

L'amélioration des soins axés sur les patients par le biais du développement des connaissances

Richard W. Redman et Mary R. Lynn

La demande pour des services de soins axés sur les patients met en évidence le besoin de développer les connaissances autant dans le domaine conceptuel qu'empirique. Les définitions et les éléments opérationnels des soins axés sur les patients comportent diverses questions conceptuelles. La satisfaction des désirs, préférences et attentes des patients constitue un élément commun à toutes les définitions. Dans le domaine de la recherche, les études portant sur les interventions comportent des défis sur les plans de la conception et du mesurage. Le développement d'interventions axées sur les patients ou conçues sur mesure selon les caractéristiques liées aux patients et l'environnement dans lequel ces actions seront menées figurent parmi ces défis. En se penchant sur ces questions vitales, la profession infirmière peut jouer un rôle clé dans l'évolution de la science de l'intervention et des connaissances dans le domaine des soins axés sur les patients.

Mots clés : soins axés sur les patients, interventions axées sur les patients

Advancing Patient-Centred Care Through Knowledge Development

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The call for health-care services that are patient-centred raises the need for knowledge development in both the conceptual and empirical domains. The definitions and operational elements of patient-centred care present a variety of conceptual issues. A common element in all definitions is accommodation of patient wants, preferences, and expectations. In the research domain, intervention studies face both design and measurement challenges. These include the development of interventions that are patient-centred or tailored for both patient characteristics and the environment in which they will be delivered. By addressing these critical issues, nursing can play a key role in advancing intervention science and knowledge development in the domain of patient-centred care.

Keywords: patient-centred care, patient-centred interventions, organizational capacity

Introduction

A recent report by the Institute of Medicine (Committee on Quality Health Care in America, 2001) on changes needed in the delivery of health services delineates six features in need of reform: safety, efficiency, timeliness, effectiveness, equity, and patient-centredness. These improvements require the generation of specific knowledge about “best practices” or optimum means by which each can be achieved. While they are essential for the enhancement of health care, the notion of care being patient-centred presents two central challenges. The first relates to the discrepancy between the conceptualization and implementation of patient-centred care. Most providers would propose that their care is always patient-centred, yet patients might disagree. The second challenge relates to the methodology for developing and testing patient-centred interventions. Research designs and methods are generally standardized and participants are often unable to express their preferences or goals, as would be expected with a patient-centred approach to care.

Patient-centred care comes about as a result of the partnership that develops between the patient and the provider to ensure that care is based on joint decision-making, fostered by adequate education and support of the patient in the decision-making role. Such care is tailored to the patient’s unique needs and preferences. Beyond the obvious oblig-

ation of nurses to know their patients' needs and preferences when planning care, the importance of patient-centred care is clearly demonstrated by the finding that patients who are centrally involved in the decision-making about their care have better outcomes than patients who are not (Holman & Lorig, 2000). However, despite the inherent appeal and obvious benefits of patient-centred care, little progress has been made in identifying ways of incorporating patient-centred concepts into health care in order to enhance the quality of care.

Several issues may be operational in the sluggishness of the movement towards patient-centred care. One issue is the lack of conceptual clarity and the lack of an operational definition of patient-centred care. Another emanates from the general lack of patient-centredness in research methods. In traditional intervention study designs, the intervention is not tailored to participant characteristics, needs, or preferences so as to be truly patient-centred. Additionally, intervention studies often do not take into account real-world contextual factors that affect the implementation of the intervention. The lack of patient-centredness in research results in a reluctance on the part of clinicians to integrate new interventions into their practice.

The development of knowledge that facilitates the delivery of patient-centred care requires clarification of the fundamental processes and the variables underlying such care as well as innovative research strategies that enable the investigation of patient-centred interventions. In this paper we will attempt to demonstrate that consideration of these factors will serve to promote patient-centred practice.

Conceptual Issues

Patient-centred care, commonly expressed as treatment of the patient as a unique person, actualizes a core value of nursing — individualization of care. This requires an understanding of specific patient needs and perceptions and, based on that understanding, the selection of optimal interventions to meet those needs. From this perspective, individualization of care is central in clinical decision-making (Radwin, 1996). Related to patient-centred care is the notion of patient participation in care. A concept analysis of patient participation has identified four essential attributes: a relationship between nurse and patient; a surrendering by the nurse of some degree of control or power; engagement, on the part of both nurse and patient, in intellectual and/or physical activities; and a positive outcome of participation (Cahill, 1996).

The benefits of patient-centred care include improvements in the patient's autonomy, functional status, quality of life, continuity of care, and health promotion behaviour (Committee on Quality Health Care in

America, 2001). Researchers, however, are not in agreement about how patient-centred care should be defined and measured. Furthermore, when researchers have attempted to measure patient-centred care, they seem to have defined it primarily from the perspective of the provider rather than that of the patient (Suhonen, Valimäki, & Leino-Kilpi, 2002).

Lutz and Bowers (2000) describe multiple perspectives on the interpretation and implementation of patient-centred care. Using concept analysis to examine these multiple perspectives, they found that the literature focuses on patient-centred care as designed in one of two ways in order to “meet the patient’s needs”: care organized around the patient’s needs, or use of one’s understanding of the patient’s needs as a framework for care. Despite this focus on the patient’s needs as central to the design of care, Lutz and Bowers found that patient-centred care was nominal only and was frequently defined and implemented from a traditional provider-centred approach, often resulting in delivery and outcomes not congruent with patient preferences. Varying definitions and conceptual views notwithstanding, an underlying theme has been identified: a fundamental concern with meeting patients’ needs, wants, and/or expectations by respecting and integrating individual differences when delivering care (Lauver et al., 2002). Nursing, with its longstanding commitment to patient-centred care, is in the best position to lead conceptual and research efforts to develop interventions and models of care that incorporate patients’ needs and preferences (Lutz & Bowers).

Issues of Research Design and Methods

One critical issue in the lack of patient-centredness in research is the prevailing view that the randomized clinical trial (RCT) design, with its standardization of treatment, application to all subjects, and random assignment to control and experimental groups, is the only acceptable way to test interventions. In the RCT model, the evaluation of interventions has two standard phases. In the efficacy phase the intervention is examined under tightly controlled conditions. Once efficacy has been established, in the effectiveness phase the intervention’s performance is examined in the practice setting, under different conditions (Sidani, 1998). The RCT rigid design presents many challenges for intervention testing, particularly in the effectiveness phase.

The problems associated with the lack of utility of many intervention research findings and the fact that they are not always embraced in clinical practice have been well documented (Conn, Rantz, Wipke-Tevis, & Maas, 2001; Gross & Fogg, 2001; Sidani, Epstein, & Moritz, 2003). Research suggests that clinicians often do not change their clinical practice as new evidence becomes available because they do not agree with

that evidence or do not believe it will lead to improved outcomes in their patients (Cabana et al., 1999; Estabrooks, Floyd, Scott-Findlay, O'Leary, & Gushta, 2003). Clinicians' scepticism about and hesitancy to incorporate new evidence into their practice may stem from a belief that the evidence is not "real world" or relevant for their practice, where the focus is on tailoring care to patients' needs.

One approach to the promotion of patient-centred care is to test interventions that are patient-centred or tailored to clinically important patient characteristics. In the patient-centred intervention approach, methodological concerns focus on "realistic evaluation of the intervention consistent with nursing perspective underlying patient-centred care that is reflective of the natural conditions of everyday practice" (Sidani et al., 2003, p. 248). The intervention is tailored, and methodological modifications are made in the areas of selection of participants, treatment assignment, choice of measures, and extraneous factors — specifically, characteristics of the participant, the intervener, and the environment. The modifications are made with a view to enhancing the patient-centredness of research.

Tailored Interventions

In patient-centred care, interventions are tailored to the patient's specific capabilities, vulnerabilities, and, to the extent possible, preferences (Azar, 1999; Coward, 2002; Lauver et al., 2002; Sidani et al., 2003). Tailoring allows for efficient use of resources and for more specific treatment and more carefully controlled delivery of treatment. Tailoring also reduces the number of treatment dropouts that result when care providers and patients have different goals (Prochaska & DiClemente, 1983).

Historically, intervention studies are based on standardized interventions, assuming that "one size fits all." This approach underestimates individual variations in dose requirement and treatment acceptance, which may be one reason why some treatments are considered ineffective from the perspective of both the provider and the recipient. If a standardized intervention runs counter to patients' lifestyles, cultures, beliefs, or resources, it will be met by non-compliance or non-adherence, which in turn will influence outcomes. Therefore, the extent to which interventions can be tailored to the needs of participants, both the patient and intervention science will benefit.

Assignment to treatment. The design of an intervention study is generally based on random allocation of purportedly homogeneous participants to an experimental or control group. An alternative approach, one that is consistent with patient-centredness, incorporates input from participants before and during implementation of the intervention. According to the theory of psychological resistance (Brehm, 1966), when

people are placed in a position of perceived lack of control (eliminated freedom), as in the case of random assignment to a study group, the ensuing reactant behaviour can result in their quitting the study or investing minimally in their participation. Assignment to a specific treatment arm should be considered in the design of a patient-centred intervention evaluation study, as is done in partial RCTs. Participants often want to choose which arm of the study they are assigned to (Nielsen-Anderson, Dixon, & Lee, 1999). In a partial RCT (Bradley, 1993; Coward, 2002), participants with no treatment preference are randomized to an intervention arm and those with a preference are assigned to their preferred treatment. This approach reduces reactance behaviour and increases treatment compliance (Bradley). Additionally, it allows for examination of the effects of treatment preference on outcomes (Corrigan & Salzer, 2003; Gross & Fogg, 2001).

The effectiveness of tailored interventions depends in part on the degree to which the patients' situation and preferences can be considered in the selection of treatment. This matching of patients' situation and preferences to treatment arm requires a systematic allocation procedure based on a comprehensive evaluation of participants' characteristics and needs and explicit guidelines that link assessment results to specific treatment strategies. Ideally, patient-treatment matching guidelines are theoretically supported and empirically justified (Del Boca & Mattson, 1994).

Participant selection. In the most liberal patient-centred approach to research, participants are selected not on the basis of an exhaustive set of inclusion or exclusion criteria but primarily on the basis of whether they have the specific condition addressed by the intervention and whether they have characteristics that would make them resistant to the intervention. The self-selection bias is tracked, in order to provide information on how to appeal to those who did not enrol in the intervention (Sidani et al., 2003).

Choice of measures. In the patient-centred paradigm of research, instruments, or measures, are chosen not only for their traditional merits — reliability, validity, sensitivity to change — but also for their usability in routine clinical practice. Specifically, measures are selected if they are acceptable to the participants, easy to administer, and easy to score (Sidani et al., 2003). They have to be responsive to change generally and to clinically significant change(s) specifically (Deyo, Diehr, & Patrick, 1991; Guyatt, Deyo, Charlson, Levine, & Mitchell, 1989; Stewart & Archbold, 1993). These aspects are particularly important in the context of eventual translation and practical evaluation of the intervention.

Another issue related to instrumentation is the degree to which standardized instruments capture factors that reflect patient values or preferences regarding care and the outcomes of that care. This is particularly

important in intervention studies in which measures of health-related quality of life and functional status are included to supplement clinical or biological measures to assess the effectiveness of interventions. Generally, such measures are viewed as a way to include the patient's perspective on the condition or treatment and thus are described as patient-centred. However, many measures of health-related quality of life and functional status have been developed by providers, based on standard models, with little or no input from patients (Carr & Higginson, 2001). This raises the question of whether they are describing the patient's health from the perspective of the patient or from the perspective of the provider or society.

If a measure does not capture changes in health status or quality of life in terms that are meaningful to patients, then the responses of patients who are subsequently asked how they feel or to comment on their health status may not relate to changes in the measured health status, because the patient and the measure are not judging "change" on the same basis. If a measure is not patient-centred in terms of content or weight given to items or scales to reflect patients' values and preferences, and if it is used to assess the effectiveness of an intervention, the results are not likely to provide the kind of practical information that clinicians need.

Extraneous Influences

Extraneous factors such as the characteristics of the patient, intervener, and/or environment can directly affect or moderate outcomes (Lipsey, 1993). Patient characteristics that can influence outcomes include personal ones such as age, gender, education, and ethnicity, as well as health-related ones such as health status, comorbidities, severity of condition, and functional status. A social focus might also be included, in terms of resource availability, social support, or employment status. Characteristics of the intervener that must be considered include personal ones such as age, gender, ethnicity, and presentation and communication skills, and professional ones such as education, job satisfaction, and intervention skills (Epstein, 1995). Physical and psychosocial features of the environment can enhance or mitigate the effects of an intervention (Conrad & Conrad, 1994). Physical features of the environment include "comfort aspects" — that is, noise, light, temperature, familiarity, and overall appeal. Psychosocial features include the geographic, social, and cultural context of the study. The importance of each of these factors varies from study to study, but each can have direct and indirect effects on the outcomes of the intervention — although for the most part they may not be controllable.

In standardized approaches to evaluating interventions, the influence of extraneous factors is generally treated as "noise" and randomly distributed across treatment arms so that, while potentially adding to error vari-

ance, it is ignored. In the patient-centred approach to research, these factors are identified at the outset and considered in the analysis, to explore rival hypotheses as to the findings. Such considerations will add to the validity of the conclusions reached (Chen & Rossi, 1987; Cook & Campbell, 1979; Sidani & Braden, 1998).

These extraneous factors may be treated as moderators in the design and analysis of the intervention. Moderators influence the direction and/or magnitude of the effect of the independent variable on the dependent variable (Baron & Kenny, 1986; Kenny, 2003). Patient characteristics may moderate the intervention effect in addition to the moderation effect of most other extraneous factors noted earlier.

The day-to-day world of nursing is reflected in the design of patient-centred interventions, characterized by treatment tailored to patients' needs and preferences, and the design and conduct of intervention studies within the patient-centred approach to research. Nurses are trained to assess their patients before providing care. A natural extension of that process is assessment of the needs and wants of patients/participants in order to determine what will be done, when it will be done, where it will be done, and who will do it. We should not presume to "know" our patients well enough to design and implement an intervention that does not include their input and perspective; we should capitalize on the interactivity of nursing to advance our understanding of the responses of patients and participants to interventions they help design (Lynn, 1987). Clinicians frequently reject the findings from intervention studies as irrelevant to their clinical situation, often because they perceive the results as having limited applicability to the patients in their particular practice setting. The advent of the patient-centred intervention approach to knowledge generation provides a means by which real-world applicability of the findings can be built into the design and conduct of the study. While this requires some methodological trade-offs, these are outweighed by the potential gains to be made with regard to the clinical relevance of the findings.

Contextual Issues

Another challenge in developing and testing nursing interventions is assessing the capacity of the clinical setting and how this might influence the implementation of the intervention. Capacity issues include readiness of the organization to adopt change, skills of the practitioners, degree of flexibility in the systems of care, and availability of resources including the technological and clinical information systems needed to implement the intervention (Snyder-Halpern, 1999). Characteristics of the practice environment are not generally assessed when interventions are tested. Patient-centred care requires a provider who thinks critically and reflec-

tively. Factors that influence patient-centred practice include the nursing practice model, the skill mix, the adequacy of staffing on any given day, and the authority vested in the clinical decision-makers to implement patient-centred interventions (Brennan, 2002).

Naylor (2003) calls for increased attention to the context of care when interventions are being designed. When an intervention is being tested, it should be evaluated from the perspective of the patients receiving it as well as the clinical environment in which it will be implemented. Identification of effective strategies to assess the organizational environment, and the building of those strategies into intervention studies, might increase the probability of promising interventions being successfully integrated into clinicians' practice.

Recommendations

Given the increased dialogue and recognition of the importance of integrating patient-centred care into both practice and research, we offer several recommendations to guide knowledge development in this domain. Nursing is well positioned to address this challenge due to its philosophic commitment to patient-centred concepts and the nature of our research questions around the needs of individuals in health and illness.

Further Conceptual Development of Patient-Centred Care

The literature supports the need for refinement of the conceptual and operational aspects of patient-centred care (Lauver et al., 2002; Lutz & Bowers, 2000; Radwin, 1996). We lack clarification on the degree to which an individual's goals or priorities are, or should be, solicited by the provider so that they can be incorporated into the care plan. In addition, we lack guidelines for consistency in the solicitation of client input and in provider/client collaboration regarding patient-centred care. These components of patient-centredness will likely vary with the patient's health status and/or health-care choices. Further work is needed in this area so that patient-centred principles can be incorporated into both research and practice.

Integration of Patient-Centred Models in Intervention Research

Several models are available to guide the research community in the use of methods that incorporate components of patient-centred care into intervention research. In many ways, the arguments against the use of patient-centred techniques in experimental designs are generational: researchers trained in methods using the rigid RCT model as the gold standard view this model as the only acceptable one for testing and eval-

uating interventions, while those currently being trained are exposed to the notion that the lack of real-world application of RCT may make it a suboptimal choice when the goal is clinical application of the research findings. A patient-centred orientation in intervention research, particularly in effectiveness research, will facilitate the movement towards patient-centred care and thus lead to improved care. The research community should carefully consider the methodologic alternatives to prevailing models.

Sidani et al. (2003) describe a theory-driven approach to the evaluation of interventions. In this approach, the theory or conceptual model drives the selection of variables and the design of an intervention that incorporates the testing of the impact of selected patient-centred factors, such as patient characteristics, on the outcomes rather than controlling for their effects through design or randomization. In the theory-driven perspective, patient-centred principles can be incorporated into the design and implementation of the intervention, assignment of participants to treatment options, and selection of outcome measures.

In another approach to the integration of a patient-centred emphasis in intervention design, the research participants take part in evaluating the dosage of the intervention received so as to ensure accurate measurement. Sidani (1998) proposes a continuous scoring scheme for quantifying intervention dosage whereby patients are engaged in recording the treatment they receive in terms of time increments, frequency, intervals, or whatever calibration may be appropriate. This approach could be extended to include participants' involvement in the design and delivery of the intervention to incorporate aspects that are meaningful from their perspective.

Measuring treatment outcomes in patient terms, though not a part of most research studies, could provide insight into what indicators to use in evaluating the effectiveness of interventions. Many clinical scoring systems address general and condition-specific indicators from the clinician's perspective, and, when the results have been compared with patients' indicators of treatment effectiveness, discrepancies have been identified in the evaluations of clinicians and patients (Bayley, London, Grunkemeier, & Lansky, 1995). Incorporating the patient's views with regard to treatment effectiveness would enhance sensitivity when pre- to post-treatment changes are being evaluated.

Gross and Fogg (2001) discuss people's growing concerns about participating in RCTs and their unwillingness to comply with protocols that do not meet their needs. These authors stress the importance of identifying outcomes that are relevant for participants. Engaging participants as knowledgeable research partners would increase the patient-centredness of the study and the utility of its results. One way to increase

participant involvement in both protocol development and outcome measures is to have a participant advisory board assist with study and intervention design and selection of outcome measures. Such a board could provide insights that are otherwise unavailable to the investigators. Alternatives to randomization could also be considered, with a view to enhancing the patient-centredness of interventions. One technique would be to allow participants to choose their group assignment. While alternatives have disadvantages, they merit further examination as a means of building patient-centred aspects into research design and into the testing of interventions.

Evaluation of Available Measures and/or Development of New Measures

Carr and Higginson (2001) identify issues that are central to many standardized measures of health-related quality of life. Frequently these measures do not account for individual values and preferences, the cultural dimension, or the specific values, or weight, that individuals may assign to specific dimensions. Often they are designed from the perspective of researchers or health professionals, who assume they know what factors are relevant instead of asking patients or participants what aspects of their lives are important to them. The broader question is how well existing measures address issues of importance to patients in terms of determining the effects of treatment on quality of life or functional status. If a measure does not capture aspects of quality of life from the perspective of individual patients, it may not be sensitive to changes post-intervention or post-treatment because it is not measuring what is important to patients.

The development of individualized measures has so far been limited. Existing measures need to be refined and new approaches developed to capture dimensions that reflect the values of individual patients and research participants. In an individualized quality-of-life questionnaire developed by Bernheim (1999), patients record the specific areas in their lives that are most important to them and rate the current status of each using visual analog scales. This patient-centred approach is likely to be sensitive to pre- and post-measurement of treatment effects in areas that are important to the patient.

Evaluation of existing instruments, particularly in the area of health-related quality of life, is essential. Revision of existing measures, or the development of new measures that are patient-centred, is an essential next step in adopting a patient-centred approach to the evaluation of treatments and interventions.

The challenges facing a patient-centred orientation in health services research are formidable. Nursing is well-positioned to lead this effort, which will require collaboration among researchers, clinicians, and

patients. A commitment to patient-centred intervention and research design holds promise for the advancement of knowledge development, nursing practice, and patient and organizational outcomes. Engaging participants as knowledgeable partners in research will increase the likelihood of our research endeavours having real meaning for both patients and clinicians.

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