EMPOWERMENTAL NURSING Experiences of Empowerment and Disempowerment Made by Patients in Need of Long Term Nursing

AUTHORS	Veijo Isokääntä Anders Johansson
PROGRAMME/COURSE	Programme in Nursing 120 credit points/ Nursing – Research Thesis
	VT 2006
EXTENT	10 Credit Points
SUPERVISOR	Dagrun Trewe
EXAMINER	Solveig Lundgren

Sahlgrenska Academy at Göteborg University - Institute of Health and Care Sciences

Title:	Empowermental Nursing - Experiences of Empowerment and Disempowerment made by Patients in Need of Long Term Nursing
Project:	Nursing - Resarch Thesis, Advanced Level 1
Programme/course occasion/ code/Class:	Nursing Programme, 120 credit points/ Nursing Research Thesis/VOM200/SPN5
Research Thesis Extent	10 credit points
Number of Pages:	17 pages
Authors:	Veijo Isokääntä Anders Johansson
Supervisor	Dagrun Trewe
Examiner	Solveig Lundgren

SUMMARY

The purpose of this literature review was to explore how empowerment strategies can intrinsically motivate healthy behavior of patients in need of long-term nursing. Apurpose model was used to understand how behavior is influenced by cognitive elements of empowerment, and how these elements can be affected by environmental events. Eight elements that facilitate empowerment were found. These were contrasted by eight elements that impede empowerment. It was established that symmetrical relationships are prerequisites for empowerment. These relationships must be built on openness, mutuality, confidence and influence to be empowering. It was also found that nurses can not influence a patient's behavior, but that all true and lasting behavioral change must be intrinsically motivated.

CONTENT

INTRODUCTION	. 4
Background	. 4
Interactional Nursing Theory of Jean Watson	. 4
Empowerment	. 5
Empowerment and the Theory of Watson	. 5
Theoretical Framework of Empowerment	. 6
Illness Assessment	. 6
Global Assessment	. 7
Environmental Events	. 8
Nursing Intervention	. 8
Behavior	. 8
PURPOSE	. 8
METHOD	. 8
FINDINGS	. 9
Facilitating Elements of Empowerment	. 9
Impeding Elements of Empowerment	13
Empowerment and Health-promoting Behavior	
Disempowerment and Health-demoting Behaviors	16
Analysis	17
DISCUSSION	18
Discussion of Method	18
Discussion of Results	19
REFERENCES	21
ENCLOSURE	23
Article overview	23

INTRODUCTION

Background

There are political intentions to increase patient influence. The European Union and the WHO consistently compares patients' rights with human rights. There are two basic human rights that are implicated when informed consent and participation of the patient are denied: human dignity and physical (and mental) integrity (1,2,3). Swedish national legislation states that health care shall be based on respect for the patient's right to self-determination and that care and treatment shall be planned and executed in consultation with the patient (4).

In order to realize these political intentions a structural change needs to take place, where power is transferred from the health care providers to the patients. As a mean of achieving this, the concept of patient empowerment is appealing. This shift of focus is especially appealing in the care of patients with chronic illness. These patients' diseases are relatively static, and instead the burden of illness can be changed. Hence, the nurse as an equal partner of the patient has a decisive role to play in the process of optimizing these patients' health and quality of life.

The concept of empowerment is not to be considered a nursing theory. To clarify our understanding of empowerment we have chosen to relate it to the nursing theory of Jean Watson (5).

Interactional Nursing Theory of Jean Watson

Watson (5) describes her theory as broad, abstract, almost metaphysical; it has great deal of generalization but lacks specific facts. It is intended to help one to see and comprehend the essence without spelling out specific behavior.

Human care: Watson views in her theory caring as the moral ideal of nursing. Caring consists of transpersonal human-to-human attempts to protect, enhance and preserve humanity. The nurse is a co-participant in a process where inter-subjectivity is the ideal which requires an engagement by the nurse as an individual person. The aim is to reach beyond traditional medicine in order to fully understand the idea of the person. Human care, hence, seeks understanding and knowledge in individual needs, strengths and limitations, and similarly the meaning of the situation for the individual and how to comfort and offer compassion for him or her. The knowledge gained in this approach help nurses in their human care. Nursing interventions is related to human care and described as carative factors that include e. g.: helping-trusting human care relationship, creative problem-solving caring process and transpersonal teaching-learning. The human care approach has the intention to offer potential for patients to find meaning in one's own existence, to discovering inner power and control and self-healing. The theory suggests approaches to fellow human beings that promote their individual spirits, souls and bodies to become a whole (5).

Health: Watson refers to health as unity and harmony within the mind, body and soul. When I = Me, Health is promoted. This can be facilitated when the individual is in harmony with the world and open to increased diversity (5).

Illness: Illness is not necessarily a synonym for disease. Watson defines illness as a subjective disharmony within a person's soul or disharmony within the spheres of a person e.g. in the mind, body and soul. Illness connotes a felt incongruence within the person. A troubled inner soul can lead to illness, and illness can produce disease. Disease itself can create disharmony and lead to added illness (5).

Goal: Watson's holistic perspective focuses on harmony within the mind, body and soul. The intention is to obtain an increased sense of self-knowledge, self-reverence, self-healing

and self-caring processes. Caring entails helping individuals to find meaning in their existence, disharmony and suffering. Nursing is intended to promote self-control, choice, and self-determination in reference to health and illness decisions. Nursing should strive to integrate the human mind, body and soul, reality and fantasy, facts and meaning, objective and subjective worlds, external and internal events, disease, illness and health (5).

Empowerment

Empowerment has its roots in the black power movement of the 1960's and the gay and women's right movement of the 1970's and 1980's (6). Since the early 1990's increased attention has been given to the concept of empowerment. Empowerment is a multi-disciplinary concept used in management, psychology, social anthropology, sociology political science, and nursing (7-12).

Antecedents to empowerment are: trust, openness, honesty, genuineness, communication and interpersonal skills, acceptance of people as they are, mutual respect, value of others, courtesy, and shared vision (8).

In nursing, empowerment can be defined as an interpersonal process between the nurse and the patient intended to facilitate healthy behaviors (9).

Gibson (7) describes empowerment as a process where patients develop a critical awareness of the root causes of their problems. Gibson assumes that: 1) the patient has the prime responsibility for his/her health, 2) patients have the ability to make their own choices, 3) patients can not be empowered by the nurse, only by him or her self, 4) the nurse need to surrender his or her need for control, 5) to succeed, the empowerment process requires a symmetrical relationship built on mutual respect between the nurse and the patient, 6) trust is the foundation of the empowerment process. Further, the empowerment process aims to promote and enhance the patients' abilities to meet their own need, solve their own problems and mobilize the necessary resources to master their own lives. This is a revolutionary approach to problem-solving: it is not so much a question of integrating into existing structures but rather then to change the structure. This implicates that individuals are not solely responsible for the status of their own health. Gibson concludes that empowerment is a useful and significant concept for nursing.

Feste and Anderson (8) have developed an empowerment philosophy based on experiences, successful health education programs, and literature regarding patients in need of long-term nursing. They realized that chronic disease care required a different approach than the traditional compliance motivated. They rather subscribe to the empowerment philosophy, defined as a method where patients through a combination of knowledge, skills, and an improved self-awareness regarding values and needs, can achieve their own goals.

Empowerment and the Theory of Watson

To care for someone is just not an attitude or a concern, it is a moral idea that aims to protect, enhance, and preserve human dignity (5). The empowerment philosophy (8,9,10) shares this idea: to feel enhanced is to be empowered, to protect and preserve human dignity is empowerment.

The empowerment approach values each individual's right and ability to formulate his or her own goals and Watson's holistic view can help us formulate goals that are health promoting. The empowerment approach is close to Watson's conceptualization of health (5). The empowerment approach values the patient's subjective notion of their own health and/or illness as a major contributor to their present and future well or ill being. The empowerment philosophy shares Watson's theory's views of illness as the central concept to understand the patient's health status. Illness is not something objective, but subjective and experienced (5).

The empowerment approach shares the theory's notions of self-control, choice and self-determination as essential in the process of goal setting (7).

Theoretical Framework of Empowerment

Thomas and Velthouse (13) present a cognitive model of empowerment (see fig. 1). We will use this model in an attempt to explore and explain the processes of intrinsic motivation through patient self-empowerment. The model originally stems from management and is intended to facilitate an understanding of a theoretical worker's way to empowerment. Four task assessments are identified: Impact, competence, meaning and choice.

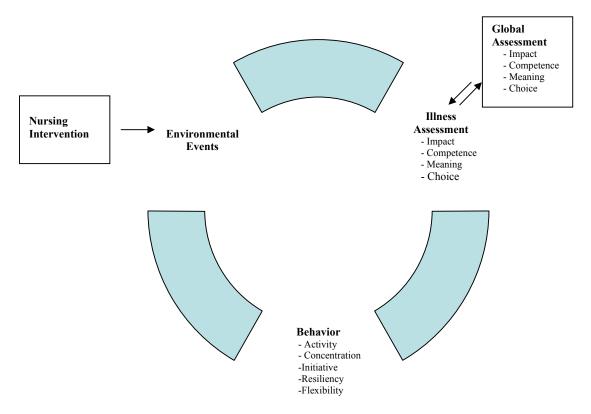


fig. 1 Model of Empowerment Modified from Thomas and Velthouse (13)

Illness Assessment

The original model use task assessment as a descriptive title on how the theoretical worker evaluates tasks ahead of him/her (13). In order to better understand this assessment in a health care perspective, and specifically, on patients in need of long-term nursing, we have used Thomas' and Velthouse' assessments and transferred their original application from task assessments to assessments of illness. Below, we intend to describe how Thomas and Velthouse explain these assessments and how we intend to apply them in the present paper.

Impact

Impact refers to the individual's capacity to produce intended effects on his or her environment (13). Or simply: the degree of which a behavior "'makes a difference'" (13 p. 672). If impact is seen as unlikely, universal helplessness can occur (13). In a health care context; if a person does not feel that he or she has an impact on the trajectory of his or her illness, a learned personal helplessness can develop. The impact dimension can play an important role to patients in need of long term nursing. Impact cannot be facilitated in a setting where the patient's will is diminished or ignored.

Competence

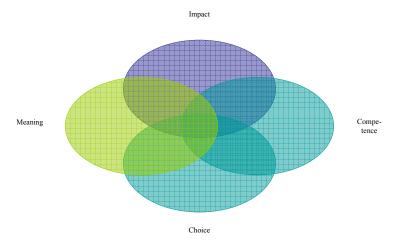
This assessment refers to how well a person can perform a task skillfully when he or she tries (13). We understand competence in reference to chronically ill patients as the skills these individuals use to master their illness. Other dimensions of competence are the factual knowledge the patient has of his or her own disease and the experiential knowledge of his or her illness.

Meaning

This assessment involves the individual's intrinsic standard about a given task (13). To find chronic illness as a meaningful part of life is a prerequisite for empowerment processes to initiate. In our view meaning can be understood as a way for the patient to link symptom control with an increased sense of well-being. Meaning has two dimensions; first to find meaning in having a disease, and second, to find meaning in self-care actions. The patient and his or her environment: social, cultural, spiritual and political, must be integrated with the disease, the illness and health. This integration can create meaning.

Choice

Choice or self-determination involves causal responsibility for a person's actions (13). It is essential for patients in need of long term nursing to be able to choose or to self-determine events in every-day-life. Impact and competence assessments become irrelevant to an individual if he or she is not able to make choices. Even if a person feels, for instance, that a diet has made an impact, but that the diet was imposed on him or her, choice, and hence the freedom to choose, has not been present.



The synergy effects of these assessments are illustrated in fig 2.

fig. 2 Illness Assessments.

Global Assessment

Global assessments are generalized beliefs about the four assessment dimensions combined over time and represent cumulative learning from past task assessments (13). Depending on previous experiences patients may assess their present illness positively, negatively or

ambiguously, consequently it will be an important factor when choosing strategic approaches to facilitate empowerment.

Behavior

Behavior is the outcome of environmental events and task assessment. A wanted behavior is characterized by activity, concentration, initiative, resiliency and flexibility. Activity and concentration can be translated to "working hard". Activity, as opposed to passivity, and concentration upon a task leads to a focused effort. The distinguishing aspect of intrinsically motivated behavior is that the effort is not dependent of others or of any rewards. Initiation of new tasks and resilience to sustain motivation as obstacles may come in the way is a result of this independence. Flexibility, as opposed to rigidity, is essential in order to adapt to changes in requirements (13). For our purpose we look upon the empowered patient as an individual who shares these characteristics with the theoretical worker in the above model.

Nursing Intervention

This element of the model refers to deliberate attempts to produce empowerment through changes in the environmental events that impinge upon individuals, or through changes in these individuals' ways of interpreting those events (13).

Environmental Events

Environmental events provide data to the individual about the consequences of ongoing task behavior and about conditions and events relevant to future behavior (13). In a health care context we use the term to describe interpersonal communication between the patient and the nurse, communicating information relevant to illness assessment, e.g. the on-set of a new symptom. This two way communication is based on trust, openness, honesty, genuineness, and interpersonal skills, acceptance of people as they are, mutual respect, value of others, courtesy, and shared vision (5). Consequences of ongoing task behavior can be translated to results of a behavior and in a health care context; improved or worse health. Hence, environmental events comprise of two dimensions; external and internal data.

PURPOSE

To explore how empowerment strategies can intrinsically motivate healthy behavior of patients in need of long-term nursing.

Questions at hand:

- 1. What facilitates, and what impedes empowerment?
- 2. Can examples of empowerment leading to health-promoting behavior and/or disempowerment leading to health-demoting behavior, according to Thomas' and Velthouse' model, be found in the literature?

METHOD

In this exploratory literature review, we have used Thomas' and Velthouse' model of empowerment to analyze qualitative (n=7) and quantitative (n=3) empirical studies on patients in need of long-term nursing (see enclosure). The articles were collected from CINAHL and PubMed, using the search-string empowerment AND chronic disease NOT children. Limitations used in CINAHL: peer-reviewed and research. The CINAHL search gave 79 hits and the PubMed gave 45 hits. Only articles written in English or Swedish, and

available in electronic form were considered. 18 articles were chosen from relevance to our purpose, and questions at hand. Inclusion criteria for the final ten articles were: empirical studies of populations matching our purpose i. e. patients in need of long term nursing, and where empowerment was used as premise or presented as an important component of the result.

Thomas' and Velthouse' model was used rasterizing the chosen articles to find illness assessments, characteristic behavior, and environmental events. When processing the data 16 categories emerged. These were used to operationalize the model to answer the first question at hand. To answer the second question at hand we scanned the articles for health-promoting behaviors sprung from empowerment and health-demoting behaviors sprung from disempowerment.

FINDINGS

Facilitating Elements of Empowerment

Eight categories that facilitate empowerment were found. Some of the categories overlap (see fig. 3).

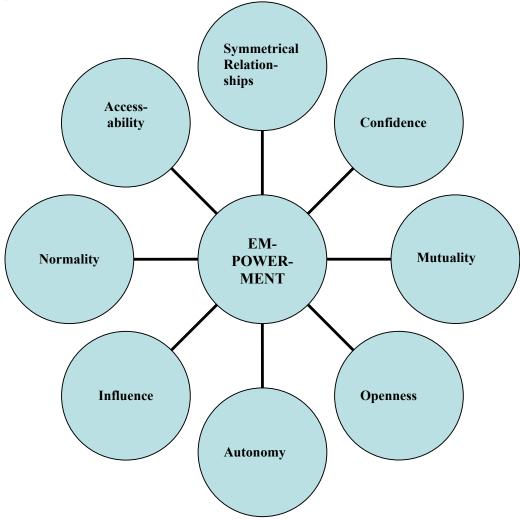


fig. 3 Facilitating Factors of Empowerment

Symmetrical Relationships:

Three studies reveal the importance of relationships (14, 15, 16). Though found in different contexts, similarities are present and include a sense of connecting and belonging. A Canadian study on chronically ill elderly presents building trust and meaning as key in establishing relationships that could evolve into symmetry and eventually empowerment (14). In a UK study on HIV- positive individuals, relationships were built within a self-help group and a sense of pride arose amongst the participants as a consequence of being able to help each other by sharing experiences (15). Health professionals, thus, are not always a necessity, within the element of relationships, for empowerment to take place. A Swedish study on a rheumatology rehabilitation unit further proves this as participants, though guided by health professionals, when sharing experiences in their interactions with co-participants produced positive self-images and positive social interactions (16). Whether with or without health professionals, relationships can be seen as a framework by which to connect the experiences of patients with the illness they suffer from.

Confidence:

A Canadian study on diabetes patients presents an example of how confidence can affect selfmanagement strategies. Based on experiential knowledge, participants altered the prescribed regime of treatment. Knowing that doctors would disapprove, they kept silent about these alterations. The study further shows that due to these alterations, participants were able to maintain good glycaemic control (17).

In a US study on peritoneal dialysis patients. Two requirements for confidence are presented; 1) Confidence in ones ability to use certain behaviors in order to achieve certain outcomes and 2) Confidence that the behavior, once successfully executed, will achieve the desired effect. Participants in the study who possessed both requirements for confidence were able to manage the treatment necessary to their needs and hence give them a feeling of control (18). One participant expressed it as: "So if I want me some red pepper in my meatballs and a little more salt in my meatballs, well, I can do that because I've kept my chemistries at a level and I know that if it goes up, I know how to bring it down" (18 p. 620).

Confidence can also be a result of interventions from health professionals. Patients living with chronic lung disease went through a pulmonary rehabilitation program. A new found ability to cope with their disease improved both control and the management of their illness. Whereas participants prior to the intervention had feelings of fear and frustration, rehabilitation replaced them with a sense of safety and confidence (19).

Mutuality:

In the context of an appropriate setting, nursing can offer mutuality. As a result of an established relationship between a participant and a health professional, the continuity of the relationship led to mutual knowledge of the participant's life. This knowledge could then be built upon to mutually create ways of (not only) managing life but also reframing ways of doing, and being, and of seeing one's self. Relationships, hence, play an important role for mutuality to emerge (14).

Mutuality with co-participants in a rehabilitation program is expressed as a dimension of experiencing health with illness. This is initiated by meeting people with similar thought perspectives and results in the reciprocation of relationships and commitment to help one another (16).

HIV infected individuals in a self-help group comprise mutuality in sharing a disease they have survived. The fact that they are alive after many years of infection is the core of the mutuality that bonds them (15).

Openness:

Communication between individuals can take place in different ways. However, within empowerment perspectives, openness is imperative. The paradigm case in a study on chronically ill older Canadians demonstrates this as openness facilitates a progression towards empowerment (14).

The study on HIV-infected individuals participating in self-help groups does not comment openness though it is implied as a way to make the group meetings meaningful e.g. sharing experiences to promote positive attitudes to living with HIV (15).

The mutuality amongst rehabilitation patients can be seen as an opportunity for openness to occur. As with the previous example, openness is implied though not mentioned. These patients participated in focus groups where living with chronic pulmonary disease was discussed as part of the program. Another aspect of openness is the tailored exercise programs each participant received, where the tailoring can be seen as a result of openness between participants and health professionals (16).

Autonomy:

Patients who are treated with peritoneal dialysis identify autonomy as an important factor. Three components of autonomy were identified: partnership in care, self-care activity, and self-care/self-efficacy. Patients with a high degree of self-care activity ask questions, seek explanations, state preferences, offer opinions and demand to be heard. Active patient involvement is found to be essential in making peritoneal dialysis a successful treatment alternative (18).

In an American study on patients who have access to their medical records on-line the results shows that patients feel more autonomous through more participation in their medical care, by learning more about their disease and by increased ability to coordinate their care (20).

Influence:

Allowing patients to set their own goals for treatment is a way for patient influence to occur. Rheumatology patients, participating in rehabilitation program "SADEL", wrote a patient goal checklist while their physiotherapists wrote a physical therapist goal checklist. These were discussed in a goal forum emanating in a goal forum checklist agreed upon by participants and health professionals (16).

Patients on peritoneal dialysis are in control of their treatment, consequently having influence and, are able to live normal lives (18).

Patient-accessible electronic medical records can be a tool for influence in healthcare. Patients in this study expressed a feeling of being able to coordinate their care by having access to their records, e.g. one patient was able to check test results, while on a vacation, contact her health professional and make appropriate adjustments in her medication (20).

Normality:

In a study set out to examine autonomy in patients with end stage renal disease who have been successfully treated with peritoneal dialysis, normality is identified as an important rationale for choosing peritoneal dialysis over hemodialysis (18). A patient expresses normality: "...I like to fish you know. I could call up the Baxter (sic) and say, you know 'I'm going fishing'...and they would have my stuff delivered right there...you can still live almost a normal life, you know. You want to go places, you can go" (18 p. 620).

HIV infected gay men, who participated in a self-help support group who identified themselves as self-empowered voice normality as an important empowering category (15). When one of the men is asked what he does to 'take care of himself', he answers: "Nothing,

just carry on with life the same as if I was negative" (15 p.1867). When he is asked why he has remained symptom free for 11 years, when others contracted the virus and died within six months, he answers: "I think one of the main reasons is positive mental attitude" (15 p.1867). Another participant answers the same question: Actually, very little...I do drugs, I go dancing, I stay up late, I have a lot of sex. *I think for me that is what keeps me alive,* just by doing all the things I used to do" (15 p. 1868).

Accessibility:

Easy access to medical records gives patients reassurance, a greater sense of control, and freedom of participation in their care and improves the communication between the patient and their physician. Patients describe a feeling of having an active role, being responsible of their own health and its management and as a result a feeling of participation (20).

An American study on female patients with a chronic illness living in rural areas shows that these patients benefit from easy access to peer support groups and information over the Internet. A positive impact on the patients' ability to manage their chronic illness is found. It is also shown that the social support scores increase in the time of the intervention and that the most vulnerable patients profit most from the intervention. Among the adaptation strategies found are: learning to set goals, recognizing their abilities, using information and getting lifelong skills for managing long-term illness. Internet based interactive computer systems can effectively be used to connect chronically ill patients in a program of support and education (21).

Another American study set in rural areas on patients with diabetes shows that patients who have access to providers trained in the empowerment approach improve their glycaemic control and scored higher on self-empowerment scales (22).

Impeding Elements of Empowerment

Eight impeding Elements of Empowerment were found:

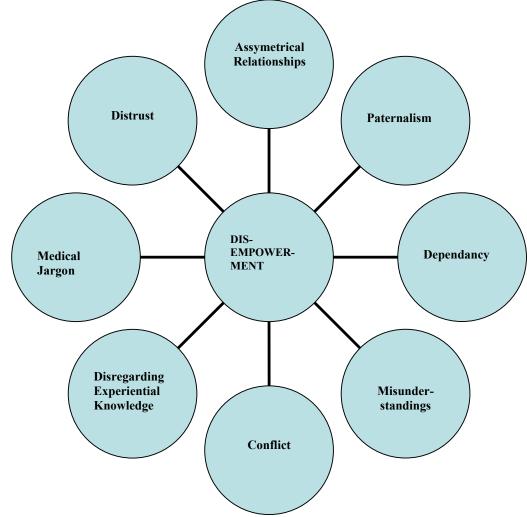


fig. 4 Impeding Factors of Empowerment

Asymmetrical Relationships:

Problem solving can prove to be an impossible task when there is an asymmetrical relationship. A Danish study on diabetes patients with poor glycaemic control presents two approaches by health professionals contradictory for symmetry: 1) Compliance-expecting approach and 2) Failure-expecting approach. In approach 1, the patient is seen as an individual with a problem that can be solved by health professionals and in approach 2, the view is that the patient is a problem. These approaches are presented as results of patient-provider relationships with difficulties in expressing feelings, notions and thoughts (23).

HIV patients' view on medical profession is summarized as: "the medical profession *denies* people the opportunity to exercise agency and control because it limits HIV positive individuals' access to knowledge and information" (15 p.1870).

Time is of essence in relationships and, as a Canadian study shows, patients were not offered enough time when meeting physicians. This resulted in short-term relationships not sufficient enough to establish a setting where they could work as a team (17).

Paternalism:

In the Danish study of Diabetes patients, one patient describes professionals as: "putting themselves on a pedestal". Further the patients feel like receivers of professional information and not competent as sources of knowledge (23).

The study of gay men living with HIV shows that for some people, self-empowerment tends to create problems when they are dealing with health care professionals. This is caused by a clash of ideologies: on the one hand, the self-empowerment philosophy that infers autonomy, and on the other hand, the medical profession that imposes authority. The individuals, with this mindset, also have a tendency to displace the threat represented by the medical authorities by constructing an image of orthodox medicine, including drugs, as anathema to self-empowerment (15).

The Canadian study defines empowerment as encouraging people to participate as equal partners in decisions about the health care they receive and for professionals to value patients' views and be "able to relinquish control when a patient rejects their advice" (17 p. 574). However, the patients identify most practitioners as professionals, rather than as equal partners. Participants in the study give examples of being met with scepticism and even anger when they want to influence decisions about their care. The health care professionals would invite the patient to participate in health care decisions, but subsequently neglect the input made by the patient. Another instance is reported when input from a patient is treated in a paternalistic fashion. Another behavior on record is professionals' habit of 'quizzing' the patients about their knowledge of diabetes (17).

Dependency:

A study of patients living with chronic lung disease shows that a rehabilitation program transforms the patients from being unable into able and empowered. It is also found that people leaving the support groups immediately had fewer resources and are at risk of falling back into a state of helplessness, thus, it is stressed that rehabilitation must be seen as an ongoing process supporting the client through their "illness career"(19).

Misunderstandings:

Patients' and health professionals' different prioritizations are a source for misunderstandings. The Danish study demonstrates it as patients focuses on life over disease and health professionals on disease over life and, generally, the patients and professionals were not conscious of the conflict between them, consisting of opposing and conflicting priorities (23).

In the study on chronically ill, a patient's fear of ending up in a nursing home resulted in panic attacks whenever a threat to her health appeared thus ending up in the hospital on a regular basis. Health professionals, unaware of her fears, misunderstood her constant admissions thinking she was abusing health care services and suggested a move to a nursing home which in return only worsened her panic attacks (14).

Conflict:

Patients with poor glycaemic control identify keeping Life and Disease apart as a core category. To maintain normality, patients strive to distance their every-day life from their disease. It is found that the health-care providers and the patients had different sets of priorities to Life and Disease in problem solving. These differences create irresolvable conflicts within and between patients and professionals (23).

In a study of patients infected by HIV who defined themselves as self-empowered it is found that some patients looked upon orthodox medicine as an opponent to the philosophy of the in-group thus becoming part of the out-group or "other" (15).

When patients' demand to influence is met by aggression by health care professionals, conflict is apparent (17).

Disregarding Experiential Knowledge

Disregarding patients has no place in modern healthcare however two studies presented results of the opposite. Diabetes patients perceived it as if they were assigned a role of recipients of professional knowledge and not valued as sources of knowledge, as a woman expressed it: "My knowledge?? Well, they don't want to know....It is like being put in a box that says: This is a diabetic who can't manage [laughs], and then they don't want to know about your experience because you can't do it right anyway- so it is the wrong experience" (23 p 757).

The discount of experiential knowledge is summed up by one of the participants as: "They say that they want you to help make decisions about your diabetes but really they only want you to decide to follow what they tell you to do"(17 p. 578). Adding to the previous statement, five other participants stated that practitioners conveyed a distrust of experiential knowledge as they emphasized objective data and dismissed the subjective statements of the person with diabetes (17).

Medical Jargon:

Participants in one study stated that the way information is given to persons with chronic illness can affect the willingness and ability to engage in decision making, e.g. when practitioners used medical jargon they could not understand, they perceived it as accentuating the power discrepancy between the practitioner and themselves. "If he can't be bothered to talk so I can understand him, he doesn't really want me to make decisions with him" (17 p. 578) is a statement that concludes an impeding approach to decision making and ultimately to empowerment (17).

Patients accessing their medical journals electronically mentioned medical jargon as difficult to decipher. Some patients recognized their own potential for error in interpreting their records. When asked on ways of improving the system of electronic journals several individuals suggested some sort of aid that would help interpret test results so that they better could assess the significance of laboratory or test findings (20).

Distrust:

Fear of losing autonomy can cause individuals to refrain from seeking healthcare. In a study of older people with various chronic illnesses one patient shares her fear of seeking health care due to the risk of being admitted to a nursing home against her will (14).

Empowerment and Health-promoting Behavior

Health promoting behavior is characterized by activity, concentration, initiative, resiliency and flexibility (13).

Environmental events:

The unique relationship between two individuals is the base of empowerment (14).

Goal forum where providers and users set goals, leads to health promotion. In these forums patients and providers are described as equal partners(16).

A symmetrical relationship can facilitate an insight into the individuals' global assessments and can help both nurse and client make positive illness assessments (14).

It is important to create and maintain an equal partnership with patients in order for them to reach informed health promoting decisions. In one population equal partnership was found in self-help groups. Health care professionals were excluded (15).

Illness assessments:

Involving patients from the outset is a way of implicitly ascribing competence to the patient. Impact, choice and competence were found in a study (16) where patient and health care providers used forums, to set goals. In these forums, mutuality and respect was prevalent. To set goals is not unproblematic. The patients' goal may be to maintain physical abilities while the physiotherapists' goal may be to improve these abilities. It is clear that empowerment is not just intended to keep up to par with the patient's goal but to set realistic, in some cases higher goals thus creating an increased sense of meaningfulness to the patient. It is implied that by letting the patient's opinions matter in a goal-setting forum, choice is apparent.

The study (15) of gay men living with HIV illustrates how choice, impact, competence, and meaningfulness facilitate empowerment. These patients' individual illness assessments put themselves apart from their illness defining themselves as survivors. These individuals are living without symptoms or perceived illness. Though threatened by a potentially terminal disease, they are nevertheless empowered by the abovementioned cognitive approach.

Behavior:

Denial is sometimes expressed as being a maladaptive coping strategy, but denial can be a way for patients with chronic illness to feel normality and empowerment, hence being adaptive (15).

Global assessment can influence illness assessments and lead to behavior characterized by activity, initiative, resiliency and flexibility (17). One respondent's behavior changed after six weeks of reflective dialogues. The patient felt more secure in reaching out to her community for social support(14). This can be attributed to an increased sense of competence and meaning

Disempowerment and Health-demoting Behaviors

Health demoting behavior is characterized by passivity and lack of: initiative, concentration, resiliency and flexibility (13).

Environmental events:

When environmental events are asymmetrical, behavior is characterized by suppression of thoughts and feelings by both patients and health care providers (17, 23).

In a study of self-care decision making among patients with diabetes type 1 it is found that if health care professionals assume an uncritical view of empowerment it may result in frustration and unmet expectations among the patients (17). The study illustrates how environmental events play a role in establishing empowerment. In this case the environmental events are represented by interactions between health care providers, both physicians and nurses, characterized by disempowering components e.g.: paternalism, asymmetrical relationships, and distrust. Even if the environmental events show traits of disempowerment, the patients still maintain relatively good glycaemic control. This result can be explained in the context of these patients' global assessment. Living with diabetes for an extensive period of time results in experiential knowledge which provides the patients with effective tools in managing their diabetes (17). Medical jargon distance patients from their treatment and life (17). Distrust can lead to that patients refrain from seeking professional health care. In an emergency setting a patient's global assessment was affected when staff told her to consider moving to a nursing home (14).

Illness assessment:

Medical jargon excludes patients from information about *their* life and bodies, hence negatively affects their competence and meaning assessments (17).

Paternalism can make patients feel like passive receivers (23). Due to assessments characterized by low competence and impact, their levels of activity and flexibility are low.

Disregarding experiential knowledge, or competence, influences illness assessment through a lesser degree of impact and meaning (17, 23).

Behavior:

Behavior characterized by inactivity, lack of initiative and flexibility can be seen as a result of the lack of impact, meaning and competence in assessing illness (23).

A patient that refrained from seeking health care due to her fear of being placed in a nursing home shows how misunderstandings and fear can lead to disempowerment and counter productive health behaviors.

In most cases the boundaries of "self" and "others" are psychologically adaptive but in some, the process is maladaptive and can prove to have negative impact on the HIV-progression (15).

When behavior results in conflict (23) and draws attention from the real (health) problem, behavior is characterized by inactivity, lack of concentration and resiliency.

When impact and choice assessments are compromised through paternalism and aggressiveness, patient behavior is characterized by passivity (20).

Analysis

Illness assessments that result in an increased sense of empowerment lead to behavior characterized by activity, concentration, initiative, resiliency, and flexibility (13). A patient with the ability to actively take part in his or her treatment, make changes when illness worsen (flexibility), to take initiative to self-care and show resiliency in coping with his or her chronic illness, will stand a better chance of obtaining optimal health. This health promoting behavior will result in an environmental event that will affect the individuals (and nurse's) illness assessments positively. This circle of empowerment will produce an upward spiral leading to more empowerment and health promoting behaviours.

Illness assessments that result in a decreased sense of empowerment lead to behavior characterized by passivity, and lack of: initiative, concentration, resiliency and flexibility (13). This behavior will result in an environmental event that will affect the individual's (and nurse's) illness assessment negatively. This can lead to a circle of disempowerment that can threaten the health of the patient.

Environmental events and global assessments are the two factors that different actors can manipulate to create empowerment or disempowerment (13). The Pyramid of Empowerment (fig 5) is an attempt to visualize the facilitating factors that nurses and patients can use when they interact to create the necessary assessments needed to install empowerment in the patient, the nurse and in their relationship. To reach the goal at the top of the pyramid, the patient and nurse need to create an environment based on the facilitating factors presented.

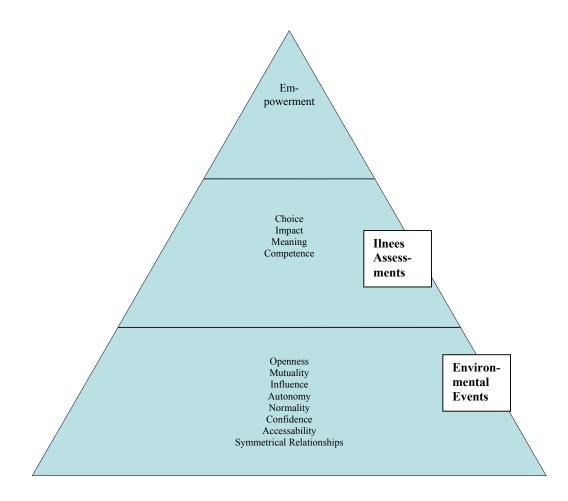


Fig. 5 Pyramid of Empowerment

DISCUSSION

Discussion of Method

The intention was to explore how empowerment can be understood through Thomas' and Velthouse' model (15). The model was used to understand how behavior is influenced by cognitive elements of empowerment, and how these elements can be affected by environmental events. In the research material, aspects of empowerment and disempowerment appeared. These aspects were categorized (see fig. 3, 4) and placed within the model of empowerment (see fig 1).

The data was collected from CINAHL and PubMed. Since these are sources of information used by fellow scholars the data found can be compared and valued with other papers on the same subject.

The material used describes conditions in countries that are comparable to the conditions Sweden, and therefore relevant to the intended reader of this paper. The empowerment philosophy, as mentioned earlier, stems from marginalized groups' whishes to gain power. In the light of this it can be argued that empowerment strategies can work in any cultural setting: The only premise that needs to be fulfilled is that one group or individual wants more power.

The data collected contained both examples of disempowerment and empowerment. For nurses working in a clinic setting, it might be helpful to have a basic understanding of the mechanisms that might work either to empower or disempower patients and to identify approaches that can either work to promote or demote health.

The model of empowerment (13) provides a superstructure to the data. This makes the findings more clear and possible to generalize. The idea that motivation only can originate within a person is structured by the model.

Some of the categories in the findings are in themselves fairly abstract and not well defined. This is truer for a broad public, than for the intended reader: Through their education nurses' understanding of these concepts are less abstract, and applicable in reality.

Thomas' and Velthouse' model is intended to provide an understanding of intrinsic motivation in workers. Whether *the worker* can be replaced with *the patient*, and whether *task* assessment can be translated into *illness* assessment is debatable and for future research to validate.

It is obvious that each facilitating and impeding factor of empowerment can be explored further to validate their individual relevance. It would also be of interest to analyze how different factors, both facilitating and impeding influence patients degree of empowerment. This is for future research to accomplish.

Limitations:

More parameters from the model (13) might have been used to make the analysis more comprehensive: interpretive styles influence illness assessments. Individuals might attribute, evaluate, and envision their illness in different ways. These dimensions have not been explored in this paper. It is also a field for future studies to compare Thomas' and Velthouse' model to other models of intrinsic motivation.

Discussion of Results

Empowerment is a way for nurses to approach the individual patient on his or her conditions, according to his or her wishes. This may seem basic to nearly all nursing ethical standards, but empowerment make a shift in perspective: it has a revolutionary, rather than reformist approach to caring: It gives the patient an equal vote and a loud voice. Hence, caring with an empowerment approach will always assume the patient's perspective.

The theory of Jean Watson states that nursing is intended to promote self-control, choice, and self-determination in reference to health and illness decisions (5). The empowerment approaches found in this paper shares these ideas. The human care approach, in Watson's theory, has the intention to offer potential for patients to find meaning in one's own existence, discovering inner power and control and self-healing (5). Both finding meaning and inner power can be understood as empowerment defined in this paper.

To optimize the health of patients in need of long-term nursing pose a challenge for nurses, today, and in the future. The present illness panorama in the industrialized world poses challenges to health care providers to facilitate healthy behaviors. The nursing profession must develop tools to make this happen. Empowerment might be such a tool. The deepening of how empowerment can be understood and achieved lies within the cognitive aspects of intrinsic motivation. The process of finding articles that describe empowerment and disempowerment and analyzing these texts from a different angle has deepened our understanding of how patients in need of long term nursing can be reached and understood as wholes, where illness and the way this illness is perceived is an intrinsic part of these patients'

lives as individuals and members of a family and a society. It has also provided an insight, that illness and even more disease are just one aspect of an individual's lived experience and that our gaze as nurses on illness and disease alone can inhibit empowerment: Nursing takes place in the domain of environmental events. To share a moment of silence or talking about the weather are environmental events. To console a patient in distress or making a bed are other ones. To help someone with chronic obstructive lung disease might be to divert attention away from the pulseoxymeter to a cup of coffee. It is important to mention that these are just examples of environmental events and not of ways to aid patients towards empowerment.

Empowermental nursing looks upon the nurse as a catalyst. He or she has the properties to start a reaction without being consumed or provide actual energy. All true and lasting behavioral change must be intrinsically motivated. The environmental event is the domain where nurses can engage and influence the patients' assessment of their illness and by doing so, indirectly, modify patient behavior. It is also in the domain of environmental events where the patients' global assessment can be changed over time. This is an extremely complicated and diverse task and underlines the essential role the antecedents play in the empowerment process.

Empowerment can be used in many different settings and be applied to different types of diagnosis. Perioperative care with an empowering approach can be to inform the patient what is expected of him and find out what he expects from the nurse. To regain optimal health provides meaning and can help patients endure painful rehabilitation. To be able to choose form of analgesic and how it should be administered provides choice and impact. The behavior these assessments might lead to is characterized by activity, resiliency, flexibility and initiative. All these characteristics are essential to recover from surgery.

Empowerment can be an inner feeling (meaning), a political force (choice), to change the world (impact), and to have the means to make things happen (competence).

It is apparent that patients can be empowered outside the health care system. The challenge for nurses is to be invited as equal partners in the health process. One instance where empowerment led to health demotion was found. HIV infected gay men felt empowered, but this led to instances of health demoting behaviors. This can be understood in the context of psychological adaptations, where the health demoting behavior, e.g. using drugs, is unrelated to the health threat posed by the HIV infection. There are parallel processes of both empowerment and disempowerment, that effect behavior simultaneously. It is a challenge for nurses to be able to facilitate an adaptive self-empowerment process opposed to a maladaptive one. If the patients lived world is harmful to him or her nursing must address this issue and make sure something is done to change the lived world of this patient to something not harmful.

The continuous circle of empowerment can not begin when environmental events prohibit patients to be heard. The way the nurse approach these events are therefore paramount to the way they will work to promote healthy behavior through empowerment.

Medicine has traditionally focused on disease rather than illness. This trend is ongoing and has been accentuated by the technical advances in modern medicine. Historically and presently there is a strong influence of the medical paradigm on nursing. This trend, if unchallenged, can corrupt a caring relationship between the nurse and the patient. By shifting focus from the reductionistic perspective of disease and illness to a holistic perspective where the chronic disease can be embraced and understood as a meaningful and integral part of the human experience, nurses both have an opportunity to create caring relationships and become more autonomous in their profession. Empowerment can work as a double edged sword in achieving this shift: By facilitating empowerment in patients the nurse will also have an opportunity to be empowered.

REFERENCES

- 1. International Covenant on Civil and Political Right. http://conventions.coe.int/Treaty/en/Treaties/Word/164.doc Tillgänglig 2006-03-29
- 2. International Covenant on Economic, Social and Cultural Rights. http://www.unhchr.ch/html/menu3/b/a_cescr.htm. Tillgänglig 2006-03-29
- Regional Office for Europe, World Health Organization (WHO), A Declaration on the Promotion of Patients' Rights in Europe, 1994. <u>http://www.who.int/genomics/public/eu_declaration1994.pdf</u> Tillgänglig 2006-03-29
- 4. HSL 1982:763 http://rixlex.riksdagen.se/htbin/thw?\${HTML}=SFST_LST&\${OOHTML}=SFST_D OK&\${SNHTML}=SFST_ERR&\${MAXPAGE}=26&\${TRIPSHOW}=format=TH W&\${BASE}=SFST&\${FREETEXT}=&BET=1982%3A763+&RUB=&ORG Tillgänglig 2006-03-29
- 5. Watson J. Nursing: Human Science and Human Care- A Theory of Nursing. New York, National League Of Nursing; 1988
- 6. Davis A. Radical perspectives on the empowerment of Afro-American women: lessons for the 1980's. *Harvard Educational Review*. 1988, 58(3)
- 7. Gibson C.H. A concept analysis of empowerment. *Journal of Advanced Nursing*. 1991, 16
- 8. Feste C Anderson R.M. Empowerment: from philosophy to practice. *Patient Education and Counseling*. 1995, 26
- 9. Hokanson Hawks J. Empowerment in nursing education: concept analysis and application to philosophy, learning and instruction. *Journal of Advanced Nursing*. 1992, 17
- 10. Rodwell C.M. An analysis of the concept of empowerment. *Journal of Advanced Nursing*. 1996, 23
- 11. Ellis-Stoll C.C. Popkess-Vawter S. A Concept Analysis on the Process of Empowerment. *Advances in Nursing Science*. 1998, 21(2)
- 12. Ryles S.M. A concept analysis of empowerment: its relationship to mental health nursing. *Journal of Advanced Nursing*. 1999, 29(3)
- Thomas K.W., Velthouse B.A. Cognitive Elements of Empowerment: An "Interpretive" Model of Intrinsic Task Motivation. *Academy of Management Review*. 1990, 15(4)
- 14. McWilliam C.L, Stewart M, Brown, J.B et. al. Creating empowerment meaning: an interactive process promoting health with chronically ill older Canadians. *Health Promotion International*. 1997, 12(2) 111-123

- Crossley M.L. "SURVIVORS" AND "VICTIMS": LONG-TERM HIV POSITIVE INDIVIDUALS AND THE ETHOS OF SELF-EMPOWERMENT. Social Science and Medicine. 1997, 45(12) 1863-1873
- Arnetz J.E., Almin I, Bergström K, Franzén Y, Nilsson H. Active Patient Involvment in the Establishment of Physical Therapy Goals: Effects on Treatment Outcome and Quality of Care. *Advances in Physiotherapy* 2004, 6, 50-69
- Paterson B. Myth of empowerment in chronic illness. *Journal of Advanced Nursing*. 2001, 34(5) 574-581
- Curtin R.B., Johnson K.H., Schatell D. The Peritoneal Dialysis Experience: Insights From Long-Term Patients. *Nefrology Nursing Journal*. 2004, 31(6) 615-624
- 19. Toms J, Harrison K. Living with Chronic Lung Disease and the Effect of Pulmonary Rehabilitation. *Physiotherapy*. 2002, 88(10) 605-619
- 20. Earnest M. A., Ross S. E., Wittevrongel L., Moore L. A., Lin C-T. Use of a Patient-Accessible Electronic Medical Record in a Practice for Congestive Heart Failure: Patient and Physician Experiences. *Journal of the American Medical Informatics* Association. 2004, 11(5) 410-417
- 21. Weinert C., Cudney S., Winters C. Social Support in Cyberspace- The Next Generation. *CIN:Computers, Informatics,Nursing.* 2005, 23(1) 7-15
- Siminereio L.M., Piatt G, Zgibor J.C. Implementing the Chronic Care Model for Improvements in Diabetes Care and Education in a Rural Primary Care Practice. *The Diabetes Educator*. 2005, 31(2) 225-234
- Zoffmann V Kirkevold M. Life Versus Disease in Diffucult Diabetes Care: Conflicting Perspectives Disempower Patients and Professionals in Problem Solving. *Qualitative Health Research*. 2005, 15(6) 750-765

ENCLOSURE

Article overview

Reference Title Authors Journal Year of publication Purpose	 14 Creating empowerment meaning: an interactive process promoting health with chronically ill older Canadians. McWilliam C.L, Stewart M, Brown J.B, McNair S, Desai K, Patterson M.L et al. Health Promotion International 1997 To evolve and test a health promotion intervention for older individuals with chronic medical problems and repeated admissions to acute care institutions for conditions which might have been managed at home. Qualitative, phenomenological where interviews were analyzed with an immersion and crystallization
Sample	interpretive technique. 13 individuals who were: >65 years of age; cognitively intact; hospitalized two or more times in the past 1 year; discharged from hospital within the past 1 week, and in receipt of professional home care to manage their chronic illness.
Country Number of references	Canada 94
Reference Title	15 "SURVIVORS" AND "VICTIMS": LONG-TERM HIV POSITIVE INDIVIDUALS AND THE ETHOS OF SELF-EMPOWERMENT.
Authors Journal	Crossley M.L. Social Science and Medicine
Year of publication	1997
Purpose	To demonstrate how oppositional type of categorisation is used by a group of HIV positive individuals with regard to the counter-opposed "healthy", "good" "responsible" self and the "unhealthy", "bad", "irresponsible" other.
Method	A combination of qualitative and quantitative approaches including survey by questionnaire, in- depth semi structured interviews and ethnographic analysis.
Sample	38 HIV positive individuals participating in NLTSG residential weekends diagnosed with HIV for an average 9 years

Country Number of references	United Kingdom 34
Reference Title	16 Active Patient Involvment in the Establishment of Physical Therapy Goals: Effects on Treatment Outcome and Quality of Care.
Authors	Arnetz J.E., Almin I, Bergström K, Franzén Y, Nilsson H.
Journal Year of publication Purpose	Advances in Physiotherapy 2004 To investigate the possible effects of active patient involvement in the establishment of physical therapy treatment goals.
Method Sample	Quantitative. Randomized controlled trial. All patients admitted to a rheumatology rehab unit between September1996 and September1997 were asked to participate in the study ending up in 77 participants with 39 patients in the intervention group and 38 in the control group.
Country Number of references	Sweden 52
Reference Title Authors Journal Year of publication Purpose	 17 Myth of empowerment in chronic illness Paterson B. Journal of Advanced Nursing 2001 To investigate self-care decision making in diabetes and to test and refine the concept of expertise in self-
Method Sample	care. Qualitative. The research was guided by the theory of symbolic interactionism. 22 adults with long-standing (15 years or more) type
Country Number of references	1 diabetes. Canada 29
Reference Title	18 The Peritoneal Dialysis Experience: Insights From Long-Term Patients
Authors Journal Year of publication Purpose	Curtin R.B., Johnson K.H., Schatell D. Nefrology Nursing Journal 2004 To examine the lived experiences of longer term patients on Peritoneal Dialysis.
Method	Qualitative. Semi-structured interviews

Sample	18 patients were recruited through dialysis facilities with an inclusion criteria of having been on PD for minimum 4 years.
Country	USA
Number of references	45
Reference	19
Title	Living with Chronic Lung Disease and the Effect of Pulmonary Rehabilitation
Authors	Toms J, Harrison K.
Journal	Physiotherapy
Year of publication	2002
Purpose	To give in-depth consideration to the views of patients on both the experience of chronic lung disease and the impact of the intervention of pulmonary rehabilitation on their lives.
Method	Qualitative. The approach was chosen allowing exploration in a naturalistic setting and from a holistic, non-reductionist approach and adopting an interpretive stance from within the philosophy of phenomenology.
Sample	Participants in a single pulmonary rehabilitation programme who were either on the maintenance programme or who had recently completed it. The only other selection criteria were that conservative management was the only option, and that participants had no other ongoing medical condition influencing their lives resulting in 7 participants.
Country	United Kingdom
Number of references	55
Reference	20
Title	Use of a Patient-Accessible Electronic Medical Record in a Practice for Congestive Heart Failure: Patient and Physician Experiences
Authors	Earnest M. A., Ross S. E., Wittevrongel L., Moore L. A., Lin C-T.
Journal	Journal of the American Medical Informatics Association
Year of publication	2004
Purpose	To evaluate the experiences of patients and physicians in a clinical trial of an online electronic medical record (SPPARO, System Providing
Method	Patients Access to Records Online). Randomized controlled trial consisting both quantitative and qualitative approaches. Questionnaires and semi structured interviews were

Sample	undertaken and Grounded Theory was used for analyzing the interviews. 107 patients enrolled in the randomized trial: 54 in the intervention group and 53 in the control group. 16 patients in the control group participated in semistructured interviews and 7 physicians agreed to participate in semistructured individual interviews.
Country Number of references	USA 16
Reference Title Authors Journal Year of publication Purpose	21 Social Support in Cyberspace- The Next Generation Weinert C., Cudney S., Winters C. CIN:Computers, Informatics,Nursing 2005 to assess the impact of the intervention on the participants' psychosocial health, computer literacy skills, and health knowledge, and to analyze the computer exchanges for insights to explicate the complex process of adapting to chronic illness within the rural context.
Method	Quantitative. Data was generated though a telephone screening interview, mail questionnaires, chat room messages, end-user information, and a technology intervention survey.
Sample	Women from 35 to 65 years of age with a chronic illness living at least 25 miles outside an urbanized area on a ranch/farm, or a small town in Montana, Idaho, North Dakota, South Dakota, or Wyoming; have the physical ability to use a computer, speak and read English; and have a telephone in their homes was the inclusion criteria resulting in 180 participants.
Country Number of references	USA 37
Reference Title Authors Journal	22 Implementing the Chronic Care Model for Improvements in Diabetes Care and Education in a Rural Primary Care Practice Siminereio L.M., Piatt G, Zgibor J.C. The Diabetes Educator
Year of publication Purpose	2005 To determine the impact of implementing elements of the chronic care model (CCM; decision support, self-management, and delivery system redesign) on

Method Sample Country Number of references	providers' diabetes care practices and patient outcomes in a rural practice setting. Quantitative. Measures that were used include the BDC instrument, the Diabetes Attitude Scale, the Diabetes Empowerment Scale (DES), the DKT, and the Diabetes Self-management Program of UPMC Health System Initial Assessment. Any patient older than 18 years with diabetes based on treatment (insulin, oral hypoglycemic medications) or 2 fasting blood glucose levels >126 mg/dL, 2 random blood glucose levels >200 mg/dL, or an A1C >7% seen in the practice during calendar year 2000 was eligible for the study. 104 patients matched inclusion criteria, 29 began participation and 17 fulfilled the study. USA 25
Reference Title Authors	23 Life Versus Disease in Diffucult Diabetes Care: Conflicting Perspectives Disempower Patients and Professionals in Problem Solving. Zoffmann V, Kirkevold M.
Journal	Qualitative Health Research
Year of publication	2005 To report on a grounded theory study of difficult
Purpose	To report on a grounded theory study of difficult problem solving in diabetes care, providing a theoretical account of how patients and professionals approach problem solving.
Method	Qualitative. grounded theory method comprising a symbolic interactionist perspective and a constant comparative method
Sample	11 patients, 18 years or older diagnosed with diabetes at least a year earlier, and admitted because of poor glycaemic control. 8 nurses familiar with traditional diabetes care and more than 1 year of experience in a specialized diabetes unit.
Country	Denmark
Number of references	42