

What Do Patients Want? Patient Preference in Wound Care

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Patient preferences are statements made or actions taken by consumers that reflect their desirability of a range of health options. The concept occupies an increasingly prominent place at the center of healthcare reform, and is connected to all aspects of healthcare, including discovery, research, delivery, outcome, and payment. Patient preference research has focused on shared decisions, decisional aids, and clinical practice guideline development, with limited study in acute and chronic wound care populations. The wound care community has focused primarily on patient focused symptoms and quality of life measurement. With increasing recognition of wound care as a medical specialty and as a public health concern that consumes extensive resources, attention to the preferences of end-users with wounds is necessary. This article will provide an overview of related patient-centered concepts and begin to establish a framework for consideration of patient preference in wound care.

FROM THE SEMINAL MODELS of evidence-based practice, patient preference has occupied a prominent place in clinical decision making.¹ More recently, consideration for patient preference emerges as a key component in the redesign of healthcare processes with significance for improving outcome and safety.² But what are patient preferences? How are they elicited, regarded, and incorporated into recommended action? What interrelated patient-centered concepts have been studied in various patient populations? Lastly, what contribution has the wound care community made to the understanding of patient preference? This article aims to introduce the reader to the issues, begin a dialogue on patient preference in wound care, and suggest opportunities for future discovery.

Patient preferences are “state-ments by individuals regarding the

relative desirability of a range of health experiences, treatment options and health states.”^{3(p259)} Preferences reflect beliefs and attitudes of the patient and family, and are related to the process, probability, and severity of potential choices.⁴ Patient preference is conceptualized and measured differently across disciplines, from health economics, patient education, psychology, ethics, and using qualitative and quantitative approaches. In the field of medicine, oncology has been the frontrunner in operationalizing methods to determine patient preference for various cancer treatment options, most notably in breast and prostate cancer treatments.⁵

Patient-centered care—an approach that emphasizes communication, partnership, and health promotion along with an appreciation for the patients’ expectations,



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Abbreviations and Acronyms

AAWC = Association for the Advancement of Wound Care
ACWHTR = American College of Wound Healing and Tissue Repair
AHRQ = Agency for Healthcare Research and Quality
CPGs = clinical practice guidelines
CWIS = Cardiff Wound Impact Schedule
DSA = decision support aide
HCAHPS = Hospital Consumer Assessment of Healthcare Providers and Systems
NIH = National Institutes of Health
PCORI = Patient-Centered Outcomes Research Institute
SDM = shared decision making

autonomy, and beliefs—is positioned prominently at the core of international healthcare reform efforts to improve the delivery of safe, quality, cost-effective services.^{6,7} For example, in the United States, federally funded agencies such as the Agency for Healthcare Research and Quality (AHRQ) are charged with operationalizing the tenets of patient-centered care to improve consumer outcome; the Patient-Centered Outcomes Research Institute (PCORI) funds and promotes comparative effectiveness research to elucidate outcomes relevant to patients, and the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey links patient satisfaction to hospital payment.⁸ Driven by the economics of national health delivery, clinicians and researchers in other countries are also exploring issues of patient priority.⁹

Patient-centered perspectives require a paradigm shift away from the traditional paternalistic view that healthcare professionals know best. Informed, actively collaborating patients become emancipated, able to assume responsibility for their care. Patient empowerment is an evidence-based “process designed to facilitate self-directed behavioral change.”^{10(p.277)} Empowerment occurs when providers support patient self-reflection, leading to enhanced awareness of the consequences of self-management decisions. Work on patient empowerment in diabetes has shown significant increases in patient capacity for critical thinking and autonomous informed healthcare decision making.¹⁰

Endorsed by the World Health Organization Alliance for Patient Safety, patient participation promotes the healthcare consumer’s right to safety, information, and voice, with potential for impact on medical error prevention. Specific roles have been proposed: patient instruction on safety training to healthcare workers, consumer involvement in safety protocol development, and patient review of error reporting systems. Patient participation to increase hand hygiene adherence by healthcare workers has been successfully tested worldwide in developed and developing countries.¹¹

Within a patient-centered care framework, the patient’s voice merges with the providers’ knowledge, resulting in collaboration about treatment. Through shared decision making (SDM), clinicians “share the best available evidence and patients are supported to consider options to achieve informed preferences.”^{12(p.1361)} At its core, SDM transcends mere informed consent; it is built on guiding ethical principles of self-determination and relational autonomy, and achieved through effective clinician–

patient interchange. In a systematic review of 115 studies on patient preference, Chewning *et al.* found that a majority of patients preferred SDM with their physicians, noting a time-related increase in shared preference over the past decade.¹³ Although no studies in this review examined preferences in wound or vascular populations, patients suffering from chronic disease conditions (including diabetes) preferred SDM over traditional delegated decision making. Whereas a majority of patients wish to participate in decisions, there appears to be a subset of patients who prefer to delegate decisions.

Patient decision support aides (DSAs) are designed to guide patients in complex decisions involving weighing risks, benefits, and scientific uncertainty. DSAs exist in varied formats, including web- and computer-based modules, graphics, algorithms, cards, decision boards, and text. The development of decision aid interventions are guided by international standards and facilitate patient/family exploration of personal values and goals along with structured breakdown of best evidence options.¹⁴ An example of a decision aide for patients with peripheral arterial disease facing a decision to undergo revascularization intervention can be found on one decision aid website.¹⁵ The patient is guided through a process of fact finding, comparing options, exploring and rating personal values, considering risks and benefits, and checking certainty. A Cochrane systematic review of 86 randomized controlled trials concluded that DSAs increase patient knowledge, create realistic perception of potential outcomes, and patients have a greater likelihood of receiving care aligned with their values. Patients who use DSAs choose less invasive surgical options and more conservative treatments than patients who do not.¹⁶ The adoption of DSAs as an evidence-based strategy to achieve SDM presents potential for improving patient-centered outcome, while reducing national health expenditures.

Effective SDM is dependent on the providers’ working knowledge of relevant evidence-based care. Clinical practice guidelines (CPGs) are systematically developed analyses of evidence—drawn from meta-analyses, systematic reviews, available literature, and expert opinion—designed to assist provider-patient deliberations about appropriate treatments for specific conditions. Implementation of CPGs theoretically promotes the use of interventions of proven benefit, while simultaneously discouraging ineffective therapeutic options. Guideline development and access have proliferated over the past decade, although the quality of CPGs is variable depending on

development methodology, panel composition, and external review by stakeholders.¹⁷ The National Guideline Clearinghouse website, an AHRQ initiative, houses thousands of internationally developed CPGs, including nearly 200 related to a wound care search.¹⁸

CPGs for a given specialty should provide the building blocks for DSA and eventually, SDM. However, currently, CPGs function more as a quality improvement tool for clinicians and fail to foster patient involvement in decision making.¹⁹ Involvement of patient stakeholders in the development of CPGs and individualizing CPGs to patient risk are two strategies for making them preference sensitive. Methods of public and patient involvement in CPG development include solicitation through professional organizations, direct CPG work group participation, consultation with focus groups, recruitment from providers, and response to surveys and public invitations. A Canadian knowledge synthesis study identified barriers to patient involvement, including recruitment challenges, achieving balanced diagnostic representation, and lack of familiarity with scientific terminology. The largest hurdle has been the difficulty of reconciling discrepancy between perspectives of the experts with experiences of the patient, suggesting a role for formalized facilitation/mediation.²⁰

Preference sensitivity and utility of CPGs could be further improved by tailoring recommendations to the specific circumstances of an individual patient. In a mathematical simulation study comparing outcomes for hypertension treatment using generic versus patient-specific CPG computations, Eddy and others demonstrated that individualized CPGs could prevent morbidity and reduce costs more often than adherence to generic guidelines.²¹ Chong proposed a patient preference decision analytic flow diagram, in which patient/physician decision points and event probability junctures could be incorporated into CPG development.²² As a wound-related example, one CPG for pressure ulcer prevention recommends, with strength of evidence rating A, "high-protein mixed oral nutritional supplements and/or tube feeding, in addition to the usual diet, to individuals with nutritional risk and pressure ulcer risk," but does not tailor the application of this recommendation to the patient with renal disease comorbidity that may require a different approach.²³ With the acceleration of electronic health records and decision support tools, the future utility of individualized versus population-based CPG is promising.

The changing model of clinical research generation also demands a new role for consideration of

patient preference. Translational research is the bench to bedside process meant to fast-track biomedical advances, help identify clinical utility to basic science exploration, foster basic science/clinical collaboration, and ultimately improve therapeutic options for clinicians and patients. The U.S. National Institutes of Health (NIH) and other international granting bodies have adopted this vision as a way of structuring and funding research. Biomedical innovations were previously developed in a unidirectional pipeline process, moving slowly from laboratory to clinical trials, and then to real-world clinical care. In the new paradigm, knowledge from the bedside informs the laboratory in an interactive two-way process. As such, patients become important stakeholders in the research process.²⁴ More than just subjects in clinical trials and adopters of research outputs, patients become active participants in the selection of a research agenda, design of technologies, and the development of patient-centered outcome measures.

A primary instrument in the translational process is the biomarker. Biomarkers are objectively measured indicators of individualized biological processes or pharmacologic responses to therapeutic interventions.²⁵ Research into biomarkers is intended to explicate causal pathways about individual susceptibility and response to treatments. The field of wound repair promises exciting advances in the identification of biomarkers, including some early findings on the correlation of biomarkers with wound healing in complex traumatic combat wounds.²⁶ The ability to detect individual biochemical differences in the wound will eventually lead to the development of personalized wound management protocols. With personalized medicine, patients can be cartographers of the roadmap, which offers the risks they are willing to take compared to the quality of life they desire.

The patient-centered care literature includes overlapping concepts relating to healthcare reform, research evidence, and patient preference. These have been briefly reviewed and a visual representation organizing concepts in a patient-centered framework is illustrated in Fig. 1.

Most of the published patient-centered wound literature to date has focused on quality of life (QOL), pain, adherence, and coping. Numerous qualitative studies, published largely by nurses, have reflected the wound patient lived experience and serve as a basis for patient preference exploration. Health-related QOL studies of patients with leg ulcers,²⁷ diabetic ulcers,²⁸ and pressure ulcers²⁹ show considerable impact with common themes of pain, a restricted life-style, loss of



Figure 1. Patient-centered framework for wound care.

mobility, powerlessness, and coping challenges. Provider solutions to alleviate the negative impact of distressing symptoms include improved care delivery, symptom control, patient education, and social support.³⁰ The distinct patient voice in this literature calls for improved professional relationship building: provider recognition of patient concerns in treatment planning and request for individualized approaches. Improved understanding of the perceived burden of illness is a vital step toward patient-centered wound care. However, the evolution from empathy to shared wound care decision making is what patients are asking for.

Some examples of patient preference focus in wound care do exist in the literature. The Cardiff Wound Impact Schedule (CWIS) tool, validated in chronic venous and diabetic wound populations, identifies issues of patient concern; ideally measured at the start of care planning or at each patient encounter to tailor patient preferred treatments.³¹ As a validated wound patient perception, wound pain has been the focus of several publications aimed at accurate assessment and treatment and is included in many of the published professional wound society CPGs.³² Grocott *et al.* published a case study investigating the perceptions of Epidermal Bullosa patients and their caregivers as a model for user engagement in medical device development.³³ The qualitative and quantitative participatory methodology utilized audiotape interview data, observation of dressing changes, three-dimensional imaging of dressing design, and product performance metrics to inte-

grate user perception into dressing research, design, and supply chain planning. Patients identified specific unmet dressing formulation needs that could generate a new product design.

In a study on dressing preferences of patients, doctors, and nurses, Vermeulen *et al.* used conjoint analysis methodology to rate dressing characteristics with clinical vignettes.³⁴ Patients preferred, in order of desired attributes, wound dressing materials that afforded quickest wound healing, pain reduction, and shortest hospitalization time, and they indicated some willingness to pay out of pocket costs. Doctors and nurses agreed on the dressing attributes. The authors contrasted these findings with many manufacturers' primary focus on dressing change frequency and cost reduction.

Another wound dressing characteristic, exudate absorption, is considered to be a property that has substantial importance to patients. There have been countless manufacturer-related claims on differences in exudate management and an international expert consensus document on exudate management in dressings.³⁵ Drainage and odor are concerns voiced by patients in qualitative studies, although they are not primary ones; this may be an example of the potential asymmetry that can develop in healthcare without authentic engagement of stakeholders. Companies spend resources creating scientific advisory boards of clinicians, but do not invite the end users, the patients, to the process. Resolving dissonance in the stakeholder's perception of product development strategy also has potential financial benefits.

An example of a wound study designed from the patient perspective, Moffat and others compared two venous compression systems in a randomized crossover study. Using the primary endpoint as slippage during wear, the study explored the impact on QOL and the overall preference for a bandage system. Results showed one system reduced slippage along with a significantly reduced impact of symptoms on daily functioning and comfort. Subjects rated a strong preference for the bandage system with less slippage, more comfort, and afforded normal shoe wear, with same healing rates.³⁶ Essentially, patients prefer dressings that allow them to lead normal lives while healing faster.

Aligning patient priorities with research agendas is supported by healthcare policy and best practice evidence. Actual methods of garnering wound patient participation in research agenda selection remain challenging. Abma and Broerse have worked for years with burn patient populations (among others) to refine the Dialogue Model

for patient participation in research agenda setting.³⁷ Through mutual learning with ongoing dialogue and trained facilitators, all stakeholders explore, collaborate, and prioritize research agendas. Issues that arise in the process include developing early commitment to a common aim, approaching politicized and morally sensitive topics, and representation of vulnerable populations. The model emphasizes the need for true commitment and resource expenditure to be able to accurately and fairly match the scientific research agenda with the context and needs of the patients.

Within the specialty of wound healing, the American College of Wound Healing and Tissue Repair (ACWHTR) held an inaugural Patient Centered Outcomes in Healing Summit on July 25th, 2012 as a first step in creating a framework for patient-centered outcomes in wound healing.³⁸ A group of patients, caregivers, practitioners, and health outcomes specialists were brought together to review the current status of patient-centered outcome research, present preliminary results from semistructured patient interviews, and propose future research methods in wound care that incorporate patient outcomes. Patients and their caregivers identified the following factors as being of significant importance to them: wound recurrence, quality of treatment for wound care, maintenance of independent living, personal interactions with doctors and healthcare professionals, living a normal life, and receiving appropriate skilled care for their non-healing wound. These items, however, were not the factors identified by the clinicians and the characteristics of the wound dressings were not given a high priority by the patients. This disconnect exemplifies the need to have all stakeholders at the table when designing clinical research and health policy. Forums such as this permit exploration into understanding true patient-centered concerns and leverage patient and caregiver questions with transparency: what is the journey like through a wound episode? What system errors have you experienced? The process involves reaching out to the trenches, the underserved, power-sharing, building relationships, and identifying researchable topics.

Still, there are dilemmas in patient participation that remain unresolved. The majority of patient preference research has focused on decisions about specific disease states or screening methods, for example, atrial fibrillation or prostate screening, which have the luxury of good quality research to guide practice. In the field of wound care, high-quality evidence is lacking for many of the interventions commonly utilized.³⁹ Even in venous ulcers, a subset of wounds with good-quality evidence and multiple

CPGs, healing rates remain low. In an analysis of real-world venous ulcer care in four settings, Jones found that only some of the evidence-based practice recommendations lead to superior outcome.⁴⁰ Future research should focus on the context of care (site), provider competence, and patient preference for varying evidence-based interventions. For example, what are the venous healing rates observed in wound centers staffed by board certified providers, who utilize CPGs and integrate the preference of the patient into compression selection? What are the re-hospitalization rates in homebound preferred elders served by board certified wound care nurse practitioners? What are the costs and functional outcomes of patients that choose extreme limb salvage treatments after shared decisions with their board certified wound podiatrist?

Much more effort should be directed at including patient involvement in wound care CPG development. One wound organization, the Association for the Advancement of Wound Care (AAWC) has developed patient educational brochures accompanying each CPG, promoting best practice interventions in patient-friendly language. AAWC also has established a patient/caregiver resource group, including web supported blog and free membership.⁴¹ This is a start, but many opportunities exist for more significant patient integration in these documents.

Certain patient and provider conditions inherent in SDM pose significant barriers. Optimal patient characteristics for SDM include the ability to make decisions under stress, significant abstract thinking aptitude to imagine future disease state and considerable health literacy. SDM is also built upon the assumption of provider core communication skills and competence in guiding ethical principles. Novice clinicians benefit from updated interprofessional educational curricula inclusive of these topics, although the majority of practicing providers have little training in these SDM critical skills. In the real world, matched ideal skill sets of the provider and patient rarely exist. Future research could identify educational gaps and remediation strategy to enhance the process.

Other future wound research directions should include the focused application of SDM and DSA preference tools described in this article. Similar to oncology, wound practitioners need to investigate the use of ranking tools, visual analogue scales, and attribute utility instrumentation for wound decisions.⁵ The application of decision support models in wound care populations must be explored. Elwyn and others have proposed a three-step model to move healthcare deliberations from "initial patient preferences" to "informed pa-

tient preferences,” using “choice talk,” “option talk” and “decision talk” interventions.^{12(p.1365)} With commonly encountered dilemmas in wound care, one could utilize this model to guide the patient with diabetes and a lower extremity wound through the maze of vascular diagnostics, debridement, topical therapies, hyperbaric oxygen therapy, and bioengineered therapies to elicit informed preferences. Perhaps, wound centers could adopt formalized decision intervention models along with their algorithms of care, and measure resulting patient satisfaction and healing outcome. What happens when the evidence is poor or options are ambiguous is less clear and requires a different approach.⁴² And for patients who prefer to delegate treatment decisions, what is the provider responsibility for defining preferred wound outcome?

Chronic wound prevalence has evolved to a significant public health concern that consumes extensive resources and affects health and quality of life. The impending demographic balloon of wound patients, coincident with a projected shortage of care providers worldwide portends the enormity of services that will be required to effectively manage wounds. With added challenges in healthcare funding, Price has proposed “it is almost inevitable that we will need to develop professional-patient partnerships, increase collaborative care and self-management education, empower people to think critically and make informed decisions in partnerships with healthcare professionals.”^{43(p18)} As we map out comparative effectiveness research in wound care, understanding patient preference is essential to the design and conduct of clinical trials

and translating new discovery into better health outcomes. Eliciting and translating patient preference into wound care is challenging. Authors in patient preference are pointing to a desired destination, but wound patients and wound clinicians will have to join hands to achieve this promising approach for progress in wound care.

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