

Advanced Practice Nursing Model for Comprehensive Care With Chronic Illness Model for Promoting Process Engagement

**Sharon A. Cumbie, PhD, RN; Virginia M. Conley, PhD, RN, FNP,C;
Mary E. Burman, PhD, RN, FNP,C**

New models of providing care to chronically ill persons are needed that can facilitate a more integrative approach to patient care. The purposes of this article are to describe the utilization of a theory synthesis process for development of a client-focused approach for advanced practice nurse (APN) management of chronic illness and to present the *Model for Promoting Process Engagement*. The model was developed as a theory-driven intervention to address complexities of chronic illness care. This APN practice model is the direct result of the synthesis of a number of differing theoretical models developed by the authors in previous individual research endeavors. **Key words:** *advanced practice nursing, chronic illness, client-centered, model of nursing care, theory development, theory synthesis*

PERSONS face a variety of needs, demands, and discomforts as they attempt to maintain quality life within the context of chronic illness. The effective management of chronic illness requires timely, appropriate, and supportive clinical care for optimal outcomes. Yet, this is generally not the experience of many persons with chronic illness. Medical care in the United States, with its acute care emphasis, often fails to contribute to effective self-management and may deviate significantly from recognized standards of pharmacological and behavioral care for specific chronic illness.¹ Typically client-initiated visits, symptom relief, normalization of abnormal physiological measures, and client assurance are the main foci of care.¹ Systematic

assessment, prevention, education, support, and routine follow-up are therefore difficult to implement due to the acute care focus inherent within health care systems. Consequently, new approaches to providing care to chronically ill persons are needed.

The purposes of this article are to describe the utilization of a theory synthesis process for the collaborative development of a client-focused approach for advanced practice nursing management of individuals with chronic illness and to provide a description of the *Model for Promoting Process Engagement*. The model was developed as a theory-driven intervention approach that specifically addresses the complexities of chronic illness care. This advanced practice nurse (APN) model is the direct result of the synthesis of a number of differing theoretical models and perspectives developed by the authors in previous individual research endeavors. These works were integrated through a theory synthesis method of theory development. A unifying model evolved from the

*From the Fay W. Whitney School of Nursing,
University of Wyoming, Laramie, Wyo.*

*Corresponding author: Sharon A. Cumbie, PhD, RN, Fay
W. Whitney School of Nursing, University of Wyoming,
Dept 3065, 1000 E University Ave, Laramie, WY 82071
(e-mail: sacumbie@uwyo.edu).*

process in which explanatory modeling, mutual goal setting, and motivational strategies are used to facilitate a client-centered approach to making sense of health information, sustaining health behavior change, and managing transitional care needs within the context of chronic illness.

BACKGROUND

Impact of chronic illness

Approximately 108 million people in the United States currently have at least one chronic health condition, and the prevalence is increasing dramatically.^{2,3} It is estimated that half of all currently required health care is due to chronic conditions and that the burden of such care will increase.³ Many definitions of chronic illness exist. The World Health Organization (WHO) defines chronic conditions as those “that require ongoing management over a period of years or decades,”^{3(p11)} and include (1) noncommunicable disease, such as cardiovascular disease and cancer; (2) persistent chronic illness, such as diabetes and HIV/AIDS; (3) certain long-term mental disorders, such as schizophrenia and bipolar disease; and (4) ongoing impairments in structure, such as amputations, paralysis, and blindness. The prevalence of chronic conditions is increasing significantly around the world. The WHO predicts that by 2020 chronic conditions will contribute to more than 60% of the global burden of disease. This pattern holds true in the United States, with almost 50% of the population projected to have a chronic condition by 2030.

Unfortunately, many people do not have just one chronic illness, and concurrent chronic illnesses are increasingly common. Approximately 25% of Americans have more than one chronic illness, and some people have as many as five.⁴ Increased numbers of concurrent chronic illnesses expand the likelihood of health complications and activity limitations, which often lead to social isolation.

Despite the increasing burden of chronic illness, health systems often lack appropriate plans for its management and simply treat symptoms, resulting in fragmented services, inefficiency, and minimal patient engagement in their own health care process.^{5,6} In the United States, approximately 15% of persons with chronic illness reported that they had received different diagnoses from different physicians for the same symptoms, had received conflicting information from providers, and had duplicate tests and procedures performed.⁷ This finding is not unique to the US health care system. An international study⁸ examined concerns of adults with serious illness and/or major surgery in 5 countries: United States, Canada, United Kingdom, Australia, and New Zealand. Participants reported having to see multiple professionals, resulting in duplicate tests and conflicting information, which can be costly and are frustrating and confusing to clients. These duplications and conflicts may occur in part because health care professionals do not feel adequately prepared to manage chronic illness. Roughly two thirds of physicians in a US survey did not feel prepared to coordinate in-home and community services, educate patients with chronic illness, manage the psychological and social aspects of chronic illness, provide effective nutritional guidance, and manage chronic pain.⁷ Additionally, the lack of a distinct transition between living with and dying from chronic illness often creates a gap in care, resulting in the continuation of curative therapy and the failure to implement adequate palliative care.

According to WHO, “When health problems are chronic, the acute care practice model doesn’t work.”^{3(p30)} WHO has outlined a number of problems in health care systems around the globe that make caring for those with chronic conditions difficult. Dominant issues include (1) the overall failure to empower patients, value patient interactions, address prevention, and connect with community resources; (2) health care workers’ lack of tools and expertise; (3) practice that is not informed by scientific evidence; and (4)

a lack of existing information systems. These issues leave both those who live with chronic illness and governments that face the challenge of coping with the escalating costs of care voicing frustration with the current systems of chronic care and calling for revision of chronic care systems.

Chronic illness care

A transformation of health care away from acute-focused, episodic care to one that is proactive and emphasizes health promotion across the life span is essential if we are to meet the rising needs of caring for chronically ill persons.³ The Robert Wood Johnson Foundation has promoted the Chronic Care Model (CCM)⁹ that focuses on comprehensive system change with alternative delivery system design, decision support, clinical information systems, and community resources to facilitate productive interactions between informed, activated clients and a prepared, proactive practice teams.⁸ According to this model, effective chronic illness care requires an "appropriately organized delivery system linked with complementary community resources available outside the organization."^{7(p7)} The focus on client self-management is foundational to the CCM in which clients are encouraged to set goals, identify barriers and challenges, and monitor their own health status⁹ with guidance from a client care team that is composed of diverse clinicians.¹⁰

Client-centered models

Client-centeredness is the "extent to which clinicians select and deliver interventions mindful of and responsive to individual and family characteristics, such as affective states, beliefs, goals, and resources."¹¹ The provision of patient-centered care has been described in the health care literature in 2 ways: (a) as the reorganization of service delivery to meet individual needs, or (b) as a mechanism to better understand patient needs, wants, priorities, preferences, and expectations for

care.¹² Although the degree to which health care goals are decided by clients or professionals differs between these 2 perspectives, they both emphasize a respect for and integration of individual differences in the delivery of care, and both are based on client-centered interventions. Persons' beliefs and goals that are relevant to either engaging in a health-related behavior or managing a particular chronic illness are assessed and the intervention is customized on the basis of this assessment.¹¹ Communication competency of the health care provider is thus foundational to and a driving force in the provision of client-centered care. A shift in the traditional balance of power between the patient and provider is fundamental to such an approach.¹²

Advanced practice nursing

Current health care systems are poorly designed for the management of chronic illnesses. To be effective, chronic care must be provided from a flexible, individualized approach, and health management must be tailored to fit illness phases, biographical needs, and interests, as well as the cultural setting in which the care is to be carried out.¹³ Advanced practice nurses (APNs) are uniquely qualified to provide the requisite flexible, individualized care for chronic illness because of their philosophical orientation, educational preparation, scope of practice, and the health model in which they provide care.

Nursing is guided by a humanistic philosophy wherein persons are regarded holistically rather than biologically; caring is coupled with understanding and purpose; and individual self-determination, independence, and decisional choice in health-related matters are privileged. The primary phenomenon of concern is not the disease or illness itself, but is focused on human responses to actual or potential health problems and emphasizes health promotion and disease prevention, as well as palliative care for end-stage illness. APN education is grounded in holistic nursing philosophy. In addition to clinical content, it

addresses cultural diversity, therapeutic communication, interpersonal relationships, health education, and health throughout the life span. The APN curriculum is, therefore, designed to enable the APN to meet the role-related core competencies of ethical decision making, consultation, expert guidance, research, clinical and professional leadership, and collaboration.¹⁴

APNs are expert clinicians engaged in active practice.¹⁵ The domains of advanced practice competency include components of both direct and supportive care, such as (a) the management of client health/illness status, (b) teaching-coaching, (c) managing and negotiating health care delivery systems, and (d) monitoring and ensuring the quality of health care practices.¹⁶ The direct care they provide is qualitatively different than that provided by other health care professionals in that it strongly reflects a nursing orientation that is characterized by (a) a holistic perspective, (b) the formation of client-provider partnerships, (c) expert clinical reasoning, (d) evidence-based practice, and (e) diverse management approaches.^{16,17} Positive effects of APN practice have been empirically documented in terms of clinical outcomes, functional outcomes, family outcomes, client satisfaction, and decreased service utilization.¹⁸⁻²¹

APN professional roles include advocacy and case management, which are foundational to a holistic approach to care. That is, using a holistic perspective and on the basis of a mutual understanding of an individual's health problem and responses to the problem, APNs use evidence-based guidelines to tailor health care treatments that are compatible with mutually defined client-provider goals. In this manner, client care provision is subsumed in the APN role of advocate, which constitutes the basic philosophical foundation of nursing. While on one end of a continuum advocacy means providing persons with the means to make informed decisions, on the other end, at a more existential level, it means helping persons find unique meaning from their health or illness experience, understanding their individual goals and values,

helping them develop or maintain problem solving skills, and helping them exercise their right to self-determination.²² In nursing, increased attention has focused on case management as a mechanism of enhancing client outcomes in chronic illness. Case management has been defined according to 1 of 3 different approaches: (a) a brokerage model in which advocacy is a primary focus and the case manager, as an independent agent, links services to needs; (b) a social entrepreneurship model where resource and budgetary control are central; or (c) a key worker/care coordinator functioning within an interdisciplinary team.²³ Case managers are generally thought to focus on assessment, monitoring, mutual planning, and coordination and evaluation of care. APNs are in a unique position to integrate clinical expertise, patient advocacy, and case management to sustain client-centered models of care that promote a more coherent approach to the care of persons with chronic illness.

THEORY SYNTHESIS AND MODEL DEVELOPMENT FOR ADVANCED PRACTICE NURSING

WHO,³ calling for innovations in thinking about and managing health, suggests that for outcomes to be improved, health systems reform is essential. Creating more integrative client-centered models of care, evaluating outcomes, and increasing the overall efficacy of health research are essential for the advancement of this global health initiative. The nursing practice model developed by the authors, advanced practice nursing faculty, represents a comprehensive approach to the clinical care of chronically ill persons that is grounded in previous and ongoing research and develops an expanded client-centered focus.

Theory synthesis: model development process

The Model for Promoting Process Engagement was developed by the authors, who, recognizing the potential to consolidate their

research efforts, came together in a conscious process of exploring individual research activities and identifying unifying areas of interest. This enabled us to develop a central focus that could synthesize research efforts and build collaborative structures from more integrative theoretical perspectives for future clinical research endeavors. Areas of commonality were identified, and the group began a process of theory synthesis, in which theoretical models developed from individual research activities were integrated to create a unifying model that is consistent with the focal concepts of chronic care provision.

From empirical evidence, Walker and Avant²⁴ propose that theory synthesis is an approach to theory construction or an interrelated system of ideas. Theory synthesis can be a valuable strategy for integrating large amounts of discrete information about a topic. Using both linguistic and graphic modalities, synthesized theories can integrate and efficiently present multiple and complex interrelationships.^{24(p166)} Congruent with the method, specific focal concepts for the synthesized theory were identified. Available information in the literature related to the phenomena of interest was reviewed and initial theoretical structures developed. Subsequently, existing individual research conducted by the research team was analyzed in order to build a base of organizing concepts and statements about interrelational elements of focal concepts and existing theoretical structures in the development of an integrative model for advanced nursing practice management of chronic illness. Evidence from these sources was synthesized into the construction and refinement of the emergent model of care.

Chinn and Kramer^{25(pp27-28)} identify 4 major processes that contribute to the development of theory in a practice discipline: (1) creating conceptual meaning, (2) structuring and contextualizing theory, (3) generating and testing theoretic relationships, and (4) deliberative application of the theory. The proposed model is currently within the developmental process described by Chinn and

Kramer. Development began through the process of identifying, examining, and clarifying conceptual constructs that are applicable to the focal concepts of concern. Subsequently, a process of organizing relationships between and among concepts led to the development of an interrelational structure, or model, that was consistent with the purposes of the theory development endeavor. Currently, a pilot study is underway to begin the process of testing structural components of the practice theory and evaluate the clinical efficacy of the model. Development and refinement of the model of care will continue to evolve through structuring and contextualizing the theoretical model for nursing practice and forming systematic linkages between and among concepts, which will result in ongoing development of a formal theoretic structure, or model of care.^{25(pp92-93)} The 3 studies and the underlying theory from which the model was developed are described in the following section. The section concludes with a description of the model for advanced nursing management of chronic illness that was developed through this theory synthesis process.

FOUNDATIONAL RESEARCH AND THEORY DEVELOPMENT

Severe and persistent mental illness study

The mentally ill are often a misunderstood population. Negative stereotypes contribute significantly to marginalization, fostering feelings of invisibility and social rejection. The absence of satisfying social relationships remains a significant problem for people with severe and persistent mental illness (SPMI). The purpose of this project-study was to explore the impact of facilitated participatory activities on the social functioning of persons with SPMI. Members of the community were brought together in an interactive participatory model of cooperation and collaboration with persons living with chronic mental illness.²⁶ Participants identified goals for the cooperative efforts of the study that focused on community building. A qualitative

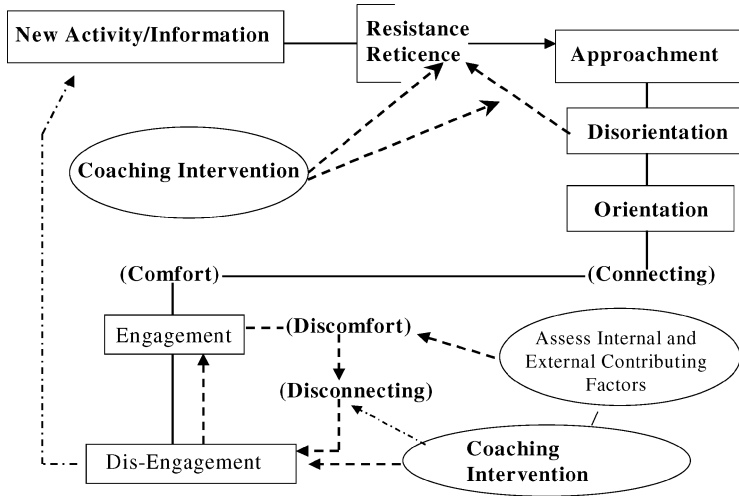


Figure 1. Coaching model for promoting process engagement.

descriptive design using cooperative action inquiry methods was utilized to facilitate the project study. During initial interviews, SPMI informants described a lack of meaningful activities and expressed feelings of social isolation, disconnection, and boredom. Despite these feelings, they communicated a strong desire to make a worthwhile contribution to the community. As part of the study project, they participated in developing creative workshops designed to decrease social isolation and foster a sense of community. The ongoing process was documented through a complex set of data that included focus group recordings and transcriptions, photographs, audio and video recordings, participant reflections, participant interviews, and researcher field and reflective notes.

Initial analytic findings identified a pattern of resistance and reticence that occurred among all participants when first introduced to a new activity. A model was developed to describe the process of this initial resistance to engagement. This conceptual framework is depicted in the Coaching Model for Promoting Process Engagement (Fig 1). According to the model, when persons encounter a new activity or new information, they are initially resistant or reticent to engage with it.

Others may interpret this reticence as disinterest, but it actually reflects a much deeper and more complex process with a disorientation component related to failure to engage in the process. Facilitating orientation to the activity or information fosters a sense of comfort and engagement. Coaching intervention strategies that ultimately facilitate the process of engagement include authenticity, modeling, reframing, communication, connection, feedback, honesty and respect, and striving and mastery.²⁶

The model is the foundation upon which the synthesized conceptual model, Model for Promoting Processes Engagement, was developed. This evolving model contributed to a broader view of how chronically ill clients might react to new activities or information and at what intersections within the process coaching intervention may be helpful in overcoming resistance, disorientation, and disconnection and in promoting and sustaining engagement with information and/or activities.

Caregiver study

Conley²⁷ explored why and how caregivers seek and use information, testing an emergent theory related to values and actions that resulted from analysis of data from an earlier

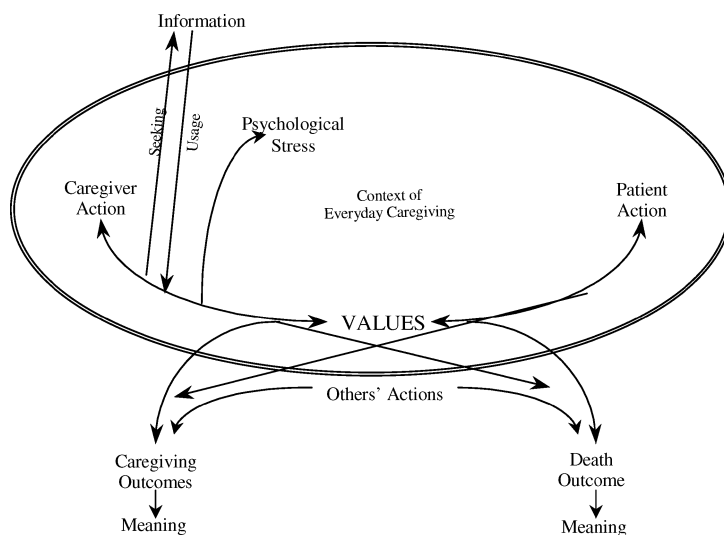


Figure 2. Caregiver value and action model.

caregiving study.²⁸ The theoretical framework was structured around sense-making theory, which holds that (1) people seek and use information to bridge a gap between what they know and what they need to know to make sense of and progress through a situation (and 2) information is a user construct rather than an independent entity or commodity.^{29,30}

Familial caregivers were interviewed and data were analyzed for content through grounded theory and analytic induction methods, using the VIND (Values in Narrative Discourse) technique,³¹ to develop theoretic structures. Results indicated that caregivers conceptually define information as a personal construct used instrumentally or as an instrumental value toward the realization of a terminal value and led to the formulation of the Caregiver Value and Action Model (Fig 2). According to this model, persons seek and use information in order to act consistently with their terminal values. Their stress is related to their ability to act according to those values, and the meaning made of their situation is related to their values and actions and the outcomes of those actions.

This model was used to inform and expand the Process Model of Resistance and Engage-

ment by explaining the importance of values to the mediation and internalization of information, its usage, and resulting actions. Additionally, according to the sense-making theory, which was foundational to and upheld by the study, making personal sense of a new situation or information is a prerequisite to engaging in that situation or progressing through it.

Therapeutic decision making by nurse practitioners study

On a daily basis, primary care nurse practitioners (NPs) make multiple decisions about what a client's problems are, how to manage them, whether to prescribe medications and what medications to prescribe, and whether to recommend other types of self-care or complementary care. The purpose of this project was to explore the diagnostic and therapeutic decision making of primary care nurse practitioners in rural and urban areas.³² Burman et al explored the process used by primary care NPs in making clinical decisions, especially decisions around diagnostic and therapeutic plans, and what factors influence this process. Two clinical vignettes, one focusing on an acute upper respiratory tract infection

and the other on diabetes, guided this grounded theory qualitative study. Purposive sampling was used to identify 36 NPs practicing in primary care settings in several western states.

The major theme in this study was “putting the pieces together.” One NP illustrates this theme when she said about her decision making: “It becomes the multiple pieces of the puzzle mixed together.” NP therapeutic decision making is characterized by purposeful integration of the client and family context, the community environment, the health care context, and the NP experience. When asked how they would treat the hypothetical clients described in the clinical vignettes, NPs said repeatedly, “It would depend.” They would need to know more about the client, what day of the week it was, where the client lived, etc. Essentially, NPs needed the whole picture before they could definitively plan care for clients.

Several findings from this study informed the Model for Promoting Process Engagement, specifically the collaborative client-centered process used by the APN with chronically ill persons. First, NPs in the study focused on the client’s agenda and needs during the visit. Second, NPs grounded their decision making in the client/family and community context and knowing the client and family context influenced diagnostic and therapeutic considerations. Third, consultation with the client, family, and other health care professionals was a common strategy NPs used as they planned care. Fourth, NPs seized opportunities to empower clients through mutual negotiation and education about self-care strategies. Finally, the NPs focused on long-term health outcomes for their clients.

Process engagement model

The Model for Promoting Process Engagement is a client-focused approach for advanced practice nursing care of individuals with chronic illness that was developed by the research team through a theory synthesis process that built upon previous research

and initial model development activities. This model is, therefore, the direct result of the synthesis of a number of differing theoretical models described previously and perspectives developed by the investigators in previous work (Fig 3). The model presents a client-focused approach to care wherein APN interventions are based on health outcome goals that are mutually set with the client and are consistent with the clients’ explanatory model for their health condition. Interventions focus on motivational strategies designed to facilitate and support individuals as they make sense of health information, engage in health promoting activities, and sustain health-related behavioral change. The model assumes that persons encountering new problems, activities, or information attempt to understand and make sense of those occurrences or information in a personalized way. This sense-making process is impacted by a variety of internal and external factors that may cause an individual to resist or engage in beneficial health behaviors that ultimately impact their quality of life. The APN helps the client identify and sustain actions that are individually congruent through mutually derived assessment, goal setting and planning, motivational exchange and ongoing support, and assistance with the management of the transitional stages of the chronic illness trajectory.

Client-centeredness requires a clinician to select and deliver interventions that are mindful of and responsive to individual and family characteristics and to strive for a better understanding of patient needs, wants, priorities, preferences, and expectations for care. All aspects of a client’s life experiences are considered relevant to this individualized treatment approach. The provision of client-centered care requires the APN to reorganize service delivery to meet individual needs. The lower section of the model represents the model’s intervention structure. The intervention structure provides the APN with strategies and activities for establishing and sustaining a client-centered approach that facilitates persons with chronic illness to engage

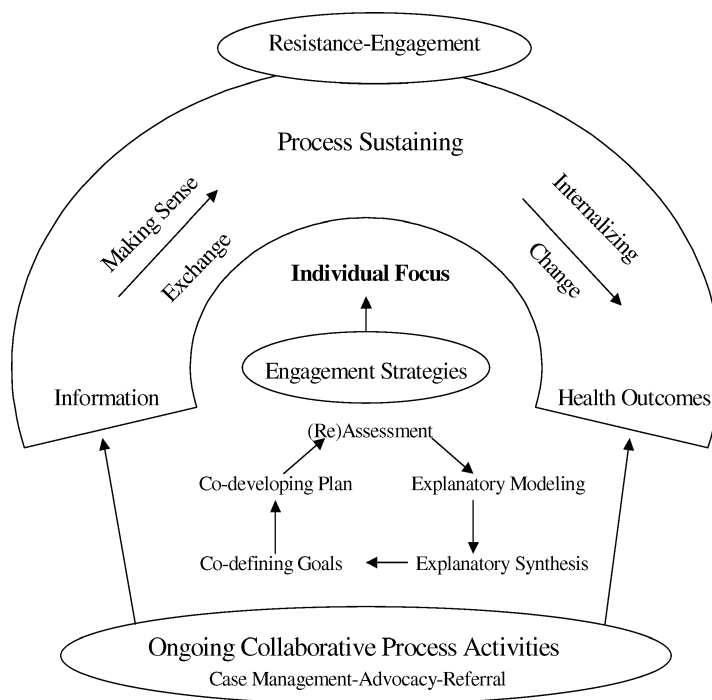


Figure 3. Model for promoting process engagement.

in their health care process. The intervention includes a combination of (1) particular engagement strategies intended to enhance practitioner-client communication toward determining a client-centered health plan, and (2) collaborative process activities of case management, advocacy, and referral to help sustain health process engagement. The foundational component of the model, then, is the client-centered perspective, which is based on the assumptions that a client-centered approach is communication-driven and that the client must make personal sense of health information in order to obtain meaning and sustain desired health outcomes and quality of life. This health process may result in either resistance or engagement with the new information. Personal sense-making must be achieved in order for new activities and information to become meaningful and therefore used to overcome resistance and to engage in and/or sustain health-related behaviors. A variety of internal and external factors impact the outcome of the internalized sense-making

process, ultimately influencing the ability to adopt and sustain new health behaviors.

The proposed intervention creates a structured approach for APNs to engage with clients to facilitate an individualized plan of care. Engagement strategies begin with a client-centered assessment to establish the individual's perspective regarding the health situation. Clients are facilitated, through a progression of therapeutic interview and communication techniques, to create an explanatory model of their illness experience. The practitioner then contributes his or her perception of the health situation and related health information in the development of a client-practitioner synthesized explanatory model. Once clarity is established regarding the health-illness experience, the engagement process includes establishing client-determined health priorities, co-defining health goals, and codeveloping a plan of action. This process for initiating and sustaining desired health outcomes is further supported by ongoing collaborative professional

role activities that include assessment, case management, advocacy, referral, and collaborative evaluation of the process.

FUTURE DIRECTIONS

Testing the model

Our next step in the ongoing practice theory development process is model testing and refinement. We are working closely with Dr Clarann Weinert, Montana State University, and have received funding from the Center for Research on Chronic Health Conditions in Rural Dwellers to conduct a pilot study to evaluate and refine the advance practice nursing protocol developed from the Model for Promoting Process Engagement. The study will use an embedded single-case study design with a multimethod component approach. The model will be implemented by using a NP case manager who will follow the intervention protocol developed from the model with chronically ill clients. Two research questions will be evaluated in the pilot study: (1) How does the intervention work from the perspective of the participants: client, practitioner, and interdisciplinary team? and (2) How and why is the process effective or ineffective in facilitating a client-centered approach to health care?

The pilot study will allow investigators to make refinements in the client-centered intervention approach that may be necessary to create better functional implementation of the model. After completion of the pilot study, we plan to further test the model using various patient populations, to examine clients' processes and outcomes within this model

of care, and to test other theoretical components of the model.

Implications for nursing clinical practice

The effective management of chronic illness requires timely, appropriate, and supportive clinical care for optimal outcomes. New models of providing client-centered care to chronically ill persons throughout all transitional stages of health and illness are needed. Current systems of care are often inadequate for the comprehensive management of chronic illnesses. To be effective, chronic care must be provided from a flexible, collaborative, and individualized approach. The focus of nursing is the holistic care of human beings and the use of multiple complementary healing modalities when participating in a healing relationship.^{33(p56)} From this holistic perspective, health management of chronic illness must be tailored to fit illness phases, promote health within illness, facilitate the management of bio-psycho-social-spiritual needs, and address human comfort and quality of life. Nursing is prepared, through our educational frameworks, to provide significant leadership in the care of persons living with chronic illness by helping the individual to make sense of the complexities of chronic illness, to create client-centered plans of care, and to promote client empowerment through ongoing client self-determination. Nursing is in a position to reduce the impact of chronic illness to the individual and to society through a commitment to quality, comprehensive, integrative, and client-centered care of persons living with chronic illness.

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