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## **Empowering Patients As Decision-Makers in the Context of Early Stage Prostate Cancer**

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Patients with early stage prostate cancer must choose between multiple treatment options. Past attempts to empower patients as consumers in this medical context have been relatively unsuccessful. In two field studies, we design and test the effect of two unique interventions (informed by behavioral decision theory) on patient empowerment.

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# A 360° View of Patients' Experiences as Medical Consumers

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## **Paper #1: Coping with Fear and Regret in Online Health Communities**

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## **Paper #2: Empowering Patients as Decision-Makers in the Context of Early Stage Prostate Cancer**

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## **Paper #3: The Neonatal Intensive Care Unit as an Assembled Servicescape: How do Technological Actors Affect Parent/Staff Decision-Making?**

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## **Paper #4: Exploring Patient-Provider Relationships in Preference-Based Health Care Choices**

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### **SESSION OVERVIEW**

The rapid consumerization of healthcare calls for detailed exploration of patients' experiences as medical consumers. The papers in this session use multiple methodologies across a range of medical domains to explore the following questions: "How do patients navigate preference-sensitive decisions as medical consumers?" and "How do patients seek decision support during this process?" We define preference-sensitive decisions as contexts in which more than one treatment is medically justified and patients' personal preferences are important (Wennberg 2004). We examine patients' experiences throughout the consumption process, from outside the formal healthcare system (online medical communities and patient education materials) to clinical appointments communication to interactions with the overall medical servicescape. Our findings span over multiple cultures and systems including U.S. private healthcare, U.S. Veterans' Affairs, India, and Finland.

Barakshina, Spanjol, and Malter examine how pregnant women use online health communities to cope with negative emotions, to seek and receive decision support, and cope with negative emotions. Using qualitative analysis of 600 threads on a popular online medical community (Babycenter.com), they find that consumers' behavior is often driven by previously-experienced regret or fear related to a particular alternative. Patients use several coping mechanisms, including repressive coping, derogation of others (including healthcare providers), and transfer of decision responsibilities to others to cope during a high-stakes decision process.

Scherr, Ubel, and Luce examine the effectiveness of two interventions designed to empower patients with early stage prostate cancer. Using a mixed methods approach, they find that increasing

declarative ("what") knowledge about prostate cancer was not enough to increase patient participation in the decision-making process. Rather, they propose that patients may also require procedural ("how") knowledge regarding communication strategies to participate in clinical appointments and become truly empowered consumers.

DuFault et al. compare how parents with children in the Neonatal Intensive Care Unit (NICU) interact with the neonatal servicescape in the US, Finland, and India. Using an ethnographic approach, they find that the degree of technology in the servicescape (high vs. low) impacts how parents "medicalize" their infants, and describe the impact of this medicalization on parents' interactions with their infants and the medical system.

Finally, Zayer, Otnes, and Fischer examine the patient-physician relationship in the context of infertility treatment. They conduct in-depth, semi-structured personal interviews using grand tour questions with 26 informants (patients and their significant others), and propose a previously unidentified type of patient-physician relationship, the "Peripheral Model," in which the physician's role is perceived as rather inconsequential.

In sum, this session features multiple methodologies and collaboration between consumer and medical scholars to examine patients' experiences as medical consumers. This research demonstrates the potential for marketing researchers to provide unique insights, highlighting the need for continued collaboration between marketing and medical professionals.

## **Coping with Fear and Regret in Online Health Communities**

### **EXTENDED ABSTRACT**

According to National Vital Statistics reports, between 3.5 and 3.9 million women give birth in the U.S. annually, and approximately 500,000 of them face a decision to choose between having a Repeat Cesarean (RCS) or Trial of Labor after Cesarean (TOLAC) delivery. Each option offers benefits, but also poses risks to mother and baby. The scope of risks varies greatly: long-term complications, uterine rupture, infections, and maternal and fetal death. Yet, existing medical evidence does not favor one alternative over another (Cox 2014; Capogna 2015), which classifies the choice between RCS and TOLAC as a preference-based decision. In preference-based decisions more than one treatment option is medically justified (Wennberg 2004).

Ideally, physician and patient work as a team to arrive at an optimal solution for the patient. However, patients facing such difficult choices consider many factors that have little or no apparent relevance to clinical practice, such as living conditions, spousal work arrangements, religious beliefs, etc. As a result, medical consumers often seek external support from family, peers and other patients (Pescosolido 1992) who can help navigate the decision process. In this paper, we examine the effect of peer advice, received through on-line health communities, on consumer decision processes and post-decision outcomes for preference-based decisions. Emotional outcomes of decisions often depend on how well patients manage to cope with negative emotions during the decision stage (Luce 2005). On-line communities are studied here as a source of advice to supplement professional medical advice. In effect, we view online com-

munity peers as “non-medical experts” whose expertise comes from having gone through similar experiences.

According to Keeling, Khan, and Newholm (2013), it is not only information exchange that patients look for in online communities, but rather a complex “knowledge negotiation” process, which includes sense-making, information seeking and sharing, and emotional support seeking and provision. Given the importance such communities might hold for consumers facing difficult medical decisions, we focus on understanding how medical consumers (pregnant women) seek and utilize online peer advice. We examine the following questions: Do medical consumers seeking advice and decision support from online peers look for complete information about available options and related experiences, do they engage in confirmation bias (seeking out confirmation for existing preferences), or both? Are medical consumers driven by fear or anticipated regret, and are they turning to online community peers to cope with these feelings? Finally, in view of decision making as coping (Luce, 2005), which strategies for coping with difficult decisions drive consumers to participate in on-line health communities?

### Methodology

We chose Babycenter.com (with about 4.6 million unique monthly visitors) as our data source. Consumers use this platform to create communities, or groups, on a variety of subjects, including getting pregnant (currently 2,220 groups), pregnancy (4,876 groups), and baby (4,370 groups). Each group includes a title, brief description and a message from the group owner. Groups are either subject-specific (e.g., breastfeeding support) or associated with a child’s birthday or due date (e.g., December 2015 Birth Club).

We employ content analysis of community posts (Spiggle 1994; Neuendorf 2002), focusing on two specific preference-based delivery decisions: (1) RCS versus TOLAC, and (2) delivering with or without epidural pain relief. These decisions were selected as representing different levels of associated medical risks and controversial patient views (Cox 2014; Parajian 2016), hence posing different decision difficulty to the patients. Within a 30-day window, we identified 1,400 threads directly relevant to the two decisions. A stratified random sample of 600 threads was drawn from the posts to form the dataset for analysis.

Using existing research (Zeelenberg and Pieters 2007; Koole 2009) combined with close reading of the excerpts, we identified categories related to our research questions. We coded for the following categories: indication of existing preference, change in preference due to community advice, emotions experienced during the decision-making process (fear, anxiety, regret), and coping strategies used to deal with negative emotions (decision justification, responsibility transfer, avoiding feedback about the forgone alternatives, etc.). A difference in proportions test was used to test for differences in dependent variables (procedure choice, emotions, types of support sought) across two independent variables: level of risk associated with the procedure and prevalence of the procedure in medical practice.

### Results

Preliminary results indicate that patients often start a community thread with a planned course of action or a preference towards one option. In many cases, they are looking for both informational and emotional support, to confirm that they’ve chosen the right path. At times, participants draw on community emotional resources to understand and potentially disagree with a course of action set by a physician. Specifically, we find that consumers who prefer a non-prevalent childbirth choice are more likely to turn to online commu-

nities to seek information and support on how to deal with the formal health care system (medical doctors, hospitals, etc.), compared to consumers who prefer a more prevalent procedure. Thus, consumers tend to post in online health communities in order to gain support for already formed preferences, rather than to initiate a search for information with no clear a priori inclination.

In parallel to the above analysis, we scanned discussion threads to extract longitudinal data, defined as a sequence of multiple posts by a single participant, often over several years. This approach allowed us to track an individual’s decision journey from initial considerations, through consideration of decision alternatives, to the decision outcome and beyond (when moms evaluate their decision or offer advice to others). This approach provides an in-depth understanding of how engagement with online communities evolves over time.

### Conclusion

Our research contributes to understanding of patient participation in online health communities. We aim to demonstrate which coping strategies, realized through online community participation, help medical consumers feel better prepared and more confident to take an active role in making difficult choices about their healthcare.

### Empowering Patients as Decision-Makers in the Context of Early Stage Prostate Cancer

#### EXTENDED ABSTRACT

Sometimes, the right treatment choice depends on both medical factors and patients’ preferences, such as risk aversion and tolerance of ambiguity (Muller-Engelmann et al. 2011). For example, patients with early stage prostate cancer (the context of this study) must choose whether to receive active treatment or active surveillance, each of which is associated with unique risks and benefits. Active treatment can cause erectile dysfunction and may not be good for patients with a high interest in sex, whereas surveillance requires living with untreated cancer and may not be good for patients with high cancer anxiety (Thompson et al. 2007). In these settings, consumer behavior theory can help us better understand how patients evaluate their alternatives, interact with physicians, and choose treatments. Ideally, patients and their physicians work together to determine which treatment alternative best fits patients’ preferences (Karni 2009). In this way, patients become empowered medical consumers.

Unfortunately, baseline rates of patient empowerment are relatively low (e.g., Barry and Engman-Levitan 2012). This is partly due to information asymmetry between patients and physicians, such that patients do not feel qualified to participate during appointments (Gafni, Charles, and Whelan 1998). Decision aids (DAs), often in the form of information pamphlets, can educate patients and decrease this asymmetry. Unfortunately, within the context of prostate cancer, DAs fail to consistently improve key outcome variables, such as knowledge and decision confidence (Violette et al. 2015).

In this research, we use consumer behavior theory on information processing, learning, and types of knowledge to develop and test the effectiveness of two unique interventions that aim to empower patients as medical consumers.

#### Study 1

We conducted a randomized controlled trial to examine the effect of increasing declarative knowledge via an empowering (vs. standard) DA on patient participation in the decision making process. Both DAs provided similar clinical information but differed in three key ways. The empowering DA was written at a lower reading

level; utilized research on choice architecture and framing to better present information; and contained balanced patient testimonials about their decision making experience. In these ways, we followed the guidelines of “ethically responsible choice architecture” (Blumenthal-Barby, Lee, and Volk 2015). We predicted that patients who received the empowering DA would have higher knowledge and increased desire to participate in the decision making process. As a result, physicians' recommendations would be more influenced by patients' values (i.e., prostate cancer related anxiety and interest in sex) in addition to medical factors (i.e., age and cancer severity). We also predicted that the empowering DA would increase the frequency with which patients and physicians discussed sex, information that should inform patients' decisions in this setting.

We recruited patients from four Veterans Affairs Medical Centers and randomly assigned them to an empowering or standard DA condition. Patients ( $n = 285$ ) completed surveys prior to the appointments in which they learned their diagnoses but after reading their DAs. Clinical appointments were recorded, transcribed, and coded for physicians' recommendations and discussions of sex using deductive content analysis. Treatment choice and medical factors were assessed via chart review. As expected, the empowering DA increased patients' knowledge ( $F(1, 248) = 5.41, p = .021$ ) and desire to participate in the decision making process ( $F(1, 247) = 5.91, p = .016$ ). However, logistic regression revealed that, regardless of condition, physicians' recommendations were heavily influenced by medical factors and not patients' values. In addition, regardless of condition, physicians rarely discussed sex-related topics (13% of appointments).

Our results suggest that increasing patients' knowledge and their desire to participate in decision making via an empowering (vs. standard) DA may not be sufficient to transform patients into truly empowered consumers. In Study 2, we drill down further into the decision process by considering whether adding procedural knowledge (*how* to participate in the decision process) to declarative knowledge (*what* the decision process entails) would more fully empower patients (Brucks 1986).

## Study 2

We conducted another randomized controlled trial to examine the effect of increasing both procedural and declarative knowledge (empowering DA plus DVD) versus declarative knowledge alone (empowering DA only) on patient participation in the decision-making process. The DVD was designed to teach patients specific communication skills to interact with their physicians during clinical appointments. We predicted that increasing procedural knowledge would increase patients' ability to actively participate during clinical appointments, and, ultimately, increase the likelihood that their treatment choices reflected their personal preferences.

We recruited participants from one academic medical center and randomized them to the procedural plus declarative knowledge or the declarative knowledge only condition. Patients diagnosed with early stage prostate cancer ( $n = 208$ ) completed surveys prior to the appointments in which they learned their diagnoses but after reading/watching the DA/DVD. Clinical appointments were recorded and transcribed. Treatment choice and medical factors were assessed via chart review. As predicted, patients in the procedural plus declarative knowledge condition expressed higher confidence that they would participate in their upcoming appointment ( $F(1, 190) = 7.61, p = .006$ ). Also as expected, actual knowledge did not differ between conditions ( $F(1, 192) = .44, p = .51$ ), consistent with our conceptualization that the DVD intervention increased implemental (not declarative) knowledge.

We are now conducting qualitative analyses of the recorded clinical appointments to determine if patients in the procedural plus declarative knowledge condition actually had higher participation (e.g., information seeking) during the appointments. Through an iterative process, we have refined the coding system, established reliability and are currently coding the transcripts. We then plan on using a similar approach to Study 1 to examine the impact of the intervention on the likelihood that patients' treatment choices incorporated their preferences, and, if so, will test whether this was mediated by increased participation during clinical appointments.

## Conclusion

We designed and tested two interventions (inspired by consumer behavior research) that aimed to transform patients into empowered consumers. We thus bridge the gap between consumer behavior theory and medical practice, providing important insights into how we might empower patients in the context of preference-sensitive medical decisions.

### The Neonatal Intensive Care Unit as an Assembled Servicescape: How do Technological Actors Affect Parent/Staff Decision-Making?

#### EXTENDED ABSTRACT

This study compares neonatal intensive care units (NICU) in three countries to analyze how variations in the presentation of medical technology in the servicescape impact parent/medical staff decision making. We conduct observations of NICUs in the U.S., Finland and India, interviews, in situ conversations, attendance at medical conferences, participation in an international multi-disciplinary NICU research group, and ethnography in process.

NICU and pediatric ICUs have been used as a context in the marketing and consumer behavior literature on difficult decision making at end-of-life (Botti, Orfali, & Iyengar 2009; Orfali and Gordon 2004; Luce, Bettman and Payne 2001). However, the vast majority of babies admitted to the NICU are discharged home to their families (Flacking et al. 2012; March of Dimes 2011). These parental medical consumers have received scant interest from marketing scholars. This is a surprising omission, given that >10% of births result in special care nursery stays in the US and Western Europe (Axelin et al. 2015; March of Dimes 2011). Studies have not explored from a marketing, consumer behavior, or managerial vantage, how these parents become proactively engaged decision makers around the materiality and design of the NICU technology before bringing their babies home.

The NICU staff faces the challenge of providing excellent care without compromising parent-child bonding during extreme care and stress-filled circumstances. All actors in the NICU—human and non-human—are interrelated and fluidly co-produce the servicescape (Bennett 2010; DeLanda 2006; Deleuze and Guattari 1987; Latour 2005; Sassen 2006, Joiner and Lusch 2016). Although medical professionals work in systems coproducing health and healing with their patients, their patients' families, and a number of support circles (Arnould 2007; Joiner and Lusch 2016), and despite the “family-centered care” movement gaining ground since the 1990's (Levin and Chalmers 2014; Chalmers 2002, WHO 2015), many parents in NICUs still feel a loss of personal control and limited understanding of what is occurring. Technology and advanced medical equipment looms large and often feels “scary” and “confusing.”

Our research question is: How do highly technical and stress infused servicescapes impact NICU parents' ability to be active decision-makers with the medical team? And more specifically: How

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.

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

### 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](http://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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