being: Americans' perceptions of life quality. New York: Plenum.
- Andrews, H. A., & Roy, C. (1991). Essentials of the Roy adaptation model. In C. Roy & H. A. Andrews (Eds.), The Roy adaptation model: The definitive statement (pp.3-25). Norwalk, CT: Appleton & Lange.
- Attig, T. (1991). The importance of conceiving grief as an active process. Death Studies, 15, 385-393.
- Barnfather, J. S., Swain, M. A. P., & Erickson, M. C. (1989). Evaluation of two assessment techniques for adaptation to stress. Nursing Science Quarterly, 2, 172-182.
- Buck, M. H. (1984). Loss. In C. Roy (Ed.), Introduction to nursing: An adaptation model (2nd ed.) (pp. 337-352). Englewood Cliffs, NJ: Prentice-Hall.
- Cook, T. D. & Campbell, D. T. (1979). Quasi-experimentation: Design and analysis issues for field settings. Boston: Houghton Mifflin.
- Derogatis, L. R. (1986). Psychosocial adjustment to illness scale (PAIS). Journal of Psychosomatic Research, 30(1), 77-91.
- Farkas, L. (1981). Adaptation problems with nursing home application for elderly persons: An application of the Roy adaptation nursing model. Journal of Advanced Practice Nursing, 6, 363-368.
- Fawcett, J. (1989). Analysis and evaluation of conceptual models of nursing (2nd. ed.). Philadelphia: Davis.

- Fawcett, J. (1990). Preparation for Caesarian childbirth: Derivation of a nursing intervention from the Roy adaptation model. Journal of Advanced Nursing, 15, 1418-1425.
- Fawcett, J., & Tulman, L. (1990). Building a programme of research from the Roy adaptation model of nursing. Journal of Advanced Nursing, 15, 720-725.
- Feldman, D. (1974). Chronic disabling illness: A holistic view. Journal of Chronic Disease, 27, 287.
- Frederickson, K., Jackson, B. S., Strauman, T., & Strauman, J. (1991). Testing hypotheses derived from the Roy adaptation model. Nursing Science Quarterly, 4, 168-174.
- Gruendemann, B. J. (1976). Problems of physical self: Loss. In C. Roy, Introduction to nursing: An adaptation model (pp. 192-201). Englewood Cliffs, NJ: Prentice-Hall.
- Harper, M. S. (1990). Mental health and older adults. In M. O. Hogstel (Ed.), Geropsychiatric nursing (pp.1-37). St. Louis: Mosby.
- Haylor, M. J. (1989). Human response to loss. Nurse Practitioner, 12(5), 63-66.
- Joffrion, L. P., & Douglas, D. (1994). Grief resolution: Facilitating self-transcendence in the bereaved. Journal of Psychosocial Nursing and Mental Health Services, 32(3), 13-19.
- Kubler-Ross, E. (1969). On death and dying. New York: Macmillan.
- Lutjens, L. R. J. (1991). The Roy adaptation model. Newbury, CA:Sage.
- Marticchio, B. C. (1985). Grief and bereavement. Nursing Clinics of North America, 20, 327-341.
- Mastal, M., Hammond, H., & Roberts, M. (1982). Theory into hospital practice: A pilot implementation. The Journal of Nursing Administration, 12(6), 9-15.
- McCloskey, J. C., & Bulechek, G. M. (Eds.). (1992). Nursing interventions classification (NIC). St. Louis: Mosby.
- Miller, J. F. (1983). Coping with chronic illness: Overcoming powerlessness. Philadelphia: Davis.

- Pollock, S. E., Christian, B. J., & Sands, D. (1990). Responses to chronic illness: Analysis of psychological and physiological adaptation. Nursing Research, 39, 300-304.
- Rando, T. A. (1984). Grief, dying, and death: Clinical interventions for the caregiver. Lexington, MA: Lexington.
- Reif, L. (1975). Beyond medical intervention strategies for managing life in face of chronic illness. In M. Davis, M. Kramer, & A. Strauss (Eds.), Nurses in practice: A perspective on work environment. St. Louis: Mosby.
- Roy, C. (1984). Introduction to nursing: An adaptation model (2nd ed.). Englewood Cliffs, NJ: Prentice-Hall.
- Roy, C., & Andrews, H. A. (1991). The Roy adaptation model: The definitive statement. Norwalk, CT: Appleton & Lange.
- Roy, C., & McLeod, D. (1981). Theory of person as an adaptive system. In C. Roy & S. L. Roberts, Theory construction in nursing: An adaptation model (pp. 49-69). Englewood Cliffs, NJ: Prentice-Hall.
- Roy, C., & Roberts, S. L. (1981). Theory construction in nursing: An adaptation model. Englewood Cliffs, NJ: Prentice-Hall.
- Schaefer, K. M. (1995). Women living in paradox: Loss and discovery in chronic illness. Holistic Nursing Practice, 9(3), 63-74.
- Schawlb, D., & Zahr, L. (1985). Nursing care for patients with an altered body image due to multiple sclerosis. Nursing Forum, 22, 72-76.
- Smith, M. C. (1988). Roy's adaptation model in practice. Nursing Science Quarterly, 1, 97-98.
- Statistical Abstract of the United States (111th ed.). (1991). Washington D.C.: U. S. Dept. of Commerce.
- Stephenson, J. S., & Murphy, E. (1986). Existential grief: The special case of the chronically ill and disabled. Death Studies, 10, 135-146.
- Tolley, K. A. (1995). Theory from practice for practice: Is this a reality? Journal of Advanced Nursing, 21, 184-190.