Disease Burden and the Family Circle

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The burden of disease and illness has traditionally been assessed from the patient’s perspective. However, a growing body of literature supports that life partners and family members, as part of the circle of persons affected, are active participants in decision choices and care equations. The first Family Reported Outcome Measure (FROM – 16)© to assess the impact of disease on the partner or family member has been developed and validated at Cardiff University in the UK.¹ As their foundation, the authors present studies relating the impact of dermatological, oncological, and physical or mental illness or disability on patients’ family members, demonstrating how widespread and severe that effect can be. Childhood illness also is cited, noting in some disease areas quality of life can be affected more profoundly in patients’ family members than in the patients themselves.

The researchers contend a skewed degree of focus on the caregiving person and patient has overlooked how the disease affects family members who are not hands-on caregivers. Further, they believed many of the generic patient and population measures fail to be directly applicable in dermatology, where studies found a unique combination of quality-of-life issues related to life with a seriously ill family member. The researchers elected to focus on dermatology as a single disease category in their research, citing evidence that emotional impact was the most commonly affected area, with 98% of family members interviewed reporting emotional distress as a result of the patient’s illness. They created a generic instrument consisting of 30 questions that can be used to measure the impact of illness on the patient’s partner or family members and subsequently hypothesized that the score of the new measure they developed would have a moderate correlation with scores of patient measures, overlapping in the ways that illness impacts family members and patients. Applying factor analysis methodology, the measure was found to exhibit high reproducibility and strong construct validity for use in identifying where partners and family members need further emotional support for their distress. I bring this to your attention because you are the protectors of skin — the body’s largest and most visible organ — in your devotion to chronic wounds, continence, and ostomies.

It is noteworthy to add that this spring the Agency for Healthcare Research and Quality (AHRQ) released a lengthy report offering strategies identified in the literature that have been used by providers to engage patients and their families in their care. Interventions were segregated into hospital-level and individual-level strategies; the latter targets changes in individual knowledge, attitudes, or skills using tools for educating, informing, activating, and engaging individuals. Barriers to engagement include fear, uncertainty, low health literacy, and provider reactions.

Demographic characteristics can influence a patient’s and family members’ openness to engagement. Patients and family members who feel socially distant from their providers due to lower levels of education, language proficiency, or socioeconomic status may be less inclined to engage. One large mixed-methods study³ cited in the AHRQ report found that patients who spoke through an interpreter made significantly fewer comments during medical encounters than English-speaking patients. Race and ethnicity may be factors as well — non-English-speaking patients often bring young family members to clinic appointments to be their personal translators. This can be awkward when topics turn to subjects about intimacy, odor, or personal hygiene. Both Hispanics and African Americans have been found in quantitative research⁴ to be more likely than Caucasians to prefer leaving decisions about medical care to the physician, thus compromising engagement efforts. The National Association For Continence’s (NAFC) unpublished, qualitative research⁵ of Latinas diagnosed with pelvic floor dysfunction, conducted through focus groups in different parts of the country, reached similar conclusions from its findings. Such impediments to consumer engagement among both patients and family members can be overcome by fostering self-efficacy and providing information, invitations to engage, and provider support, according to the AHRQ report.²

The interventions that most impact the potential for engagement of patients and family members with providers generally involve communications. But tools that provide broad guidance to patients and family members about how to engage in successful interactions or encounters with...
their providers are lacking, especially regarding how to engage in difficult conversations or how to initiate awkward topics with providers.\textsuperscript{6,7}

Communication behaviors of physicians with patients and even family members tend to focus largely on correcting low health literacy rather than encouraging them as equal partners in care. In addition to professional norms and traditional paternalism, perceived level of effort and time are viewed as barriers to engagement of physicians with their patients in shared decision making.\textsuperscript{8} Research\textsuperscript{9} offers effective communication techniques, such as speaking simply, directly, and slowly using plain English; providing specific information and only a few pieces of new information at a time; using repetition; and employing active listening. Allowing patients to tell their own story without interruption invites them to contribute to the interaction.\textsuperscript{10} Physicians who nonverbally affirm the patient by showing empathy and reading a patient’s nonverbal behavior tend to have more satisfied patients.\textsuperscript{11} Such techniques can create an atmosphere where patients and their families are more comfortable with dialogue, more trusting to ask questions, and thus more likely to have an open and equitable exchange of viewpoints, concerns, and decision criteria. Nurses can play an essential role in facilitating this dialogue and in assuming responsibility for ease of conversation, especially when discussing nonsurgical interventions that do not necessarily require physician input.

With each and every encounter, I encourage you to think about the potential barriers to communication between patients and family members and their provider and how you might remove the obstacles to understanding, trust, information-exchange, knowledge acquisition, and ultimately shared decision-making. The end goal is to optimize satisfaction among patients, partners, and family members to facilitate the free exchange of information necessary to make good decisions and achieve satisfying outcomes.

References


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