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Healthcare’s Responsibility to Care: The Call to Support Both Patients and Their Families Through Illness

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Healthcare's Responsibility to Care: The Call to Support Both Patients and Their Families Through Illness

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and Renée Crown University Honors
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Honors Capstone Project in Political Philosophy with Human Dynamics & Family Science

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Abstract

The contemporary healthcare institution operates on the philosophy of patient-centered care [PCC], growing from the medical culture of the past: care centered around an omniscient provider, defining the patient by their illness versus their identities. While this widely practiced philosophy succeeds in meeting the chief complaint and needs of a patient, it neglects to care for the patient in the context of his or her broader life constituents: the family and loved ones. Health care providers and their institutions are stopping short of adequate, all-encompassing healthcare when the family is not regarded as an equal member of the care team. The family is excluded from communication in the patient-doctor duo, and is not provided accessible resources to them. Not only does a patient's illness affect the entire family unit, but the family's health and wellness can also influence the patient's outcome. The philosophy of patient-and-family centered care [PFCC] includes all beneficial aspects of PCC, while additionally fulfilling healthcare's responsibly to the family. This results in promoting better quality care, producing healthier outcomes, and reducing both patient and hospital costs.

This thesis argues for an institutional shift in healthcare to adopt the PFCC philosophy into practice and enact uniform implementation. Through a review of contemporary literature and the long-practiced foundations of medical principles, a call to action has been issued for the healthcare system and its providers. In actively practicing communication and education, collaboration, inclusion, and accessibility of supportive services, providers can ensure well-rounded support for the family's needs and patient's needs. There are public health programs and communities already in place that operate on a PFCC philosophy, such as Camp Kesem: a week-long summer camp, and year-round support system specifically for children affected by a parent or primary caregiver's cancer. Learning about these programs and communicating them personally to patients' and their families is a simple progression in upholding their health care responsibility. PFCC takes active engagement of providers in order to promote an optimal, healthy quality of life.

Executive Summary

The philosophy of healthcare has made a significant shift towards improving patient care, experience, and outcomes since the paternalistic, omniscient physician-powered care of the past. This is largely in part to the wide-spread practice of the patient-centered care [PCC] philosophy. A healthcare philosophy is a fundamental nature of knowledge, practices, ideals, and beliefs central to the foundation and motivation of the healthcare system—healthcare providers and institutions— and its function. PCC lacks a universal definition, but is widely accepted as "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (IOM, 2001, p. 40). This philosophy is characterized by a physician-patient dynamic focused on valuing a patient's identity, autonomy, and beliefs in their own treatment. However, healthcare is due for an update.

Despite the benefits of the PCC philosophy, it neglects a crucial piece of a patient's well-being: the family unit. A family, in this context, should be understood as a group of individuals related by blood or marriage or by a feeling of closeness, but patients and families should be able to define their understanding of "family" as it pertains to care, decision-making, and serving as potential caregivers (Institute for Patient-and Family-Centered Care, 2010). A family member's illness may not physiologically impact the family; however, the impact can propagate through the family unit to impact their psychosocial wellbeing and life (Golics et al., 2013). Just as the patient influences the health of the family unit, the reverse is also true.

The responsibility of healthcare is to treat the chief complaint of the patient and beyond, by acknowledging, assessing, and caring for the environment of the patient, which includes the family members comprising it. As PCC stops at the patient, healthcare institutions must shift to practicing an inclusive philosophy of patient-and-family-centered care [PFCC]: "is an approach

to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families" (Institute for Patient- and Family-Centered Care, 2010). This philosophy requires engaged and proactive medical providers to communicate and educate the patient and family, to collaborate with families, to exercise cultural humility—learning about, including, and reflecting on other's and one's own identities, beliefs, and actions—through inclusion of families, and to provide proactive versus reactive supportive services. The uniform practice of PFCC is especially important for children. The parent or primary caregiver of a child lays the foundation for healthy social, emotional, and mental development (Bowlby, 1969). Therefore, when this role is compromised by illness, it is crucial to provide the child with substantial support to help them cope and adjust to this new developmental impact.

This thesis will assess the philosophy driving the relationship between the healthcare system—health care providers and institutions—and the family system. It will address the former's ethical responsibility to not only the primary patient, but the entire family unit, with support from health care literature review and a personal narrative. An overview of the organization Camp Kesem, is given as an example of a supportive resource that succeeds in providing healing family care and support for the entire family unit. The focus of contemporary health care is primarily on the individual facing illness, which is expected as this person requires immediate attention, treatment, and care. However, this does not negate that while serious illness, like cancer, may only physically affect a singular person, the impact of an illness is experienced by the patient's entire family unit. Treating the patient and the family is both an institutional and ethical responsibility of health care providers and institutions. As patient healing and family heath are interdependent, the healthcare system ought to shift to an operating philosophy inclusive of the family system.

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I dedicate this thesis to my mom, who was the patient and is now the survivor.

Advice to Future Honors Students

Write about your passion and create something you are proud of. Let this project be a labor of love.

Create a Thesis Support Group with your buddies. Love you, Danielle Schaf, April Kessler, Kyra Meister, Claudia Heritage, Hairol Ma, Dina Eldawy, Jake Smith, Jess Beyer, Julia Leyden, Julia Trainor, Katie Berrell, Katie Munster, Martina Morris, Nathan Shearn, Yona Lei, and Lorena Kanzki.

Chapter 1

The Focus of Contemporary Care

The visit is primarily an independent undertaking. A trip to the doctor is generally understood as an individual endeavor, no matter where one falls on the age spectrum, from a newly legal 18-year-old to an elderly person dependent on others. The family doesn't go on behalf of the individual, nor does the entire family unit need to be present in order for a patient to be seen. When considering one's treatment and recovery, the common relationship is between the patient and the physician. This two-person dynamic is the foundation of health care methodology: patient presents a chief complaint and the provider bears the responsibility to treat it. The role and attitude of the patient and provider have fluctuated historically. It began as a traditional, paternalistic doctor with control of treatment and the patient at whim of the provider's best judgement. Now, we have an approach that sees the patient as an active participant, beyond the ailment, and the doctor no longer serving as the ultimate decider. The latter trend is the result of modern healthcare's philosophy: patient-centered care [PCC].

Patient-centered care grew to popularity in the 20th century, as the medical field shifted to improve patient experience, satisfaction, and outcome (Jaen et al., 2010). Balint first described PCC as "understanding the patient as a unique human being" in 1969. This style and understanding extends beyond the provision of health care into medical education, law, research, and quality improvement. While ubiquitous internationally, there is still a diverse consensus on what in fact constitutes PCC (Fix et al., 2018). It is agreed in the medical community that PCC represents the shift from a traditional, paternalistic, provider‐driven and disease‐focused approach to a methodology that respects the patient as an autonomous person with experiences, emotions, and opinions affecting their course of treatment (Fix et al., 2018). In their literature reviews, Mead and Bower describe PCC as encompassing five conceptual dimensions: the biopsychosocial perspective; patient‐as‐person; sharing power and responsibility; therapeutic alliance; and doctor‐as‐person (Mead & Bower, 2000).

The traditional philosophy of healthcare prioritized eradicating the illness, following doctor's orders, and considering very few outside influences, including the family. This old method was even farther from family-centered healthcare than PCC. The five dimensions of Mead and Bower centralize the healthcare philosophy of PCC around a patient being valued beyond their illness. The doctor in turn serves as an understanding human, versus omniscient being. who provides relevance for a family's role in a patient's healthcare (Mead & Bower, 2000). The biopsychosocial perspective broadens treatment beyond the disease state to include the psychological and social domains of illness (Mead & Bower, 2000). This opens the perspective to understand the patient's illness in the context of their psychological and social wellbeing as a result of one's family history—genetic medical conditions, predispositions, or environmental health implications—and one's family dynamic (Mead & Bower, 2000). For example, one's family may be a main source of support and affirmation to a patient but is a traumatic trigger for others; the people around a patient can affect them in unseen ways, but to the same degree as a physical disease. People do not exist in a vacuum, and neither does illness. The importance of family and other social institutions also ties into the next dimension of the patient-as-person: understanding the patient's experience, in light of his/her life context (Mead & Bower, 2000). In addition to family, a person's work, education, culture, and community can play into illness onset, treatment, and recovery success (Bronfenbrenner, 1994).

The last three dimensions of patient-centered care focus more on the doctor-patient relationship but continue to neglect the family as essential social institution contributing to the patient's health. These principles are sharing power and responsibility: an egalitarian doctor—patient relationship; the therapeutic alliance: a professional provider-patient relationship encompassing empathy, cooperation, and beneficence; and the doctor - as - person: humanizing the physician with the patient (Mead & Bower, 2000). Here the PCC philosophy is the most exclusive. There is no availability for additional players in these dimensions. While the power of patient choice and autonomy should be left to the patient—a rational and self-governed person with medically protected rights and privacy—the responsibility extends beyond the confines of the primary duo. The responsibility of care rests on the provider, but the execution, commitment, and recovery tasks family, friends, and community, too. For example, it may be the responsibility of the doctor to schedule a chemotherapy treatment for a cancer patient, whose responsibility is to then get to the chemotherapy appointment. However, if the patient is too weak to drive or walk themselves to the appointment, it is the responsibility of family or the community to fulfill this care plan by serving as a partner in the treatment process.

Mead and Bower's dimensions of the therapeutic alliance and doctor-as-person dimensions have the potential to expand beyond an exclusively professional or exclusively doctor-patient relationship. Interaction and relation of the families with the hospital treatment team should be an essential components of patient care. In efforts to improve these relations with patients and the resident provider, Dr. Isabel Chen of University of Southern California took the lead on a new practice deemed the sixth vital sign. This method places an assessment in getting to know the patient on the same level of importance as physiological vitals such as blood pressure and pulse. The same approach of valuing interpersonal connection should be taken with families of a patient. Neglecting the emotional or mental needs of the patients' family, in addition to their need for connection and trust with the provider, has negative effects on the family's health (Khosravan et al., 2014). Lack of communication imposes unrealistic responsibility to the family, potentially resulting in adverse effects such as feelings of inadequacy, psychological burden, anxiety, depression, tiredness, and feeling of being alone in their patient care responsibilities (Khosravan et al., 2014). The provision of patient-centered care seems complex and exclusively practiced, as it ultimately lacks involvement and collaboration of the patient, the family, and the care team in considering and addressing all impacts on the patient's care (Smith, 2013).

In addition to five dimensions of PCC relayed by Mead and Bower, it is important to understand the foundational principles that guide all aspects of health care. These are the four commonly accepted principles of health care ethics, excerpted from Beauchamp and Childress: principle of respect for autonomy, principle of nonmaleficence, principle of beneficence, and principle of justice (Beauchamp and Childress, 2009). One thing these principles all have in common is that they are patient focused. The principle of respect for autonomy serves to uphold the patient's right to be treated as an independent, rational, and sovereign person with authority in his or her care. The principle of nonmaleficence requires that providers never intentionally create damage or injury to the patient, in either acts of omission or inclusion. The reverse of this is the principle of beneficence, which calls providers to solely and unconditionally act for the patient's best interest. Finally, the patient's right to fair treatment and availability of treatment is protected by the principle of justice. Every healthcare provider and institution is held accountable in upholding these four principles. They serve as the compass for any difficult decisions, ethical dilemmas, and patient care in general.

Yet, nowhere in the principle code of ethics does it mention a clause along the lines of a principle of external support or a principle of holistic care (American Medical Association, 2016). Of the population who are able to rely on others when their health fails, the current code of ethics in healthcare philosophy and the understanding of PCC is not sufficient. There is no responsibility of the physician to the family, and no standard form of assessing the family's well-being. Principle of respect for *patient* autonomy, principle of nonmaleficence is directed towards the *patient*, principle of beneficence aimed towards the *patient*, and principle of justice for the *patient*. Another patient-centered care outlined in *Crossing the Quality Chasm* only references the family inclusion through educating them to help make informed and safe health decisions, but still focuses on "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (IOM, 2001, p. 40). The philosophy of PCC upholds respect for patient rights and autonomy, but lacks the necessary inclusion of family into contemporary healthcare methodology. The core operating guidelines of not only PCC, but all medical care, practice as mutually exclusive systems on an isolated patient, when it needs to operate on collaboration from outside the patient-provider duo (Khosravan et al., 2014).

There are some circumstances, however, where the contemporary PCC model is sufficient. The current philosophy of healthcare and medical code of ethics especially suits and protects the minority of people who are left alone without a form of non-hospital support. Nearly 3 percent to 4 percent of the total nursing home population is without living family, friends, or non-hospital support, and the prevalence of incapacitated and alone adults range from 3 to 10% of hospital and long-term care populations (N. K., & E. W., 2004). The doctor of individuals like these, deemed the “unbefriended”, work under this medical ethics code with hospital staff to provide public guardianship to the patients without full functional capacity and without familial caregivers (Teaster, 2010). For this population under doctor and hospital guardianship, patient care needs to be completely centered around them, as their health is solely dependent on their own, life, body, and environment. It is in this circumstance that our contemporary, patient-centered healthcare philosophy offers the necessary direct and individualized support. If a patient has no family or close companions to look after the patient’s best interest, then a provider, whose care is completely centered around the patient, protects and respects them. It fosters the trust, communication, collaboration, and beneficence of a strong doctor-patient relationship, or provides a system to protect the patient’s rights and wishes if he or she is unable.

The importance of family engagement in healthcare decision-making and participation is a key aspect of pediatrics. However, in adult medicine, the *patient* and *family* are less linked as adults are their own autonomous decision-maker (Clay & Parsh, 2016). For cases of adults with severe cognitive impairments—significant developmental delays or disabilities—or conditions preventing full independence from others, the role of engagement is similar to pediatrics, as these adults require familial participation in their care (Cené, et al., 2016). Some actively engaged siblings gradually take over the role as core caregiver for a sibling with disabilities, by becoming the legal next of kin or assuming the responsibilities of the parent (Richards et al., 2016). It is increasingly understood or expected for a family to adopt an active caretaker role when another family member is dependent of them.

The contemporary model has certainly served its role in changing health care from a one-sided and paternalistic philosophy, to one that values the patient as a necessary voice in the care. This helps those, like the “unbefriended” or without secondary support, have control over their health. Exclusive doctor-patient communication is something widely practiced in Japan and European countries to give the patient a space to communicate candidly with the doctor without worrying about the family (Kimura, 2014). For families that are severely dysfunctional, have abusive emotional, substance, or physical relationships, or need a greater amount of separation and privacy, the PCC philosophy provides exceptional care and safety for the patient before anything else.

The patient-centered care philosophy has made healthcare a safer place to be a patient. The patient feels heard, the patient's needs are communicated, received, and met, the patient has a relationship with the provider, and the patient reserves the right to personal autonomy and respect in the healthcare realm. The definitions and descriptions put forward by Mead and Bowers' dimensions of PCC and the foundational ethics of Beauchamp and Childress make the patient paramount, or practically equal to the doctor interpersonally. As a result of this universally accepted patient care model, patients are healthier and using the healthcare system less, healthcare providers are more satisfied and better performing (Smith, 2013).

With adults who do not need significant assistance with daily life and live functionally independent, patient engagement and familial engagement are distinct from each other. The implied assumption is that familial engagement is optional or unnecessary (Cené et al., 2016). This is true for cases when a patient choses to exclude their family for confidentiality with the provider, or a family wishes to not be involved in a family members care, in which case PCC is an acceptable model. However, the patient is not the only person affected by an illness. The practiced healthcare philosophy must be able to accommodate and support families impacted by disease in their family unit: "We need systems in place in primary and specialty care practices, and across the entire healthcare continuum that encourage family involvement in appropriate facets of patient care to the extent patients desire" (Cené, et al. 2016). The patient's choice and need must be respected. This entails expressing the availability to have their family, in the patient's definition, as involved in decision-making and engagement in order to enhance patient care and provide the best patient outcome.

While patient self-management is a realistic expectation in some cases, for the greater patient population in who have an engaged family or who rely on family and others as the primary care managers, PCC is not an adequate care philosophy. Health literacy—"the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions"—paired with a communicative relationship with the family, helps family members support patients who are able and unable of self-management (Nielsen-Bohlman, 2004). It is important to provide the information and skills to all supporting members of the family unit for the specific ailment. This prepares them to better understand caregiver responsibilities, adapt to potential lifestyle or personal changes, and can practice the appropriate skills to manage and cope with the condition. While PCC is a universal healthcare philosophy that is positively changing the way the medical field operates, patient-centered health care is only the initial step. Achieving the patient and family inclusive care philosophy to support the patient and his or her networks and ultimately to promote an optimal quality of life outside of the hospital requires an institutional philosophy shift.

Chapter 2

Transitioning to Patient-and-family-Centered Care

The emergence of patient-and-family-centered care [PFCC] manifested into the medical field of practice behind the momentum of PCC, but specifically through pediatrics (Igel & Lerner, 2016) (Clay &Parsh, 2016). This incoming methodology of healthcare practice was pioneered and fought for by the families of children and youth with special health care needs [CYSHCN] and visionary professional leaders in medicine, surgery, and psychology (Family-Centered Care and the Pediatricians Role, 2003). They identified the effective and necessary components to the collaborative family provider relationship. Over the last 40 years, starting with civil rights legislation and advocacy for familial medical and educational rights in the 1960s, families have been able to advocate for the medical needs of their children alongside their doctor and the law (Wells, 2011). Today, educational equality for children with disabilities and early intervention laws are practiced as a result. The laws provide families' unique rights and responsibilities in their child's health, as well as created the expectation that families had important roles to play in their children's health care (Wells, 2011). These efforts have transformed the relationship between families and health care providers, laying down the necessary foundation for the future application of PFCC.

The Institute for Patient-and Family-Centered Care published a simple definition of the philosophy as "an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families" (Institute for Patient- and Family-Centered Care, 2010). It is also characterized by four core concepts: respect and dignity, information sharing, participation, and collaboration (Institute for Patient- and Family-Centered Care, 2010). There is a lack in medicine for the understanding of a patient in respect to his or her ecological environment of lifelong development with other human beings in the PCC philosophy. The ecological model of family systems proposes that throughout life, human development occurs through progressively more complex reciprocal reactions between people and objects in the immediate environment on a regular basis and over a long period of time (Bronfenbrenner, 1994). It is proven that the form, power, context, and direction of this development—the proximal process— among significant people and objects in the environment are more powerful in a person's development than the environment or context in which they occur (Bronfenbrenner, 1994). This model shows how illness of a family member can direct one's proximal process in a negative direction. People are increasingly shaped by others in their lives as the connection with another is closer. Thus, in healthcare, the effect of a patient on the family must be addressed, and vice versa.

This theory of ecological interaction also explains the importance and impact of the systems within a family and that a family resides within. There are five types of systems. Microsystems encompass the relationships and interactions a person has with the immediate surroundings like family, school, neighborhood, or developmental environments (Bronfenbrenner, 1994). Mesosystems link two or more systems in which the person, parent, and family live, providing the connection between the structures of the person's microsystem (Bronfenbrenner, 1994). The exosystem defines a person's greater social environment, that may or may not directly affect the person, but certainly imposes positive or negative impacts from the force on the microsystems (Bronfenbrenner, 1994). Examples include workplace schedules or community resources. A person's macrosystem combines the different laws, beliefs, customs, and influences of micro-, meso-, and exosystems to form an overarching pattern of a culture or subculture (Bronfenbrenner, 1994). These are greater systems that the collective life of a person creates, such as the stress of a parent’s illness impacting a child’s performance in competitive sports. The parent does not directly affect the sport, but through a child’s coping mechanisms, support system, and disposition, the parent’s illness caused an impact through the greater macrosystem. Finally, the largest system, the chronosystem, embeds the dimension of time in relation to changes in a person’s characteristics and environment (Bronfenbrenner, 1994).

There is a lapse of fulfilled responsibility of the healthcare system to the whole patient. The responsibility tasked to healthcare is to treat beyond the chief complaint by acknowledging, assessing, and caring for the environment of the patient and the family members comprising it. It needs to deliver care that is motivated by the understanding and protection of a person’s ecological family systems. The people, events, and environments a person develops around and within can affect them in a myriad of ways. PCC aims to serve the activities, personal roles, and function of the individual person in the context of illness, but lacks nourishment and acknowledgment of the interpersonal relationships, social roles, and the interactive components of the microsystem (Bronfenbrenner, 1994). The patient affects the microsystem and visa versa, all the way through to the chronosystem. PFCC accounts for this instrumental framework in its care philosophy. In supplying support and care for family members and supplying resources for the patient to interact with their environment as a person impacted by illness, PFCC formulates the practice around both patient and environments (Clay & Parsh, 2016). The responsibility of healthcare institutions is to deliver care equally and comprehensively to the full extent it is needed in a patient’s care, with regard to the family and the mesosystem.

Patient-and-family-centered health care does not suggest that contemporary healthcare systems scratch their current philosophies that do not directly address or include a patient’s family or ecological spheres. Rather, it calls upon these systems to expand the current practicing philosophy. PCC came to its widely practiced status in response to both patients and families refusing to participate in the medical world that belittled their opinions, disregarded input and suggestion, kept them ill-informed, and worked above them in a paternalistic mindset (Fix et al., 2018). Yet, in efforts to remedy these old-fashioned ways, healthcare systems mostly adopted changes from the patient’s perspective. PCC does not include the family in the communication, cooperation, trust, and confidence building between patients and providers. This methodology of treatment and patient-provider relationship formation needs to reconsider this philosophy, reopen the qualms and drawbacks that brought healthcare practice to the PCC philosophy, and continue addressing the remainder of the changes. This added effort in consideration for the family completes the patient experience.

Practicing PFCC is practicing true holistic medicine. This is a type of medicine that “approaches the physical, emotional, spiritual, and social aspects of a person as they relate to health and disease” (Borins, 1984). In the clinical setting, the holistic approach to medicine uses treatments and interventions outside of the manufactured or chemical realm. This medical philosophy looks deeper into potential effects on the whole patient—home and outdoor environment, past injuries, habits, mental health, spirit, emotion, the body—and how alternative methods of medicine can remedy the illness. Holistic medicine accounts for the aspects of illness that can’t be seen in blood tests or scans. It aims to heal patients with medicinal alternatives from natural sources or one’s own mind. For example, many cancer patients prefer a lifestyle change to further prevent cancer, by avoiding carcinogens and becoming more active. People with orthopedic or physical illness may chose a treatment regimen that contains herbal teas, oils, mental coaching, and physical therapy to treat the internal and external aspects of the body equally.

PCC practices in this holistic theme by seeing the patient beyond the illness, as a human with emotions, autonomy, and rationale. However, PFCC is truly holistic in that it values the impact of illness on the entire family unit and the entire family unit's impact on the patient. This philosophy brings holistic medicine to the whole family, because it recognizes how important the family is to a patient's healing process. Hospitals where PFCC is part of the organizational culture find not only that patient, family, and staff satisfaction ratings significantly increase, but also that patients' health outcomes improve by needing less frequent check ups, getting proper diagnoses, and following through with post-hospital instruction (Family Presence, 2012). The patient-and-family-centered care philosophy is the most ethical because of this all encompassing, holistic methodology: caring for the whole patient in the microsystem and all people affecting the patient in the meso- and exosystems. Centering around the patient while using an exclusive patient-provider relationship only goes so far until consideration must be made to continue healing in the family in order to promote the patient's health.

Arguing the importance and preference of patient-and-family-centered care does not remove the patient as the autonomous owner of his or her healthcare decisions (Clay & Parsh, 2016). Rather, it is a medical care philosophy that better supports a patient's choices through the context of his or her broader life constituents. PFCC respects a patient's autonomy beyond the defined scope of patient-centered care, in acknowledging and supporting the role a family takes or does not take in a patient's life. For the "unbefriended" adults under medical care, or the patients who opt out of an informed and inclusive medical relationship with their family, PFCC still provides these situations with a better healthcare philosophy. While PCC stops short of treatment beyond the patient as a rational being in the patient-physician relationship, PFCC acknowledges and incorporates the influence of one's family and domestic sphere, in all definitions in which it manifests for a patient (Clay & Parsh, 2016). A patient's family may be non-existent or abusive in some way to the patient. PFCC does not necessarily require the family to be involved in every aspect of care in these cases, as involvement would further harm the patient or is not applicable. This care philosophy is meant to recognize the effect of family or lack of family on a patient, as both can impact the patient's wellbeing and long-term health. The scope of care is expanded with respect to the patient and the other people that affect the patient.

While like PCC, there is no universal definition of PFCC. Yet, recalling the Institute for Patient- and Family-Centered Care's simple definition comprising of the four core concepts of respect and dignity, information sharing, participation, and collaboration, the two bases of PCC and PFCC can be compared (Institute for Patient- and Family-Centered Care, 2010). Using this working definition and simplifying its terms, we find that PFCC is paramount to PCC in four ways: communication and education, collaboration, inclusion, and supportive services. PFCC starts with open communication between doctor, patient, and family, with active education and health literacy promotion. The team can then collaborate under the same medical and personal understanding, resulting with inclusion of the family in delivering the best care to the patient. This communal physical, emotional, spiritual, and social healing is nourished by the healthcare institution and then sustained through the accessibility of supportive services, such as support groups or sustainable health programs. By promoting all four of these aspects in healthcare dedicated to the patient and family network, healthcare fulfills its role and responsibility to serving people in the present with care that lasts into the future.

Communication and Education:

Patients and their families can provide crucial information to healthcare providers in regard to improving the patient's care. This information can range from allergies, past illnesses, family history, predispositions, personal preferences, religious or social customs, and more. Some families or patients may feel comfortable bringing up any pertinent information naturally, but others need the invitation to do so. Openly communicating with the family and the patient includes the family as a vital part of the care team, while establishing trust in the provider. Creating this safe space for dialogue between all parties is how PFCC fosters communication. Family members may bring a different perspective to the care plan, provide information missing on medical charts, and be able to recognize and prevent errors in care delivery. Using a personalized approach to connect with the patient compliments the open dialogue created between all parties.

This communication requires providers to take the time to understand and connect with the patient and family to gauge their health literacy. Health literacy is synonymous to medical literacy as “an individual's ability to obtain, understand, and apply health information to make appropriate health decisions” (Nielsen-Bohlman, 2004). Healthcare professionals should have a competency in relaying information in clear and common language to patients and families to ensure all members have the tools and knowledge needed to support the patient. Healthcare providers should also be expected to foster an environment where the patient and family feel comfortable and able to ask questions. A method for this is using patient-focused interviewing, which is a less authoritative style that indicates to the patient that the provider values both non biomedical and biomedical perspectives, plans, and beliefs (Tervalon & Murray-Garcia, 1998). This practice should be adapted to be patient-and-family centered care in order to form an atmosphere that gives the patient a voice in their own care and illness story, but also allows the family to express their needs, communicate the effect of illness or treatment on them, and open a cross-cultural understanding of their family unit mircosystem.

Establishing this common ground is essential, as lower levels of health literacy have been associated with more frequent hospitalizations, increased emergency room use, less utilization of preventive services, and inability to manage complex interventions (Berkman et al., 2011). The discrepancies in health literacy between provider, patient, and family can negatively impact the patient's wellbeing, and have shown to especially perpetuate lower rates of health service use and worse health outcomes of people with lower health literacy, than people with higher health literacy (Batterham et al., 2016). The World Health Organization adds to the definition of health literacy in that it "implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions" (Nutbeam, 1998). Including references to one's community and living conditions recognizes that proper health literacy communicated and educated from the healthcare institution providers is not only important for the patient's person care, but the care of the mesosystems and individuals that comprise it. Providers must be conscious of how information is received and executed in order to best utilize family members' as additional patient knowledge and care takers.

Collaboration:

Once the family is educated alongside the patient with transparent communication, they can be utilized as an integral part of the healthcare team. The holistic care of PFCC comes from this familial support in execution of the treatment plan within the hospital. This philosophy recognizes the incredibly beneficial role that family members play in the extended outpatient planning and at-home care giving. Patients are only as successful as the instructions provided to them and the follow through of post-hospital care plans. A study on the decision-making experience among women diagnosed with stage I and II breast cancer observed that women who adopted a collaborative role in their breast cancer or general health treatment were overall more satisfied than those who were less active (Sabo et al., 2006). The results also proved the increased popularity of the shared-decision-making model, "in which decisions about treatment arise as a direct result of mutual negotiation between the patient and physician and not exclusively from the physician's own opinion" (Sabo et al., 2006). This concept extends beyond the patient-physician duo, as nurses reported in a study that "financial, emotional, and value-based considerations should be part of the family's involvement in decision-making" with a patient, yet ranking the emotional consideration for involving the family as the most important (Itzhaki at al., 2016).

The family inclusion and proper communication in PFCC also protects the patient from the domination of a provider in the treatment plan, and can prevent uneducated or lone decision making (Tervalon & Murray-Garcia, 1998). This requires the treatment plan to be taught to the family members, so they feel confident in fulfilling their role. By valuing the patient's family in the patients' health care experiences, clinicians can better work towards the individual's health with the whole family unit in a mutually beneficial relationship. This mutually beneficial relationship is a core component to the benefits of PFCC; when all three components of the healthcare trio—provider, family, and patient—are equally valued and included to the extent expressed by the patient, then the patient receives better quality hospital care and at home care, and the providers have extra support in their responsibilities from the family. One study showed family members often voluntarily took over low skill, routine patient care tasks for the patient, which helped over worked nursing staff, increased familial confidence in providing care for their loved one, and accelerated performance of the care (Khosravan et al., 2014). Yet without sufficient information on care responsibilities for the family, this collaboration leads the patient's to worry and fall into a sense of insecurity, versus the feeling of security and comfort for the patient when care was provided by family (Khosravan et al., 2014). Beneficial results, such as fewer hospitalizations, faster recovery, and successful adoption of healthier habits, can come from using the family as a post-hospitalization and home-care ally, but only when properly educated on the care needed with adequate inclusion and integration into the healthcare team.

Inclusion:

With respect to the patient's choice and doctor-patient confidentiality, the family should be incorporated into the development and sustainability of a relationship with the medical providers. The effort should be made by all staff on the healthcare team, such as nurses, therapists, social workers, residents, and physical assistants; however, the majority of the responsibility is on the primary provider, typically the physician. When doctors work to create a professional, respectful, and communicative relationship with the patient, the family members should be entitled to the same relationship formation. This includes noting communication needs of the family members, such as a translator or being mindful of impairments. Accommodating and understanding the needs of each patient's family can only be fully fulfilled in creating an inclusive healthcare team with the family.

Additionally, understanding a family's religious and cultural practices enables the physician to adapt treatment options and care to appropriately accommodate the family, in addition to enforcing conscious self-awareness of culture. Forming this inclusive healthcare team relationship is one of many areas in healthcare that requires immense cultural understanding and competency. This can be achieved through cultural humility, which calls providers to commit to self-evaluation and critique, to redressing the power imbalances in the physician-patient dynamic, and to developing mutually beneficial and non-paternalistic partnerships with communities on behalf of individuals and defined populations" (Tervalon & Murray-García, 1998, p 123). Providers need to communicate to the patient's and family's cultural understandings, in order to reach health literacy, understand the patient and their ecological family systems, and form strong trust. Cultural humility can be utilized in contexts from individuals "with ethnic and racial differences, to differences in sexual preference, social status, interprofessional roles, to health care provider–patient relationship" (Foronda, 2016).

In a conceptual research design by Dr. Cynthia Foronda, there were six attributes found essential to achieving cultural humility in the medical field: openness, self-awareness, egoless, supportive interactions, and self-reflection and critique (Foronda, 2016). Openness—the willingness to explore new ideas—and egolessness—being humble and equitable—can be practiced by physicians seeing their patients and families as teachers of their culture, normative medical practices, family histories, and identities (Foronda, 2016). The physician can then incorporate the patient's cultural norms and family practices into the treatment and care plan, valuing each perspectives of health. Self-awareness is practiced when providers acknowledge one's own limitations, abilities, beliefs, and potential biases to provide inclusive and uniform medical education, communication, opportunity, and care for all patients (Foronda, 2016). Supportive interactions are driven by the healthcare institution emphasizing self-reflection and critique in all employees' patient care. By reflecting on one's thoughts, feelings, motivations, and actions to adjust one's self in providing better care and learning from mistakes, the interactions with patients and families are supportive and validating "as intersections of existence among individuals that result in positive human exchanges" (Foronda, 2016). In exercising each of these with co-workers, patients, and the families, a provider can promote and appreciate diversity in care and medicine, while preventing a power imbalance. The healthcare team achieves “mutual empowerment, partnerships, respect, optimal care, and lifelong learning” when making cultural humility a core component of patient care and familial inclusion (Foronda, 2016).

By including the family in the healthcare team, the family can support the providers and staff by executing busy work and minor tasks for the patient, in accordance with the patient’s wishes of the family’s inclusion. Family members can be used to fulfill minor tasks like feeding the patient, changing bedding, and other tasks dependent on the level of training needed, like administering medications. Performing these tasks help the family gain more control of their situation that is mainly dictated by the illness, as well as makes the patient feel more comfortable with the personal touch of family (Khosravan et al., 2014). As a result, the medical providers are able to be more mindful and intentional with the care they provide, as they have more time to focus on the treatment and care that only trained professionals can provide. Creating this mutually beneficial relationship forms trust with the patient’s family (Khosravan et al., 2014). In turn, the formation of trust makes the primary care of the patient easier: family members will be involved in promotion and follow through of discharge orders, providing emotional support for the patient, assisting the doctor with information, and occupying one less area of concern. This element is key in the therapeutic and supportive relationship of the doctor, family, and patient dynamic.

Support Services:

The most significant difference from PCC to PFCC is the availability and promotion of supportive services for families. Services like rehabilitation programs, emotional health resources, and support groups are provided to patients to help them cope with their new life affected by illness. In practicing PFCC, these resources should be equally available for the patient with their family, and exclusively for the family members. Supportive services help families adapt to and process a loved one's conditions or treatments, as well as provide post-hospital support following discharge in adjusting to the new medical challenges in life. Supportive services specific only to the patient are important for the patient's self-growth through their medical needs by introducing them to a community of people experiencing similar illnesses, increasing functional confidence in the new routine, and overall improving their psychological adjustment to illness and disease. However, the patient is not the only one affected by an illness or the only one adapting to life with an illness; family members are indirectly affected and need equal support as the patient. A social worker, cited in research on patient-centered care, reported, "[Medical providers] go into the healthcare field with a certain perspective, but patients have an entire family and environment that is affected by their health" (Fix et al., 2018). It is the philosophy of PFCC that acknowledges the health of the family with respect to the patient and how their environment may be changing.

Providing resources for families and their role as caretakers early in the treatment process allows them to ease into any new changes in their lives, as well as better support the patient. They can feel more comfortable with the news of a diagnosis, knowing there is support for them from the healthcare team and from alternative sources. Hearing that a loved one was just diagnosed with cancer can be earth shattering for families. However, being told they can use the hospital therapists and chaplains, while receiving contact information for support groups, and having a doctor that immediately looks to support the family in parallel with the patient, can positively route the next steps and emotions for the family. The goal is to provide more proactive support, as opposed to reactive support. Families and patients should be met with accessible and known supports upfront, as opposed to supports reacting to help an individual experiencing a negative response. This is key. Proactive and preventative support should be based on the initial patient and family assessment conducted by the physician when interactions are just beginning. This foundation then serves as a continuum of care and reassessment. Some family units may not need and outpouring of these resources, while the opposite is needed for others. However, these psychosocial support services—social worker, chaplain, community groups—complete the role of the medical assessment: to address the needs presented with available and accessible resources.

Continuing these services and checking in on the family's well-being is a continued benefit for the provider. This upkeep can alert the provider of any changes in the patient's environment that may not come up in a routine check in. For example, a caretaker could have fallen into a bout of depression and been neglecting a designated responsibility of care to the patient. Or, family members may have been introduced to an incredibly beneficial support group, and influenced the patient with more positive energy that is improving the patient's mental state. Communication with the family as a contributing segment to the healthcare team minimizes detective work by the doctor in the patient's life, as the communication channels are opened and frequented. These supportive resources serve as an ongoing assessment of the psychosocial well-being of the patient and family. Healthcare systems would be beneficially expending its energy and resources by engaging not only patients, but their families in the supportive services offered.

Focusing on the family, alongside the patient, adds a whole aspect of necessary and proactive healthcare to a provider's job that benefits them and the patient in the long run. By including the family in the initial diagnosis, rationale of treatment, and education of the ailment as part of the healthcare team, the provider creates a relationship with the patient and family through opened communication. If the patient allows familial inclusion, this foundation is crucial for families to understand what responsibilities they have in caring for their loved one. It is equally important for the provider to establish this base, so he or she knows the family and patient are aware of all pertinent information, all expectations, and the plan of action. From this introduction, the provider can assess what services the patient needs to heal physically, emotionally, and mentally, **and** additionally address what service the family needs to best adapt to this environment and support the patient. Families should know they do not serve as helpless spectators, alone in their loved one's diagnosis. Rather, they should feel empowered in knowing the essential role the family unit plays on the healthcare team.

Chapter 3

Exploring the Hesitation to Family Inclusive Care

After exploring the few, yet crucial differences between patient-centered care and patient-and-family-centered care, it is challenging to understand why healthcare has never included the family. The family unit serves as a major factor in the influential microsystem, and deserves a place in medicine's foundational and operating principles. PFCC requires healthcare providers to take that extra step beyond the patient, into their life, relationships, and support networks, in order to further improve the care being delivered to the patient. The arguments that favor PCC over PFCC are similar to those seen before healthcare evolved to the PCC methods practiced now. Unfortunately, the issues lie in the front line of role models for execution of a new philosophy of healthcare. Many clinicians still fear PFCC is a “touchy-feely” approach that costs staff too much time while depleting numbers to focus beyond the primary patient. There are arguments that this is not a cost or time efficient model, and that engaging in a patient-and-family centered care philosophy can come dangerously close to violating the patient’s right to autonomy (Smith, 2013). These are perpetuated by the systematic barriers in the healthcare system: nonuniform technology and policy, no singular model that fits all specialties, and providers being unengaged in PFCC policies that require additional work and individual attention (Small, 2011). These barriers, while identified and studied in one Cleveland clinic by nursing staff, can be applied to healthcare as a whole.

Current implementation of consistent patient-and-family-centered care policies without its uniform enforcement in all care facilities is challenging and inadequate. Different geographic locations, health administrations, and technological availability keep the national healthcare scheme in a stagnant and slow cycle for each patient. There is no code of PFCC or standing order that requires every provider and health system to create a relationship with the family alongside the patient. The basic code of ethics leave room for mediocre additional emotional and supportive care from providers in two of the five concepts: the biopsychosocial perspective and the patient - as - person. Yet, all five dimensions of PCC neglect the explicit recognition of the family and support group in a patient's recovery and treatment, when it could be categorized sensibly in the concept of the therapeutic alliance (Mead & Bower, 2000). Policies promoting the code of ethics and the five dimensions are barely standardized in the diverse fields and levels of healthcare, which makes instating a new philosophy of healthcare a seemingly unrealistic endeavor and a waste of efforts. However, faster standardization of PFCC needs independence from other standardization projects (Small, 2011). Waiting for technology and the era to catch up to the needs of healthcare now, only slows PFCC implementation. Successful institution and practice implementations are done with what is available in the moment. These efforts are supported by the overarching facility's administration through continued education and role modeling (Small, 2011). Every member of the healthcare field must make the best effort possible to be diligent in learning, instating, and modeling these PFCC practices.

The lack of uniformed implementation also decreases the effectiveness of the PFCC model itself. In an ideal, wipe-spread implementation, PFCC actually reduces costs on hospitals and promotes better patient outcomes. In a study on the type and amount of care that families provide the patient, the nursing staff was utilized increasingly for their occupational skills and delivered more efficient health care (Khosravan et al., 2014). This is a result of families assisting the nurses in unskilled tasks to care for the patient that then free more time for the nurses and bring satisfaction to the patient from increased interaction with family: "Most of the nurses and families believed that family participation is both voluntary and compulsory" (Khosravan et al., 2014). Families have an inherent desire to help their loved one and feel a familial obligation to care for them, they only need to be directed how. This is where executing cultural humility in educating families with health literacy is essential to their collaboration and inclusion with the healthcare team. Family members are available to be utilized for the tasks that exhaust providers and allow fatigue and stress to interfere with their patient care. With more familial responsibility in the care plan, doctors and nurses are able to create better relationships with families and communicate their expectations for the family.

Along with saving money from reducing extra staffing numbers, meaningful engagement of providers with their patients to fully educate them on diagnosis, treatment options, and recovery, is found to decrease costs (Smith, 2013). By patients choosing the best options for their care with advice from the provider, the patient will hopefully spend less on future hospital visits. For instance, reports show that informed patients, compared to less informed or included patients, are up to 20% less likely to choose elective surgery (Smith, 2013). This shows that with when patients are given more time with the physician to learn their options, they are able to choose less aggressive and costly therapies that better suit their quality of life. Having an informed family only complements these statistics in finishing rehabilitation tasks and supporting post-hospital care. Families are engaged by promoting their loved one’s health, spending less money on reoccurring doctor’s appointment, being affect with less chronic illness in the family, and having more time to spend on family.

One of the most frustrating experiences for patients is the referral process (Neimanis et al., 2017). Providers tend to excel in their practiced specialty due to their expertise in this one field after many years of specific education and training. However, this can often install a culture of mutual exclusivity among physicians and nurses. Traveling from appointment to appointment, and changing physicians and staff takes as much of a toll on the patient as it does on the family supporting them. This process dissipates any continuity for the patient's care and treatment. This is especially true when the original provider assumes a diagnosis outside his or her realm of practice, and sends off the patient with no effort to problem solve, meager attempts to grow a connection to obtain more information from the patient or family, and little personal or time investment in the patient. The patient and family are then left to the whim and practicing philosophy of the next physician, as there is no singular patient care model that fits all specialties and roles. Surgeons struggle establishing trust with a patient, for they may never connect beyond an exchange of first names and a concise debrief of the procedure (Chipidza et al., 2015). While, alternatively, family doctors may know the patient's history—both personal and physiological—from when he or she was born (Chipidza et al., 2015). Yet, a dermatologist could know more about a patient, than the patient's primary physician. It is dependent on which provider nourishes a connection with the family and patient and which does not. Even more often, a nurse will know the patient exceptionally better than the physician, because they are a role that supports at the bedside for every need of the patient and family (Hayward & Tuckey, 2011).

Commitment to the same policies is essential for all members of the healthcare team—from nurses to physicians and every role in between, representing each field—in order to change healthcare's philosophy to practice PFCC. This means being an expert in one's specialty, along with being well versed in all other specialties, but mostly in the patient. Problem-solving practices and knowledge-acquisition strategizes need to be clarified and standardized, while promoting inter-specialty flexibility and cooperation (Small, 2011). In practice, this takes shape in providers using their open-mindedness and self-reflection from cultural humility. This practicing culture promotes providers' continued education in looking deeper for the solution a patient needs, instead hastily passing them off as a referral. This will prevent providers from dangerously practicing outside of their scope, but enhance their patient care involvement and level of connection with the family. The healthcare institution needs to define referrals as a final option in making a trusting transition of the patient and family to another area of healthcare, not a hand off that removes them from the patient.

PFCC is only successful when the people embodying it are engaged and dedicated. Its successful implementation needs more than the standardization and inter-specialty competence of policies and procedures discussed above; it needs active participation, consistent management, and motivation to apply these skills and knowledge (Small, 2011). Nurse engagement with patients and families is shown to be more important for the health of the patient than staffing size (Blizzard, 2005). This is also shown with clinician involvement: physicians that engage with their patients as active members in their own health care, along with effectively communicating with the family on expectations and engagement, have been associated with improved patient conditions (Smith, 2013). The time spent on emotional connection and understanding of the physician with the patient is more important than booking the maximum number of patients with a physician. The same goes for family. The better connection the family has with the patient and doctor, the better the patient's outcome. These deeper, more personal connections propagate empathy—the ability for the doctor to put themselves in the patient's and family's position. This is another crucial quality to a strong provider-patient-family relationship. The PFCC model emphasizes the value of the family through an empathetic understanding that they affect the patient profoundly.

The push back on PFCC implementation due the fear of violating patient autonomy is perpetuated by the inherent barriers of the medical field. This claim is less well-founded and more indolent in reality. It results when providers do not use the engagement and consistent reinforcement required for PFCC, such as taking time to get to know the patient and family, ensuring all members are at the same health literacy, and maintaining open, collaborative communication. The ethical power of PFCC, while largely emphasizing patient and family rights, is actually concerning patient autonomy. PFCC represents a shift in medical culture that has a solid ethical standing, as “behaviors associated with patient-centered care, such as respecting patients’ preferences, should be justified on moral grounds alone, independent of their relationship to health outcomes” (Millenson et al., 2016) (Epstein & Street, 2011). The mission behind this philosophy is to be aware of the moral implications providers face, based on their respect for patients as unique human beings, who doctors are obligated to care for in that person’s best interest (Epstein & Street, 2011). There is no requirement of patients to release medical information or access to family, nor is there a requirement to make family a part of the healthcare team regardless of the patient’s will. The issue lies in the healthcare system being able to support any family member of the patient willingly, and to integrate them into the care program, if in the patient’s best interest. Patient autonomy is paramount. If a patient is more comfortable alone with the provider, excluding the family from a role in the healthcare team, then that care will be most beneficial to that patient. However, if the patient is most comfortable and engaged with an emotionally supported and reciprocally supportive family, then this will create a better outcome for that patient. It is healthcare’s responsibility to be equally prepared to adapt its approach to each.

The Institute for Patient and Family-Centered Care serves as a locus for the definition, mission, and outcome goals of PFCC. The organization upholds four core concepts for the philosophy: dignity and respect, information sharing, participation, and collaboration (Institute for Patient- and Family-Centered Care, 2010). The first core concept supports patient autonomy, as it is the healthcare team’s job to uphold respect and dignity for the individuality of the patient and their wishes. From this basis, the patient is in control of information sharing between the health care providers and the family. The patient is in control from the start with the level of participation from the family in the medical decisions and planning, and collaboration between all members of the health care team with the family. The patient is given the choice of involvement degree with in the PFCC model. Its primary goal is “to promote the health and well-being of individuals and families and to maintain their control” (Institute for Patient- and Family-Centered Care, 2010). Patient autonomy is the valued start of a patient’s control and involvement in their healthcare, partnered with exceptional familial support.

Chapter 4

Patient-and-family Centered Care through Supporting Models

As patient-centered care has grown to be more widely accepted, patient-and-family care has also developed a base of support and research from healthcare providers calling for a rewrite of their guiding philosophy. The literature includes the principles of Patient and Family Engagement (PFE), the Patient-Centered Medical Home (PCMH) model, and the approach of Patient- and Family-Centered Care Methodology and Practice (PFCC M/P). As opposed to focusing on the patient-provider relationship, these models and guides prioritize cultivating the triad of patient, family, and provider. All of these are supporting components towards the end goal of PFCC.

Along with the models discussed, there have been additions to promote the PFCC philosophy from other sources through mandating and quantifying the quality of care. In an effort to move from healthcare compensation for providers based on volume of patients, under the Medicare Access and CHIP Reauthorization Act (MACRA), physicians were paid for the value of patient care (Michael et al. 2016). Physicians’ pay was reliant on both the patient-caregiver experience and the patient-reported outcomes. In other legislature, the Patient Protection and Affordable Care Act of 2010 (ACA) set requirements for inpatient hospital visit funds to be linked with quality and value measures. The Center for Medicare and Medicaid Services (CMS) saw this could be consumer driven by the patient, and they initiated the Value-Based Purchasing program as an incentive for hospitals to instate improvements continually and adapt PFCC changes to the complex structure of healthcare. CMS also launched Partnership for Patients (PFP) hoping to challenge organizations to be increasingly patient and family centered in the care delivery processes (CMS, 2010). These are just a few examples of national government and massive corporation support of PFCC.

The guidelines of Patient Family Engagement (PFE) and the Patient-Centered Medical Home (PCMH) model go hand in hand to ensure optimal health outcomes. PFE has showed to produce improved quality assessments of care, but has yet to show great improvements beyond satisfaction (Cené, et al., 2016). However, the aspects of partnering with patients and families supports strong potential for a future of high-quality health care and optimize outcomes via the patient's engaged family. PFE is an essential component of the PCMH, whose joint principles include an available personal physician, physician directed medical practice, whole person orientation, and coordinated and/or integrated care (AAFP et. al, 2017). Within these principles are two points that encompass the benefit of this model; PCMH is "a care planning process driven by partnerships between physicians, patients, and the patient's family" and supports "active participation of patients and families in quality improvement at the practice level" (Cené, et al., 2016).

The PCMH model provides a crucial stepping platform for universalizing PFCC, however, it negates the inclusion of "family" in its name. Including PFE as a component, ensures that family will be a strong consideration in a patient's care, but the specific and consistent inclusion of the term "family" in the philosophy of healthcare is crucial (Cené, et al., 2016). Philosophies like PFC need to be permanently placed in care practices across the entire healthcare continuum in order to support family involvement in the appropriate facets of patient care to the desired extent of the patient. Keeping the explicit emphasis on family in patient care— all types of families falling in the definition as "two or more persons related in any way- biologically, legally, or emotionally" or as defined by the patient—ensures that these healthcare systems will respect a patients' choices about who will participate in their care (Cené, et al., 2016). PCMH provides a supportive framework for this family centered approach to take viable roots and grow in health care practice.

The Patient- and Family-Centered Care Methodology and Practice (PFCC M/P) was developed at the University of Pittsburgh Medical Center by Anthony M. DiGioia and his team, to be an attainable practice of transitioning patient-and-family-centered care from an ideal to reality. This model is transformative in the evolution to PFCC for it redesigns six dimensions of PCC domains into progressive steps. These steps now consider all health care experiences through the eyes of patients *and* families, with ethical actions to improve clinical results is a central tenet (Millenson, M. L. et. al, 2016).

The six steps of the PFCC Methodology and Practice:
Step 1: Define the care experience for improvement, including the beginning and end points
Step 2: Create a PFCC Guiding Council to lead the effort and break down barriers
Step 3: Define the current state of the care experience through Shadowing, surveys, and other tools
Step 4: Expand the PFCC Guiding Council into a PFCC Working Group with representative from every "Touch point" of the care experience identified through Shadowing.
Step 5: Write the ideal story, from the patient and family's perspective and in first person
Step 6: Create PFCC Project Teams to close the gaps between the current and ideal state

(DiGioia et al., 2016).

The outstanding factor of this methodology is the accountability for not only doctors, but all those playing a part in the patient's life and healthcare experience, to practice patient centeredness. It is not equating the family to the attention level of the patient, but instead brings this organization of support up to the level of the team working with the physician and medical professionals. Family inclusion not only improves familial confidence in the loved one's care. By increasing communication and collaboration on the patient care team, providers feel more confident speaking up for themselves and the patient. When patient-oriented communication is prioritized through better language use, more pre-operation education, and a redesigned pain measurement, a North Carolina based Orthopedics went form a three percent to zero surgical infection rate, halved its unplanned readmissions of post-operative patients, increased patient satisfaction significantly, and decreased patient costs by $1,000 (PFCC Press, 2015). In the Royal United Hospital of Bath, only nine months after implementing the PFCC M/P, the practiced communication methods with end-of-life patients made a phenomenal change from reports of physicians lacking confidence in these charged discussions, nurses feeling unable to voice treatment concerns, and other medical members feeling unsupported in their work (Millenson, M. L. et. al, 2016). Physicians having end-of-life discussions with patients went from zero to 100% and with family members from 50% to 100%, paralleling an increase in advance care planning being communicated to the primary health care team (Meehan, 2015).

PFCC M/P showed the attainable goals of PFCC and dismissed many worries against the model such as expending costs, time, and additional resources. The institutions that piloted the methodology found a quick improvement of positive results within a matter of weeks, significantly reduced expenditures, increased inter-member communication and confidence on the medical team, and better support for the patient through and alongside the family (Millenson, M. L. et. al, 2016). This philosophy is comparable to personal habits we know should permanently adopted, like flossing, better eating, and wearing sunscreen. In the long run, these aspects add up to better health, but in the moment, take a little extra time. Physicians participating in PFCC M/P spend about one hour a week on fulfilling the model, which replaces more hours expended working around broken system's process (Millenson, M. L. et. al, 2016). By holding the ethical approach of protecting patients and families as essential partners in the medical care experience, the PFCC M/P approach enable "clinicians to uncover issues important to patients that they might not otherwise recognize and, with patient input, devise genuinely patient-centered solutions" (Millenson, M. L. et. al, 2016). The philosophy of patient-and-family-centered-care is becoming more widely accepted and practiced as professionals are reminded that all those involved in care, physician or non-physician, are operating under the same ethical values to help the patient.

Of the vast foreseen and proven patient care improvements projected from these models and principles, one of the most significant is to the well-being of the family. From adopting principles of PFCC M/P, families with loved ones nearing the end of their life were given more information, attention, and care by physicians in the end-of-life process (Meehan, 2015). Not only were the patient's themselves more involved in their end of life plans and treatment, but the family was regarded with the same amount of care and consideration. Care for serious illness should not simply include the one patient directly affected. The family is incredibly influential on the medical care experience, just as is the patient's disposition and outcome. In utilizing PFCC, the professional medical care team can acknowledge and address this fragile, two-way relationship that the professionals serve in as crucial members. Additionally, PFE applied in direct care can positively effect "communication and information sharing, self-care, decision making, and safety" (Cené, et al., 2016). Increasing family inclusion and communication should translate to families being aware of and provided with the resources, education, and support for coping with their loved one’s illness. This aspect of care for the family, along with the patient, is how the philosophy of PFCC is set apart from PCC. However, it adds a greater level of complexity and commitment by all involved in medicine. Moving to PCC took the medical field a great deal of time, and adding aspects of PFCC is also a slowly evolving process. Yet, in order to serve up to the ethical standards of whole patient care, the patient’s family must be included.

Many of these patient-and-family-centered care practices have been more widely exercised or known than current literature and medical trends would suggest. This is because PFCC is a strong tenant of pediatrics. This is due to children not being considered autonomous decision makers, which requires involvement of guardians. In pediatrics, the family is an active part of the patient’s care, and the PFCC philosophy used makes the family-provider relationship a widely accepted practice. It is positively associated with various outcomes, including: efficient use of services; better health status in psychological functioning, quality of life, and symptom severity; satisfaction with communication, systems of care, family functioning, and family impact/cost (Cené, et al., 2016). The explicit concern and support for family functioning and family impact is where pediatrics excels and fulfills the PFCC philosophy with action. There is a greater sense of compassion, education, and care from the hospital staff, hospital system, health insurance, and providers for the families of a pediatric patient, as there are more people involved and advocating in the process than for a typical adult patient’s care.

The reverse of pediatric PFCC implementation does not serve as true, and this is an issue in healthcare. PFCC is not exclusively for pediatric practice, and should not be treated as such. Due to the previously discussed concerns of respect for patient autonomy, additional expenditures, and issues in universal implementation, the PFCC practiced in pediatrics is not practiced in the same extent for adult care. The family of adult patients do not receive the same kind of care or quality of support (The Joint Commission, 2010). Many families may not need, nor want, any more attention from the medical system in their loved one's illness; being grown adults and autonomous beings, may enable some to cope in healthy ways and find other avenues of support. Yet, many other families do not fall in this population, and it should not be assumed any families are able to maintain psychosocial wellbeing on their own, without supportive services. While the current PCC philosophy does lack in support for the adult family members of these patients, it also fails the children of adult patients. Children of adult patients should receive even greater PFCC resources and support, than that of the degree which parents of pediatric patients are provided. Children have not yet developed the same skills, abilities, and experiences that provide adults with the greater ability to cope with a family member's illness. It is the PCC philosophy that unethically negates the family, but especially children of patients. It is the current pediatric PFCC philosophy that needs to extend its application in all areas of the medical field, adapting to all types, definitions, and ages of families and their members.

Chapter 5

The Family as a Social Unit

Childhood is meant to be a period of play, limitless imagination, adventure, and innocence. There are very few responsibilities for children, as they rely heavily on their parents and care givers. Even as they grow into adolescents and teens with greater independence, their lives were shaped by the guidance and support of their providers. This allows this age group to live in a form of ignorant bliss; they are typically protected from the real world of finances, employment, and sickness. They hopefully have yet to experience the trials and tribulations life provides. Children have far too much biological, emotional, mental, and physical development to undergo, which the playful, worry-free lifestyle allows. They can trust in the consistency of routine, expect nourishment and shelter, and remain preoccupied from crisis in a childhood life. The care giver is responsible for the formation of this trust in childhood, which serves as a foundation for the rest of a child’s life (Enns, Cox, & Clara, 2002).

This childhood foundation can take shape by parenting styles, roles, and family systems. The massive effect of parenting styles on children’s psychology was proven by John Bowlby in his Attachment theory. The three types attachment theories are a direct result of the parenting style (Bowlby, 1969). A Secure attachment is formed when the caregiver supports the child, so they feel able to rely on their caregiver to meet their needs of proximity, emotional support and protection (Bowlby, 1969). The Anxious-Ambivalent attachment results when a child feels separation anxiety from the caregiver, yet does not feel reassured when the caregiver returns to the infant (Bowlby, 1969). This parent has provided enough security to be missed by the child, but also been inconsistent or neglectful to a degree that the child no longer trusts or cares about the intentions of the caregiver. Anxious-Avoidant attachment is an aftermath of parenting that produces a child who avoids their caregiver (Bowlby, 1969). The child forms insecure attachments in which they act both anxious and distant. Finally, disorganized behavior is when no attachment is formed between caregiver and child (Bowlby, 1969). Of all these attachment styles, secure attachment is the goal for all parent styles (Bowlby, 1969). This attachment results in the healthy parent child relationship that fosters trust, self-growth, and conviction in children with their environment.

Just like the anxious-ambivalent, anxious-avoidant, and disorganized forms of attachment show progressive negative behavior results in children, parental somatic illnesses, like cancer, show detrimental impacts on a child. Parental illnesses are associated with an increased likelihood of internalizing disorders like anxiety and depression in the children, and externalizing disorders such as behavioral problems (Krattenmacher, et al., 2013). Not only is the simplicity of a child’s life lost when a parent is diagnosed with a serious illness like cancer, but regardless of the prognosis, the type, or the treatment, the diseases take one of the most precious items of life from a child: the trust in a stable parent. Every role in a family system holds a particular responsibility to the system. These roles can be defined by prescriptive and performance means. Roles in the family system are mutualistic and rely on reciprocity to achieve success of the family (Brim, 346). This means that one role in the family should be complimented by other roles in a reciprocal manner. Prescribed roles advocate a behavior that results from the function of a specific role in the system (Brim, 348). A parent or caregiver’s role to their children is to promote their health, help them develop into independent beings, guide them through mistakes and failures, provide them food and shelter, and provide compassionate support to them. Performance means provide the amount or degree to which the prescribed aspect of the role is executed. Suboptimal parenting as a result of unfulfilled role responsibility is an important risk factor for psychological disorder in clinical and representative community samples (Enns, Cox, & Clara, 2002). Illness can affect parenting, in minor and sever ways, regardless of the extend of parenting before the illness. It destabilizes the trust a child has in their parent's roles.

Through two of its primary tenets—involvement and communication—a patient-and-family-centered care philosophy can help minimize the negative impact a child experiences and maximize the promotion of healthy growth and development through a parent's serious illness. A child's need to be involved in a family member's care should be clearly recognized and understood by healthcare professionals and nonprofessional family members alike. A sick parent may not want to inform their child in order to save them worry and fear, but they also need additional education on the benefits of including their child in their care, despite the perceived upset it would cause. Research has shown children that are being involved and given education on what is happening to the parent is imperative to the child's health, wellbeing, and relationships (Davey et al., 2012). It is not only a physiologic necessity for children to be involved, but beginning to be a legal obligation. Sweden in 2010 launched an addendum to the Health and Medical Services Act (HMSA), which stated it was the "responsibility of healthcare policy to consider the child's need for information, advice and support when his/her parent has a physical or mental illness, or dies unexpectedly" (Knutsson, et al., 2016). Children should be informed individually with physician and parent, with special consideration of each child's different needs, medical knowledge, physical age, and cognitive age (Knutsson, et al., 2016).

Despite the knowledge and research behind the benefits of engaged children in a parent's illness, there is a disconnect in the enactment of legislation like the HMSA addendum. Sweden's initiative has slowly been adopted throughout medical specialties domestically, and is hoped to be taken up by more nations (Knutsson, et al., 2017). This kind of PFCC implementation takes initiative and effort in creating structured approaches to give family specific information. In order to meet a child's needs, promote their health, and ensure their wellbeing, PFCC practices require careful intention to support children in coping with relatives in healthcare settings. In research questioning on the extent of physician contact with a patient's child, it was reported that physicians "describe not thinking in terms of involving children; the primary focus is the patient" (Knutsson, et al., 2017). This is an old methodology, just as it once was to have a paternalistic physician and not have the patient be centered in care. Difficulties in consistent implementation are also echoed, such as providers lack experience in speaking families, and specifically with children. They lack the experience and knowledge of facilitating these charged conversations, they don't see children as essential care participants, or even family members always allowed in the hospital setting (Knutsson, et al., 2017). There is also a concern that they do not have enough time to engage children, and that providing a child friendly environment adds an additional expenditure (Knutsson, et al., 2017).

All of these concerns have been aired before in the push back against PFCC, despite the proven benefits. It is a matter of health institutions making the ethical decision to expend this effort in best interest for the patient and the family. Healthcare must adapt for the increased health of these children and, by association, their parents. A parent has one less worry on their mind, and one more source of support, in knowing that his or her child is aware of the disease, diagnosis, and treatment, in communication and relationship with the health care providers, and is receiving specific and catered support for understanding all that is happening. Parents aim to protect their children from harm, which is a motive for supplying less information on their illness.

However, by facilitating a child friendly environment of open communication, questioning, and additional support resources, healthcare systems can support parents proactively supporting their child in a healthier way. This improves a child's mental health around the fear of an ill parent, and the parents physical and mental health by knowing their child is also being cared for. Health care providers expressed a lack of knowledge and experience of children as relatives, which is an area of growth for health provider education (Knutsson, et al., 2017). They also reported that co-operation with other child life-specific professions could be improved, in order to fulfill their responsibility to regard a child's health in terms of giving information, advice and support on a relative's illness (Knutsson, et al., 2017).

PFCC is a large undertaking, but many studies have helped provide specific kinds of support that benefit children during a parent's illness. In other research specifically from the different kinds of social support among children of parents diagnosed with cancer, five common themes were depicted from participants' perceived social support received during their parent's illness (Wong, et al., 2010). These consisted of "(a) listening and understanding; (b) encouragement and reassurance; (c) tangible assistance; (d) communication about cancer and treatment; and (e) engaging in normal life experiences" (Wong, et al., 2010). Some children may need all of these support methods, while others may only respond to one or two. Either way, the availability of child specific support in the medical environment, with trained professionals able to interact with this population is vital.

Using the four ways PFCC exceeds PCC—communication and education, collaboration, inclusion, and supportive services—providers can meet children at their individual level with any or all of the outlined support above, specialize to each need. With an effective training on a regular basis, covering tools, recent discoveries, and practice methods, health care professionals can double as patient care and family care experts. Any doctor should be able to listen and understand, through empathetic perspective taking, the experience of a child. A provider may not be a “kid person”, but anyone in the healthcare profession should be capable of basic encouragement and reassurance after the proper communication training. Additionally, there is no one better than the primary physician along with the assistance of a social worker, to explain to the child the diagnosis of their parent, who they are directly treating. These skills undoubtedly give health care providers more responsibility, but also provides them with skills to be a more adaptable, understanding, and personable providers.

Parent–child relationships are central to a child’s healthy psychological development (Enns, Cox, & Clara, 2002). Adopting the PFCC philosophy continues to foster this relationship through and beyond an illness. Healthcare’s initial responsibility is clearly to the ailing patient, yet if ethically fulfilled, should support the patient’s family, especially children, just as much. The precious, mutualistic bond of parent and child is one in which a child bases his or her security in the world, forms trust in relationships, understands life and death, develops healthy emotional stability, and learns how to integrate into the world. A parent fosters this bond, and when ill, can no longer support the needs of the child developmentally, socially, or even physically. The parent is occupied with their own health, along with that of the child’s. In caring for the patient, healthcare systems should see that equal assessment, prevention, and education is needed for any children involved. Through providing therapies and additional public health opportunities, educating on the illness, and creating an environment for the child and parent to be open about illness together, PFCC fully meets healthcare’s responsibility to the patient.

Chapter 6

A Narrative of Need

I never felt like my family was being over looked, or that I wasn't receiving the care I needed, when my mom diagnosed with stage III triple PR-positive breast cancer. Frankly, I didn't think my mom's cancer had anything to do with me. My eleven-year-old understanding equated cancer to a really nasty relative of the flu. I had experienced other family members diagnosed with cancer, all happy survivors. So, when my mom sat my brother and I down the day after the 2009 new year, I wasn't too concerned. I remember my mom asking us how we felt after she told us. We both just shrugged, saying we knew she would be okay.

I come from a working-class family living in the rural farm country of Northern California. I never experienced a lack of health care or adverse health circumstance for myself or my loved ones. My dad and brother were seen by the town's primary care physician, who had cared for three generations of our family. My mom and I happened to have different doctors in the city of Sacramento, and had a less personal relationship with them. In her cancer experience, she received more of the old-fashioned, paternalistic patient care than care rooted in a patient-centered care philosophy. This was a time when she needed a team that worked on her and our whole family's well-being. Of her three oncologists, none ever spoke with her about the added responsibility as a parent to properly communicate her medical experience with her children or how it would drastically change our family dynamic (K. Ruth, email, March 25, 2019). I asked my mom, Karlin Ruth, to recount her experience.

The Healthcare Team

Following her diagnosis, her oncologist mentioned the resources my mom's healthcare team provided. The specific resources were explained by the nurses. One such resource was a social worker.

> It took three weeks to get an appointment. She was like a website—she trailed off resources. Resources included breast cancer support groups, a cancer patient writing group, and places to buy wigs and warm knit caps. When I asked her if there were resources for [my kids], the only referral she had was an art therapy class which met once a month on Saturdays (K. Ruth, email, March 25, 2019).

Aside from this brief meeting, the consistent core of my mom's healthcare team remained her oncologist and her surgeon, with the nurses who helped her changing on a given day. Even still, her oncologist changed three times and her surgeon served no other supportive role outside of the operating room. Due to the difficulty of making an appointment with the social worker, she did not return, and lucky received extensive support from our friends and family. My brother and I evidently attended the art therapy group once. However, the fact that I do not remember ever going suggests to me that it lacked the support I needed.

Treatment

After diagnosis, the oncologist explained the treatment plan to my mom. She was to undergo aggressive chemotherapy administered through a port, inserted just under the skin on her chest, in order to reduce the amount of intravenous disruption of needles when given chemo and taking blood. Following the treatment, she was put on Zometa, a chemotherapy medication, to prevent the cancer moving to her bones. This drug gave my mom unexpected side effects that decreased her quality of life. The side effects were not entertained or explained by her oncologist when she consulted him, so she sought an additional opinion. Upon receiving her third opinion from Stanford, my mom learned she had been taking Zometa too often and for too long. The physician reassured that her symptoms were real and common, but amplified by her aggressive dosage (K. Ruth, email, March 25, 2019). Three years after diagnosis, my mom found a new oncologist, Dr. Blair, who prescribed Arimidex for five years. At five years, Dr. Blair recommended she stay on it for another five years for the lowest chance of cancer relapse, based on recent research (K. Ruth, email, March 25, 2019). The following are symptoms experienced by my mom on Arimidex.

> Symptoms of Arimidex:
>
> - Mood and emotion swings that seemed to come out of nowhere and that I could not stop or change
> - Joint pain. For example, it was painful to walk up or down stairs, painful to walk farther than about 1/8 mile – [recalling our family trip to Disneyland] remember I had to be in a wheelchair at Disneyland?
> - Restricted range of motion - going up or down stairs, standing up from sitting, getting out of car - my joints simply did not work, it was like I had arthritis
> - Weight gain
> - Muscle and joint aches - felt like I had the flu everyday
> - Difficulty sleeping - the muscle aches made it difficult to sleep for more than two or three hours at a time
> - Exhaustion - only out of bed for 3-4 hours before having to lie down again

> - Lack of concentration - it was very difficult to concentrate, for example, on work tasks for more than an hour at a time [leading to my mom being accepted onto government funded disability] (K. Ruth, email, March 25, 2019)

After eight years, my mom had endured enough from the symptoms, and asked to stop taking the drug. Since then, she was able to get off disability, go back to school, receive a master's degree in education, and work full time as a high school teacher.

In PCC, open communication and collaboration with the patient is paramount. The particular healthcare system in my mom's narrative failed in both PCC and PFCC. It failed on many accounts, but mainly on educating and preparing my mom on how to live with this illness and of the side effects of her medications. With limited research and knowledge behind the full impact of the drugs, my mom was told that the side effects of Zometa and Arimidex would manifest as minor disruptions and discomforts in daily life. The information was given in a manner that assumed she, as the patient, would take the information and go decide the next steps for herself. There was no discussion of how this drug would completely alter her abilities to perform in her prescribed role and responsibility as a mother.

Chemotherapy is a pretty common cancer intervention, so my mom had an idea of how this would affect our family, despite lack of lifestyle education from her providers. She could no longer work, cook, clean, get up in the morning to make school lunches, direct theater at my brother's middle school, come to my sporting games, or attend church. Our community stepped up to help alongside our family, adapting to compensate for my mom's new responsibility and role of "getting better". After the chemotherapy, she thought she had finished the worst of it, and could, quite literally, start living again. However, the second “remission” drug, was only the lesser of two evils.

“Only 30% of my patients are continuing to take Zometa after 9 months”, my mom’s oncologist responded, when she raised concerns regarding the side effects of this new drug she was prescribed to take for the next five years. Both the oncologist and surgeon disregarded her reports of extreme symptoms when she began taking the Swedish cancer drug, Zometa. It was not until my mom sought out the third opinion at Stanford Medical, two and a half years after her diagnosis and after one full year of taking Zometa, that her symptoms and feelings were validated. She traveled three hours away to have a doctor listen to her.

PFCC takes into account the family unit in the healthcare team, and thus addresses the roles each family member fulfills. In executing this healthcare philosophy, medications, treatments, surgeries, and other interventions should be explained and taught to patients and family members in the context of not only physiological changes, but side effects that will alter one’s daily livelihood. For example, just as a physical therapist gives an athlete a modified accessibility plan in a workout schedule for a post-operation recovery, cancer patients should be given instruction and suggested adaptations catered to their lives. This takes communication and relationship forming between the patient and physician, so the appropriate accommodations can be implimented. However, it also needs a change in outlook by providers to understand how the treatment pairs not only with the patient biologically, but with the patient’s environment and family.

Chapter 7

Camp Kesem: A Patient-and-family Centered Care Model from a Personal Account

As the healthcare world moves forward by accepting the benefits and necessity of patient-and-family centered healthcare, some public health organizations have already been upholding this healthcare philosophy. They range from community support groups, foundations, government agencies, and non-profits. These organizations and institutions provide patient-and-family centered care simply through the provider's connection with the patient. If the provider and healthcare team know of all available resources and personally know the needs of his or her patient, connecting the patient to resources specifically catered to their needs is a simple task. These institutions and groups then give a patient-and-family centered care unique to anything offered within the walls of a hospital.

A particularly special form of this patient-and-family centered care is summer camp. There are numerous camps all across the world specifically focused towards different demographics of people and their families, with many centered around illness. Supportive and specifically focused camps include camps for children with cancer, camps for the families of children with life threatening illnesses, camps for adults with disabilities, and just about any other medical demographic. One thing all of these have in common is the community around illness. At camp, the person is more than the title of patient experiencing an illness alone among family and doctors. Instead, this person is able to be surrounded by peers or mentors who have experienced the same challenges, joys, loss, and growth (Bialeschki et al., 2007). For families, a specialized summer camp gives them a rejuvenating break from the real world, with other families to lean on, learn from, and share experiences with (Laing, C. M., & Moules, N. J., 2014). The healing effect of summer camp does not even require the family to attend. When the camper, whether it is the patient or a loved one of the patient, returns from the dedicated camp, the behavioral and emotional change is unparalleled. Growing confidence with people in similar situations gives a person a new outlook on life. An outlook that they are not the only one experiencing something. Because camps are typically only a week long or at most the span of a summer, campers learn that the spirit and lessons gained from camp translate into daily life. Families are indirectly positively affected by the healing of summer camp, as the camper returns with a confident light and empowered outlook (K. Ruth, email, March 25, 2019).

A unique summer camp that provided me and my family with the patient-and-family centered care we needed was Camp Kesem. Camp Kesem is the only camp in the country that specifically serves the population of children affected by a parent or primary caregiver's cancer. This organization is student run at college campuses across the U.S. to provide children ages 6-18 with a week long, completely free summer camp, in addition to a year-long support system. When a parent is diagnosed with cancer, the attention shifts towards them and their healing, as is expected. Yet just as cancer is taking away the health of a parent, cancer is also robbing the child of a crucial developmental period. The child, more so in the adolescent years, is forced to grow up rapidly, as cancer uproots daily life (Huizinga et al., 2011). Even with less serious cancer diagnoses, watching a parent—their rock and constant—fall ill from an unseen mass of replicating cells is a traumatic experience. The security in life and health of the person who has cared for them since birth has been compromised, leaving a substantial psychological and emotional ridge in a child's perception of life (Wong et al., 2019). Camp Kesem gives the child an opportunity to escape all of this for a week to grow through and beyond a parent's cancer.

Camp Kesem is solely devoted to giving these children a week to simply be a kid. It is not a week of group therapy, emotional processing, or psychoanalysis. The catharsis and empowerment the campers receive emerges naturally from the week's programming. The day is structured like a typical summer camp—archery, arts and crafts, swimming, water Olympics, messy games—but each night the campers break off into their respective age units for cabin chat. Cabin chat is a quiet time before bed where the campers circle up together to talk about anything and everything, with intentional discussion led by the counselors. Cancer is usually the naturally produced topic. The counselors, still within an age able to relate and empathize with the campers, serve as role models and support systems for the campers to feel comfortable sharing how cancer has impacted their lives, and then validate each individual's response. The second special program at Camp Kesem is Empowerment night. This is an activity when every person at camp comes together and those who choose to share, answer one prompt: "Why do you Kesem?". The common connection to cancer is told through the eyes of the youngest six years old campers, to the 22-year-old counselors. The shared strength of every person in the camp grows with each story of loss and pain, to an understanding, unyielding community of support. Simply knowing one is not alone in their experience, gives campers a courage that cancer could never take away.

It is this week, full of constant attention, endless fun, zero judgement, and absolutely no worries, that these children can truly feel and process a parent's cancer, on their own time and in their own way. For myself, the week of camp was a week to final feel like me. I felt I needed to be strong and brave at home for my mom in her cancer, because she always managed to be strong for me. All year, I held back tears of fear for losing my mom, anger at cancer, sadness for the pain my mom endured, and resentment at my mom because she could no longer care for me in the way she used to, but constantly tried to compensate. I suppressed anxiety after every consecutive surgery of my mom's. I held in frustration at my friends for not understanding my grief. I bottled-up my constant energy, as to not exhaust my mom.

I felt alone.

Yet, at camp, my peers understood me, my counselors listened to me, and the community empowered me to be strong amongst others, instead of scared, battling my emotions on my own. The care provided by Camp Kesem for me, translated into care for my entire family. Camp Kesem helped make my mom's cancer a healthy topic for discussion, as opposed to a taboo subject to protect each other from. I realize now that I brought home healthy coping mechanisms and lessons from my fellow campers, that I subconsciously applied to my home life. Without Camp Kesem, I would have developed in a critical period without the adequate support crucial to its success. However, with camper and counselor role models, a safe environment, and an empowering community, I was encouraged to grow as my own person, undefined by my parent's cancer.

Whenever my mom is asked what Camp Kesem does, she always gives the same response: "Camp Kesem gave Maddie her smile back. It brought back her light". While it took me a few years to feel the effect of Camp Kesem on my life, my mom noticed the impact immediately after I got off the bus my first year. The change she saw in me gave her hope and strength in herself. She had one less worry, knowing I would be taken care of by Kesem. This solace of knowing one's family is being cared for heals a patient in ways that medicine cannot replicate.

The care of a patient’s family is a crucial core element of healthcare prioritized by PFCC, that is achieved by programs like Camp Kesem. Knowing their loved ones are being supported in the specific ways needed by the healthcare system, in turn aids the patient to better focus on their own health. Yet, my mom was never given information on Kesem, or any similar program. She found out by word of mouth from her past theater student, who was a counselor at another university. The second a parent is diagnosed with cancer, it should be the physician’s responsibility to hand the patient a brochure on Camp Kesem, along with other resources for the patient. It should not be left to the one afflicted by illness or the social worker to hopefully meet in an appointment, or for the patient to come across these life changing resources by chance. It should be the physician’s job to know their patient, and meet their known needs.

Chapter 8

Conclusion

Healthcare institutions and providers are in need of a philosophy adjustment. Reviewing the literature on healthcare history, principles, and ethics served as an audit of the PCC philosophy in practice, revealing an evident deficit in fulfilling responsibility to the patient with holistic care. In comparing PCC and PFCC philosophies, the latter requires more active engagement of providers and accessibility of the institution, but provides a better quality experience for the patient and family through equally valuing each. My personal narrative on the lack of support my family and I received from the healthcare system and the overwhelming support provided by the PFCC in Camp Kesem proves the need for the uniform practice of PFCC philosophy to be integrated into the foundation of medicine. The issues raised in this thesis call for a shift in the paradigm.

This PFCC philosophy requires providers to look at the bigger picture of illness, to identify a patient’s micro-, meso-, and exosystems in respect to illness, and to know their patient as a person, beyond their illness. However, medical school does not prepare our providers to practice in this way. Some institutions provide a clinical patient-family-experience for first hand exposure to the trials and tribulations facing families affected by illness (Family-centered Experience (FCE) program). However, in my research of medical school curriculum, there are no course to specifically educate on family development, family systems, or the family dynamic. No matter the specialty one enters, every future provider needs a thorough understanding of people in the context of their family and ecological systems. This will prepare them to understand the family’s effect on the patient’s health and how to provide the best treatment to the entire unit. People are multileveled with multiple systems. Physicians in less family-oriented specialties, like radiology or anesthesiology, must be equally prepared as family practitioners for the different family dynamics they will encounter.

Patient-and-family-centered care execution is non-discretionary. It should not be a voluntary choice or option for the provider, rather, it needs to become the institutional and ethical standard for healthcare. Physicians need to make the effort to familiarize themselves with the patient psychosocially, just as they would physically in order to treat them. In fact, it is the same premise. Medical providers must complete specific education and prove competency in its application to be qualified to medically treat others. The same standard should be expected of providers to know what supportive services are available, the qualities and characteristics of each, and how to specifically apply the resources to a patient or family member based on their individual needs. Just as a provider is continuously improving their functional and technical patient care skills, they should be required to stay educated on the available supportive services, as they nourish an interactive relationship with the patients and their families. For example, when my mom was diagnosed with breast cancer, her oncologist should have recognized she was a mother of two and proceed to hand her a brochure on Camp Kesem while explaining its benefits.

One suggestion for enforcing PFCC implementation is to require a specific rotation in residency for incoming physicians to learn about the supportive services available. Changing the beliefs and perspectives of people takes more energy than merely providing brochures and informationals that encourage physicians to advertise different programs to the patient and family. The power is in personal narrative and connection. If physicians were immersed in these supportive services, by sitting in support groups with consenting patients or attending Visitor’s Day at Camp Kesem, then they would be able to better understand the benefit of these programs for themselves. They may then better understand the crucial role that they serve as the primary care provider in making these accessible. The responsibility should not solely fall on the social worker to relay supportive resources, for this staff member is not directly treating the patient and knows them significantly less than the provider does. It should be a non-discretionary practice for doctors to serve as a support network for the patient and family, as well as educate them on the most beneficial support services.

This patient *and* family care philosophy shapes the patient experience holistically with inclusion and consideration for the family. It is in the best interest of healthcare to make this shift in taking the additional steps required to form a trustworthy relationship beyond the pertinent and surface level information. I recommend this conscious and intentional reconfiguration of healthcare's philosophy. By chance, my family found services that supported us in my mom's cancer, but most people do not share this good fortune. There are over five million children in the country who are affected by the cancer of a parent or primary caregiver (About Kesem). In 2018, Camp Kesem served 9,000 of these children (About Kesem). This is a huge lapse in healthcare's responsibility to care. Programs that offer crucial psychosocial developmental support, provide a peer environment for coping with the trauma of family illness, and that place no financial burden on the patient, should be promoted by every place of healthcare in the country.

This is only one example concerning one disease among an infinite combination of illnesses, family dynamics, outcomes, treatments, and health care providers. However, with our current philosophy in place, it will not be the last. Adopting patient-family-centered care requires full commitment to its true practice—communicating with and educating the family, collaborating with family, exercising inclusion of the family's culture and beliefs, and providing supportive services to the family, all to the same extent as the patient. It is healthcare's responsibility to not only treat the illness in the patient, but to treat the family as impacted by the illness. PFCC philosophy ensures healthcare’s responsibility to the patient, through support of the family, is met and the full well-being of all involved in the provider-patient-family dynamic is achieved.

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