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Exploring Patient-Provider Relationships in Preference-Based Health Care Choices

Linda Tuncay Zayer

Loyola University Chicago, ltuncay@luc.edu

Cele C. Otnes

University of Illinois at Urbana-Champaign

Eileen M. Fischer

York University

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can NICU servicescapes mitigate the impact of the medicalization of the infant to foster better healthcare decision making in the NICU and beyond?

Our data show that in the United States NICU where the medical technology is front-and-center, parents “medicalize” themselves to learn the machines, the medical language, and use the “medical gaze” to interact with their medicalized baby and medical staff (Foucault 2012/1973; 1977). The nurses and doctors often look not to the baby, but to the machines to see how the baby is doing and to make decisions. The parents follow suit. The medicalization process for parents includes assessing their child through the technological assemblage of monitors, alarms, electrodes, IV pump status, and ventilator settings, to name just a few. Upon release from the hospital, in fact, parents feel scared by the lack of equipment and objective ways to assess their baby. Although they can be heavily involved with medical decisions once they can “talk the talk” to be “part of the team,” parents have little to no say of when their baby is released, and often end their NICU stay with an ironic trepidation over the lack of technological entanglement.

In contrast, in the Finnish NICU, parents are taught to talk to their babies and not look to the monitors. They can hold their babies for skin-to-skin contact 24-7 if desired, and sleep in the room if there are available beds. Parents are also given an extended period of time to “room in” with their baby in bedrooms at the hospital—without any monitors—before they go home. They actively participate in decision making by telling staff when they feel comfortable going home. They stay on, rooming with their baby without monitors, in the unit, until they do. There is less of a sense of medicalization of parents and baby, and less angst upon discharge.

In contrast to Western NICUs, in India there is minimal focus on medical equipment and bedsides and unobtrusive monitors, which in many cases may be minimal or nonexistent. However, the parents cannot enter the NICU (which may not even be called a NICU) due to the hospital’s fear of sepsis (infection). The babies are brought out from inside the NICU to visit the extended family when staff feels the babies are stable enough, generally with minimal technological equipment at that point. The doctors and nurses become surrogate parents, staying highly engaged with the baby physically, preferring to interact with the child directly rather than interact with the technology, providing ritual massage, and holding or carrying the baby when it is fussy. Decisions involving referral and discharge are highly fluid, depending on available NICU capacity, the seriousness of the condition and the financial status of the family.

We find that parents in the US NICU make decisions more confidently when they achieve a Foucauldian medicalized state and could discuss their baby’s care with staff using formal medical terminology. Parents in the Finnish NICU made decisions more confidently when they were de-medicalized and taught to look to their babies as a baby, not a patient. Indian parents are never medicalized and have no part in medical decisions, with the occasional exception of termination of care when patients run out of funds.

In conclusion, our initial sample findings of three NICUs in the US, Finland and India reveal that parental decision making can be enhanced in a high-tech environment by assuring parents learn the medical terminology and procedures. However, whether it is beneficial to have parents act as medical staff and see their newborn with Foucault’s medical gaze remains to be seen. It also appears that parental decision making can be enhanced by toning down the technological equipment presence and teaching family how to parent a neonatal patient as they would a non-hospitalized baby. Further work is needed to study decision making in more stratified hospitals in each country.

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EXTENDED ABSTRACT

Many health care related decisions can be complex because they are not always driven by evidence-based prescriptions from a health care provider, such as a physician, but are preference-based, where the patient often has a range of treatments to choose from. In such instances, the relationship between the physician and patient is even more consequential. Scholarship outside of consumer research has detailed different models of patient-health care provider relationships (e.g., Emanuel and Emanuel 1992; Ballard-Reisch 1990), differentiated patient roles in medical decision-making (Orfali 2004; Thomson et al. 2013), and measured patient autonomy in health care (Stiggelbout et al. 2004), among many other important aspects. For example, Emanuel and Emanuel (1992) identify four different models of patient-physician relationships. The paternalistic model advocates the primacy of the physician irrespective of the patient’s preferences while an informative model advocates for the physician to simply present factual information. In an interpretive model, information is presented but care is provided based on eliciting the patient’s values. Lastly, in a deliberative model, which the authors identify as “ideal,” the physician provides information, assesses patient’s values, and persuades the patient through dialogue on the best-perceived course of care. In contrast, Ballard-Reisch (1992) advocates for a model of participative decision making with four relational types with regard to the physician—patient abdication, collaboration, patient autonomy, and relationship termination. While this research from medicine and health communications is useful in shedding light on the different types of patient-physician relationships, they do not capture the full range of relationships that patients may have with providers, nor do they consider the role of the market. Moreover, in the last two decades, discourses regarding medicine, health care, and the role of the “consumer” in society have shifted. Factors such as vast online informational resources as well as online support groups serve to fundamentally change the way patients approach their health care.

Thus, in this research, we ask, what is the patient-provider relationship dynamic as consumers engage in difficult, preference-based choices with regard to their health care? We explore these questions within the context of individuals seeking infertility treatment, a context that often involves extended, emotionally laden, high-risk interactions (Boshoff 2002) that are both costly and often times physically taxing. According to the Centers for Disease Control, infertility is defined as the inability to conceive a baby within one year of trying (www.cdc.gov/ART). Average cost of treatments can start at thousands of dollars (Marchione 2012) and often require multiple tries, entailing a range of treatments that can be pursued by individuals and couples seeking to have a child.

In-depth, semi-structured personal interviews using grand tour questions (McCracken 1988) with 26 informants were conducted, which allowed us to acquire patients’ narratives of their experiences with health care providers. Interviews with 26 individuals (mostly women) generated over 450 pages of text. While seeking patterns in the data we reflexively read the relevant literature (i.e. dialectical tacking; Strauss and Corbin 1998). Using data from informants engaged with various types of infertility services, the researchers identified how consumers engage with health care providers as they make difficult choices in their health care.

Findings outline the saliency of many of the models of patient-provider relationships identified in past research (e.g., Emanuel and Emanuel 1992; Ballard-Reisch 1990). In addition, these decisions

are not made in isolation; thus, the research reveals other influencers on the choices consumers make in this context, as well as the tools that aid in making preference-based medical decisions. In addition to interactions with the physicians and key other health providers, close loved ones, information resources, as well as a belief in higher powers, such as God, were critical during the decision-making and coping processes.

However, what this research contributes is that a new type of patient-provider relationship is identified, not previously captured by these past studies. While past research has discussed patient-provider relations whereby the patient acts autonomously, "shopping" for doctors or treatments (Ballard-Reisch 1990) or engages in co creation of value (McCull-Kennedy et al. 2012), we illustrate how some consumers go even further to regard the health care provider as rather inconsequential, or what we label as the Peripheral Model. These patients' relationships with their providers are unique across four distinct dimensions that Emanuel and Emanuel (1992) identify as critical in understanding patient-physician relationships: 1. goals of the patient-physician interaction; 2. physician's obligations; 3. role of the patient's values; and 4. patient autonomy. Some consumers engage in entrepreneurial activities to diagnose, treat and even create consumer choices and marketplace options that did not previously exist for them. That is, if consumers do not attain what they seek from the physician in terms of what they perceive are the best chances for a successful outcome, they seek out other opportunities. The physician's role and obligation are minimized, the patient's agenda takes precedence and they autonomously seek out and/or create alternative options in the marketplace. Another manifestation of the provider in the Peripheral Model is when patients perceive that the physician played a largely limited role in their decision making process. One informant characterizes the role of the physician as, "just there to do the tests and leave." While in these cases, the patient may have hoped for more interaction, they perceive the physician as fulfilling the minimum obligation with little discussion of values, and thus, the patient relies on others (e.g. nurses) for support.

In sum, while patient-provider relationships are key in health care services, particularly in preference-based decisions, traditional models of patient-physician relationships previously identified in research do not always capture the full range of consumers' experiences. Thus, by identifying the Peripheral Model, the current research holds theoretical implications as it examines the saliency of typologies of patient-provider relationships from medicine and health communications while identifying a new model of relationship. Further, understanding the ways in which patients behave outside the traditional models of patient-physician relationships can help to illuminate ways to enhance the patient experience and well being in these contexts.

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