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SCREEN DOOR MEDICINE: THE INFORMAL MEDICAL CONSULTATION

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ABSTRACT OF DISSERTATION

Debra Faith Nickell

The Graduate School
University of Kentucky
2010

SCREEN DOOR MEDICINE:
THE INFORMAL MEDICAL CONSULTATION

ABSTRACT OF DISSERTATION

A dissertation submitted in partial fulfillment of the
Requirements for the degree of Doctor of Philosophy in the
College of Communications and Information Studies
at the University of Kentucky

By
Debra Faith Nickell

Lexington, Kentucky

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Professor of Communications and Information Studies
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Lexington, Kentucky

2010

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ABSTRACT OF DISSERTATION

SCREEN DOOR MEDICINE: THE INFORMAL MEDICAL CONSULTATION

This study explores the phenomenon of the informal medical consultation, a communication event in which an individual asks for medical information, advice, or care from an off-duty health professional with whom the individual has no formal patient-provider relationship. Using surveys and interviews, the study describes these consultations from the perspective of the health care professional and the informal patient. The study explores foundational theories that offer explanations for the phenomenon. The theories considered include social support, decision-making, social exchange, perceived partner responsiveness to needs, and uncertainty management.

This study suggests health care providers perceive informal medical consultations to be more problematic than do the informal patients who consult them. The problematic nature of informal consultations increases as the type of request moves from purely informational to a request for treatment. Informal patients do not perceive this distinction. The informal patient's motivation to pursue an informal consultation instead of a formal consult is affected by the relationship with, trust in, and access to the informal consultant. The willingness of the informal consultant to engage in an informal consultation is affected by the relationship with the informal patient, the type of request made, and perception of risk/benefit for both the provider and the patient.

The study supports the idea that informal medical consultations are potentially problematic within the current medico-legal-ethical environment. Alternately, these consultations may be viewed as offering positive contributions to the health and well-being of informal patients. The study suggests translational research is needed to guide health professionals in considering requests for informal medical consultations.

Keywords: Informal Medical Consultation, Health Communication, Social Support, Uncertainty, Medical Decision Making

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CHAPTER ONE: INTRODUCTION

After a year of collecting data I sat down to write the dissertation. I had taken a stay-vacation from work and was committed to putting to paper the first draft within the 50-60 hours I had carefully reserved. My office table was covered with stacks of pertinent texts, journal articles, interview transcripts, caffeine, protein bars, chocolate and all the other materials conducive to doctoral productivity. There was a “do not disturb” sign on my door, an “out of office” notice on my email account, and a suitably professional message on the office phone voicemail indicating I would not be returning calls. The only remaining contact with the outside world was my cell phone, which, in retrospect, perhaps should have been stowed with ringer off. As my fingers paused over the keyboard to begin the great task, the cell phone ringtone indicated a relative calling from several states away. As habit dictated and without thinking, I answered. Thus began the familiar phenomenon with familiar questions. When did the pain start? Where is it? Does it come and go? Have you taken anything for it? Does a change in position help? For the next five minutes the questions and answers continued. I gave my opinion and final advice about the appropriate next step and asked the relative to call me later to let me know her status. As I tried to shift my attention back to the writing and away from her symptoms and all the various benign or troublesome diagnoses they could represent, the irony of the timing of her call resulted in a brief smile. (Author, journal entry)

Definition of the Screen Door Consultation

The practice of informal medicine takes many different forms. The scenarios represent ubiquitous events in the lives of health care professionals as they routinely experience medically-related requests from friends, family, co-workers, and neighbors. These events may begin as early as when individuals are still in professional school.

Informal medicine covers a broad range of phenomena. The phrases “hallway consultations,” “off the cuff medicine,” or “curbside consultations” have been used to describe informal consultations *between* medical professionals on behalf of patients or themselves (Fox, Siegel, & Weinstein, 1996; Kuo, Gifford, & Stein, 1998; Magnussen, 1992; Peleg, Peleg, & Porath, 1999). These consultations generally take place in a formal medical setting, such as a hospital or medical clinic, although some do occur in informal settings (Keating, Zaslavsky, & Ayanian, 1998; Manian & Janssen, 1996; Perley, 2001, 2006). An informal consultation also describes the requests patients make of their formal health care provider in informal settings, such as social gatherings or unplanned meetings

outside the clinic setting (Johnson, 2007; Leavitt, Peleg, & Peleg, 2005). However, one aspect of informal medicine that has received little attention is the “screen door” informal medical consultation.

The screen door informal medical consultation differs from a *formal* consultation in that it occurs outside of the medical setting, typically in a social setting where the medical professional is off duty. It differs from other *informal* consultations because it occurs between a health care professional and a layperson with no formal patient-provider relationship. The metaphor of the screen door is used because the consultation is predicated on the presence of a personal relationship and the absence of a formal patient-provider relationship. A screen door is usually found on a house, not on a hospital or clinic building, and therefore is used to evoke the sense of informality, casualness, and personal relationship surrounding this type of consultation. The use of the phrase “screen door” seeks to clarify and distinguish this phenomenon from the types of informal consultations described above (e.g., curbside, off the cuff, or hallway).

Similarities exist between the screen door medical consultation and the other types of informal medical consultations. The screen door medical consultation may consist of a request for (a) medical information (or an explanation of medical information previously received through formal consultations); (b) advice or an opinion regarding an upcoming medical decision; or (c) medical care (including observation, examination, treatment or therapeutics). A screen door medical consultation may occur either before formal medical care is sought or after formal medical care has already been obtained.

For the purposes of this study, a screen door medical consultation is defined as a patient-initiated request for information, advice, or care made to an individual who is part of the patient’s social network, with whom no formal provider-patient relationship exists, and who has, by the nature of his/her profession, more medical knowledge than the patient.

The Problematic Informal Consultation

Informal medicine, in any form, has potential consequences for the health professional, the patient, and ultimately also for the health care system. Of all the types of informal consultations, the screen door medical consultation potentially is the most problematic. The primary issue is that the health care professional being informally

consulted operates within a highly regulated system, and the screen door consultation clearly falls outside what is deemed by multiple regulators (e.g., society, government, medical professional groups, medical ethics, and medical institutions) as the standard of care. In contrast, health professionals have the personal and professional expectation that they will use their special knowledge and skills to help people. Although there may be regulations, ethical standards and professional codes in place that discourage informal consultations, for most health care professionals there is no logical mental distinction that permits helping people within the formal system but forbids helping those outside of the formal system. Health care professionals operate within social networks in which helping someone is both desirable and expected. Violation of this expectancy could have negative personal consequences and, perhaps more importantly, significant negative relationship consequences. Therefore, it is not unreasonable to take the description of a “complex dyadic phenomenon” in which “partners must not only cope with a stressor but also cope with the relational strains created” as a result (Albrecht & Goldsmith, 2003, p. 272) and apply it to the screen door medical consultation.

The informal patient seeking a screen door medical consultation may be unaware of the problematic nature the consultation represents to the health care professional. An initial inquiry in this area supports this view (Nickell, 2006). Other than not wanting to trouble or inconvenience the health care professional while off duty, the informal patients in the 2006 study never considered that the request for information, advice, or care could present ethical, professional, legal, or relational risks to the health care professional. Therefore, the screen door medical consultation represents a ubiquitous, potentially problematic communication phenomenon about which little is known. Similar to formal patient-provider communication, it is a phenomenon with the potential to impact the health of a large portion of the population and subsequently worthy of further inquiry.

CHAPTER TWO: LITERATURE REVIEW

Although informal consultations have been reported anecdotally in the literature as early as the 1950s (Anderson, 1997) and are discussed openly and often by health care professionals, little research has investigated this communication phenomenon. Where informal consultations are mentioned, the description is usually that of a formal patient seeking a consultation in an informal setting, for example, a patient meeting her physician at a dinner party (Leavitt, Peleg, & Peleg, 2005; Weingarten, 1985). While informal settings for consultations between a formal patient and formal provider present their own challenges, the focus of this study is on the screen door informal medical consultation.

In the literature, few articles either directly or even tangentially address issues pertinent to screen door consultations. Johnson (2007) mentions the situation where relatives and friends approach providers for advice or care, but does so with the perspective of an attorney who is suggesting ways to avoid malpractice suits. Most articles on informal medical care reference the ubiquity of the phenomenon: health professionals providing advice, information, prescriptions, or other forms of medical care to individuals who are not their formal patients (Ares, 2008; Fromme, Farber, Babbott, Pickett, & Beasley, 2008; La Puma & Priest, 1992; La Puma & Stocking, 1991). These articles emphasize the dangers of engaging in informal medical care and focus on the risks to providers who informally treat friends or family members. La Puma (1991) reports that 99% of 465 physician respondents indicated they had been asked for medical advice or care by a relative. Of these, 57% reported they had at some point refused a relative's request for diagnosis or treatment, and most indicated some degree of discomfort with requests. The primary reason given for refusal or discomfort was inadequate medical information. However, Cornwell and Cornwell (2008) express an alternate positive perspective that "informal relationships with experts not only lower the costs of accessing expertise they may also render expert advice more effective. Experts consulted by individuals with whom they have an informal relationship have better access to personal information that is pertinent to their case and they may be able to more closely monitor the client or patient" (p. 857).

Fromme et al. (2008) present five cases, one of which involves the misdiagnosis of an ectopic pregnancy by the physician-husband. The other cases also present troublesome aspects of care by a family member; however, in one of the cases, going outside of the formal medical system probably saved a child's life. Overall, the authors describe a ubiquitous phenomenon but one that lacks the objectivity present in formal consultations and blurs the distinction between personal and professional roles. They do not say that physicians should never be involved in caring for family members; however, they support using the seven-question test proposed by La Puma and Priest (1992) to help the practitioner decide whether providing care for a family member is appropriate. Fromme et al. also suggest that an overriding question providers should ask before providing informal care is whether they could provide this care without a medical degree. The inference is that only care that any layperson could provide should be considered appropriate when caring for a family member. This leads to the question asked by a physician-participant in another study (Chen, Rhodes, & Green, 2001, p. 764): "You know, what good is all that training if you can't help your own family?" Interestingly, Fromme et al. present a chart of activities they consider to be low, medium or high risk when caring for a close friend or family member. They do not delineate what the specific risk is or if it applies to the physician or the family member.

In a single case study, Ares (2008) focuses on the legal and medical hazards of writing a prescription for a friend who is not a formal patient. The author, without any supporting citation, states that a legally binding provider-patient relationship is established when informal care is provided outside of the medical office. While many might take issue with the validity of the author's statement regarding a legally binding relationship, no one in health care doubts that an ethical duty of care exists even in informal medicine. Ares is correct in stating that "casually giving prescriptions to family, friends, and co-workers is a practice fraught with legal, ethical and medical difficulties" (p. 390). The two legal cases referenced in this article involved physicians who were sued by the relatives of deceased informal patients.

A further search of medicolegal cases reveals only one other case related to issues surrounding informal medical consultations. In *Poli v. Mountain States* (Quilter, 2006), the central legal issue was not the informal consultation; the case focused primarily on

the privacy of patient information and the potential violation of the Health Insurance Portability and Accountability Act of 1996 (HIPAA). A health care provider had informally consulted his physician-employer and subsequently called in a prescription for himself under the physician's name. However, the author suggests the health care provider probably would not have been dismissed from his employment if a medical chart had existed for him that contained an appropriate entry approving the prescription and the signature of the physician he had informally consulted. In other words, there would not have been an issue if a formal consultation had been conducted and documented.

Historical Context of the Informal Medical Consultation

In the last 30 years health communication has become a fertile area for research and promises to remain so for a long time to come. The health literature is replete with studies of patient-provider communication, patient decision-making, and models of health behavior. As this research area has blossomed, the health care system in the United States and the environment in which health care is provided have changed dramatically. However, to understand fully the origins of the screen door medical consultation, one must go back further than these recent changes in health care delivery in western society.

Folk-traditional medical care has been practiced for thousands of years (Kennedy, 2004). Typically this type of care was provided by a family member (e.g., mother, grandmother) who served as the reservoir of medical knowledge for the family group. Occasionally there was a need for a healer who had knowledge or skills beyond that of the family member (e.g., shaman, healer, witch doctor, granny). This individual was consulted when the family-held medical knowledge had been exhausted. This model of care is still practiced in developing countries and among those who cannot access the western model of medical care.

In the last century, the practice of medicine in western societies became regulated and controlled. Allopathic medicine became the dominant model for formal centers of medical training. Governments instigated laws limiting who could practice medicine. Practitioners who were not trained in recognized colleges of allopathic medicine and not licensed through government sanctioned licensing boards could be criminally prosecuted.

This limitation, regulation, and formalization of medical knowledge and practice created the formal medical system that is now familiar in western society (Pickstone, 2006).

Until the latter half of the twentieth century, the predominant provider of health care under the western model of medicine was the generalist or “family doctor” (Shorter, 2006). A person had a good chance of receiving care from this type of practitioner for a substantial part, if not all, of his/her life. American tradition carries familiar stories of the small town doctor who birthed, cared for, and ultimately buried his¹ patients. The family doctor was generally accessible to his patients because he probably went to the same drugstore, church or barber as they did. He never charged for advice and patients were faithful to repay his off duty counsel with an apple pie or invitation to Sunday dinner. He knew where every patient lived, how every patient lived, and shared most, if not all, of the community’s values. He probably knew his patients as well as he knew his own children. Rarely would anyone think of questioning his advice or his care because he was known to have his patients’ best interests at heart. Patients could confidently follow his instructions without requiring explanations of the cause or the cure for their problem. Patients left their health in his capable hands much like they left their car for the mechanic to fix. Or so the traditional view goes. The rise of this model of medical care represented the age of medical paternalism and it has since fallen out of favor.

In recent years, the number of traditional family doctors as described above has declined to almost zero (Shorter, 2006). The shift of the locus of care from home to clinic/hospital and the rise of the medico-surgical specialties have corresponded with a sharp increase in the number of medical specialists and exponential increases in medical technologies. There are now complexities such as third party billing, HMOs, PPOs, and prior authorization. The family doctor of today is far more likely to have been assigned to patients when their insurance plan changed than to have delivered them at birth. Add to this the societal shifts toward patient autonomy and consumerism, and the result is the patient-centered model of health care (Roter & McNellis, 2003).

¹ Gendered language is used intentionally in this section to emphasize the historical exclusion of females from the allopathic model of medical training. This exclusion no longer exists.

The patient-centered model has subsequently produced the concept of “shared decision-making,” which promotes the idea that the health care provider and the patient should exchange sufficient information in order to make a “good” decision (Brown, Stewart, & Ryan, 2003). “Doctors will increasingly become interpreters of information rather than decision makers,” which puts the responsibility on patients to inform themselves (Consumer Reports on Health, 2007, p. 1). However, communication as a critical medical skill has been overshadowed by technology and science. With the rise of the “molecular and chemistry-oriented sciences as the predominant 20th century medical paradigm” the centrality of communication to the patient care process has declined, resulting in the “directing of medical inquiry away from the person of the patient to the biochemistry and pathophysiology of the patient” (Roter & McNellis, 2003, p. 121). However, in the patient-centered model, the standard of care is good communication, shared decision making, and good documentation. A discrepancy between the standard of care and what patients actually experience may aid in understanding why patients seek informal consultations.

There is a long and consistent history of physician-physician informal consultations in which “in essence, the consulted physician provides a free service for the physician requesting a curbside consultation” (Perley, 2001, p. 3). So, why might the screen door informal consultation, between an informal patient and an informal medical provider, be viewed differently?

Patient Motivations for Screen Door Consultations

Under the allopathic model of medicine, standard of care dictates that patients should seek care within the formal medical setting. So, what would prompt a patient to go outside this formal setting to seek information, advice, or care? Logic would suggest that there must something missing in the formal medical encounter that is gained through the informal consultation. There is significant literature to suggest that patients often feel dissatisfied with formal medical consultations (Roter & McNellis, 2003; Watts, 2006). Sources of dissatisfaction reported in the literature focus on the quality, quantity, and content of communication with the provider (Brown et al., 2003). Rapport-building is essential to good provider-patient communication, which in turn depends on trust built on repeated interactions and consistent experiences (Norling, 2003). Perhaps the formal

medical encounter is lacking in these repeated interactions and consistent experiences; whereas, informal consultations may be based on years of personal relationship. Research by Forrest, Leiya, Von Schrader, and Ng (2002) suggests the gatekeeping strategies used by health care systems that limit access or continuity of relationship with a primary care provider have detrimental effects on patients' relationships with those providers and ultimately impact patient satisfaction.

Not only satisfaction is affected by patient-provider interactions. Research has shown that health outcomes are affected by positive aspects of patient-provider communication such as helping patients fully describe their experience, showing empathy and support, giving patients clear information, and sharing decision-making (Brown et al., 2003). Is it possible that the same positive outcomes are achieved in a screen door informal medical consultation?

In an essay on the ethics of informal medical consultations, Leavitt, Peleg, and Peleg (2005) identify time savings, money savings, and the desire to see a particular physician as potential reasons for patients to consult physicians outside of the formal clinic setting. Information seeking may also play a role. Cegala and Broz (2003) comment on research showing that patients do not ask physicians many questions during formal encounters. They suggest that patients may not be able to "formulate questions until they have had time to process what the physician has said or do not realize their lack of understanding until they try to follow the recommended treatment or explain their illness to someone" (p. 110). They add that cultural and personality factors might also affect patients' willingness to seek information from the physician. Their comments suggest that patients may seek additional or clarifying information in an informal setting after a formal consultation.

One other motivation, which is assumed to be a significant motivator in pursuit of an informal consultation, is the desire to avoid the costs of health care. Forrest, Leiya, Von Schrader, and Ng (2002) found that those who were uninsured had even worse access to primary care providers, less choice in choosing a primary care provider, and less continuity of the relationship with a primary care provider when compared with those who had insurance. Therefore these individuals might pursue informal consults more often than those with insurance. This is an assumption that remains to be

confirmed. It is reasonable to consider that with the cost of health care increasing, fewer individuals having access to health insurance, and the general economic recession playing so prominently in the public forum, patients would look for ways to lower their health care expenses. With these pressures in mind, Kent (2010) discussed the return of bartering as a popular and accepted method of paying for formal health care. Informal medical consultations may also use a form of informal bartering as a way for patients to avoid paying for services.

Provider Motivations for Screen Door Consultations

The literature suggests several reasons a patient may pursue an informal consultation, but why does a health professional agree to an informal medical consultation? The practice is certainly fraught with potential risks. Johnson (2007) points out the potential legal liability in engaging in informal medical consultations. The case previously mentioned, *Poli v. Mountain States* (Quilter, 2006), points to the absence of a formal medical record as a pivotal antecedent in the outcome; the plaintiff was placed on administrative leave and subsequently terminated from his position. Health care providers might assume that provision of informal care is covered under Good Samaritan laws. Most Good Samaritan laws include language stating the health care provider is liable only if willful or wanton misconduct can be proven. However, Good Samaritan laws typically result from emergency medical situations, and there have been no cases testing whether these laws apply to screen door medical consultations.

Beyond legal and professional liability, there also may be potential risks to personal relationships when health care professionals either agree to or decline a screen door medical consultation with friends, family members, or co-workers (Nickell, 2006). Given the potential risks, one must assume that the perceived benefits of engaging in screen door informal medical consultations must outweigh the perceived risks for both health care professionals and their informal patients.

Theoretical Foundations

Social Support Theory

As defined previously, a screen door medical consultation is a patient-initiated request for information, advice or care made to an individual who is part of the patient's social network. Albrecht and Goldsmith (2003) suggest that social support is a communication behavior within the context of health communication and should be viewed as an "umbrella term for providing a sense of reassurance, validation and acceptance, the sharing of needed resources and assistance, and connecting or integrating structurally within a web of ties in a supportive network" (p. 265). Comparing these two definitions, one can see how a screen door medical consultation could be viewed as a communication act of social support.

Social support is generally embraced as desirable and beneficial for the individual and for society. Although social support is universally practiced, it is not well understood. Researchers, health professionals and the general public "have strong beliefs concerning the ability of social support interventions to produce beneficial effects on well being. These beliefs are founded on a modest empirical foundation and may persist because they embody values that many wish to foster" (Albrecht & Goldsmith, 2003, p. 274). Although many models exist for categorizing social support, one that is parsimonious and useful is presented by Langford, Bowshear, Maloney, and Lillis (1997). These authors divide social support into four types: emotional support, instrumental support, informational support, and appraisal support. Emotional support is provided through communication and informs recipients that they are loved, are valued, and belong. Instrumental support provides tangible goods or services. Informational support provides information that the recipient needs for problem solving during stress. Appraisal support is the communication of information that is relevant to self evaluation; it communicates the appropriateness of the acts, statements or feelings of the recipient.

If information is viewed as a tangible resource, one could easily make the argument that informational support is actually a form of instrumental support. Similarly, appraisal support can be viewed as a form of emotional support, since it attempts to modify the emotional state of the recipient. This would leave an even more parsimonious typology in which social support is categorized as instrumental or emotional (without

precluding the possibility that any supportive act may be both). In referring to Albrecht and Goldsmith's (2003) "umbrella" definition of social support, reassurance, validation and acceptance fall into the emotional support category, while the sharing of needed resources and assistance falls into the instrumental support category. What remains of their definition, "connecting or integrating structurally within a web of ties in a supportive network," is addressed by Langford et al. (1997) as antecedents of social support, not social support itself. These antecedents (social networks, social embeddedness and social climate) are the infrastructure necessary for social support to occur.

In summary, social support may be viewed as the communication of desirable, emotion-positive messages (e.g., caring, respect, empathy, love, belonging, validation, reassurance) and the sharing of resources (e.g., information, tangible goods, services) that are helpful to the individual in situations of anxiety or stress. Functioning social networks are necessary antecedents to acts of social support. Albrecht and Goldsmith (2003) further summarize social support as a fundamental communication behavior and a "process embedded in structures of ordinary relationships in social life" (p. 263), including those surrounding health and wellness.

Social support has been studied in a variety of health contexts that include a diverse collection of diseases and disorders (Abboud & Liamputtong, 2005; Albrecht & Goldsmith, 2003; Arntson & Doge, 1987; Arrington, 2010; Brashers, Neidig, & Goldsmith, 2004; Cawyer & Smith-Dupre, 1995; Drummond, 2005; Ford, Babrow, & Stohl, 1996; Mishel, Belyea et al., 2002; Hines, 2001; Hines, Babrow, Badzek, and Moss, 2001; Kelly, Soderlund, Albert & McGarrahan, 1999; McKinely, 2009; Robinson & Turner, 2003; Uchino, 2004). Although informal support is represented in the literature, research has focused primarily on formal support and social support interventions.

There is nearly universal consensus that social support can have a positive influence on health (Faulkner & Davies, 2005; Jones & Wirtz, 2006). However, the research data have not conclusively or consistently supported that claim. "The extent to which supportive behavior contributes to the reduction of mortality and morbidity and improves the quality of life for patients, families, and communities remains relatively unknown, unexplored and underfunded" (Albrecht & Goldsmith, 2003, p. 266).

However, Uchino (2004) states broadly that social support appears to be a robust predictor of all-cause mortality. Uchino proposes that health outcomes are affected by social support in two ways: stress related mechanisms or direct effects mechanisms. Stress related models of social support suggest that social support improves health outcomes by either buffering the effects of stress or preventing stress through decreased exposure to stressful events. Direct effects models suggest that social support impacts health outcomes either through social control that promotes healthier behaviors or through social capital that addresses community level attitudes and access to services.

Arnston and Droge (1987) suggest that the formal patient-provider communication encounter represents a dialectical environment that is intense and does not lend itself to providing emotional support. From the provider viewpoint, it is a highly scripted, repetitious, and time limited encounter. For the patient, the encounter is laced with power differentials that do not favor emotionally supportive communication. Instrumental support, the bedrock of the patient-provider encounter, is not always patient-centered. The language of the encounter is often characterized by patients as hierarchical and stigmatizing, which is antithetical to the goals of emotional support: acceptance, value, respect, and love (Arnston & Droge, 1987).

Uchino (2004) looks at social support interventions and divides the interventions into three types: support from professionals (e.g., health care providers), support from peers (e.g., those with the same diagnosis), and support from social network members (primarily friends and family). Support from professionals is viewed as primarily informational with two significant limitations. First, individuals cannot access professional support as easily as they can access peers or network members. Second, professionals will probably not be able to provide emotional support. Uchino notes, however, that peers and network members may not be able to provide the same quality of informational support as a professional. Albrecht and Goldsmith (2003) observe that informational support in the form of advice is often discouraged as part of formal support interventions, yet within social networks advice giving is a common form of social support and is often sought by the recipient. These observations imply that an individual has support needs (in the health care context) that can only be met by a combination of professionals, peers, and social network members. Therefore, it would follow that a

health care professional who is also a peer or member of the individual's social network has the potential to provide both instrumental support (most notably, high quality information and advice) and emotional support. A recent study (McKinley, 2009) concludes that informational social support from "important others" may be a significant factor in influencing certain positive health behaviors.

Medical knowledge, advice on issues of health and well being, and most forms of care and treatment have been exchanged between socially connected individuals for thousands of years (Kennedy, 2004). It is only since the rise of allopathic medicine as the dominant model of health care (and the subsequent governmental regulation of medicine) that folk-traditional methods and networks of care (now referred to as alternative or complementary medicine) have fallen into decline, or at least disfavor, in western society. Further limitations on access to those who are the holders of medical knowledge and treatments (provider shortages, insurance limitations on payment of services, decreased access to providers) may result in increased information seeking, advice seeking, and care seeking outside the formal system. The availability of medical information through the Internet may have depressurized the need for instrumental (informational) social support in one capacity but may have increased it in other ways; individuals do not always understand the information they have accessed via the Internet or know if they can trust it.

In this environment (increased regulation and decreased access), the screen door informal medical consultation may be viewed as a return to (if indeed we ever completely left) the traditional model of care in which mother, grandmother, or local village healer provided trusted information, emotional support, and medical treatment. The price of such advice and care was either free (part of being a good neighbor) or was negotiated between the individuals.

Clearly the screen door medical consultation, as a pervasive communication phenomenon of significant relevance in the health care context, deserves research attention. Framing the research within the social support perspective is appropriate, especially considering that formal medical interactions have been studied within this same framework. The social support framework allows for investigation of the dyadic and close interpersonal nature of the consultation while situating it within the overarching

influences of societal norms, the formal health care system, and health care regulation and policy. However, social support does not entirely account for all the attributes of screen door medical consultations. There are additional theoretical underpinnings of the phenomenon that provide further explanation.

Uncertainty Theories

The theories of uncertainty management include uncertainty reduction (Berger & Calabrese, 1975; Gudykunst, 1983), uncertainty management (Babrow & Kline, 2000), anxiety reduction (Brashers, 2001; Hurley, Miller, Costalas, Gillespie, & Daly, 2001), and problematic integration theory (Babrow, 1992; Bradac, 2001). These theories propose that uncertainty, non-optimal levels of uncertainty, or anxiety about uncertainty prompt individuals to engage in certain behaviors. Within the health care context, information seeking is one such behavior that is intended to modify uncertainty (Babrow, Kasch, & Ford, 1998). The screen door consultation may be seen as an effort by the informal patient to reduce uncertainty or to bring uncertainty and/or anxiety about uncertainty to more optimal levels. However, the informal consultation may increase uncertainty for the consultant because the nature of an informal medical consultation puts it at odds with our current notions of “good medicine.” The screen door medical consultation is unregulated, there is no documentation, there are no official communications with the formal medical providers, and there are rarely any objective sources of information with which the consultant can work. The consultant is working virtually in the dark, without the usual tools of the trade and is at risk for damaging the personal relationship that exists with the informal patient if his/her advice is taken and subsequently results in a less than positive outcome. Patients sometimes withhold information from providers in formal consultations (Gillotti, 2003) and it is unknown if such withholding exists in the screen door medical consultation. There is substantial potential for the informal consultation, which may aid the patient’s management of uncertainty, to increase uncertainty or anxiety for the consultant. This uncertainty may influence the decision to engage in a screen door consultation.

Uncertainty management theories (Babrow & Kline, 2000; Bailey, Wallace, & Mishel, 2007; Ford, Babrow, & Stohl, 1996; Germino et al., 1998; Gil et al., 2004, 2005; Hurley, Miller, Costalas, Gillespie, & Daly, 2001; Mishel et al., 1987, 2002, 2003, 2005)

are well connected to the concept of social support and health. Brashers et al. (2000, 2001, 2005) and Goldsmith (2004) suggest that one of the mechanisms whereby social support contributes to health and well being is by aiding in uncertainty management. “Communication with others often is the means whereby people seek or avoid information to manipulate uncertainty to a comfortable level...the ways in which others help facilitate uncertainty management have been studied under the rubric of social support” (Goldsmith, p. 307). They propose that social support is essentially assisted uncertainty management.

This concept, when applied to the screen door medical consultation, provides a logical framework that may explain this phenomenon from the patient perspective. Individuals experiencing an uncomfortable level of uncertainty about a health issue may seek assistance from someone in their social network who they believe can help them manage the uncertainty. However, this would not account for the reason health care professionals would agree to consultations outside of the formal health care system.

Social Exchange and Relationship Theory

There appear to be potential negative consequences for the health care professional who engages in screen door consultations. Why, then, would professionals agree to participate in such consultations? Social exchange theory (Thibaut & Kelley, 1959) provides a possible explanation. Thibaut and Kelley proposed individuals engage in a social exchange for one or more reasons: anticipated reciprocity, expected gain in reputation or influence on others, altruism and perception of efficacy, or direct reward. Any or all of these reasons may apply to informal consultations. Informal consultants may feel inclined or obligated to participate because the exchange of rewards and favors is expected in relationships. Informal consultants may derive personal satisfaction from screen door consultations, especially if the consult improves their sense of clinical competence or provides the sense of “doing good.” On a societal level, this activity may represent “unpaid work” that benefits the collective.

Access within one’s social networks to individuals with significant expertise represents a form of social capital that is highly valued in society (Cornwell, 2008). Cornwell notes that racial minorities and individuals with lower socioeconomic status may have fewer experts within their social network whom they can access. Also they

may not have expertise or services that they can offer in exchange to an informal consultant.

The use of social exchange theory as a possible explanation gives the screen door medical consultation mercenary overtones. Perhaps a better explanation comes from the field of relationship science. Reis (2007) proposed perceived partner responsiveness to needs as a central organizing principal for the field of relationship science. Perceived partner responsiveness to needs “refers to the belief that relationship partners are cognizant of, sensitive to, and behaviorally supportive of the self” (p. 9). The concept is complex and, according to Reis, central to social support.

Responsiveness to needs is one of the dimensions of the construct that has attracted significant attention and is applicable to this inquiry. Reis stated that “one of the defining features of close relationships is the expectation that partners will monitor and respond appropriately to these needs” (p.14). Further, the closer or more communal the relationship, the higher the expectation that the partner will be responsive to needs. A primary source from which these expectations arise is the normative definitions for social roles. In other words, individuals expect a spouse or parent to be more responsive to their needs than a co-worker.

Shaver and Mikulincer (2002) identify the availability of significant persons early in life as an important factor in the formation of a secure individual. Therefore, the availability of caregivers help form the expectation later in life that close relational others will be “available and caring when needed” (Reis, 2007, p. 15). Meeting these expectations provides a possible motivation for health care providers to engage in screen door informal medical consultations, especially with those individuals with whom they share a close relationship. This concept of availability in interpersonal relationships may be comparable to the concept of access in relationships with formal health care providers.

Decision Theory

Decision theories are numerous and cross multiple disciplines. The societal shifts toward patient autonomy and consumerism have created the patient-centered model of health care with its emphasis on shared decision making. While pursuing patient autonomy is ethically desirable, shared decision-making has not always resulted in

increased satisfaction or favorable outcomes for either the patient or the provider (Edwards, Elwyn, Smith, Williams, & Thornton, 2001; Saba et al., 2006).

The concept of a “good” decision is troublesome. Broadstock and Michie (2000) begin with the commonly shared premise that a good decision is both autonomous and informed. They subsequently question that any decision is ever truly autonomous, informed, or even rational. They describe one study that showed “deliberative, analytic [decision-making] was least common, was associated with the greatest psychological distress, and required the most resources of time, energy, information and clinical input” (p. 194).

It has been proposed, and is generally accepted amongst clinicians, that the more control a patient has over the decision process, the greater the satisfaction with the decision and the more likely the patient is to make the best decision (Edwards, Elwyn, Smith, Williams, & Thornton, 2001; Pierce & Hicks, 2001). In reality, this process may mean that the patient is given increasing amounts of complex and confusing information and is then asked to make an “informed” decision that may satisfy the risk management department but is anything but informed (O’Connor et al., 1999). There is evidence that patients desire different amounts of information and participation in decision-making; however, clinicians do a poor job of assessing what that level is (Ford, Schofield, & Hope, 2003; Pierce & Hicks, 2001). Pierce and Hicks also report that information from the provider may be presented to the patient “in such a way as to influence the decision-making process toward the outcome preferred by the health care provider” (p. 268).

According to the patient-centered/shared decision-making model, the ideal formal medical consultation would involve the patient and the provider exchanging information about diagnosis, treatment options, the patient’s preferences, lifestyle, and values and subsequently arriving at a treatment decision together that is the best for the patient. In many cases, from the patient’s perspective, the actual experience in the formal medical setting does not match this ideal. This may suggest a reason for screen door consultations. An additional problem with the shared decision-making model is that it assumes the provider-patient dyad is the unit of decision-making. It ignores the possibility of significant outside influence from others (Broadstock & Michie, 2000; Lewis, Gray, Freres, & Hornik, 2009). Those “others” may include informal consultants.

In a systematic review of research on informed decision making, Bekker et al. conclude that “information and education are relatively ineffective ways of facilitating informed decision making compared with... social influences” (1999, p. 3).

Research Questions

The literature review suggests the screen door medical consultation is pervasive and potentially problematic but the review provides little clarification or insight into the characteristics that shape the event. Our understanding of the phenomenon is speculative at best and based primarily on anecdotal reports. The literature suggests that friends and relatives are the primary informal consultees; however, there are also references to co-workers. Physicians have been the primary type of consultant discussed in the literature; however, nurses and other professionals also have been anecdotally identified as informal consultants. Therefore, it is important to determine who is engaging in informal consultations and the nature of the phenomenon. The literature suggests there are potential risks for those engaging in informal consultations. The questions that follow naturally are “why do individuals engage in the consultations” and “what are the risks and benefits?” Finally, since even a basic investigation of the informal medical consultation has not yet made its way into the literature, no suggestions for the theoretical foundations for the phenomenon have been suggested.

This study offers a description of the phenomenon and attempts to understand, from the participants’ perspectives (both health care professionals and informal patients), how the phenomenon may be situated within the frameworks of the theories previously discussed: social support, uncertainty management, social exchange, perceived partner responsiveness to needs, and decision-making. The project also seeks to elicit areas of commonality in the consultations including participant characteristics, motivations, attitudes, perceived risks and benefits, and impact, if any, on patient medical decision-making. The research questions pursued were basic, yet appropriate to this initial investigation of the phenomenon:

RQ1: Who participates in screen door consultations?

RQ2: Where, when, and how often do these consultations occur?

RQ3: What is the topic and nature of these consultations?

RQ4: What are the perceived risks and benefits for the participants?

RQ5: Why do the participants engage in these consultations?

RQ6: What are the theoretical underpinnings of these consultations?

CHAPTER THREE: METHODS

The primary objective of this research project is to describe the phenomenon of the screen door informal medical consultation. Since no prior research on the phenomenon was identified in the published literature, it was necessary to first acquire a thorough description of this type of informal consultation before subsequent research could be contemplated or designed. A secondary objective of this project is to explore the reasons health care professionals and informal patients engage in screen door medical consultations. The third objective of this study is to explore the experienced or perceived risks and benefits of the screen door medical consultation from the perspective of the health care professional and the informal patient. The fourth objective is to suggest theories that may be foundational to the phenomenon.

The Rationale for a Qualitative Approach

Qualitative methods provide the best opportunity to meet this study's objectives because they can "provide rich detail about communicative practices and performances and how they interact in the delivery of care" (Roter & McNellis, 2003, p. 131). In the social sciences, both qualitative and quantitative research can focus on the individual (Denzin & Lincoln, 2005). However, a qualitative approach allows a much closer examination of the individual's point of view through methods such as participant observation and interviews. "Qualitative researchers strive for 'understanding,' that deep structure of knowledge that comes from visiting personally with informants, spending extensive time in the field, and probing to obtain detailed meanings" (Creswell, 1998, p. 193). The quantitative perspective utilizes "more remote, inferential empirical methods and materials" (Denzin & Lincoln, 2000, p. 10). Qualitative research takes place in the everyday world; quantitative research is typically removed from the "real" world and relocated into an experimental environment where the control of variables is attempted (even if not achieved). Denzin and Lincoln promote the idea that qualitative research is based in an emic approach in which meaning is assigned by the member, while quantitative research takes an etic approach in which the researcher controls and assigns meaning based on "probabilities derived from the study of large numbers of randomly selected cases" (2000, p. 10). Qualitative research embraces complexity rather than

trying to eliminate it. While quantitative research specifically and deliberately loses individual details in favor of the representative statistic that will support generalizations, qualitative research privileges and retains the individual details provided by rich description. Qualitative research focuses on description and understanding rather than explanation and prediction. Quantitative and qualitative approaches, although different, are not mutually exclusive. The categorization of research as either qualitative or quantitative belies the iterative, interactive and complementary nature of the qualitative and quantitative perspectives (Donohew & Palmgreen, 1989).

Validity and Reliability

Validity and reliability are cornerstones of rigorous quantitative research, but the application of the terms to qualitative research stirs some debate among qualitative researchers (Creswell, 1998). Despite the debate, the questions that underlie the concepts are appropriate to any area of inquiry. Can one accurately draw conclusions about (measuring, describing, explaining) the phenomenon under investigation? Would someone else, following the same methods and using the same instruments, draw the same conclusions if the study were repeated? Answering these questions in the affirmative may or may not attest to the quality of the research and credibility of the conclusions regardless of whether quantitative methods or qualitative methods were used. In the case of reliability in a study using interviews, the research instrument is the interviewer. Therefore, if another person repeats the study, the instrument has changed and reliability cannot be assessed. Similarly, in the case of focus groups, each “event” is unique and considered non-repeatable (Lindlof & Taylor, 2002).

Maxwell (2005) posits that validity is a key issue and the appropriate term to use in qualitative research design, but he stresses that (1) it is a goal (rather than a product), (2) it is relative, and (3) it is supported by evidence not methods. His definition of validity is “fairly straightforward... the correctness or credibility of a description, conclusion, explanation, interpretation, or other sort of account” (p. 106). Maxwell discusses two specific validity threats: bias and reactivity. Researcher bias he reframes as “experiential knowledge.” This should be viewed as an asset to a qualitative project rather than a negative influence to be totally eliminated. While acknowledging there can be negative influences to a project as a result of a researcher’s assumptions, values and

expectations, Maxwell says these can never be eliminated in any type of research. Instead, they should be foregrounded and explained. He quotes a fellow researcher in espousing that “validity in qualitative research is not the result of indifference, but of integrity” (p. 108).

The second type of validity threat, reactivity, is the influence of the researcher on the researched. While it is appropriate to control for this influence in quantitative approaches, Maxwell makes the point that “eliminating the *actual* influence of the researcher is impossible” (p. 108). For the qualitative study, the influence of the researcher needs to be understood, explained and embraced. Such influences may be negligible in participant observation, where the researcher attempts to blend in and go unnoticed; however, in interviewing and focus groups, the researcher influence is central and inescapable and often contributes positively to the quality of the study (e.g., rapport).

Maxwell (2005) provides a checklist of validity tests as strategies for increasing the credibility of conclusions; other authors also identify these concepts as adding to the quality of qualitative research (Creswell, 1998; Denzin & Lincoln, 2000; Lindlof & Taylor, 2002). First, intensive, long term involvement is an ideal validity check because it helps eliminate premature conclusions drawn from outliers and allows for the collection of rich data. Repetition of observations and saturation of themes are “endpoints.” Second, collection of rich data is appropriate to interviews and focus groups. It is the “weight” of the data (through saturation and repetition) that points to credibility. Third, member checks allow for confirmation (or disconfirmation) of the researcher’s interpretations, spotlighting potential areas of researcher bias. These checks are critical to focus group and interview based studies. It may be impractical or impossible to get feedback from the actual participants; however, it may be possible to get feedback from others who are equally representative of the group observed. Fourth, presentation of discrepant data (negative cases) that do not fit with the rest of the study can actually strengthen the primary conclusions. Fifth, the use of quasi-statistics (simple numerical results supported from the data) can add weight to the claims of the study. Sixth, triangulation through the use of multiple methods does not automatically increase validity, since methods may be at risk for the same kind of bias (for example, data supplied by self report). However, the use of varied sources, researchers or methods,

such as the use of both surveys and interviews in the same study, can either add weight to a conclusion or point to important discrepancies. Janesick (2000) prefers to view triangulation not as a tool of validation but rather as an alternative to validation that reflects the inherently multi-method focus of qualitative research. Her preferred metaphor for this process is “crystallization,” which, in going beyond the two dimensional triangle, evokes the image of a complex, dynamic, multifaceted, prism through which to view knowledge.

Qualitative Methods and the Present Study

A qualitative approach was both necessary and desirable for an initial study of screen door informal consultations. The screen door consultation is a phenomenon that should be appreciated for its complexity and approached, at least at this stage, through a holistic perspective. There is no single explanatory theoretical foundation to explore, no prior research to guide hypothesis testing, and insufficient knowledge from which to design an experiment.

A qualitative approach makes use of the researcher as a key instrument of data collection (Lindlof & Taylor, 2002). In this study, the researcher has over 15 years of experience participating in and observing screen door consultations *in vivo*. This experience, combined with the desire to gain understanding and to present the patient’s perspective, allows for the possibility of a richly descriptive exploration of the topic. A qualitative approach allows for telling the stories of the participants as opposed to merely distilling their stories into statistics. The phenomenon of the screen door consultation occurs frequently; it is not a phenomenon that is hard to observe or difficult to find. Potentially, every individual has at some point engaged in this communication event. After all, even something as benign and simple as asking a friend, who happens to be a nurse, which over-the-counter cough medicine she buys for her own children qualifies as a screen door medical consultation.

Study Design

To describe and understand the screen door medical consultation from the perspective of the health care professional being consulted and the perspective of the informal patient, the study used two Web-based survey instruments and follow-up

interviews. A pilot study (Nickell, 2006) was conducted in order to elicit appropriate areas of inquiry for the main study. Eight individuals (four health professionals and four informal patients) were interviewed. The findings of the pilot study led to the creation of the two online surveys for use in the dissertation study: one for health care providers and one for informal patients. MRInterview® was used as the platform for the survey instruments.

The sampling technique combined snowball sampling through the professional contacts of the researcher and theoretical construct sampling to obtain participant informants. The health care professionals recruited were medical doctors or doctors of osteopathy (MD, DO), physician assistants, nurses, allied health professionals, and students of any of these professions. These individuals reported that they had been informally consulted by a friend, relative or acquaintance. Informal patients were recruited who reported they had informally consulted a friend, relative or acquaintance who is a health care professional. The informants were not dyadically linked (i.e., there was no attempt to “match” the data obtained from an informal consultant with the data obtained from the informal patient who consulted them). In order to protect the health care professional informants from any potential HIPAA violation, the study excluded any consultation if there was a pre-existing or subsequent formal provider-patient relationship.

The use of the Web-based surveys also allowed for recruitment to extend beyond the personal contacts of the researcher. A combination of previously obtained email distribution lists was used to recruit participants (e.g., health care professional societies, employment lists). A recruitment email was sent inviting potential participants to visit the appropriate website and to complete the survey. At the end of the survey, the participants were invited to share their email addresses with the researcher if they agreed to a follow-up interview. The 40 individuals contacted for interviews were selected from the sample of those responding to the web survey based on availability and continued interest in participation. Thirty interviews were successfully completed. Additional email comments from individuals who could not complete in-depth interviews were also considered. One of the goals of the follow-up interviews was to provide member checks of information obtained in the pilot study and the surveys.

The researcher, as a practicing health care provider, had multiple opportunities to observe or engage in screen door medical consultations during the conduct of this study. Those consultations contributed to the findings of this study. Such an inclusion is consistent with the principles of qualitative inquiry and is a strength of qualitative research, since the researcher had the advantage and privilege of observing the actual phenomenon in its natural setting.

Methods of Analysis

The surveys used a combination of multiple choice questions and open-ended questions. The answers offered in the multiple choice questions were based on responses obtained in the pilot study (Nickell, 2006) and provided support for any conclusions regarding commonalities among screen door medical consultations. Two open-ended survey questions allowed study participants to describe freely episodes of screen door medical consultations they had experienced and their feelings about such consultations. Open coding was used to analyze the responses to the open-ended survey questions and all interviews. A quasi-statistical approach was taken to the analysis of answers to the multiple choice survey questions. Statements in the results section that describe in quantitative terms (e.g., percentages) the “typical” or most “prevalent” responses are inherently quantitative conclusions and, therefore, fall under quasi-statistical methodology (Maxwell, 2005). Results of the multiple choice questions, the open-ended survey questions, and the follow-up interviews were compared to look for commonalities that addressed the research questions and identification of new areas not covered by the research questions.

Questions in the surveys and interviews (Appendices A and B) were designed to elicit connections with theories believed to underpin the screen door consultation. Participants were asked to describe the motivations for, content and circumstances of, as well as their attitudes about, the screen door consultation. The analysis of their responses specifically looked for examples of social support (e.g., information), uncertainty management (e.g., anxiety or uncertainty over treatment options), social exchange and perceived partner responsiveness (e.g., attitudes toward refusal to engage in a screen door consultation), and utility in decision-making (e.g., deciding to seek formal emergent treatment).

Ethical Considerations

The primary ethical concern of this research was protection of privacy, particularly since the subject matter deals with health information and personal relationships. Because of the lack of a formal provider-patient relationship, the health care professional participants in the study did not violate HIPAA regulations in discussing medical information provided to them during the informal consultation. Specifically, the medical professional in this context does not meet the definition of either a covered entity or a health care provider, nor does there exist a direct or indirect treatment relationship (United States Department of Health and Human Services, 2006). Participants were assured that, via an on-line or hard copy consent instrument, no identifying information would appear in the final report. IRB exemption was granted for the study. Participants provided consent to participate via an electronic agreement on the web-based survey. Those who were subsequently interviewed were asked to read and sign a written copy of the consent. The risks to the participants, none of whom were recruited from vulnerable populations, were negligible and, from a theoretical perspective, were presumed to be potential emotional distress from (a) discussing personal health issues or (b) discussing their interpersonal relationships. Such risks were unavoidable if the research was to be conducted.

Identifying medical information was modified appropriately to preserve anonymity for all participants. Since the answers to open-ended survey questions could not be traced back to specific respondents, pseudonyms are not used when these individuals are quoted. Their designation is either “health care provider survey respondent” or “informal patient survey respondent.” For presenting data from the in-depth interviews, pseudonyms were assigned to each participant and their status as a patient or provider is also noted.

CHAPTER FOUR: RESULTS

My neighbor, three year old Emma, writhed in her car seat, shrieking in pain. The car door was open when I arrived so the entire neighborhood was now aware of her agony. I tramped over to the car in flannel pajama pants and sock feet, a cordless phone still in my hand. I had been on a call when Emma's distraught mother rang my doorbell and beckoned me through the screen door to follow her out to my driveway. Her car engine was still running. I fired off the basic clinical questions as I observed Emma for a moment. I fished my hand through her seat belt straps and clothing and touched her bare belly. While still asking her mom questions, I very gently and slowly increased the pressure of my hand. She didn't like it one bit. She felt hot and was very sweaty but she was also in pain, wearing winter clothes and strapped into a car seat. I would be hot, mad and sweaty, too. Based on the answers Emma's mom gave me, I told her that Emma needed to be evaluated for appendicitis immediately but that ultimately it was more likely to wind up being a very bad case of constipation. She took my advice and drove straight to the emergency room.

The phone call I had been on when Emma and her mom showed up had been a conversation with Beverly, a friend of mine from church whose husband had been advised to consult a neurosurgeon for his back pain. The surgeon, a specialist who had been recommended by their insurance company, had given them three different treatment options. One option involved no surgery at all. The other two options were very different surgical procedures with very different outcome profiles, complications, and recovery time. The surgeon had refused to make a recommendation and told them it was up to them to decide. Despite doing an Internet search seeking more information about the treatment options, Beverly and her husband remained confused and uncertain about a decision. They asked for my advice.

After Emma and her mother were on their way to the ER, I called Beverly back and picked up our conversation where we had left off. I never mentioned Emma's visit despite the fact Beverly knew her quite well. I feel uncomfortable revealing any information even if Emma is not one of my patients. That night, while trying to get to sleep, questions ripped through my mind. I wondered if I had given good advice to Beverly. What if her husband wound up worse than he was now? Was Emma getting the tests she needed to make sure she didn't have appendicitis? Was some overworked ER doctor berating Emma's mother for bringing in the child for constipation? Or was Emma in surgery at that very moment?

If I had seen these individuals as patients in my clinic I would have had tools, equipment, tests, and medical charts. I could have consulted with other health care providers to either facilitate treatment or clarify options.

But instead, I have spent the entire evening at home doling out care in flannel pajama pants and sock feet.” (Author’s journal entry)

Study Participants

A total of 255 individuals participated in the online surveys. For the patient survey, 168 individuals attempted the survey and 63 completed the survey successfully. Of the 105 who did not complete the survey, the interview software indicated that the interview “timed out.” For the provider survey, 87 individuals attempted the survey and 59 completed the survey successfully. Ultimately, a total of 122 individuals completed the survey. No attempt was made to prevent individuals from re-taking the survey (e.g., if they had timed-out in a previous attempt); therefore, it cannot be determined whether every survey represents a unique individual.

All survey question data were included even if the survey was not completed. This accounts for the inter-question variability in the number of subjects represented in the data. Selected demographics for the participants appear in Table 4.1 (informal patients) and Table 4.2 (health care providers). The study participants for both the informal patient survey and the health care provider survey were predominately female (79% and 65%, respectively). The age range of the participants was 23-72 years for informal patients and 26-69 years for health care providers. Ethnicity/race was predominately Caucasian for both groups.

In addition to providing demographic information, health care provider participants were asked to report their profession (Table 4.2). Most of the participants were physician assistants (40%) or students in a health care profession (33%). Physicians represented 14% of the sample, while nurses represented only 5% of the sample. The “other” types of health care providers who participated included a dentist, nursing assistant, health care executive, emergency medical technician (EMT), veterinarian, social worker and an acupuncturist.

Three questions were designed to elicit the socioeconomic status of the informal patient participants: medical insurance coverage, household income and income sufficiency. The majority of the survey participants had private insurance coverage (91%), had household incomes over \$50,000 (70%), and reported their income was sufficient to meet needs (60%).

One of the goals of the study was to extend the reach of the study to those outside of the social network of the researcher. An analysis of the zip codes of the survey participants revealed that, although most of the participants were from Kentucky or Colorado (where the researcher has the largest social networks), additional states were represented. These included California, Idaho, Illinois, Indiana, Nebraska, Ohio, Pennsylvania, Texas, Virginia, and West Virginia.

Subsequent to completion of the online survey, volunteer informants were recruited to participate in individual interviews that were conducted either face-to-face, via telephone or via email. Thirty interviews were completed. No demographics were collected on the interviewees.

RQ1: Consultation Participants

The Informal Patient

The patient survey asked informal patients for basic demographic information and who was involved in their experiences with screen door consultations. Specific questions were designed to elicit socioeconomic status (SES) and insurance status (factors believed by the researcher to be possible influences to pursue informal consults). However, the study respondents were primarily from middle/upper SES and were mostly insured; therefore, the assumption that there is an association of SES and insurance status with motivation to pursue informal consults was not able to be tested by this study. One might assume the individuals represented in this survey would be the least likely to engage in an informal medical consultation (IMC) because presumably they have access to a formal health care provider and have the resources to pay for formal care.

The description of the relationship between the informal patient and the informal consultant is most often that of friend (71%) or relative (50%). Co-workers (42%) and neighbors (13%) were the next most frequently consulted informal health care providers. It is interesting that 5% of the survey respondents reported that they had at some time asked a stranger for an informal consultation (Table 4.3).

Informal patients reported consulting many types of professionals off duty. According to the patient survey, nurses represent the type of health care professional most often consulted among the health professions (71%). However, those in the nursing

professions (nurse practitioners, nurses, and nursing assistants) were not well represented among the health care provider survey participants, constituting only 7% of the sample. Physicians (MD/DO) and physician assistants were the next most frequently consulted professionals (53% and 35% respectively).

The Informal Consultant

The health care provider survey revealed there is a wide range of individuals who ask for informal medical consultations including friends, relatives, co-workers, neighbors, students, strangers, and others (Table 4.3). The health care providers reported that it is most frequently a relative (51%) or friend (37%) who requests a consult. Co-workers (10%) and neighbors (2%) were the next most frequently reported informal patients.

When this theme was pursued in the interviews, all of the informal consultants indicated that they had been asked for an informal consultation by a wide range of individuals in their social network as well as by the occasional stranger. However, most often the request was made by someone with whom they had a close relationship. “I think at some point, everybody I know has asked me for medical advice. In fact, I can’t think of a single friend or relative who hasn’t done it at least once” (Ellie, physician assistant).

RQ2: Frequency, Timing, and Location

The informal patients in this study report that they approach an informal provider for a consultation ranging from once every other month to twice a month. Informal patients, when asked, will acknowledge that they feel comfortable in making these requests on off duty hours or in a variety of geographical settings. They are more likely to contact an informal consultant during odd hours than their formal provider even though a formal system exists for just such contact (after hours call numbers).

There is a number I can call for the pediatric office... you get a call back from whoever is covering that night. But I know it’s OK to call [relative] at 2 a.m. or whenever about the baby, but I’m afraid to call the doctor. I’m afraid they will be mad that I got them up for a stupid question, if something’s not really wrong. My [relative] won’t yell at me, and I know she will tell me the right thing to do. (Informal patient survey respondent)

This preference to consult an informal provider over a formal provider is not restricted to the mothers of sick children in the middle of the night.

A co-worker of mine is also an RN. We got her out of a meeting... a very important meeting...to look at me and tell me what was going on and what I should do... This person is a close friend and co-worker. I value her opinion...I trust her.” (Dorothy, informal patient)

Health care providers believe that they are on call “24/7” for screen door consultations. They report that requests for consultations can come at anytime and anywhere.

This weekend I went away for a break with a very large extended family, probably 20 people, and I had three people ask me about their health care at what was supposed to be a vacation, but they still have to ask. My uncle asked me about whether I thought it was a good idea for them to get another back surgery. (Tonya, physician)

When asked about the frequency of screen door medical consultations, 80% of the health care professionals in the survey responded that they had experienced up to 8 informal consultations in the 8 weeks prior to survey completion. Ten percent of the health care professionals had experienced 9-32 informal consults in the 8 weeks prior to survey completion; this translated into consultations that occurred up to 4 times a week. Only 5 (8%) health care professionals had not experienced any informal consultations in the 8 weeks prior to survey completion. The majority (59%) of the informal patient survey respondents indicated they had approached an off duty health care professional for an informal consult up to four times in the 8 weeks prior to completing the survey. A very few patients (3%) had initiated an informal consultation 5-8 times in the 8 weeks prior to survey completion. The remainder of the patient respondents (38%) had not initiated an informal consult in the prior 8 weeks.

Although the location of the informal consult was not a specific question in the surveys, answers to open-ended questions gave support to the idea that there is little geographic limitation to screen door consultations. “My neighbor asked me check out (her) boyfriend, something’s wrong. [He] was at the local bar” (health care provider survey respondent).

While many screen door consultations occur in person or over the phone, they can originate from across the backyard fence or across the country and they can use the most up-to-date communication technologies. Email is a common format for informal consultations.

I actually had a second opinion on my cancer before I went to my official oncologist because I sent [a friend] by email my pathology report. They actually sat down and discussed my case [at the oncology practice several states away] (Candace, informal patient)

Electronic health information systems that allow patients access to their lab results provide the perfect set up for an informal consult to occur before the patient sees their formal provider for explanations.

I had a friend email me her CBC [complete blood count] lab results. She had noticed some of the counts were down and she didn't know why. She hadn't talked to her doctor yet because she gets the lab results electronically. She actually emailed me the document. And she said, we can't figure out why these are low. So she wanted me to look at it and see what I thought. The only thing that was low was her red cell count... and it was just slightly out of range. When this came back out of range she was like, oh my god, what's going on?...She has also had some problem with her knees and sent me an x-ray of her knee and asked me what do you think about this?... I had another friend 'Facebook' me asking for medical advice. (Deidre, physician assistant student)

Texting and cell phone camera technologies are used increasingly by informal patients.

The last time I was out of town at a conference, my son texted me from another state to tell me my grandson had been hit in the eye with a baseball. He took a picture of him with his cell phone and sent it to me with a text 'do you think I should take him to the doctor?' (Jill, physician assistant)

Subsequent to a follow-up interview, one of the physician respondents (Tonya) came and related an incident the previous weekend where her sister had texted her about a pregnant friend who was having problems. The sister wanted her to text back answers to medical questions that she could then relay to the friend. The physician indicated this was an example of a request for an informal consult that exceeded the bounds of rationality on multiple levels. Not only did she not know or have a relationship with the friend, she felt texting was a particularly bad method to communicate medical information, especially about a high risk pregnancy. The physician related that this was one of the few times she had ever refused to engage in a screen door informal medical consultation. While she acknowledged that the pregnant friend was probably just seeking reassurance that her pregnancy would end well despite certain risks, the physician was somewhat taken aback that anyone (her sister or the friend) would think a texted medical opinion was a good idea.

Communication technologies have been reducing geographical obstacles for the general population; this is true for informal patients and their consultants as well.

It's been fascinating to me, how much we are using technology... people are actually passing along what they're getting from their doctor to these other friends, relatives, etc. to get a second opinion or verification or clarification. My mom sent me her upper endoscopy via email; pictures, reports, the whole nine yards, and this is from a doctor in Tennessee. Mom lives in Kentucky, her surgeon is in Cleveland, and she's sending me the pictures out here in Colorado and asking 'what do you think about this?' (Faith, physician assistant)

RQ3: Topic and Nature of the Consultation

Typically, from the health care professional's perspective, informal patients are usually consulting about themselves (95%), although they may be asking about a partner/spouse (57%), child (57%), parent (37%) or others (19%). This was consistent with the reports from informal patients; consultations are primarily about themselves (86%) but may be about a first degree relative (child 51%, spouse 42%, parent 25%) or others (13%). As one health care provider reported in the survey,

My sister called me to explain the CBC results a friend of hers told her about. It had a WBC of 80,000... I thought it was likely leukemia but didn't want to tell my sister this who would relay it back to [her friend]. I thought this information should come from her own doctor. I simply told my sister that she needs to make sure her friend calls her doctor (health care provider survey respondent).

The medical problems for which the informal patients reported that they consulted health care professionals displayed an extensive range of subject matter and medical acuity, from minor colds and rashes to brain tumors and impending myocardial infarction. Screen door consultations were frequently about topics of minor significance, such as colds or respiratory viruses and what over-the-counter (OTC) medications to purchase to relieve symptoms. Consultations of intermediate significance involved topics such as chronic knee pain, irritable bowel syndrome, or urinary tract infection. Medical topics considered significant included topics such as brain tumors, myocardial infarction, osteosarcoma, cardiac arrhythmias, and gastrointestinal bleeding.

The range of topics and acuity of the consultations discussed in the follow-up interviews were a spectrum from the minor and humorous to the critical and scary.

We were at a homecoming dance sponsored by our church... absolutely hysterical, everybody dressed up in their old dresses and things....our pastor was doing the worm....and cut his chin wide open on the floor. Bleeding everywhere. They said go find [me]. So I looked at it and told him he needed to go have stitches. A few days later they emailed me and asked if I could take the stitches out. ...Then three weeks later they asked me to take stitches out of their son!...Once you do it once...(laughter)
(Kathy, physician assistant).

Having one's personal, although informal, health care provider while on vacation can be seen as a benefit.

A few years ago I had a friend. He twisted his knee and we were fishing. He said, 'this is really bugging me.' We're out in the middle of nowhere, so I looked at it and it had some laxity and I said you really need to see someone. He said, 'Can't you just wrap it and [I'll] have an extra beer and keep fishing?' I said, 'You can do what you want, but I'm not carrying you back to the truck.' So I drove him into town and he saw someone
(Tim, physician assistant).

Having access to an informal consultation may make the difference in an otherwise serious and potentially life-threatening situation.

I had an exchange student this last year who became depressed...and suicidal. I didn't know what to do. I asked for advice from several different people. What I needed was a direction. I went to a pediatrician friend to ask who I should take him to. I also asked a clinical social worker. One was a friend and one was a church member. It helped me to decide the right type of provider to take him to
(Kelly, informal patient).

When the formal provider fails to provide supportive care, it may be the informal consultant who steps in and fills the gap.

When I developed cancer, we weren't prepared for that...we had gotten completely blindsided. The doctor comes out from my colonoscopy and he says 'I think you have cancer. Do you have any questions?' I'm coming out of it [anesthesia]. I'm not even really awake....It was like being in Alice in Wonderland.... At that point we reached out to [a friend with medical knowledge] to get more information.... Because we didn't trust Kaiser. Kaiser is a business and this is my life. And I don't want you to compromise my life because it costs more or less.
(Candace, informal patient)

Patient Expectations

Informal consultants believe there is a wide range of patient expectations (what the patient wants) with regard to informal consultations. The three most frequently cited perceived patient goals were more information on a diagnosis or treatment (84%), an explanation or clarification of what a doctor has told them (83%), and recommendation whether they should seek medical care immediately or wait (triage) (73%). Twenty-five percent of the health care provider respondents indicated that they believe the informal patient expected a prescription for medication.

When informal patients were asked what they wanted from the off duty health care professional they consulted, their answers were consistent with those reported by the health care professionals, although not in the same order. They wanted more information about a diagnosis or treatment (61%), a recommendation whether they should seek medical care immediately or wait (58%), or an explanation/clarification of what another health care professional had told them (54%). Only 15% of the respondents indicated that they expected to receive a prescription for medication as a result of the consultation. The in-depth interviews helped further clarify and categorize the patient expectations of informal consultations into three categories: information, advice/triage, and care.

Information

Patients often “walk out of the office with these huge uncertainties about what to do or what it means, that they’re going to have to make this medical decision and they don’t understand the scientific information. So I think they seek out people that they trust who do have some medical expertise, to help them make the decision or at least understand so they aren’t so anxious about it.” (Faith, physician assistant)

Lana, a nurse, added to this perspective on information seeking:

People are usually pretty respectful of my time and say when you have a minute can I show you this or can I ask you a question. So I never feel annoyed... [They come to me] because I am a nurse, because I do respond to them, I preach about wellness all the time... The most recent event a person brought me her labs and wanted me to look at them because there was something elevated. And, of course, it was barely over the norm. And that is a very typical question I get. They ask me to explain it to them...The other one was a person who has low iron and she wanted me to look at the supplements she had purchased...I think they continue to come to me because I welcome that. I don’t feel like I’m giving anybody

information that's outside the norm. But I never hesitate to say, you need to see your health care provider about that. I'm all about referring people. (Lana, nurse)

From the patient perspective, a lack of information provided in the formal consultation (perhaps because patients don't ask) and the lack of a formal system for information transfer to significant others are valid reasons for pursuing screen door consultations.

We have a lifelong friend, she is a nurse practitioner, her strength is as a diagnostician. She is really good. And we have used her repeatedly over the years. ... when my husband's mom was going through Alzheimer's and we couldn't get a lot of information... and what we found dealing with our parents is true of lots of people of that generation, at that age they don't ask a lot of questions of their doctor. Even if you send them a list of questions, this is what you need to ask the doctor, you don't get that information. [The friend] gave us what we needed to know. It helped us a lot. It helped us to prepare. (Candace, informal patient)

Advice

Health care providers perceive informal advice giving to be more reflective of the typical interactions in a relationship rather than providing medical care.

There's that whole other piece of medicine that is just advice. It's not medication based. And that's a little bit different. There's a lot of questions and advice that, yeah, this is medicine but it's also just life... this is like asking your grandma. They're asking me like I was their mother, not a doctor. (Tonya, physician)

Ellie, a physician assistant, expands on this theme of relationship and advice giving;

One friend in particular... it's like she doesn't trust all the doctors' opinions she's gotten... she would call me up after she had already talked to her physician, a nurse in the office, a PA, and a pharmacist to ask me if it was OK for her to take a medication that they had all already told her it was OK to take. And I don't know why she thought my opinion was going to be more valuable or important in her decision making. I guess because I knew her as a friend, and she probably thought I would care about her and her well being more than the rest of them. (Ellie, physician assistant)

With the demise of the paternalistic medical model, increased support for patient autonomy, and the increase in medical litigation, most providers in the formal setting no longer make decisions for patients and are even reticent to suggest which option they are presenting to the patient they think is best.

I think we all still have in us that desire to say to a physician, ‘What would you do if you were me?’ and the day I think has passed when physicians will answer that question and yet we want to go to someone with medical expertise and be able to really get down to a personal level, get their expertise and yet get that humanness that comes in there as well... to give us some basis on which to make a decision that is really important.
(Valerie, informal patient)

Triage

Within the informal medical consultation, the concept of triage can be considered a special subset of advice. Triage is the decision process involved in sorting patients by medical acuity in order to decide what resources they need and how quickly. Most health care providers are comfortable with this form of informal medical advice and actually see it as a legitimate reason for an informal consultation. “I almost feel like ask-a-nurse. It’s almost this triage, algorithmic protocol I have in my head” (Tonya, physician). Two physician assistant respondents concurred with this approach.

I’m aggressive in saying, especially on the phone, look, I cannot hear, see, or touch [the patient]. You are worried about [the patient] so that tells me that they need to be seen....I’m still comfortable with someone calling me up and asking if this is something I should go to the ER for. [It is] just triage. (Tim)

I find I do a lot of triage and I’m OK with that. If the question is just ‘Do I go to the ER now or to the doctor tomorrow’ that’s OK. And nine times out of ten there’s always going to be a referral on the end of my advice... you need to be seen by your PCP... maybe not in the next 24 hours but at some point.” (Faith)

Informal patients may or may not know the word but most understand the concept of triage. A substantial number of requests for an informal consultation are actually requests for the health care professional to provide triage.

She is a close friend. I met her 11 years ago when I was pregnant. She is a pediatric nurse... so it’s very smart to make friends with a pediatric nurse when you are expecting your first child. Typical things I would ask her about, my daughter’s ear is hurting, ‘Can I wait to go to the doctor tomorrow?’... It was nice, it was great. I actually think it would be nice if everyone could have a health care consultant...like a patient advocate, who helps you negotiate the system. I mean, how many times have you heard people say, ‘Oh, I took my kid to the doctor and nothing was wrong. They said wait two weeks.’ So, that’s what you think is going to happen to you when you go to the doctor. So, should I or should I not go to the doctor? (Kelly, informal patient)

In some cases the informal consultant knows without further information or examination that the situation warrants immediate formal care but will provide an additional face to face consultation as a courtesy.

Our neighbor who's elderly, his wife had called and asked me to come over and take a look at him. He'd had a history of a heart attack and bilateral eye surgeries in the past. He notices a sudden diminution of vision in one eye. I said I would come over and take a peek to be courteous. But I told him that you should really go in, like now, and be seen in the ER. So they did. It was more along the lines of, 'Is this something we need to take him in for right away?' rather than, 'Is this something you can take care of for me here at home?' It was more, 'How urgent is this?' (Tim, physician assistant)

In other situations, the informal consultant may quickly surmise that the situation is medically benign but will continue the consultation out of courtesy and to foster the existing relationship with the informal patient.

I have a cousin that's driving me crazy. Because she calls me at least once a week and she is a new mother. I have these younger women in my life who call me and ask me about the well being of their children, often. The call is usually about a runny nose and a low grade fever. Moms these days think anything over 98 is a fever. I spend a lot of time reassuring these mothers... it's more 'do you think I need to take him in, is this serious enough for a visit,' 'Do you think I should bother my pediatrician?' To which my response is, 'That's what they get paid for.' So the answer is always yes, call your pediatrician. They expect calls from new moms. They expect calls where they are reassuring you. But I have become the first line for this group of young family members before they go to their own [primary care provider]. They all have [primary care providers] but I am the one they call, even in the middle of the night... I purposefully don't ever sound annoyed even though I am annoyed in my head sometimes. I feel like they are family. I don't want anyone to feel that I am not approachable because of my profession. I like to be part of the girlfriend gang just like everyone else... I get annoyed, sure, but I don't discourage it. (Tonya, physician)

Care

Informal consultants see an increase in the potential for the screen door consultation to be more problematic when treatment is the expectation. Requests for treatment considered to be first aid or clearly within the scope of practice of the provider and with low levels of risk for the patient are generally not seen as problematic. "Yeah, I've stitched up a laceration on my kid when we've been camping. And I wouldn't

hesitate to do it for someone else. It's just first aid, wilderness medicine" (Tonya, physician). "My mom had cancer and needed injections. She would have had to have driven a long way to get them while she was visiting me. My friend [a nurse] did the injections for her. It was very helpful for my mother and my friend felt really good about being able to help." (Kelly, informal patient)

The most problematic of the types of screen door consultations is the one in which a prescription for a medication is requested or expected. There are essentially no regulations against prescribing non-controlled medications outside of a formal clinic setting; although, because there is no documentation, the practice is frowned upon and does not meet the standard of care.

Early in my first year of residency I asked my faculty advisor when we were going to learn about what was appropriate prescribing privileges in the context of family and friends. And I fully expected there to be laws or rules that we were supposed to follow. She chuckled a bit and told me that there were no laws and that there were only moral and ethical lines that we drew for ourselves in the sand. She also told me that those lines would move, that how I felt about prescribing for family and friends today as a new resident would not be the way I felt as a senior resident and would not be the same as after I had been out in practice a few years... it was always going to be a work in progress. I was shocked. She also didn't really give me any guidance. It wasn't a conversation in which she said, 'and here are some things to think about.' (Tonya, physician)

For most providers, writing a prescription for a formal patient without the benefit of even a cursory physical exam would be troublesome. Being asked to provide a prescription without an exam and as the result of a consultation that is outside of the formal system of care is even more problematic.

There were a couple of times I was asked for prescriptions without having seen the person... I haven't laid eyes on them, let alone hands... [they] asked for a script for an antibiotic. I absolutely can't do that. I think they understood. (Tim, physician assistant)

Faith, a physician assistant, was referring to a co-worker who asked her for a prescription when she said:

There are times when I think people really are taking advantage, whether they realize it or not. Because it's not good medicine and they are putting me in an awkward position of having to say 'No, this is not appropriate' and then I still have to work with them for the rest of the day.

Tonya, a physician, agreed and expanded on the problem when she related the following experience:

I have a cousin who had called, initially one time for a sinus infection, that's what she had told me. So I called her in an antibiotic and then it became routine for her. She started calling me more frequently, always for an antibiotic, always for another sinus infection until at some point I had to tell her I could not prescribe for her anymore because there was no chart for her. She would either have to come see me [in the formal clinic] or go to someone else. Even though it was just sinusitis I wasn't sure she had an established PCP or she would follow up and that made me more uncomfortable that I was calling in a prescription for a person that to my knowledge was not getting health care anywhere else. And she wasn't being seen by me either. She just wanted the antibiotics called in. She had self-diagnosed and I was not willing to do that anymore. (Tonya, physician)

The recent and well publicized death of a celebrity who was the recipient of informal care has made some providers rethink providing prescriptions to informal patients under any circumstances:

A friend asked me for [prescriptions for] "just in case" medications to have for traveling in [another country] which I, after chastising myself for doing it, went ahead and did.... I should not have done it because I'm not her medical provider, I don't hold medical records for her, I do not do a physical exam on her... I don't know what her allergies are. My head tells me that I need to tell her that she should ask her own physician for that...I don't think she thinks about it the same way I do... It is not good medical practice, that it is not good ethics. I think she thinks of it as doing a favor...saving a co-pay...And now this whole thing with Michael Jackson has come up...and the fact that there are people out there that are writing for narcotics...They are not seeing the patients, they are not keeping medical records on these patients, so that brings up a whole other legal ball of wax.... It's just one more reason why we should not be doing this. (Jill, physician assistant)

Refusal of a Consultation

Informal patients were asked whether they thought there might be reasons health care professionals should not give information, advice, or care outside of a professional setting. Over 75% of the patients never identified that there might be reasons a health care provider should not provide them with informal information, advice or care. Only 7 (10%) respondents reported that a health care provider had ever refused an informal medical consultation. This is particularly interesting since 70% of providers said they

have refused such a request at some time. Perhaps providers refuse in such a way patients do not recognize it as a refusal. Possibly it could reflect a mismatch of the participants in this particular data set. Informal consultants cited two primary reasons for refusal: the providers did not believe they had sufficient/accurate information from the patient, or they did not believe they had the clinical knowledge or expertise to fulfill the request. The reasons informal patients related for the refusal were spread equally among the options selected (Table 4.4). None of the patient respondents reported being told that either ethical problems or legal problems were the reason for a consultation refusal, although 38% of providers said it was an ethical problem and 12% of providers said it was a legal problem.

The researcher expected that informal patients would not distinguish between their expectations for the consultation and the subsequent difference in the willingness of the informal consultant to fulfill those expectations; therefore, this was explored in the follow-up interviews.

I have two friends who are always saying “I have a medical question” ... and a lot of times I really don’t mind. I am more than willing to take a look in your kid’s ears and tell you whether you need to go [to the doctor] or not. But every once in awhile it is “I’m not really feeling great, can you write me for some antibiotics?” and I’m like “Not really, not without knowing what’s going on.” ...It’s the self diagnosis thing that make me uncomfortable...where they think they know what they have and they think they know what they need. (Dorothy, physician assistant)

Quality of the Information, Advice or Care

When informal patients were asked in the survey about the quality of information, advice or care they received in informal consultations, 46% thought it was better than they would have received in a formal setting, and 43% thought it was about the same. Only 3% reported it was not as good. The informal consultants were more hesitant to say the information, advice or care they gave in an informal consultation was better than what they gave in a formal setting (2%), but 81% were willing to say it was comparable, and 13% felt it was not as good. Even though the majority said the quality of care was comparable, over half of the health care professional respondents still reported that they were concerned about the potential difference in the quality of care they provided in formal versus informal settings. In other words, they believed they were giving similar

quality of care informally and formally, but were uncertain if that confidence was justified. They recognized the potential for poor care in the informal setting. By comparison, 81% of the patient respondents expressed no concern about any potential difference in the quality of care they might receive in formal versus informal consultations.

Another area of concern for health care professionals is whether the informal patient is providing complete or accurate information. Informal consultants were either somewhat or greatly concerned (68%) they were not getting correct information from informal patients, information that would be the basis for providing information, advice, or care in the screen door consultation. The interviews confirmed this perspective. The informants were asked about the quality of the information they gave and received during screen door consultations. Specifically they were asked about the accuracy and completeness of the information. The health care professionals reported that the information or advice they gave to the informal patient was complete and accurate to the extent that the information they had *received* from the informal patient was complete and accurate. However, they had significant concerns that they were not getting complete information from the informal patient, either intentionally or unintentionally. The information received from the patient was probably not as good because,

I didn't have a thorough history. I don't know the rest of the medical background. I don't know for sure everything that's been done or I didn't at the time because this is something that she was telling me about... I didn't have access to records. I think that the history was not as good as I would get out of a patient at the clinic. (John, physician assistant)

At least one professional, however, believed that the quality of information she got in informal consultations was actually better than what a physician was getting in the formal setting.

When you are in the helping field, people give you information that they don't give their doctor. You look at them and go, "Did you tell her that? In the scheme of this conversation, did you tell your doctor that? No? You need to!" (Jennifer, clinical social worker)

However, the professionals often felt unprepared to answer questions about medical issues beyond the scope of their practice or knowledge.

I practice in an adult specialty. I have friends with young children and every once in awhile they'll bring them over show me the head or the rash

and say “What do you think this is?” and I’m like, you know, rashes were not my thing in school but I think this is. (Jill, physician assistant)

Providers reported that most informal patients over-estimated the amount of medical knowledge the providers have.

People think you are skilled about knowing all things about medicine and that makes me very uncomfortable. The average lay person doesn’t realize you have to go look up things all the time. You practice the same thing over and over so you get really comfortable with that. But they’ll throw anything at you, the most obscure, crazy stuff that you never see, that you’ve never heard of, that’s rare. They’ll want you to know everything. And that kind of conversation makes me hugely uncomfortable and is very short-lived for me. Usually ending with, you need to see a specialist. (Tonya, physician)

Despite this ubiquitous over-estimation of knowledge, the provider was usually willing to research the medical topic and provide additional information to the informal patient.

I do have a friend of mine whose brother was diagnosed with osteosarcoma and she called me to ask me about the treatment and the prognosis and wanted to know if I felt the physicians were giving them the truth, if I agreed with the treatment plan. I practice in neurology so that certainly is not my field of expertise. And I essentially told her that that was way beyond my scope of practice. I would be very uncomfortable giving her medical advice in this situation. I would be willing to perhaps look up some articles for her in the medical literature and discuss what osteosarcoma is and discuss vaguely about the various treatments that are available, but I certainly was not in a position to give her guaranteed medical advice about this situation. Because...as a physician assistant, I think she feels that I have a general medical background, which I do. But I think that there is a misperception that just because you are a health care practitioner that you know it all. And, she trusts me as a person. She was trusting that she would get some sound medical advice because she trusts my character and the health care background. (Ann, physician assistant)

In referring to her mother’s request for her to review the reports and pictures of a colonoscopy, Faith, a primary care physician assistant, had this comment: “In her mind I am a medical expert on everything. [laughter] ‘Holy cow, Mom, yeah, I can see the big hole there in the picture, but I’m not sure I can help you out with anything more than that!’” Ann, another primary care physician assistant, continues by explaining the difficulty in not crossing the line from helping others to harming others.

In one respect it makes you feel good because the people who come to you in these types of situations must have some level of respect for you as a health care provider. And I think it goes back because you are a PA, wow,

you must know it all, know how to treat everything and ... so I guess it's flattering to some extent but ... the other side of the coin is that you can't go around acting like you know everything. You have to know your limitations as a provider whether you are a physician or a PA. I think you have to have enough self esteem in order to draw that line, be able to tell people ... ultimately it's their safety, it's their health, you know, do no harm. That's the last thing I want to do to anybody. So it's flattering to some extent but you have to put the safety of the person first. (Ann, physician assistant)

How the Information, Advice, or Care is Used

When informal patients were asked how they used the information, advice, or care they received in the consultation, the most frequent response was to make a decision about specific treatment options (54%). The next three most frequent responses were almost tied: it helped them feel less anxious (47%), they used it to decide if they go see a doctor soon or go to the ER immediately (46%), and it helped them feel better about specific health care decisions (43%).

Perceived Impact on Relationships

The majority of patient respondents (87%) were not concerned about their request for an informal consultation having a negative effect on their relationship with the health care professional. This level of comfort was not shared by the health care professionals. Over 80% had at least some level of concern about negative relationship consequences (Table 4.5). When asked about actual effects on the relationship, more informal consultants reported a positive effect on the relationship (49%) than did patients (29%). No patient respondents reported negative effects. Two (3%) of the informal consultants reported a negative effect on the relationship (Table 4.6).

Answers to open-ended survey questions revealed some of the relationship concerns: “[I had to tell] my best friend that I would not call in a prescription for a medication that I do not use in my practice... I think she was very disappointed” (Health care provider survey respondent). “I had a drug rep ask me to tide her over and give her a prescription for birth control pills since she couldn't get in to see her doc. I refused since my scope of practice is pediatrics. She was never as friendly [after that]” (Health care provider survey respondent).

Although most providers have refused a screen door consultation at some point, only one survey respondent provided a comment that indicated there was a negative impact on a relationship with a family member as a result of a refusal. “A family member was five days post-op and requested a call to his pharmacy for Vicodin.[®] I refused... the person felt I had let them down and it affected our relationship in a mildly negative way ever since” (Health care provider survey respondent).

None of the health care providers who participated in the in-depth interviews could identify actual negative relationship outcomes for the screen door consultations in which they had participated; they could only identify *potential* negative outcomes. The interviews provided further clarification. The strength of the relationship between the health care professional and the person requesting the informal consults appears to impact whether the consultation is granted and how the health care professional feels about the consultation. If the relationship is weak, the consultation is less likely to take place and more likely to make the health care professional feel uncomfortable or frustrated.

I was on a train and this young lady just started to have this long winded conversation with me and proceeded to tell me her entire psych history. And, first of all I'm definitely not on duty, so I definitely do not want to have this conversation. It was real uncomfortable. (Jennifer, clinical social worker)

Comments by a physician assistant student indicate that trust and familiarity may be important facilitating factors in informal consultations.

He was asking what I thought was going on because no one else could figure it out. That one I was a little more hesitant because I don't know him that well... The main difference is trust. The trust we have between us and my familiarity with what is going on with them compared with this other person who I don't know that well. (Deidre, physician assistant student)

One informant indicated he had no problem asking his brother for an informal consultation “because we often engage in that in life, not just with physicians...my wife and I are teachers and with this same family we regularly talk to them about choices they have to make about their children's education. So, for me it feels very reciprocal” (Ray, informal patient). When asked if his brother ever indicated annoyance or reluctance to participate in an informal consultation with him, he replied,

Not at all, but he talks about dealing with it with other people. He doesn't have the same relationship. Somebody comes up to him at church on a

Sunday morning and says I've got this pain in my neck here...what do you think? And he doesn't want to make a diagnosis without making a proper evaluation and he can't do that standing with them in the hallway. Also I think it is the sense of people wanting something for free. There is a level of trust. I would never dream of suing my brother because he told me to do something that didn't work out. Probably in the back of his mind there would be that concern... you know, I know you but not all that well, and six months down the road if something more serious happens, he doesn't have any backup (malpractice) from the hospital he works for if this was not a patient. (Ray, informal patient)

Tim, a physician assistant, talked about family members who call for advice.

Sometimes they want advice. Sometimes you have to say, "Gee, you really ought to see your PCP [primary care provider]." Brand new moms calling us in the middle of the night saying here's what's going on with my baby. Most of the time all it required was talking on the phone or if it was something more serious, you need to take your baby in. It was kind of like being a phone nurse. People felt a real need and nobody abused that.

Jennifer presented the patient side of this emphasis on relationship.

My sister and I were both diagnosed at the same time with [a rare disorder] that did not make any sense. I have a close friend who is an RN who I discussed it with...she knows me, we've been friends for almost 20 years. And she is an incredible nurse. We were having this discussion especially in terms of holistic medical interventions, practical stress management, how not to freak out about this diagnosis, what does it really mean, where could it be coming from...I trust her. We have a relationship...There is no reason she would be uncomfortable with me, but I know she doesn't do this for other people only because I have seen her in action. I have seen people ask her something, and she will tell them you really need to go see someone about that. I think it is relationship. I think she knows how I will use the information she gives me. She trusts that I wouldn't go off and do something irresponsible with it. (Jennifer, informal patient)

It is possible that individuals who are refused an informal consultation and told to go see their primary care provider may interpret this to mean they have something seriously wrong and that the informal consultant does not want to tell them bad news. Although there were no comments by informal patients to support this premise, at least one health professional survey respondent previously quoted in this study did refuse a consult for this reason. "I thought it was likely leukemia but didn't want to tell my sister this who would relay it back to [her friend]." However, based on the comments above it is more likely that refusals in general reflect the informal consultant's discomfort with

engaging in the consultation, perhaps primarily because of the lack of a strong relationship with the requestor.

Also, despite a strong relationship between the requestor and the informal consultant, frustration may result if the subject of the consultation is not well known to the consultant. The case presented earlier where Tonya's sister texted her questions on behalf of a pregnant friend is a good example. "It would have been different if my sister was the one asking for herself. Of course I would have answered her questions, but a friend of hers I've never met? No way!" Another physician respondent concurred with this view but still felt obligated to engage in the informal consultation.

The circumstance that I find the most frustrating, but of course I never say anything, is when my mother gets me on the phone long distance to solve a medical problem or give advice, but it's not even about her or dad. It's a friend of hers. Or better yet, the adult child of a friend of hers. They will want me to diagnose something or tell them if the care this unknown person is getting is reasonable. Medicine is difficult enough when you have the patient standing in front of you, let alone when they are five states away and three people removed. I'm really sure I am not getting anywhere close to accurate information to even hold an intelligent conversation about the issue. But what do you say to your mother? She helped pay for my medical education. (Willa, physician)

While the strength of a relationship may be a driver toward an informal medical consultation, the lack of relationship with a formal provider may also be driving patients toward informal consultations. Informal patient informants had strong statements about the lack of relationship in modern medical care.

In the culture of managed care I don't think people actually trust their doctors... If people trusted their providers more, they would follow their treatment plan... And I know that they don't have a relationship with them. Very few people have a relationship with their physician... You don't have enough time...I might see my doctor for 15 minutes once a year. (Jennifer, informal patient)

Another patient respondent agreed with this view.

I can email my doctor, I can call the nurse, I can make an appointment, but it's not like sitting down face to face with somebody I know and trust...I called a friend who is a nurse practitioner about an issue with my sister who was here with the flu... My doctor is very informative but he has a limited amount of time, and I don't always think of all the questions I want to ask at that time. And it's not that friendship, not that personal interaction, because I only see him every once in awhile. I don't have personal relationships with these people. It's not like it used to be with

your family doctor...My nurse practitioner friend has told me, you can call me anytime... I was out of the country and I hurt my back and when I came back it was spasming. I tried chiropractic and treatments for a week and finally it went into spasm and I couldn't take the pain and I went to the emergency room and it was a terrible experience. They gave me medicine that made me throw up all the way home. It just was not a good experience. And I would have done fine at home if somebody could have just come and given me medication. When I told my friend, she said you should have called me. And I will next time, because Kaiser doesn't make house calls. (Clarice, informal patient)

Health care providers are not ignorant of the barriers to formal care and the drivers toward informal consultations. When a nurse was asked why people aren't seeking formal providers for information, advice or care, she responded:

It is access and relationship. A lot of times it's young people who don't have a relationship with their doctor. I think there has always been a wall around the physician's office... they're busy, overwhelmed... just last week a friend was talking, she started weaning herself off her estrogen, and I said you need to be sure you talk to your doctor and that they know you are doing this and you have guidance. And she said that means I'd have to call and explain it to the nurse and then the nurse will have to explain it to the doctor... and I think that is a barrier for folks...The norm is still, I gotta leave a message with a nurse or medical assistant who may not be conveying the information as you had stated it, so you know it is third hand information. And people don't want to make appointments just to have a discussion... and have a co-pay and wait in the office. I do think our system has barriers. (Lana, nurse)

A physician similarly commented on the fact that the person easiest to access through the formal system is rarely the primary care provider.

Your doctor, who you have become comfortable with, that you have rapport with, isn't it. A lot of times it's a call group where there are four or five, ten people on call and you are not going to get the person that you're comfortable with. I think that you see different providers when you go in, so you may never establish that level of comfort. The large health care systems never allow you to see the same provider. So I think knowing someone who knows a little bit or a lot about health care...they get a lot of questions and I think it is driven by comfort. Comfort is twofold: one, I can call you and two, I can believe you. There is a trust issue... they have to trust what they say. (Tonya, physician)

Presenting a companion argument for why people consult friends and relatives, the same physician respondent was speaking as a patient when she explained,

There is also the piece of they don't know me, they don't recognize me. I can't call and say this is Tonya and my son David is sick, because he

won't even know who David is. He's never seen David. He doesn't remember David. A while ago, you literally could call your doctor and say this is (Tonya) and I have David, Katy and Seth...and I know I did this with my own pediatrician... and he would say, "Yeah what's up with David?" And you would feel that this provider knew you and could visualize your child. And that gave you comfort and reassurance. And that is gone. That is at a very low level now, if not completely gone in health care now. I remember I was in med school and my son woke up in the middle of the night in tears with an earache. I called our pediatrician at 2:00 in the morning. This is a pediatrician that my kids had grown up with. They had gone there since the day they were born and he came to the hospital. They had never seen anyone else. I truly felt like he knew my kids. (Tonya, physician)

Through observation of their parents' behaviors children learn how to engage in informal medical consultations. Kelly described a long term relationship with a nurse practitioner friend with whom she has consulted often over the years and how her daughter also has now started consulting the friend. "Now my daughter jokes around about Nurse Amy. If she has some problem she'll say, 'I'm going to call Nurse Amy about this, I need help.'"

RQ4: Perceived Risks and Benefits for Participants

The previous section discussed the effects relationship has on the informal consultation and, conversely, the effects the informal consultation has on relationship. There are also non-relationship risks and benefits for those who participate in informal medical consultations.

Informal Patients

The primary positive outcomes of informal medical consultations most frequently reported by survey respondents were making a better medical decision and/or feeling less anxious about a health matter. Additionally, there were other tangible benefits. In some cases they were able to avoid a trip to the doctor and subsequent insurance co-payments. They sought further and appropriate formal medical care. Their understanding of complex medical information improved. They understood why their formal provider told them to do certain things so their adherence to treatment plans improved. Their symptoms or illnesses improved because they followed over-the-counter (OTC) medication advice, tried alternative therapies (e.g., ice packs), or made lifestyle changes

(e.g., diet). Their anxiety or uncertainty about a medical issue was reduced to a manageable level.

Candace (an informal patient) clarified that the positive outcomes for her have included how the informal consultation was conducted by the health care provider. “They’ve been forthright, honest and helpful. They’ve never used it as a substitute, it’s more of an adjunct, and that’s the key...when it’s used as an adjunct to ease your fears, or whatever.” Another patient confirmed convenience and cost as benefits.

I was having back problems and my brother is a physical therapist. He has had me try different exercises. So it was convenience, he was right there on the phone. And then expense... I didn’t need to pay the co-pay. And I just needed information from him. (Ray, informal patient)

Health care providers seem to be particularly sensitive to the cost of care and how avoiding those costs may be seen as a benefit by their friends, relatives, and even students.

I think the time it is hardest for me is when a student comes and says I can’t take time off to go to my primary care provider or a person who doesn’t have health insurance who says should I really suck it up and go to the doctor?... [informal consultations] make you feel uncomfortable but she’s just looking for some help. She doesn’t want to pay the \$120 for a visit to see a doctor they’ve only seen once or twice in the last five years...and she’s not in a very good place to know if it’s viral or bacterial. (Susan, physician assistant)

Interestingly, a request for emotional support masquerading as a request for an informal consultation was viewed by one patient as a benefit.

I had two breast biopsies in the spring and I just freaked out after the second one. I got all emotional and weird...I thought my bandage had come off, which was stupid. Really I just wanted her to come over so I called her. And I’m like, “I can’t see the spot and there’s blood. Could you just come over?” She knew I just needed her to come over, that it wasn’t really that medical. The pretense was “I need you to look at my bandage.” I never would have sought treatment from anybody else. (Kelly, informal patient)

All informants were asked if the consultation was used to make a medical decision. In every consultation there was some element of patient decision making that followed the screen door consultation. Gaining information to help make a “good” decision was viewed as a benefit for the informal patient. “I called my friend when I was afraid my child had appendicitis. I took him to the emergency room based on her

recommendation” (informal patient survey respondent). Another survey respondent also related how valuable her friend was in influencing her decision to take her newborn to be seen formally.

I didn’t know if I should take the baby to the doctor... I just told a friend and [she] recommended I take the baby on to the doctor that day. Thank goodness I did because the baby...ended up on meds and a breathing treatment.

A third survey respondent indicated a physician friend’s advice helped him/her “avoid a couple of doctors who don’t have the best reputations.” The conclusion from these data is that informal patients can identify many personal benefits of informal consultations but do not perceive any substantial risks.

Informal Consultants

In the survey, informal consultants most often identified increased feelings of doing good and a better relationship with the informal patient as the potential positive outcomes of screen door consultations. Having increased confidence in clinical skills was the next most cited potential benefit.

When asked to identify potentially negative outcomes of screen door consultations, informal consultants were much more adept at identifying potential risks than were the patients. They indicated that a poor health outcome for the patient was their top concern, followed by a negative effect on the relationship with the patient or conflict with the patient’s formal health care provider. For example, providers often expressed that a potential risk of screen door consultations included litigation or loss of license or other negative legal action. However, they did not believe the actual risk of litigation was substantial because of the mitigating impact of the strength of the relationship with the informal patient. They were concerned that either current or future policies or regulations regarding informal consultations could jeopardize their employment or license if they continued to engage in informal medical consultations. They typically referred to the absence of records (a chart) for the informal patient as the most likely attribute of the informal consultation that would potentially place it at odds with standard of care, institutional policies, or state regulations.

Screen door consultations tended to show the consultants’ professions in a positive light and confirmed their position as well-trained medical providers (especially

when their advice was later confirmed by circumstances or by the formal medical provider). “I always go back and tell them that their diagnosis was correct, that it was dead on. It makes them feel validated.” (Dorothy, informal patient)

Shared Risks and Benefits

There are benefits and risks that are shared by both providers and patients who engage in informal consultations. The mutual benefits were frequently described by the informants as the typical social exchange that is part of a relationship.

I would ask a computer guy, friend, to triage my computer. Is this something I can deal with myself or do I need to take it in? I wouldn't ask him to fix it but if he volunteered I'd be OK with it. It's the same with me as a PA.... A friend called me right after I got home from work and asked me to look at her kid's ear ...I sucked it up and didn't tell her no. It's a friend thing. Next time she can watch my kid when I need it. (Kathy, physician assistant)

Sometimes the thought process for the provider becomes quite mercenary.

Some of it is timing. I don't want to deal with you when I'm in the middle of something else. Sometimes I get in these conversations in my head where it's like I'm providing a free professional service for you. But I have justification for that because they [friends and family] all have professional services that I can milk them back for... I call for free plumbing advice... or one who cuts hair. It's almost an unspoken barter system. (Tonya, physician)

The mutual risks for both patient and consultant involve the troublesome observation that informal consultations, no matter how good they are, do not meet the standard of care and therefore cannot be considered “good medicine.”

Yeah, it's the normal give and take of friendship, but because it's somebody's health, the stakes are a little bit higher. When we engage in that exchange, the potential risks are way different than your computer dying or your car not starting.” (Faith, physician assistant)

Informal consultants seem to live under the constant fear of a bad outcome for their informal patients, which usually leads to the internal question of should they be engaging in informal consultations at all.

Sometimes I have had the thought, what if I give them bad triage advice? I am seeing someone over the phone. I can't visualize them. What if that goes sour? But on the flip side I tend to be ultra, ultra conservative. So that I have probably sent them to their pediatrician too many times because I can't see the kid and I can't do an assessment so I'll say, “You

know, they really need to see someone.” That is the way the majority of the conversations go. If not, I usually say, “Call me back tomorrow and we will talk about it again, but remember if between now and then this, this, or this happens, you go immediately to the emergency room.”
(Tonya, physician)

The realization that an informal consultation can have significant risks is often realized quite early in the professional student’s tenure.

At first I thought this is kinda cool. But then you get to thinking about it and you think, god, I hope I don’t tell her anything wrong. It’s in the back of my mind and it worries me. If I am wrong what kind of repercussions could come back on me? I always tell her, make sure you check with your doctor; remember I’m just a student. (Deidre, physician assistant student)

Kathy expressed concern over legal action, but was quick to add that her bigger concern is the negative health outcome and its impact on the relationship with the informal patient.

Worst case scenario is someone decides to take legal action because I overlooked something or something serious happens... being responsible for... the bad outcome. Oh my gosh, if something happened to them and I gave them some [bad] advice because I had half the story or I wasn’t thinking of this [symptom] in a clinical setting... to have something like that happen within a relationship would be devastating. (Kathy, physician assistant)

Conflicts appear to be inevitable when trying to balance the sometimes multiple goals of helping a friend, maintaining a relationship, ultimately doing what is the standard of care and best for a patient, and the ethical issues of informal prescribing.

The one I struggle with most and have the hardest time with is saying no to my friend [for prescriptions]...I need to say stop, I can’t do this for you anymore. If you need sleeping pills... or pain medicine... you need to see somebody. How do I know if she has a dependency problem and I’m perpetuating that dependency? I know it is unethical and I would not do it for anyone else. (Jill, physician assistant)

RQ5: Reasons Participants Engage in Consultations

There are potential risks for both the informal consultant and the informal patient in going outside of the formal medical system to engage in screen door consultations, so what are the drivers that perpetuate the phenomenon? When providers were asked in the survey why they think others consult them informally, access (83%) and trust (83%) tied for the top response and reflected a significant majority over the other responses. When

asked to select one reason others consult them informally, access won out slightly over trust. Few health care providers believed avoiding the cost of a visit was a motivation for the consult (19%) and only 3% believed it was the primary reason.

When informal patients were asked why they consulted an off duty health care professional instead of a formal provider, the most common responses were again trust (86%) and access (74%). However, it should be noted that almost half (45%) of the responses indicated anxiety or uncertainty about a medical diagnosis was a reason for the consult. When asked to give the single primary reason they consulted the off duty health care provider, the most frequent response was trust (48%) followed by access (28%). Only 16% of respondents indicated that avoiding a co-pay or cost of a visit was a reason for the consult and only 6% rated it as the primary reason for the consult. In the follow up interviews, the concepts of access and trust were mentioned most often as the reasons informal consultations were sought.

RQ6: Theoretical Underpinnings

Although the survey and interview questions were not designed to directly expose the theories that underpin the screen door consultation, the results previously discussed do point in the direction of the identified theories as foundations. The most explicit display of connectivity was with social support. When informal patients were asked what they wanted from the consultation, the top results fell under the headings of information, advice or treatment. Information and advice clearly falls under the parameters of informational social support. Treatment falls within the description of instrumental social support. The interviews provided insight that emotional and appraisal types of social support were also likely to be part of a screen door medical consultation.

When asked why they engaged in an informal consultation, up to 45% of survey respondents indicated anxiety or uncertainty was involved. When asked how they used the consultation, up to 47% of the respondents indicated it was to decrease anxiety or increase certainty. These responses point to the theories of uncertainty. Additionally, in response to the question of how they used the consultation, up to 43% of informal patients indicated it was to make a decision or to feel better about a decision. These responses indicate the involvement of decision theories.

The potential usefulness of looking at screen door consultations through the lens of relationship theory is indicated by the top answers given by patients for why they engaged in informal consultations: relationship, access and trust and the fact that most consultations were between friends or relatives. Some support for social exchange theory was found in comments during interviews indicating that consultants were willing to engage in informal consultations because they either had in the past, or could in the future, expect some form of reciprocation from the informal patient.

The Spectrum Question

At the end of each follow-up interview, informants were asked the following question:

“If you think of a spectrum with one end as the opinion that screen door medical consultations are positive (good, ethical, provide a needed service, should be encouraged, etc.) and the other end as that these consultations are negative (bad, unethical, should be regulated or forbidden, etc.), where do you fall along that spectrum and why?”

The range of answers extended from one extreme to the other; however, most respondents were of the opinion that screen door consultations are good and should not be regulated or forbidden. “I’m on the unregulated side because of free speech in our country. I can see where there could be abuses... but I think regulation would limit knowledge” (Clarice, informal patient). However, there were also providers who fell on the other end of the spectrum. “They should not be encouraged or allowed” (Susan, physician assistant).

One informal patient provided an explanation for his opinion that informal consultations should not be regulated.

Formalization of health care is a mistake. This idea that we get medical advice only from people who are trained and only when we pay for it, is really limiting. Health is a very broad thing. This idea of compartmentalizing things so rigidly, saying this is where our health care happens, in this little box over here, and the rest of this stuff we have to be suspicious of, which would include advice from other people who have this experience and interactions we have with people who have knowledge of this who can share it with us in informal situations is too limiting. I am a believer in western medicine; I’m just not ready to lock it up in a little box and say this is the way it must be done. (Ray, informal patient)

Informal consultants were more concerned with how the consultation falls outside the standard of care.

Illegal is an awfully strong word, unethical is a more fitting word just because of the potential for harm. They're not your patient. If there is any sort of complication down the line, there's no chart, no documentation. My basic instinct is I'm here to help everyone. My reality when I am actually approached is this does not serve you well and it's potentially unethical if something happens or I minimize something with you because I'm not actually seeing you and I might be causing more harm and I would feel horrible if that happened. (Tim, physician assistant)

Other informal consultants take a middle of the road perspective, realizing engaging in informal consultations may look bad when compared to the standard of care but may actually be beneficial to society and the individual.

There is this idea that you shouldn't be giving that medical advice outside of the exam room or hospital but my opinion is this is a work of society that we engage in at all levels. To take health or wellness out of that cultural model would be extreme and a disservice and just wrong....There is a subtle pressure on health care providers not to engage in these activities for fear of litigation. But, we are trained to do good and that doesn't stop when we walk out the clinic door. (Faith, physician assistant)

One of the informal patient informants agrees with this perspective.

That question creates in me a crisis of trust versus being pragmatic. [Informal consultant] is really careful about who she gives advice to. But even if my friend told me something that was completely wrong I would never do anything. But that's a level of trust that's part of a relationship, part of a friendship. Besides, you can never regulate what goes on between friends. But going over to the other side, you look at things like Michael Jackson, you don't know at what point people who have unhealthy dependencies exploit the good will of people. So you get illegal scripts [prescriptions]... but forbidding it is way too far on the other extreme because it's not going to work. I can see some value in some regulation; on the other hand, I do think it provides a great service to society. The more we go toward doctors having to see patients every 15 minutes, where you cannot do the breadth that the patient requires [the stronger the motivation to seek out informal consultations]." (Candace, informal patient)

Those who thought it fell on the negative end of the spectrum and that some form of regulation should be considered were quick to point out that given the current medical environment, the screen door consultation would probably not go away unless significant changes occur.

From a systems perspective it needs to be regulated. Because you know that you don't have all the information on this patient. On the other side of it, we need universal health coverage that will allow people to have relationships with their personal physicians. (Jennifer, clinical social worker)

Health care providers were quick to point out that they thought it depended on the type of consultation. Their line on the spectrum differed if advice, information or triage was being requested versus a prescription or interventional care.

They are probably not a good thing. I'm almost middle of the road. I don't mind giving advice about a lot of things. I don't like necessarily prescribing for people. I rarely do that without looking at the person. I think the fact that people will try to take advantage of you will move you [toward regulation]. (Tonya, physician)

This provider categorized informal consultations as falling on either one end of the spectrum or the other.

There's probably at least two notches on that spectrum, one for prescribing and actual treatment or procedures, which I would say needs to be far over toward the illegal/unethical side. But... information, advice, triage, explanation and clarification should be way over on the other side. (Faith, physician assistant)

This provider promotes a balanced approach:

If it's just a conversation to help them decide what to do, that's not a bad thing. It's no different than asking your neighbor that's a car mechanic. "My car is making this noise. What do you think could be going on?" In that context I don't think it's a bad thing. I don't like regulation. I don't want to keep charts on my friends and neighbors at my house... I think as professionals we should have better ethics. Some of it is that we have this need to help and sometimes our desire to help has a tendency to go too far. We have a talent and a knowledge base and a skill that we can help people and really when it comes down to it, that's what we are trying to do. (Jill, physician assistant)

An interesting finding was that although health care providers in this study believed they were providing good, safe and conservative informal advice, they were concerned about other health care professionals who provide screen door consultations. For other providers in specific circumstances a nurse respondent supported the restriction of informal consultations.

It's a service to friends and family and I'm happy to help them. I'm confident I am never going to overstep my bounds... or my scope. I would always be about referring people to where they need to be

seen...The only concern I have is with people who present themselves as having more knowledge than they have. The people who believe they have more knowledge than they do and actually have a limited scope of practice, I have concerns about them because they do offer information and they bring things home from work they shouldn't. (Lana, nurse)

Based on the survey and interview data, the answers to the research questions would appear to be that screen door medical consultations are ubiquitous, cover a wide range of topics and acuity, and are expected by providers and those individuals within their social networks. The consultations may include requests for information, advice, or treatment; however, providers and patients view these three types of requests differently. The strength of the relationship between the patient and provider and what is requested are the determinants of how the provider responds to a request for a screen door consultation. The concepts of trust, access and relationship appear to play an important role in the patient's reasons for seeking an informal consultation versus seeking a formal consultation. The next chapter will explore these areas more fully and will analyze them through the lens of the theoretical constructs discussed in the review of the literature.

Table 4.1
 Selected Demographics of Informal Patients

		Informal Patient
Gender	Male	(18%) 16
	Female	(79%) 69
	No answer	(2%) 2
Race	Caucasian	(93%) 82
	African American	(2%) 2
	Asian	(2%) 2
	Hispanic	(2%) 2
	Other/NA	(5%) 5
Insurance	None	(1%) 1
	Medicaid/Medicare	(11%) 10
	Private	(91%) 73
	Other	(9%) 7
Income	Not enough	(9%) 7
	Just enough	(28%) 22
	Comfortable	(51%) 40
	More than enough	(9%) 7
	No answer	(4%) 3

Table 4.2
 Selected Demographics of Informal Consultants

		Consultant
Gender	Male	(33%) 21
	Female	(65%) 41
	No answer	(2%) 1
Profession	MD/DO	(14%) 9
	PA	(40%) 25
	NP	(0) 0
	Nurse	(5%) 3
	NA/MA	(2%) 1
	Pharmacist	(0) 0
	Student	(33%) 21
	Other	(13%) 8

Table 4.3

Relationship Between Informal Consultant and Patient

	Reported by Informal Patient	Reported by Informal Consultant
Friend	(71%) 55	(100%) 63
Relative	(50%) 39	(100%) 63
Co-worker	(42%) 33	(76%) 48
Neighbor	(13%) 10	(62%) 39
Stranger	(5%) 4	(22%) 14
Other	(8%) 6	(10%) 6
Student	N/A	(52%) 33
No Answer	(1%) 1	(0) 0

Table 4.4
Reasons for Refusing an Informal Consult

	Reported by Informal Patient	Reported by the Informal Consultant
Provider didn't think they had sufficient information or accurate information	(29%) 2	(71%) 30
Provider didn't think provider had the clinical knowledge or expertise	(29%) 2	(71%) 30
It would cause legal problems for provider	0	(12%) 5
Provider didn't want to give a prescription or medication	(29%) 2	(33%) 14
Provider didn't feel it was ethical to fulfill the request	0	(38%) 16
Provider thought request was inconvenient or annoying	(29%) 2	(19%) 8
Provider didn't give a reason or Other	(29%) 2	(5%) 2

Table 4.5

Concern that Informal Consult Will Affect Relationship

	Informal Patient's Level of concern	Informal Consultant's Level of concern
Never concerned or not concerned	(87%) 59	(16%) 10
Rarely concerned or have been concerned in specific cases	(12%) 8	(46%) 28
Often concerned or somewhat concerned	(0%) 0	(28%) 17
Always concerned or concerned a great deal	(1%) 1	(10%) 6
No Answer	(0%) 0	(0%) 0

Table 4.6
Effect of Informal Consult on Relationship

	Informal Patient's Perception	Informal Consultant's Perception
It has a positive effect	(29%) 20	(49%) 30
It has no effect	(66%) 45	(28%) 17
It has a negative effect	(0%) 0	(3%) 2
It has both negative and positive effects or variable effects	(4%) 3	(20%) 12
No Answer	(0%) 0	(0%) 0

CHAPTER FIVE: DISCUSSION

Interpretation of Results

RQ1: Consultation Participants

This study supports the ubiquity of screen door consultations and that the phenomenon is experienced by a broad range of health care providers. It is less clear, because of the lack of ethnic and economic diversity in the study population, whether the ubiquity holds true for all types of informal patients. It is unknown if potential informal patients who are non-Caucasian or of lower SES have access to individuals with medical knowledge within their social networks who can provide screen door consultations.

The study had substantially more female participants than male; 79% of the informal patients and 65% of the informal consultants were female. The survey data and the follow-up interviews did not provide any insight into whether the screen door consultation is primarily a female phenomenon or a reflection of the study's recruiting techniques. Over 70% of the provider respondents in the survey were physician assistants (PA) or PA students. There is a higher ratio of females to males in the physician assistant profession; according to 2009 data 65.2% of PAs are female (AAPA, 2009). This may account for the higher proportion of female provider respondents in this study.

RQ2: Frequency, timing and Location

Informal patients who engage in informal consultations use a variety of communication channels to conduct the consultations (face-to-face, phone, text, email). Informal patients do not appear to limit requests for informal consultations to particular times, days, or settings. The health care professionals also confirmed that requests for informal consultations are not limited by time, day or geography. They experience informal consultations quite often, usually weekly.

RQ3: Topic and Nature of the Consultation

There was a high level of congruity between the answers the informal patients gave and the answers the informal health care providers gave when it came to the expectations for the consultation. The health care providers recognized that the informal

patients were primarily looking for information they could use to make a medical decision and to reduce their anxiety about the decision. There did not seem to be any medical topic or situation either too mundane or too complex to be excluded from a screen door consultation. Informal patients appeared to have an over-confidence in the range and depth of knowledge of the individuals they were consulting, but, for the most part, health care providers were exquisitely aware of the limits of their own medical knowledge and expertise.

There were two areas in which there was a lack of congruity in the perceptions of providers and their informal patients. First, providers and patients believed that the quality of information they were exchanging was good, although providers had more concerns about the quality of information they received from informal patients. Second, informal patients had an extremely low level of awareness that there could be a negative impact on the relationship as a result of the informal consultation or that the consultation could be professionally or ethically problematic for the health care provider. Health care providers appeared to have a fairly well defined mental hierarchy of what types of informal requests were more problematic (e.g., requests for advice or information versus requests for prescriptions).

I pride myself in knowing my limits and in expressing that to the person asking for assistance. I have very clear boundaries as to what I will and will not do and when I can do it. Therefore it is easier for me to say no. (Health care provider survey respondent)

Students in professional programs seemed to be acutely aware of their discomfort when asked to engage in an informal consultation, but they did not have the tools (mental protocols or a sense of the hierarchy of risk) that their more experienced colleagues had developed over time to deal with requests for informal consults.

RQ4: Perceived Risks and Benefits for Participants

The screen door consultation represents certain risks for the patients and the health professionals they are informally consulting. Informal consultants were more aware of potential risks for themselves and the patient than were the informal patients. The interviews suggest that informal consultants assess the risks versus benefits for both themselves and the patient when making a decision whether to grant or refuse an informal consultation. This double risk-benefit assessment may account for a source of the

informal consultant's increased uncertainty/anxiety subsequent to an informal consultation. The providers' comments in this study indicated they were concerned about their career and professional reputation if the patient outcome was bad; however, they were also concerned about the patient and their relationship with the patient if the outcome was bad. One health care provider survey respondent told the story of a friend asking him about a tick bite. The provider told the friend that the likelihood of contracting an illness was low but he should see his doctor as soon as possible. "My simple reassurance had the undesired affect of him delaying the visit a couple of days... time which could have been spent on antibiotic prophylaxis." The respondent did not relate the outcome of the patient's delay or the effect on their relationship. Another survey respondent indicated that the "formal health care provider chided the patient for bringing my informal consultation into the diagnostic visit." A third health care professional survey respondent wrote that after requesting and receiving an informal exam during a social event, a friend complained that the exam was not very thorough. The informal consultant wrote a comment in the survey that "you can't help feeling guilty after an experience like that." A fourth respondent related details of a consultation after which the formal primary care provider gave a different and more serious diagnosis (which turned out not to be the case). The informal consultant worried that the friend thought "I didn't know what I was talking about."

It is unclear from this study whether the double risk-benefit assessment is made through social exchange perspective in which the consultant mentally weighs the possible negative and positive outcomes in order to reach a decision or if it is through a perceived partner responsiveness perspective in which any risks and benefits to the consultant are secondary to responding to a close other's needs. This should certainly be investigated in the future.

Most participants identified the benefits of informal consultations at both the individual and societal levels. It appears that, in general and at the lower end of the risk hierarchy, the benefits outweigh the risks. At higher perceived risk levels, the strength of the relationship between the informal consultant and the informal patient may buffer the potential risk, or at least the perception of risk, held by the participants in the consultation. In an email following an interview, a patient informant wrote,

I told [the nurse friend whom she consults] about it and she will be interested to read your paper. She told me she is very careful about who she will give information to...in her world, it is only those with strong relationships that get treatment/information. (Kelly, informal patient)

A respondent in the informal patient survey said, “I would only ask a person for medical advice [who] cared about me and my family.” This was reiterated by another respondent: “I only consult one person who I have come to trust implicitly over the years.”

Despite perceived potential risks of engaging in screen door consultations, with very few exceptions, study participants expressed that there should not be an attempt to restrict or eliminate these types of consults.

I am a supporter of informal medical consultations. They are helpful in supporting patients’ concerns, the psychic side of illness. They are part of a successful health care delivery system...[Restrictions] would act to the detriment of informal medical consultations and close the door to an important human resource and interaction that has as a positive goal, the comfort and support [of the patient]” (health care provider survey respondent).

RQ5: Reasons Participants Engage in Consultations

When viewed from a societal level, the reasons informal medical consultations occur may represent one of two conditions. It may represent a socio-historical phenomenon entrenched in societal and relational norms. This condition provides support for the idea that social exchange and/or relationship theories such as perceived partner responsiveness to needs are plausible explanations for the resilience and ubiquity of screen door consultations. Alternatively, it represents a failure of the medical system to provide patients with formal medical providers who embody the attributes of accessibility, trust, and relationship strength (attributes previously held by the traditional family doctor). This study does not suggest that the two conditions are mutually exclusive.

Unfortunately my family doctor and I were really close. I had been his patient for almost 40 years. He and I had chatted about stuff like that [a relative’s health] ...I had the ability to be able to talk to him about things that I generally would not have discussed in the regular doctor setting now. He died. He had a partner I would have started seeing except my husband and I had taken [HMO insurance] and I had to use one of their doctors. That was difficult. Especially since I had known him [previous family doctor] since he had delivered my second child. I felt really comfortable with him, more as a friend than even as a physician. Now [with the current physician], I go when I have to. It’s not the same. [The previous family doctor] knew me and my family from our early beginnings... I

think I have a pretty good relationship with the doctor I have now, but I can't tell you his name. (Rachel, informal patient)

The failure to provide primary care providers who are perceived as easy to access, trustworthy and with whom the patient has a strong relationship is occurring at the same time the medical system is placing increased responsibility on patients to make their own and, supposedly, informed medical decisions based on complex medical information. The combination of increased responsibility for potentially high risk decisions with less access to and trust in those who hold the knowledge needed to make the decisions supports the view that the informal medical consultation is a form of social support that assists in uncertainty management.

The first condition (that the informal medical consultation is entrenched in relational and social norms and has existed for thousands of years) suggests that the phenomenon will continue to exist despite any improvements in the qualities of the formal health care provider or the medical system. As one health care professional study participant expressed it, when we need advice, "we always ask a friend before we look elsewhere."

Probably 50% of my medical practice actually occurs outside of clinic walls, in informal settings, with people who are my friends and family. I would never do surgery on them and I rarely give them a prescription for anything but everything else is fair game. Any knowledge, wisdom I have...everything is at their disposal. They deserve it. They are the ones who supported me emotionally and financially through my training. I just think of it as they have a prepaid health care plan with me. (Faith, physician assistant)

RQ6: Theory Development

This study suggests that the theories of social support, uncertainty, decision making, social exchange, and perceived partner responsiveness to needs provide a reasonable foundation for the phenomenon of the screen door consultation. However, each theory only partially explains the phenomenon; no single theory offers a comprehensive explanation. While attempting to integrate these theories to provide a unified explanation for the phenomenon of the screen door consultation would be a worthy scholarly pursuit, it also would be well beyond the scope of this dissertation project. Instead, each theory will be discussed individually below, and, when appropriate, potential intersections of theories will be suggested.

Social Support Theory

This study supports the idea that the phenomenon of the screen door medical consultation meets the accepted definitions of social support as a relational transaction between individuals involving the provision of information, comfort, or help by others (McKinley, 2009). The phenomenon embraces all four types of social support (Langford, Bowsher, Maloney, & Lillis, 1997). Informational support was found in the consults that provided information. Instrumental support was found in consults that involved treatment or care such as an examination or a prescription. Appraisal support was provided in consults when the provider indicated the patient's situation or request was not unusual or when the provider validated the patient's concerns. Emotional support was provided when the provider provided messages of empathy, respect, caring or comfort.

The study provides evidence that the quality of the four types of social support given in an informal consultation may be very different from the quality of the support given in formal consultations (Arnston & Droge, 1987). Informal consultations often lack the power differential and hierarchy present in formal consultations, therefore, providing an environment conducive to emotional support. "My friend is my friend and she does not talk down to me" (Kelly, informal patient).

The language of informal consultations is more patient-centered, making informational support more effective. "In our increasingly complex medical world, I feel I can provide a simpler explanation of what they...have been told" (health care provider survey respondent). Informal consultations often lack the highly scripted, repetitious and time limited qualities of formal consultations, qualities that are a source of provider and patient dissatisfaction. "[Unlike my regular doctor] my friend explained things in detail, was caring, concerned, [and] spent time with me" (patient survey respondent).

It's more helpful and comfortable to ask them than my own doctors who always seem too hurried to explain things to me... [and are] a little intimidating and sometimes aloof. (patient survey respondent)

Appraisal support was given often; for example, "She let me know that I was a normal first time mom for worrying. She didn't make me feel bad for asking basic questions" (Julie, informal patient).

The definition used in this study for informal medical consultations included the type of request made by the patient: information, advice, or care. However, the

respondents in this study also indicated that, although requests for emotional support were not overtly made, emotional support was generally provided in informal consultations and was expected by the patient, especially if the relationship between the consultant and the informal patient was close (a friend or relative). “Personally, I feel comforted [by my friend]... and I feel that is something that’s very needful” (Valerie, informal patient).

Although much research has been devoted to correlating social support research with positive health outcomes, the results of that research have provided only a “modest empirical foundation” (Albrecht & Goldsmith, 2003, p. 274). Similarly, the results of this study suggest that both providers and patients believe there were positive health outcomes from the informal medical consultations. “My friend advised stopping the [medication] and her advice was right on. My stomach stopped burning and the diarrhea abated within the next couple of hours” (patient survey respondent).

Patient C asked me if it was OK for her to take anxiety medications more than prescribed. I explained the potential for abuse and the side effects from taking too much of that medication. She was grateful and agreed to consult her physician since the medication was not as effective as she was hoping, rather than self-medicate with extra pills. She was also happy to know what the potential long-term side effects of that med were, since she had not realized those existed.” (health care provider survey respondent)

However, showing positive health outcomes for screen door consultations may provide just as much of a research challenge as it has been other forms of social support. If future research is able to show such a correlation, then it would be reasonable to direct further inquiry toward whether the outcomes are due to direct effects or stress buffering mechanisms; the results of this study would suggest it may be either. For example, an informal consultation in which a mother was encouraged to go straight to the ER with her child who had symptoms of appendicitis is likely to show a positive direct health outcome. Conversely, an informal consultation in which confusing medical information was clarified and subsequently reduced the anxiety levels of the informal patient would point toward stress buffering mechanisms. The patient respondents in this study indicated improved emotional states after an informal medical consultation. This was often related to feelings of decreased uncertainty, decreased anxiety, or increased confidence in a medical decision. The following phrases or their equivalents were found

repeatedly in the patient survey responses: “it made me less nervous,” “I was relieved,” “I was concerned [prior to an informal consult],” “calm her fears.”

As discussed in chapter two, social support may be viewed as the communication of desirable emotional messages (caring, respect, empathy, love, belonging, validation, or reassurance) and the sharing of resources (information, tangible goods, or services) that are helpful to the individual in situations of anxiety or stress. This study indicates that screen door medical consultations typically provide both desirable emotional messages and resources. Also discussed in chapter two was the concept that social support may be considered essentially as assisted uncertainty management. Therefore, the emotional messages and resources provided in the informal consultation may help modify the levels of uncertainty or anxiety for the informal patient.

Uncertainty Theories

The results of this study confirm that the theory of uncertainty management and its correlate, anxiety management, provide a sound basis for explaining the motivation for pursuing an informal consultation. Both patients and providers indicated in their responses that prior to a request for an informal consultation the patient had an uncomfortable level of uncertainty about a health question that prompted the request (e.g., Do I need to go to the ER or should I wait? Is treatment X a better option for me than treatment Y?) Rarely did informal patients report in the survey or in interviews that the sole motivation for the consult was to obtain free care. Frequently reported immediate outcomes for the informal patients included less anxiety about his/her health and feeling more certain about health care decisions. “She gave me some very good advice and directed my mother to see a specialist so that correct test could be run” (patient survey respondent). “She helped me sort out my thoughts/concerns so that I could be better at assisting my husband in making his decision” (patient survey respondent). These outcomes may be translated as a return to manageable or desirable levels of uncertainty or anxiety. The informal medical consultation might balance competing uncertainties/anxieties. Consider the uncertainty/anxiety regarding the seriousness of a symptom and if formal care needs to be sought immediately. Then consider the competing uncertainty/anxiety regarding the financial impact of seeking

immediate care (e.g., the cost of going to an ER versus waiting to see a family doctor in a few days).

I have a newborn baby and didn't know if I should take the baby to the doctor, worrying they may think I am too cautious. I told a friend my daughter's symptoms and the friend recommended I take the baby on to the doctor that day. Thank goodness I did because the baby had an upper respiratory infection and ended up on meds and a breathing treatment. (patient survey respondent)

Another survey respondent related a common scenario for screen door consultations. "I busted my chin on the side of a pool. I asked a neighbor, who is a nurse, if she believed it needed stitches. She said yes. We went to the ER and they sutured it" (patient survey respondent). In these examples an informal consultation may provide the information necessary to justify one decision over the other and therefore reduce the uncertainty/anxiety associated with it.

For those few instances when the only goal of the informal consultation was perceived to be avoidance of the costs of formal care or avoidance of the inconveniences of formal care (appointment scheduling or doubt if a desired prescription will be provided), the motivation to pursue an informal medical consultation might also be related to an attempt to manage the anxiety/uncertainty of the financial impact of formal care.

I asked an EMT friend if my child's burn was something I needed immediate care for. I did not go to the ER and just treated it at home. It was good advice because it saved a trip and the cost. I have also asked about my asthma, if they knew of a drug that was less expensive. (patient survey respondent)

Therefore, although the theories of uncertainty/anxiety management explain formal consultations, they also may offer an explanation for the patient's motivation to pursue an informal medical consultation when cost of care is a concern.

Social Exchange Theory and Perceived Partner Responsiveness to Needs Theory

For the health care provider, engaging in an informal consultation may result in uncomfortable or increased levels of uncertainty or anxiety (see the story at the beginning of chapter four). The uncertainty/anxiety is driven by the provider's perception of potential risks in conducting an informal medical consultation. The perception of risk increases as the type of consultation progresses from a request for simple information to a request for medical treatment (e.g., a prescription for a medication). These risks include

a poor health outcome for the patient, a negative effect on the relationship, and potential professional liabilities. However, the potential benefits to the provider and/or to the patient may offset the potential discomfort (uncertainty/anxiety) experienced.

The theory of social exchange may account for these benefits and therefore the provider's willingness to engage in an informal medical consultation despite increased uncertainty/anxiety and perceived risk. The willingness may be the result of an expectation that some form of benefit will be received by the provider: reciprocity, gain in reputation, altruism, gain in self-efficacy, or direct reward. While, this study provided no evidence that direct reward is an actual or expected outcome of a screen door consultation, evidence for future expected reciprocity was provided by several participants comments. The reciprocity did not take the form of medical information, advice or care but rather other services, e.g., babysitting (Kathy, physician assistant) or haircuts (Tonya, physician). The comments referenced that the consultant could expect reciprocity, not that the reciprocity had actually taken place. The survey results suggested that altruism ("increased feelings of doing good") and gain in self-efficacy ("increased confidence in clinical skills") are common outcomes of screen door consultations; however, these areas were not explored sufficiently in the interviews to provide additional data. These areas and "gain in reputation" will need to be explored more fully in the future.

The health care respondents in this study often talked about the informal consultation as a way to help a person who had either helped them in the past or might help them in the future (e.g., Kathy expecting free babysitting from her neighbor or Tonya expecting free haircuts or plumbing advice from her cousins). The types of help they provided to informal patients included all four types of social support: instrumental (actual exams or treatment), informational (advice, explanation, or clarification), appraisal (reassurance) and emotional (comfort). On a more global level, the health care providers saw informal consultations as a way to give back to society as a whole for the privileges they had been afforded (e.g., their education). "Any knowledge, wisdom I have...everything is at their disposal. They deserve it. They are the ones who supported me emotionally and financially through my training...this is a work of society that we engage in at all levels. To take health... out of that cultural model would be extreme and

a disservice and just wrong” (Faith, physician assistant). In general, social exchange theory may provide a basis for the patient’s expectation that a provider, with whom they have a relationship and perhaps have helped in the past, will engage in an informal consultation. It may explain a provider’s hesitancy to refuse a consultation to an individual who has helped in the past or is likely to provide help in the future. “My boss had just provided our department with a huge professional favor, in terms of money, and on my way out the door he asks me to look at a skin lesion he is worried about. What was I going to do after that, say no?” (Faith, physician assistant). However, this view limits the informal consultation to a basic model of bartered services, current or future.

Another explanation, and one that is better supported by the data, is provided by the theory of perceived partner responsiveness to needs. This theory provides some explanation for why it is the closeness of the relationship between the informal patient and the informal consultant that determines the provider’s willingness to engage in the consult and the extent of the subsequent information, advice, or care provided. It also provides some explanation for why providers are willing to engage in informal consultations despite discomfort with the circumstances. “Expectations about responsiveness to needs in both the giver and recipient roles, vary as a function of the communal strength of relationships” (Reis, 2007, p. 14). A mutually perceived close relationship may be the primary motivation that drives the initiation and acceptance of a screen door consultation.

While the theory of uncertainty/anxiety management accounts for the patient’s motivation to pursue a medical consultation, it does not help distinguish why a patient pursues an informal consultation instead of a formal consultation. For the informal patient the choice of whether to initiate a formal or informal consultation appears to be related to three characteristics of the informal consultant: relationship, accessibility, and trust (important constructs in the theory of perceived partner responsiveness to needs). The majority of the informants’ comments support the idea that these three factors are increasingly missing in formal medical consultations. The concepts of trust and availability are usually considered to be relational attributes necessary for a close relationship (Reis, 2002). The combination of the survey results and the interviews clearly points to access and trust as major components in the motivation to engage in a

screen door medical consultation. In every follow-up interview conducted the concepts were brought up at least once (either the words “trust” or “access” were mentioned or a synonym of these words).

A review of the informant quotes presented in previous sections reveals the emphasis placed on relationship (including trust and access) in engaging in screen door consultations and also seems to explain why the patients did not pursue formal consultations. “There is this level of trust. I would never dream of suing my brother because he told me to do something that didn’t work out” (Ray, informal patient). “I trust her. We have a relationship... If people trusted their providers more, they would follow their treatment plan” (Jennifer, informal patient). “It is only those with strong relationships that get treatment/information” (Kelly, informal patient).

Informal patients have access to informal consultants and informal consultants make themselves available to informal patients. A review of comments by patients and providers indicates that informal patients have cell phone numbers, home phone numbers, email addresses, home addresses, and other personal information about the individual whom they are consulting. They often have physical access through living in close proximity or participating in the same social events. The closer the relationship, the more likely the informal patient has information which gives him/her greater access to the informal consultant. The informal consultant generally accepts this access as reasonable and is available during off-duty hours to those with whom they have a close relationship. Although this type of arrangement may have existed historically in medicine, it is not typical of current formal provider-patient relationships. Few, if any, formal providers give out cell numbers, home numbers or other personal information to patients as a matter of practice. In fact, there are increasingly greater formal barriers being erected to prevent patients from having access to providers. The current patient experience is that it is almost impossible to talk to a provider by phone. Even if a phone conversation does occur, it is usually after multiple prior conversations with receptionists, nurses, or other staff. These gatekeeping measures are a source of patient dissatisfaction along with the discontinuity of relationship with the same provider over time (Forrest, Leiyu, von Shrader, & Ng, 2002).

Decision Theory

The informal medical consultation influences the patient's health care decision making. Both patients and providers alike recognize the utility of the informal consultation in helping the patient make a decision about health care, the desired outcome of which is a return of uncertainty/anxiety to manageable levels and an optimized health outcome. Theories of decision making are probably even more intrinsic to informal medical consultations when one considers that there are two decisions required in order for an informal medical consultation to occur (the patient decides to request the informal consultation and the provider decides to grant the request).

For most of the respondents in this study, it was clear that the informal medical consultation would be used by the patient to make a decision regarding a health care issue. Valerie and her husband needed to choose a procedure for his back problem. Multiple participants had to decide to go to the ER or to wait and seek care later. Participants needed to decide which formal provider to see after being diagnosed with a serious illness such as cancer. A brother experiencing chest pain called his sister who called a physician friend to help them decide where he should go for care. Another survey respondent needed to decide if the breast lump she discovered was worth getting checked; therefore, she asked a nurse friend her opinion.

The current predominant model for "good" decision-making in the health care context involves a formal provider exchanging high quality information with a formal patient, the goal of which is for the patient to make a well-informed decision that will optimize a health outcome. Recent studies have begun to question this model, specifically, the fact that it fails to account for outside influences on decision making. Lewis, Gray, Freres, and Hornik (2009) report that over 30% of the patients in their study brought information to their formal provider from family, friends or co-workers; over 28% brought information from other health professionals. The researchers did not report if there was overlap between these two categories or if any of the information brought from other health professionals was as the result of an informal consultation. In this dissertation study, the family member, friend or co-worker is also a health professional and has had a significant influence on the patient's decision via an informal consultation. Future revisions to models of decision making will need to take this into account.

Limitations of the Study

The purpose of this study was to describe the phenomenon of screen door medical consultations. Although the researcher attempted to reach a broad population, there was no attempt to select informants randomly. Therefore, the demographic scope of the participants in this study was limited. The surveys failed to attract a broad spectrum of health care providers (e.g., nurses, pharmacists, physical therapists). More importantly, the surveys attracted few minorities or those of lower SES. This might be expected, since the surveys were web-based and were offered primarily through the social and professional contacts of the researcher. The conclusions from this study, that avoidance of the costs of formal care are not a significant motivator for initiation of an informal consultation, may not hold true if a larger group of minority or lower SES individuals is queried. Given the findings of the Cornwell study (2008) that minorities and lower SES groups do not have as many experts within their social networks, even the most well supported conclusion of this study, screen door medical consultations are ubiquitous, also may not hold true. Therefore, the findings of this study may not be generalized to the whole range of possible variations in screen door consultations.

The use of the survey software platform created problems that were not identified until after the survey was active. The researcher had hoped to gain detailed descriptions of the informants' experiences with screen door consultations through several open ended survey questions to which the informants could respond. However, a 'time out' feature resulted in premature termination of the survey prior to completion if the allotted time to answer any particular question was exceeded. For the open-ended questions, this meant that a warning had to be placed in the instructions informing the respondents that they only had a few minutes to respond to the open-ended questions. This significantly reduced the level of detail and richness of their responses. It also meant that a significant number of respondents were not able to complete the survey because they "timed out." If this had been known prior to going live with the surveys, another interview software platform would have been considered. Additionally, as a matter of convenience to the participants, interviews or portions of interviews were conducted in a variety of formats and locations. These variations included face-to-face interviews, phone conversations, and email. This variation may have impacted the quality of data obtained.

As mentioned in the methods section, no attempt was made to dyadically link the responses and comments of the informal consultant with the patient who consulted him/her. In fact, there is no evidence (other than the researcher's personal knowledge of some of the participants) that there were any consultant-consultee pairs among the study participants. Dyadic results would strengthen the evidence for relationship effects and the effects of a refusal to engage in a consultation.

As noted previously, the researcher for this dissertation study is a practicing health care professional who experiences and observes screen door consultations frequently. While it is believed that this experience added to the richness of the description of the phenomenon and assisted in engaging participants to share their experiences, it is possible that the researcher may have influenced what interviewees chose to reveal. Also, it must be frankly admitted that the interpretation of the participants' experiences are filtered through the perceptions and experiences of the researcher. It will be important for others to confirm, negate or modify the findings presented here through their own research.

Future Research

This was the first investigation into the phenomenon of the screen door medical consultation; therefore, there is considerable need for further inquiry. This research should include inquiries targeting specific populations and specific questions, as well as focusing on confirming the theoretical underpinnings suggested here. Translational research is needed to provide clinicians and policy-makers with guidance in formulating responses to requests for informal consultations.

Specific Populations

The informal patient participants in this study were primarily female, Caucasian and from middle/upper socioeconomic groups. The informal consultant participants were primarily from one profession: physician assistant. The study should be repeated, focusing on recruitment of important populations not well represented in this study. On the health care provider side, future inquiry should focus on nurses, medical assistants, MDs/DOs and other health professions. Students of these professions should also be queried, since this study indicates that screen door consults begin early in the health care

professional's training. On the informal patient side, inquiry should focus on males, specific ethnic groups, and individuals in lower SES groups. Lastly, inquiry should focus on dyads. It will be important to discover if the informal consultant's perspectives match or are discordant with those of the informal patient who initiated the screen door medical consultation.

Specific Questions

A fertile area for future research will be to look at differences across types of screen door consultations. This study provided minimal insight in this area; therefore, it is unknown if the topics discussed, the expectations for the consult, or perceived risks and benefits differ depending on the characteristics of the consultant or the patient. For example, since relatives constitute a high percentage of consultation requests and relationships with relatives tend to be complex, future studies might focus on how consults involving requests from relatives differ from other individuals. Future inquiry should also determine if specific types of providers experience screen door consultations differently from other health professionals. These differences, if any, will be important if practice guidelines or curricula dealing with screen door consultations are to be developed for each profession.

An area that was identified after the interviews were completed was the possible connection between a refusal to engage in an informal consultation, the type of request, the relationship with the patient, and the reason given for the refusal. It was suggested in the data that those individuals without a strong relationship to the provider were less likely to be granted an informal consultation. It was also suggested that if the request was for treatment and/or a prescription, the consult was less likely to be granted. However, there is some evidence from comments in the interviews that the strength of the relationship might offset this trend, that the stronger the relationship the more likely the provider was to provide higher and riskier levels of care. If so, the strength of the relationship may be a stronger predictor of granting/refusing informal consultations than either the type of request or perceived benefits.

Also, since the question on refusing an informal consultation on the provider survey asked "Why did you refuse?" it is unclear if the same reason was communicated to the informal patient. Future research might clarify this. Additionally, the question

arises whether providers use some or all of the reasons for refusal listed on the survey as cover stories, as socially acceptable reasons for refusal that may not reflect their actual reasons. Tonya, a physician, gave some insight to this possibility when she described refusing to write prescriptions for a relative. “I actually lied to her and told her it was illegal so that I didn’t have to go through an inquisition of why I wouldn’t do it anymore.... I did not feel comfortable calling in prescription after prescription for her without seeing her. I did not think that was a good way to practice medicine.”

This study did not specifically attempt to address actual outcomes of screen door consultations; it only described those outcomes the respondents chose to relate. Future research should focus on these outcomes, including health, quality of health care decisions, benefits to the informal consultant, actual relationship effects, and uncertainty/anxiety management. In order to accomplish these goals, especially assessment of relationship outcomes, it will be necessary to study dyads. Therefore future studies will need to identify and recruit informal consultants and those individuals who have consulted them informally.

Theory Development

In this study broad overarching theories are posited to offer explanations for the screen door medical consultation. Specifically, the theories of social support, uncertainty/anxiety management, social exchange, perceived partner responsiveness to needs, and decision making may play roles in the various stages of the screen door consultation. The next level of inquiry will need to identify specific theories within each of these umbrella categories that explain the phenomenon more precisely.

Does the social support provided in screen door medical consultations result in better health outcomes? If so, is it through stress buffering/prevention mechanisms or through direct effect mechanisms? Is it more important to patient or provider satisfaction for a screen door consultation to contain instrumental and informational support or appraisal and emotional support, or vice versa? Or are all equally necessary?

What resources do informal consultants engage to manage the increased uncertainty/anxiety produced as a result of informal consultations? For informal patients, is there a measurable change in uncertainty/anxiety immediately after the informal

consultation? As a result, is there a difference in levels of uncertainty/anxiety in subsequent formal consultations?

This study has posited that both social exchange and perceived partner responsiveness to needs may account for the provider's willingness to engage in an informal consultation. Future research may clarify this and establish one as the dominant factor. If social exchange is a better explanation, the next step will be to determine if it is through anticipated reciprocity, expected gain in reputation or influence, altruism, increased perceived self-efficacy, or direct reward. If perceived partner responsiveness to needs is a better explanation, it will establish relationship as a major influence on informal medical consultations and the exact qualities of the relationship will be fertile ground for further inquiry.

Do patients make better health care decisions if they have participated in a screen door informal medical consultation? Can we identify and associate various decision theories for the stages of the informal medical consultation? It appears from this study that the provider's decision to engage in an informal consultation is based in part on a double risk/benefit assessment (for self and the patient), but it cannot be strictly attributed to a utility based decision theory (Frisch & Clemen, 1994). Therefore, one of the theories of naturalistic decision making may be more appropriate (Zsombok, 1997). There may be other theories that have not been suggested here that offer better explanations of the phenomenon. Those, too, will need to be identified and explored.

Translational Research

The topics covered in this study are neither purely philosophical nor esoteric. Screen door medical consultations impact the lives, careers, health, and relationships of all who participate in the phenomenon. There will be substantial opportunities for applied research on these types of consultations as providers and policy makers decide what to do, if anything, about restriction or regulation of these consultations. There is insufficient knowledge to do anything at present. In addition to exploring the quality of the outcomes of informal consultations, understanding patients' and providers' motivations in engaging in these consults will be critical to formulating an appropriate approach. However, at the very least, the professional training programs for health care providers should be supplied with evidence-based findings from which they can develop

educational materials for their students. On a recent national level medical board exam there was a question relating to a screen door informal medical consultation. The presumed correct answer was that the consultation should not be granted because there was no formal patient-provider relationship. However, to the knowledge of the author and as discussed previously, there are no regulations, guidelines, policies, or curriculum from which that answer could be derived. It would be interesting to discover the evidence or assumptions on which the question was based. The next step for health care training programs will be to develop a curriculum that prepares their students for the inevitable requests for screen door consultations and provides the student with criteria for accepting and conducting such consultations.

Conclusions

This inquiry confirmed the ubiquity of the communication phenomenon of the screen door medical consultation. It identified that health care providers perceive informal medical consultations to be more problematic than do the informal patients who consult them. The problematic nature of the informal consultations increases as the type of request moves from purely informational to a request for actual treatment. Since over 75% of the patients in the survey indicated there were not any reasons a provider should not provide informal consultations it is evident that informal patients do not perceive this distinction. The informal patient's motivation to pursue an informal consultation instead of a formal consultation is affected by relationship with, trust in, and access to the informal consultant. The willingness of the informal consultant to engage in an informal consultation is affected by relationship with the informal patient, the type of request made, and perception of risk/benefit for both the provider and the patient. Relationship may be primary to the other factors. Reiterating Kelly's nurse consultant, "it is only those with strong relationships that get treatment/information."

Individual health care providers should be prepared to respond to requests for informal medical consultations as soon as they are admitted to their professional training programs. Likewise, the health care system and society will need more data on the risks and benefits of these consultations for the individual as well as for society as a whole. Too little is known at this point to make evidence-based guidelines, policies or regulations for screen door medical consultations. If such guidelines, policies or

regulations are made in the future, it will be critical that they support the health care needs of patients and are consistent with cultural and societal expectations. If not, as Faith, a physician assistant, put it, “we would just have a new kind of prohibition. Instead of forbidding the sale of alcohol, they would be forbidding the provision of free health care. And that would go over just about as well as the first prohibition did.”

APPENDICES

Appendix A: HEALTH PROFESSIONAL SURVEY

I am a practicing physician assistant and a health communication researcher. I have had many experiences when people who are not my patients ask me for medical advice, information or care at times when I am “off duty.” I have learned from other health professionals that they often experience similar encounters. We call these encounters “informal medical consultations.”

This survey is about your experiences with informal medical consultations. By participating in this survey, you will help me understand how common these experiences are and what the similarities and dissimilarities are between the encounters. I am also interested in problems you have encountered or concerns about potential problems as a result of informal medical consultations.

The survey will take about 15-20 minutes to complete. At the end you will have an opportunity to provide me with your email address if you would be interested in participating in a follow-up interview.

Thank you.

Debra F. Nickell, MBA, PA-C
Doctoral Candidate
College of Communication
University of Kentucky

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

TITLE OF THE STUDY: A Qualitative Study of the Informal Medical Consultation

INVESTIGATOR INFORMATION: The researcher for this study is Debra F. Nickell, PA-C who is a graduate student in the Department of Communication, and is a faculty member with the Division of Physician Assistant Studies, University of Kentucky. Other individuals may assist with this study (transcriptionist).

PURPOSE: This research study will help Ms. Nickell understand the nature of informal communication between health care providers (such as physicians or physician assistants) and their friends who ask them for medical information or advice.

Dissertation advisors:

Nancy Grant Harrington, PhD
nancy.harrington@uky.edu

Michael I. Arrington, PhD
michaelarrington@uky.edu

DURATION AND LOCATION: This is a web-based survey. You may be contacted for an optional telephone, in person, or email interview if you choose to participate in that portion of the study and provide an email address.

PROCEDURES: You will be asked a number of questions about your experiences in informal medical consultation situations you have participated in. If you participate in the optional post-survey interview it may be recorded and transcribed into written text for study. After transcription any audio recordings of your interview will be destroyed.

CONFIDENTIALITY: Your name and any identifying information will not be used in any written report or publication resulting from this study. Any specific information that could identify you will be changed to ensure your privacy. Officials of the University of Kentucky will be allowed to review the research records related to this study. No one else will be able to see

any part of your interview transcript. If you supply your email address to Ms. Nickell, it will not be shared with anyone else. It will only be used to contact you in regard to this study.

RISKS AND DISCOMFORTS: The only risk to you as a participant is the discomfort you might feel in discussing some types of personal medical information or your friendships.

COMPENSATION: No form of payment is available from the University of Kentucky for participation in this study or for emotional discomfort as a result of participation.

BENEFITS: Discussing how you seek and use medical information may help you make better medical decisions in the future.

RIGHT TO REFUSE OR WITHDRAW: You may refuse to participate in this study or withdraw from participation at any time without any penalty.

OFFER TO ANSWER QUESTIONS: If you have questions about this study you may contact Debra F. Nickell at nickell@uky.edu. If you have questions regarding your rights as a participant of this study you may call the Office of Research Integrity of the University of Kentucky at 1-888-400-9428.

ELECTRONIC SIGNATURE:

I have read the information on the previous page. I am 18 years of age or older and I agree to participate in the study.

I do not agree to participate

Section one: Information about you

1. What is your profession? (Check all that apply)

MD/DO

Physician Assistant

Nurse Practitioner

Nurse

Nursing Assistant/CMA

Pharmacist

Physical Therapist

Student in one of the above professions

Other _____

2. What year were you born?

3. Are you male or female?

Male

Female

No answer

4. What is your race/ethnicity? (check all that apply)

Caucasian/White

African American/Black

Asian

Hispanic

Native American

Other

No Answer

5. In what Zip code do you live? _____

Section two: Think about the times that individuals *who are not your formal patients* have asked you for medical information, advice, or care while you were off-duty. (Please do not provide any information about individuals who are, or have ever been, your patient in your official practice setting.)

2. Who has asked you for medical information, advice or care while you were off duty?
(check all that apply)

- Friend
- Relative
- Co-worker
- Neighbor
- Stranger
- Student
- Other _____
- No answer

3. Who do you think asks you most often for medical information, advice or care while you are off duty? (Check only one)

- Friend
- Relative
- Co-worker
- Neighbor
- Stranger
- Student
- Other _____
- No answer

4. What do you think these individuals want when they consult you off duty? (Check all that apply)

- Explanation or clarification of what another doctor has told them
- More information on a diagnosis or treatment

Whether they should see a particular doctor (Is this a good doctor?)

Whether they should see a specialist

Which treatment (medical or surgical) should they choose

Whether they should seek medical care immediately or wait

What over the counter medication should they purchase

An examination

A diagnosis

Non prescription treatment

Prescription or medication request

Other

No answer

5. About whom do they consult you? (Check all that apply)

Self

Spouse/partner

Child

Parent

Another person (not listed above)

No answer

6. Why do you think people consult you off duty? (Check all that apply)

It is convenient/they have easy access to me

They trust/respect my medical knowledge

They value our relationship as friends, relatives, or coworkers

They want to avoid a trip to the doctor

They want to avoid co-pay or cost of visit

Frustration with medical system or their health care provider

Anxiety or uncertainty over a medical diagnosis

Anxiety or uncertainty over treatment decisions

Lack of access to the primary care provider

Lack of understanding about what they have been told by health care provider

Intimidated by or afraid to question health care provider

They are more comfortable talking to me than to their health care provider

7. Of the reasons you just identified, what is the primary reason people consult you off duty? (Check only one)

It is convenient/they have easy access to me

They trust/respect my medical knowledge

They value our relationship as friends, relatives, or coworkers

They want to avoid a trip to the doctor

They want to avoid co-pay or cost of visit

Frustration with medical system or their health care provider

Anxiety or uncertainty over a medical diagnosis

Anxiety or uncertainty over treatment decisions

Lack of access to the primary care provider

Lack of understanding about what they have been told by health care provider

Intimidated by or afraid to question health care provider

They are more comfortable talking to me than to their health care provider

No answer

8. Think about the information, advice or care you have provided to these individuals. Was it, in general, the same in quality/accuracy as you would have given to a formal patient in your clinic setting? (IMC = informal medical consultation)

The quality of information, advice or care I have given to individuals in an IMC is better than I give in my professional health care setting (clinic).

The quality of information, advice or care I have given to individuals in an IMC is about the same as what I give in my professional health care setting (clinic).

The quality of information, advice or care I have given to individuals in an IMC is not as good as what I give in my professional health care setting (clinic).

I do not know how the quality of information, advice or care I have given to individuals in an IMC compares to what I give in my professional health care setting (clinic).

No answer

9. How concerned are you that the quality of information, advice or care you have given to individuals in an IMC may not be as good as what you can give in your professional health care setting (clinic)?

It concerns me a great deal

It concerns me somewhat

It rarely concerns me

It never concerns me

No answer

10. How concerned are you that the individual consulting you may not be providing you with complete or accurate information?

It concerns me a great deal

It concerns me somewhat

It rarely concerns me

It never concerns me

No answer

11. What are the potentially positive outcomes for you as a health care professional as a result of IMCs ? (Check all that apply)

No potential positive outcomes

Increased confidence in my clinical skills

Better reputation

Better relationship with other health care providers

Better relationship with informal patient

Increased feelings of “doing good”

Other: _____

No answer

12. What are the potentially negative outcomes for you as a health care professional as a result of engaging in informal medical consultations? (Check all that apply)

No potential negative outcomes

Malpractice or litigation

A poor outcome for the patient

Loss of my license or employment

Conflict with the patient's formal health care provider

Loss of reputation

Loss of confidence

Other: _____

No answer

13. How often in the last 8 weeks have you experienced an IMC? (Please count each incident even if it is the same person consulting you.)

0

1-8 (up to once per week)

9-32 (up to 4 times a week)

33-56 (up to 7 times a week)

More than 56 (more than 7 times a week)

No answer

14. How concerned are you that the information, advice, or care you provide in an IMC may have a negative impact on your relationship with the person who consulted you?

It concerns me a great deal

It concerns me somewhat

It rarely concerns me

It never concerns me

No answer

15. In general, what effect does providing information, advice, or care to individuals outside of your professional health care setting have on your relationships with these individuals?

It has a positive effect on the relationships

It has no effect on the relationships

It has a negative effect on the relationships

It has both negative and positive effects or it is too variable to make a general statement

No answer

16. Have you ever refused a request for information, advice or care from a relative, friend, coworker, neighbor or stranger?

No

Yes

No answer

16a. Why did you refuse? (Check all that apply)

I did not think I had sufficient information or accurate information from the individual

I did not have the clinical knowledge or expertise to fulfill their request

The individual was requesting a prescription/medication

I did not feel it was ethical to fulfill the request

I feared potential malpractice or other legal ramifications

The request was inconvenient or annoying

Other _____

16b. Was your relationship with the individual negatively affected as a result of your refusal to provide information, advice or care?

It was not negatively impacted at all

It was somewhat negatively impacted

It was definitely negatively impacted

Section three: A survey cannot reflect all the varied experiences you have had with informal medical consultations. In the next section you will be asked to provide any additional comments you wish to make or describe experiences you have had that have not been addressed by the survey. You will be asked to describe a consultation that was particularly good and one that was particularly bad. I am interested in whatever you would like to say about these encounters. If you are willing to provide some additional details about your experiences you will have an opportunity to share your email address with me.

17. Please describe, in 200 words or less, an informal medical consultation that you have had that was “good” or rewarding in your opinion. Tell me why you thought it was good. (Please do not use the informal patient’s real name.) You have about 4-5 minutes to complete this question.

18. Please describe, in 200 words or less, an informal medical consultation that you have had that was “bad” or unpleasant in some way. Tell me why you thought it was bad. (Please do not use the informal patient’s real name.) You have about 4-5 minutes to complete this question.

19. Do you have any additional comments you would like to make about your experiences with informal medical consultations? (200 words or less. You have about 4-5 minutes to complete this question.)

20. I would like to obtain some additional details about the encounters you have described. If you would be interested in participating in this next phase of the study, please provide me with an email address below. (Your email address will not be shared

with anyone else and will not be used for any purpose other than to discuss informal medical consultations.)

Thank you for participating in this survey. Feel free to share this website with others who may be interested in completing the survey.

Appendix B: PATIENT SURVEY

I am a practicing physician assistant and a health communication researcher. I have had many experiences when people (friends, relatives or co-workers) who are not my patients ask me for medical advice, information or care at times when I am “off duty.” I have learned from other health professionals that they often experience similar encounters. We call these encounters “informal medical consultations.”

I am interested in finding out about times when you have asked an “off-duty” health professional who might be your friend, neighbor, relative, or co-worker for advice, information or care. I am not talking about times you might run into your regular doctor or nurse outside the office (for example, at the store). If you complete this survey, you will help me understand more about these encounters.

The survey will take about 15-20 minutes to complete. At the end you will have an opportunity to provide me with your email address if you would be interested in participating in a follow-up email interview.

Thank you.

Debra F. Nickell, MBA, PA-C
University of Kentucky

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

TITLE OF THE STUDY: A Qualitative Study of the Informal Medical Consultation

INVESTIGATOR INFORMATION: The researcher for this study is Debra F. Nickell, PA-C who is a graduate student in the Department of Communication, and is a faculty member with the Division of Physician Assistant Studies, University of Kentucky. Other individuals may assist with this study (transcriptionist).

Dissertation advisors:

Nancy Grant Harrington, PhD
nancy.harrington@uky.edu

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DURATION AND LOCATION: This is a web-based survey. You may be contacted for an optional telephone, in person, or email interview if you choose to participate in that portion of the study and provide an email address.

PROCEDURES: You will be asked a number of questions about your experiences in informal medical consultation situations you have participated in. If you participate in the optional post-survey interview it may be recorded and transcribed into written text for study. After transcription any audio recordings of your interview will be destroyed.

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any part of your interview transcript. If you supply your email address to Ms. Nickell, it will not be shared with anyone else. It will only be used to contact you in regard to this study.

RISKS AND DISCOMFORTS: The only risk to you as a participant is the discomfort you might feel in discussing some types of personal medical information or your friendships.

COMPENSATION: No form of payment is available from the University of Kentucky for participation in this study or for emotional discomfort as a result of participation.

BENEFITS: Discussing how you seek and use medical information may help you make better medical decisions in the future.

RIGHT TO REFUSE OR WITHDRAW: You may refuse to participate in this study or withdraw from participation at any time without any penalty.

OFFER TO ANSWER QUESTIONS: If you have questions about this study you may contact Debra F. Nickell at nickell@uky.edu. If you have questions regarding your rights as a participant of this study you may call the Office of Research Integrity of the University of Kentucky at 1-888-400-9428.

ELECTRONIC SIGNATURE:

I have read the information on the previous page. I am 18 years of age or older and I agree to participate in the study.

I do not agree to participate

Section one: Information about you

1. Are you male or female?

Male

Female

No answer

2. What year were you born? _____

3. What is your race/ethnicity? (Check all that apply)

Caucasian/White

African American/Black

Asian

Hispanic

Native American

Other

No Answer

4. In what Zip code do you live? _____

5. How many people live in your house? (Including yourself?) _____

6. What is the combined yearly income of everyone living in your house?

\$0-9,999

\$10,000-19,999

\$20,000-29,999

\$30,000-49,999

\$50,000-99,999

Over \$100,000

Prefer not to answer

7. How would you describe your household income?

Not enough to make ends meet

Just enough to get by

Comfortable

More than enough

Prefer not to answer

8. What kind of medical insurance do you have? (Check all that apply.)

I do not have any medical insurance

Medicaid

Medicare

Private insurance (for example, Humana or an HMO)

Other

No Answer

Section two: Think about the times that you have approached an off-duty health care professional to ask for medical information, advice, or care. This person might be your friend, a relative, a co-worker, or even a stranger. It is important that they have never been your formal health care provider. (In other words, you have never seen them in a clinic, office or hospital setting.)

9. Who have you asked for medical information, advice or care when they were off duty?

(Check all that apply)

Friend

Relative

Co-worker

Neighbor

Stranger

Other _____

No answer

10. What kind of health care professional have you asked for medical information, advice or care while they were off duty? (Check all that apply)

MD/DO (doctor)

Physician Assistant

Nurse Practitioner

Nurse

Nursing Assistant/Medical assistant

Pharmacist

Student (in a health care professional program)

Other _____

No answer

11. What did you want from the off duty health care professionals you have approached? (Check all that apply)

Explanation or clarification of what another health care professional has told you

More information about a diagnosis or treatment

Whether a particular doctor is a good doctor?

Whether you should see a specialist

Which treatment (medical or surgical) should you choose?

Whether you should seek medical care immediately or wait

What over the counter medication should you purchase?

An examination (For example, would you look at this rash?)

A diagnosis (For example, what do you think it is?)

Non prescription treatment (For example, should I put ice on it/?)

Prescription or medication request (For example, would you give me an antibiotic?)

Other: _____

No answer

12. What medical problem(s) did you ask the health care professional about? (For example, diabetes or pain.) _____

13. Who have you approached an off duty health care professional about? (Check all that apply)

Yourself

Spouse/partner

Child

Parent

Other _____

No answer

14. Why did you consult an off duty health care professional instead of your own doctor or another on-duty professional? (Check all that apply)

It was more convenient. (I have easier access to my friend/neighbor/co-worker/relative.)

I trusted/respected my friend/neighbor/co-worker/relative's medical knowledge

I valued my relationship with them as a friend/neighbor/coworker/relative

I wanted to avoid a trip to the doctor/ER

I wanted to avoid co-pay or cost of visit

I was frustrated with medical system

I was frustrated with my doctor

I was anxious or uncertain about a medical diagnosis

I was anxious or uncertain over treatment decisions I must make

I didn't have access to my doctor

I didn't understand what my doctor told me

I was intimidated or afraid to ask my doctor questions

I was more comfortable talking to my friend/neighbor/co-worker/ relative, than to my doctor

No answer

15. What is the main reason you consulted an off-duty health care professional? (Check only one)

It was more convenient. (I have easier access to my friend/neighbor/co-worker/relative.)

I trusted/respected my friend/neighbor/co-worker/relative's medical knowledge

I valued my relationship with them as a friend/neighbor/coworker/relative

I wanted to avoid a trip to the doctor/ER

I wanted to avoid co-pay or cost of visit

I was frustrated with medical system

I was frustrated with my doctor

I was anxious or uncertain about a medical diagnosis

I was anxious or uncertain over treatment decisions I must make

I didn't have access to my doctor

I didn't understand what my doctor told me

I was intimidated or afraid to ask my doctor questions

I was more comfortable talking to my friend/neighbor/co-worker/ relative, than to my doctor

No answer

16. Think about the information, advice or care you were given by the off duty health care professional. Do you think you received the same quality of information, advice or care that you would have received if you had been seen in a professional health care setting? (For example, in a clinic or hospital)

The quality of information, advice or care I received was BETTER than what I would have received in a professional health care setting.

The quality of information, advice or care I received was ABOUT THE SAME as what I would have received in a professional health care setting.

The quality of information, advice or care I received was NOT AS GOOD as what I would have received in a professional health care setting.

I DO NOT KNOW if the quality of information, advice or care I received was better or worse than what I would have received in a professional health care setting.

No answer

17. Did it concern you that the quality of information, advice or care you received from an off duty health care professional may not be as good as what you could have received in a professional health care setting?

It greatly concerned me

It somewhat concerned me

I never even thought about it

No answer

18. At the time you consulted the health care professional, did you think there might be reasons they should not give you information, advice or care outside of a professional setting? (Check all that apply.)

No, I did not think there were any reasons

I thought the health care professional might be uncomfortable with my request

I thought the health care professional might be afraid of giving me "bad" information, advice, or care

I thought the health care professional might be afraid of a lawsuit, or other legal problems

I thought the health care professional might be afraid of getting into "trouble" for giving me information, advice or care

I thought the health care professional might be afraid that our personal relationship could be harmed

No Answer

19. How did you use the information, advice or care received from your friend, co-worker, neighbor or relative? (Check all that apply)

I used it to make a decision whether to go to the doctor soon or to the ER
immediately

I used it to make a decision about seeing a specific doctor

I used it to make a decision about specific treatment options

I used it to make a decision about buying over-the-counter medications

I used it to make a decision about lifestyle changes (changing my behaviors)

It helped me be less anxious about my health, doctor's care, or treatment options

It helped me feel better about decisions I need to make about my health

It helped me understand the medical words my doctor uses

It helped me feel more certain about what decision I should make

It helped me understand my medical problem (how to take care of it on my own,
what I can expect)

It helped me understand better why my doctor wants me to do specific things or
take a specific medicine

Other _____

No answer

20. How often in the last eight weeks have you approached an off duty health care professional for information, advice or care? (Please count each time even if you approached the same person more than once.)

0

1-4 (up to once every two weeks)

5-8 (up to once a week)

More than 8 times (more than once a week)

No answer

21. Were you concerned that approaching your friend, neighbor, co-worker or relative for medical information, advice, or care might have a negative effect on your relationship with them?

Not concerned at all

Somewhat concerned or have been concerned in specific cases

- Often concerned
- Always concerned
- No answer

22. In general, what effect do you feel asking for medical information, advice, or care from your friend, neighbor, co-worker or relative has had on your relationship with them?

- It has a positive effect on the relationship
- It has no effect on the relationship
- It has a negative effect on the relationship
- It has both negative and positive effects or it is too variable to make a general statement
- No answer

23. Has a friend, co-worker, relative or neighbor ever refused your request for medical information, advice or care?

- No
- Yes
- No answer

23a. What reason, if any, did they give you for refusing? (Check all that apply)

- They did not give a reason
- They didn't think they had sufficient information or accurate information from me or about my situation.
- They didn't think they had the clinical knowledge or expertise to fulfill the request
- They said it would cause legal problems for them
- They did not want to give me a prescription or medication
- They did not feel it was ethical to fulfill the request
- They thought my request was inconvenient or annoying
- Other _____

23b. Was your relationship with the individual negatively impacted as a result of their refusal to provide medical information, advice or care?

It was not negatively affected at all

It was somewhat negatively affected

It was definitely negatively affected

Section three: A survey cannot reflect all the varied experiences you have had with informal medical consultations. In the next section you will be asked to provide any additional comments or experiences that have not been addressed by the survey. You will be asked to describe a consultation that was particularly good and one that was particularly bad. I am interested in whatever you would like to say about these encounters. If you are willing to provide some additional details about your experiences you will have an opportunity to share your email address with me.

24. Please describe, in 200 words or less, a time when you asked a friend, co-worker or relative for medical information, advice or care while they were off-duty and you thought it was a good experience. Please tell me why you thought it was good. (You have about 4-5 minutes to answer this question.)

25. Please describe, in 200 words or less, a time when you asked a friend, co-worker or relative for medical information, advice or care while they were off-duty and you thought it was a bad experience. Please tell me why you thought it was bad. (You have about 4-5 minutes to complete this question.)

16. Do you have any additional comments you would like to make about your experiences asking friends, co-workers or relatives for medical information, advice or care? (200 words or less. You have about 4-5 minutes to complete this question.)

I would like to obtain some additional details about the encounters you have described. If you would be interested in participating in this next phase of the study, please provide me

with an email address below. (Your email address will not be shared with anyone else and will not be used for any purpose other than to discuss informal medical consultations.)

How did you hear about this survey?

Sparkpeople.com

Craigslist.org

Someone told me about it

Other _____

No answer

Thank you for participating in this survey. Feel free to share this website with others who may be interested in completing this survey.

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