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Involving Patient/Family Advisors and Advisory Councils with Patient and Family Engagement

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Walden University
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Abstract

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MBA, Walden University, 2008

BA, The Ohio State University, 2003

Dissertation Submitted in Partial Fulfillment

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Abstract

Health care consumers are under-represented in literature when defining patient and family engagement. The proportion of people living longer is rapidly growing. Future research is needed to evaluate which strategies of patient and family engagement are most useful in real-world health care settings for patient and families. The purpose of this study was to describe the lived experiences of patient/family advisors working within patient family advisory councils at an academic medical center in the Midwestern United States. The conceptual framework is based on Greenleaf's servant leadership and Bass's transformational leadership. The research questions examined how patient/family advisors describe patient and family engagement, their experiences from the advisor program, and what is most meaningful to them. A phenomenological design was employed with a purposeful sample of 19 interview respondents drawn from 5 different advisory councils. Data analysis consisted of interpretive phenomenological analysis and a detailed, in-depth account of participant experiences. Transcripts from semi structured face-to-face interviews were collected, coded, validated by member checking, and triangulated with emergent themes. Emergent themes included patient/family advisors' descriptions of patient and family engagement within the patient family advisory councils and organizational efforts most meaningful to patient/family advisors. The results of this study may help create social change by improving the standards and quality of patient and family engagement by preparing health care professionals to better meet the needs of health care consumers.

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Dedication

First, I would like to dedicate my dissertation to my children, Donny and Chloe, who have endured many hours of my absence and who have thrived in school. They have been so patient throughout my professional learning. This journey has made us learn to love and respect one another, to appreciate the value of family, and celebrate the small goals in life.

Second, I would like to dedicate this dissertation to my mother who is living proof of persistence, hard work, and strong will. My mother has taught me the will to persevere and the importance of staying true to oneself. Throughout her life, I have watched her gracefully take care of others without expecting anything in return. Her grace, wisdom, and unconditional love are something I will always cherish.

Third, I would like to dedicate this dissertation to my father who has always supported my education. My father became mentally and physically disabled in the summer of 2009 from a life threatening stroke. He is an inspiration to me and I admire his will to live life.

Lastly, I would like to dedicate my dissertation to the rest of my family and friends for all of their love and support. I am forever grateful for all of their love and support during this academic journey.

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Thank you to my chair, Dr. David Banner, for your generous, wonderful, and dedicated support during this dissertation journey. I am grateful for the many inspiring and encouraging conversations with Dr. Banner through which he guided me on how to make this research study worthwhile and narrow down the leadership topics for discussion. The encouraging words of wisdom and often reminded me the journey is worthwhile.

Thanks to my committee member Dr. William Shriner, for the methodological support. Thank you to Dr. Barbara Turner, the URR, for the review and feedback of my dissertation. Thank you to Sharon Cross, my dear mentor and all advisors who helped make this research possible. Thank you Dr. Cynthia Sieck, you have been my guiding light overseeing my research and data analysis.

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Chapter 1: Introduction to the Study

Globally, literature concerning patient and family engagement (PFE) is enormous, but the resources on engagement are still largely untapped and undocumented (Laurance et al., 2014). An increased body of evidence indicated patient and family engagement has been incorporated in all aspects of patient-centered-care including areas such as planning, design, delivery, improvement, and evaluation of clinical and managerial outcomes (The American Academy of Pediatrics, 2012; Bardes, 2012; Barry & Edgman-Levitan, 2012; Institute of Medicine, 2012). Literature surrounding patient-and-family-centered care emphasizes the need for an increased understanding of patient and family engagement as a way to craft and respond to change in organizations (Taloney & Flores, 2013; Moretz & Abraham, 2012).

The Institute for Patient-and-Family-Centered Care (IPFCC) explained patient-centeredness has been used interchangeably with patient-centered care and patient-and-family-centered care (Danis & Solomon, 2013). Patient-centeredness is grounded in the fundamental and active role patients and their families play in the well-being, health, and recovery of patients (Ricciardi, Mostashari, Murphy, Daniel, & Siminerio, 2013; IPFCC, 2012). The (IPFCC) defined four core concepts for patient-and-family-centered care, including collaboration, participation, information sharing, and dignity and respect.

Collaboration includes patients, families, and health professionals who work together on improving program and policy developments, delivery of health care and professional education, (IPFCC, 2012). Collaboration can also help health care professionals share and communicate information to patients and their families in ways that are easily understood (IPFCC, 2012). Health care professionals and patients share and communicate unbiased and complete information in ways that are useful (IPFCC, 2012). Patients and families receive accurate, timely, and complete information to actively particulate in care and decision-making (IPFCC, 2012).

Health care professionals honor patients with respect and dignity by actively listening to the perspectives, preferences, and choices of patients and their families **(**Abraham, Ahmann, & Dokken, 2013). The Institute of Medicine (IOM) (2001) and the (IPFCC) (2012) have embraced patient-centered care to show dignity and respect to individual patients and families, including personalizing choices, values, and preferences (IOM, 2001; Moretz & Abraham, 2012; Roseman, Osborne-Stafsnes, Helwig, Boslaugh, & Slate-Miller, 2013). Patient and family engagement acknowledges patients and families may have different cultural backgrounds, values, and beliefs (Moretz & Abraham, 2012).

Patient and family engagement helps enhance healthcare experiences when families partner with health care professionals among various levels of healthcare systems (Moretz & Abraham, 2012; Roseman et al., 2013). The partnerships between patients, families, and medical staff can range among three levels of engagement (Carman et al., 2013). The three levels of engagement include: (a) direct care-involving patients with their personalized health care, (b) organizational governance and design consisting of partnerships with patients and families within the hospital setting and outpatient settings, and (c) involvement with policy making on the national level (Carman et al., 2013). Patient and family engagement can be used as a strategy to help transform the organizations culture by shifting the focus to the voice of patients and their families (Laurance et al., 2014).

Beyond involving patients and families in their personalized care, health care organizations are integrating patients and families into patient safety services and quality improvements (Willis, Krichten, Eldredge, & Carney, 2013). Patients have been involved as working partners in organizational settings and in research projects across the United States to help identify and assess measurable outcomes in addition to evaluating programs and interventions for organizations (Krumholz & Selby, 2012; Gabriel & Normand, 2012). Engaging patients as working partners helped to empower patients and families by engaging them in different levels of the clinical paradigm by asking what matters most to them which has been used as an effort to enhance the cultural transformation of patient and family engagement within their organizations (Edgman-Levitan, Brady, & Howitt, 2013; Laurance et al., 2014).

One way of involving patients and families in engagement efforts within the organizational level of hospital settings includes using patient/family advisors (Wynn, 2015). Patient/family advisors are volunteers who are patients or caregivers of patients who have become engaged in a new advisory role within a healthcare organization (Warren, 2012). Wynn (2015) explained,

> Patient advisors are people who use their personal experiences as a lens to see how care and experiences might be improved. They are not so positive that they cannot identify opportunities to improve, nor are they so negative that they cannot

> move beyond their personal experiences to focus on system-level improvements (p. 172).

Patient/family advisors are also known as patient leaders or patient partners who often work in consumer advisory roles such as advisory councils and focus groups to shape services, polices, and initiatives to improve outcomes (Mende & Roseman, 2013). Many health care organizations utilize patient/family advisors and patient family advisory councils to enhance patient and family engagement within the inpatient and outpatient settings (Newton, Atkinson, Parker, & Gwynne, 2015). Howrey et al. (2015) and Hodgetts et al. (2014) explained advisory councils can create opportunities for patients and families to provide direct feedback and create constructive conversations between people with very diverse opinions.

Haycock and Wahl (2013) described patient and family engagement as a strategy to help organize patient family advisory councils. Many organizations “do not know how to establish a professional partnership with their patients, and many may still question the appropriateness of empowering patients with equal partners hip and accountability for their health and experience within the healthcare system” (Haycock & Wahl, 2013, p. 242-243). Haycock and Wahl (2013) also confirmed patient family advisory councils are well positioned to become the voice of the healthcare consumer.

Qualitative interviews with patient/family advisors could assess different patient and family engagement strategies (Domecq et al., 2014). Such strategies may include, gaining a better understanding how patient-centered-care is delivered and how patient and family engagement is received and perceived by patient and their families to find out what is most meaningful to them (Kuntz et al., 2014).

Friesen, Herbst, Turner, Speroni, and Robinson (2013) explained the implications for future research may be used to help health care professionals better understand the most effective techniques to support patient-centered outcomes within various patient settings and populations. Cosgrove et al. (2013) illustrated further research is needed to explore the methods, measurements, and modes of effective patient and family engagement in different care settings and patient populations. Health care organizations will need to include new norms and make significant changes in their processes, culture, and organizational structures (Carman et al., 2013).

Roseman et al. (2013) discussed the implications for social change related to patient and family engagement, linking emerging evidence showing a transformative shift towards improved health outcomes with patients and their personalized health care. Using patient family advisory councils to ensure transformational changes within the organization reflects meaningful improvements for health care consumers (Friesen et al., 2013). The transformation in culture may also create a shift in leadership, by putting the needs of patients and families in the center of health care, creating partnerships among physicians, nurses, patients, families, and organizations (Warren, 2012).

Chapter 1 includes the background of the problem surrounding patient and family engagement from the patient/family advisors perspective. The need for the study indicates the importance of creating best practices for patient family engagement. The statement of problem shows there is a gap in evidence-based literate and scholarly research surrounding the topic of patient and family engagement from the perspective of health care consumers. The purpose of study, research questions, conceptual framework, methodology, and the significance of study can also be related back to leadership and management. Health care professionals play a significant role in developing and creating awareness within organizations. The definitions of terms, scope of the study, assumptions, limitations, delimitations, and implications surrounding patient and family engagement and patient-centeredness will be discussed in further detail.

Background of the Study

Patient-centeredness began several decades ago out of a collaborative approach to form partnerships among health care professionals, patients, and their families to incorporate the perspectives of patients and families into the evaluation, planning, and delivery of health care (Abraham et al., 2013). Abraham et al. (2013) explained since the mid-90s, the concept of patient-centeredness has faced radical changes in health care such as increased health care costs, longer life expectancies, and a movement toward putting the patient and their families in the center of health care. Patient-centeredness and patient and family engagement have become a high priority in many strategic plans within healthcare organizations (Minnie & Abraham, 2013) and are considered the “blockbuster drug” for the 21st century (Dentzer, 2013). In this example, the “blockbuster drug” is referred to concept revolving around patient and family engagement (Dentzer, 2013).

In 2001, the (IOM) published, *Crossing the Quality Chasm*, explaining six aims for improving the health care system. Among them was adopting a patient-centered care approach, respecting individuals’ needs and preferences while allowing the values of patients and families to guide the decision-making process (IOM 2001). The IOM recognized the practice and philosophy of patient-centered-care should be a goal in the 21st century for health care systems (Feinberg, 2014; IOM, 2012; Minnie & Abraham, 2013).

In 2012, (IOM) published, *Best Care at Lower Cost*, explaining the importance of including the perspectives and needs of patients, caregivers, and families into health care organizations and systems. The (IOM) promotes patients, families, and caregivers as fundamental members of a continuously learning care team. In the same publication, the (IOM) stated, “improved patient engagement is associated with better patient experience, health, and quality of life and better economic outcomes, yet patient and family participation in care decisions remains limited” (Minnie & Abraham, 2013, p, VII).

With the emerging evidence that patients are important stakeholders in their personal health care and decision making, patient and family engagement is recognized by health care professionals as a contributing a factor for promoting and improving health outcomes and experiences across the continuum of care (Barello et al., 2014; Dentzer, 2013; Barello & Graffigna, 2012). Patient/family advisors partner with medical staff to improve patient safety and quality issues, patient experience, and partnerships based on dignity and respect (IOM, 2001; Abraham et al., 2013).

I found a gap in literature, showing a need for promising practices to support patient and family engagement and how patients can help inform researchers in the development, evaluation, and refinement supporting the patient-centeredness processes

(Krumholz & Selby, 2012; Gabriel & Normand, 2012). In this study, I asked questions related to the patient/family advisors personal health care experiences and their advisory roles within the academic medical center. Gabriel and Normand (2012) and Krumholz and Selby (2012) helped to justify my study by showing the subsequent emergence of patient and family engagement as a need for patients and caregivers to help define and incorporate best practices and methods for an engaged and robust community of stakeholders.

Organizational policies can support this transformative shift in health care with the partnership of patient/family advisors, providing opportunities to measure engagement, leading to increased patient-and-family-centered care with effective and reliable health care (Moretz & Abraham, 2012). Previous research in other industries has been used to explain how the patient experience can be a measured by services, loyalty, and transactions (Needham, 2012). Organizational and policy support is needed for patient and family engagement to create measurable improvements (Moretz & Abraham, 2012). Dentzer (2013) suggested emerging evidence showed "patients who are actively involved in their health and health care achieve better health outcomes, and have lower health care costs than those who aren't” (p. 202).

By looking at themes surrounding patient and family engagement, I searched topics including patient-family-centered care, patient-centered-care, patient-centeredness, patient engagement, patient and family engagement, hospitals patient/family advisors, and patient family advisory councils. For example, Mende and Roseman (2013) discussed the Robert Wood Johnson Foundation’s effort to improve health care with the aligning forces of quality with models to provide reform nationally. The alliances' integrated multiple stakeholders such as consumers, payees, and health care providers and used their perspectives to create improved transparency and health outcomes (Mende & Roseman, 2013). The aligning forces for quality initiatives included regions such as New Mexico, Ohio, Michigan Massachusetts, California, Missouri, Maine, Tennessee, Minnesota, Oregon, Washington, Pennsylvania, New York, and Wisconsin (Mende & Roseman, 2013).

With the use of servant leadership, transactional leadership, transformational leadership, and leader-member exchange, I showed how shifting roles with patient/family advisors and medical staff connects patient and family engagement within different departments of the medical center. Patient/family advisors have been engaged within the organizational level of health care organizations in various ways. Linking leadership styles to patient and family engagement within the field of management created the rationale for this research study. Involving patients and families in engaged care processes has been highlighted by numerous authors within the health care industry.

Barello, Graffigna, Vegni, and Bosio (2014) scholarly research focused on defining the relationship between patient and family engagement as a critical element of the patient-centered-care paradigm. Health care professionals will need to acquire new skills so they can communicate partnerships with consumers to improve health care organizations (Laurance et al., 2014). Patients are interested in having a leadership role and involvement in patient-centered research because they have the greatest stake and feel they are an underutilized resource for identifying research gaps in shaping the research agenda (Newhouse, Barksdale, & Miller, 2015). More research on both patient care indicators such as patient and family engagement and patient-centeredness can help to create opportunities for both the patients, families, and the health care professionals who care for them (Barry & Edgman-Levitan, 2012).

The research literature related to patient and family engagement surrounding patient/family advisors within the hospital level is somewhat limited. There is lack of clinical tools designed from the perspectives of patients and families from their personalized hospital stay experiences (Rockville et al., 2012). Rockville et al. (2012) explained,

> Most of the literature on patient and family engagement roles focuses on what patients could do (or what researchers and policymakers want patients to do) instead of discussing what behaviors patients and family members currently engage in or would be willing to engage in during clinical encounters (p. 2).

Problem Statement

Future research is needed to evaluate which strategies of patient and family engagement are most useful in real-world health care settings (Laurance et al., 2014). The general business problem shows patient and family engagement has been defined differently by others within the health care industry (Gallivant, Burns, Bellows, & Eigenseher, 2012; Prey et al., 2014). There is no universal definition on patient and family engagement or how it is applied to patient/family advisors or patient family advisory councils. According to Warren (2012), there is little information on how patient/family advisors describe patient and family engagement within the planning, processes, procedures, programs, services, and initiatives. The specific business problem shows limited research on how patient/family advisors describe patient and family engagement from the health care consumers' perspective.

Health care consumers' voice is under-represented in literature when defining patient and family engagement (Barello et al., 2014; Barello & Graffigna, 2012). With people living longer, the world population is rapidly rising. Worldwide, the proportion of people age 60 and over is growing faster than any other age group (Graffigna, Barello, & Wiederhold, 2013). By 2025, approximately 1.2 billion people will be over the age of 60 and by 2050, there will be over two billion people, with 80% of them living in developing countries (Graffigna, Barello, & Wiederhold, 2013). Graffigna, Barello, and Wiederhold (2013) suggested there is a need for taking a universal perspective to directly engage consumers in the delivery and design of services to meet their personalized needs.

Purpose of the Study

The purpose of this qualitative phenomenological research study was to interview a purposeful sample of patient/family advisors at an academic medical center in the Midwestern United States known for their participation within patient family advisory councils and who have knowledge of patient and family engagement. The focus of this study was to describe the experiences, perceptions, and meanings patient/family advisors associate with patient and family engagement. The data from this study might contribute to new knowledge/insights and possible financial savings for health care consumers, managers, leaders, and organizations within the health care industry. The social change impact of the study might also improve the standards and quality of patient and family engagement by preparing health care professionals to better meet the needs of health care consumers.

Research Questions

The central research question for this study was: How do patient/family advisors describe patient and family engagement within patient family advisory councils?

Research Question 1: How can the results of the patient family advisory councils change health outcomes for patients and families?

Research Question 2: What has the organization done or asked patient/family advisors to be involved in that is most meaningful to patients and families?

Research Question 3: How have patient/family advisors perceptions of health care changed since working on patient family advisory councils?

Conceptual Framework

The conceptual framework of this research study was Robert K. Greenleaf's servant leadership in combination with other prominent leadership styles such as servant leadership, transactional leadership, transformational leadership, and leader-member exchange theory. I used servant leadership, transactional leadership, transformational leadership, and leader-member exchange theoretically as a framework to connect the development and expansion of patient and family engagement within organizations. One interpretation is that servant leadership is a philosophy that can be integrated into a theory such as transformational leadership (Greenleaf, 1970). The philosophy of servant leadership creates new opportunities for leaders to include followers in the decision-making process, thus dismissing top-down approaches or paternalistic or authoritative leadership (Savage-Austin & Honeycutt, 2011).

Greenleaf proposed a leadership model that embedded contributions to better society and to nurture others. Servant leadership (Greenleaf, 1970) is one leadership style that has become popular because it emphasizes improving organizations through empowerment and building the culture and successfully leading to increased revenue due to becoming customer-focused (Jones, 2012b). Robert Greenleaf (1970) defined the term servant leadership through the essay, *The Servant as Leader*, and explained how this style of leadership could be applied to educational, health care, and business institutions. To Greenleaf, a servant-leader could be any individual who views themselves as servants first and a leader second.

Greenleaf (1977) insisted true leadership is fundamentally one and the same with service and noble leaders are recognized through the services they offer to people and society. Greenleaf (1977) stated servant leaders can shift the leadership paradigm by adopting the attitude of service while managing employees. Greenleaf's (1998) principles of servant leadership are consistent with other leadership styles such as transformational leadership. Greenleaf (1998) stated, "At its core, servant-leadership is a long-term transformational approach to life and work – in essence, a way of being – that has the potential for creating positive change throughout our society" (p.5). Greenleaf (2003) suggested servant leaders prioritize the needs of others, with the goal to serve and strengthen others.

The principles of servant leadership are similar to other specialized leadership styles such as transactional leadership and transformational leadership in addition to the leader-member exchange theory. For example, the principles of transformational leadership can be applied to multiple areas of life, social change efforts, work, and education (Bass & Riggio, 2006). Transformational leadership was developed by James MacGregor Burns (1978). Bass (1985), further developed transformational leadership, assuming various elements of leader's behaviors.

Avolio and Bass (1991) developed the full range leadership model (see Figure 1). The full range leadership model created a continuum with transformational leadership on one end, transactional leadership in the center and laissez-faire leadership at the other end (Fischer, 2016). As the model shows, leaders who use more transformational behaviors (individualized consideration, intellectual stimulation, inspirational motivation, and idealized influence) and use fewer transactional leadership behaviors (contingent reward and management by exception - active) are by and large considered to be more effective than leaders who more frequently utilize transactional or highly avoidant (management by exception, passive, and laissez-faire) behaviors (Fischer, 2016). In reference to transactional leadership, laissez-faire represents a non-transaction or lack of leadership and is the most ineffective and most inactive style of leadership (Bass & Riggio, 2006).

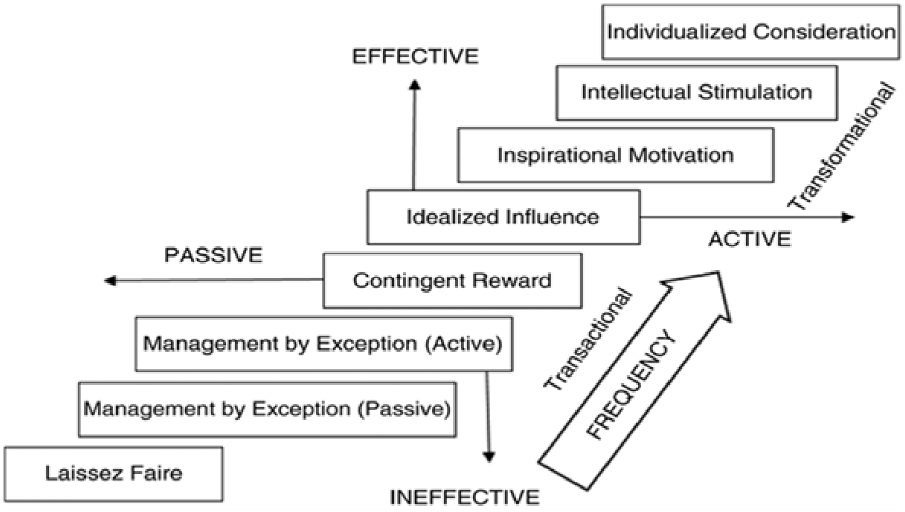


Figure 1. The Full Range Leadership Model adapted from "Developing Potential Across a Full Range of Leadership (TM)," by B.J. Avolio and B.M. Bass, 1991, Psychology Press: New York, p. 4. Copyright 1991 by Bruce J. Avolio & Bernard M. Bass.

Transactional leadership is characterized by active management by exception, passive management by exception, and the use of contingent rewards (Fischer, 2016). Active and passive management by exception are characterized as leadership behaviors that are reactive when mistakes happen or when something is not right, compared with transformational leaderships practical, preventive approach (Fischer, 2016). Bass and Avolio (1994) indicated contingent reward offers compensations otherwise known as rewards for a desired behavior as the primary concept of leadership and is considered very effective (Bass & Riggio, 2006).

Contingent rewards suggest the recognition offered to a follower pursuing the achievement of a particular goal, a type of economic exchange (Fischer, 2016).

Employees who receive only contingent rewards are not engaged and committed to the organization because they are not self-motivated (Merrill, 2015). Successful leaders may demonstrate both transactional and transformational leadership attributes (Bass et al., 2003). Transformational leadership does not act as a replacement for transactional leadership, but to a certain extent acts as an equal by making certain both functions of management and leadership are correctly paid attention to (Fischer, 2016).

Bass (1985) included inspirational motivation (creating a stimulating vision), idealized influence (serving as a role model), individual consideration (supportive environment for the development of followers), and intellectual stimulation (motivating follower to think outside the box). Bass and Avolio (1994) recognized transformational leadership assumed a consistent leadership style across followers. Transformational leaders acknowledge individual differences to each follower's capability to meet organizational goals and objectives, and to make followers feel empowered and challenged (Bass & Riggio, 2006).

Contemporary leadership styles such as transformational leadership and servant leadership have focused on the effects of the leader's behaviors with employee's motivation, attitudes and team outcomes (Bauer & Erdogan, 2015). Both servant leaders and transformational leaders focus on followers, deliver futuristic visions, and encompass leadership with positively correlated outcome measures (Dierendonck, Stam, Boersma, Windt, & Alkema, 2014). Transformational leadership emphasizes attributes of charismatic leadership with the ability to transform their followers with a vision, but does not put the needs of the followers first (Burch & Guarana, 2014). The difference between these two leadership styles may be in the way leaders influence their followers along with the external environment (Dierendonck et al., 2014). Servant leaders serve followers by putting the follower’s needs first whereas transformational leaders do not put the needs of their followers first.

On the other hand, the leader-member exchange views the quality of the dyadic relationship between leaders and members, fundamentally to understand the effect of the organizations, its members, and teams (Bauer & Erdogan., 2015). Leader-member exchange exemplifies building trusting relationships and creating transparency between the leader and their followers (Hanse, Harlin, Jarebrant, Ulin, & Winkel, 2015). The leader-member exchange approach focuses on the leader-follower or the leader and follower dyad and the quality and nature of their relationship (Bauer & Erdogan, 2015; Wong, Cummings, & Ducharme, 2013).

Leader-member exchange suggests the relationships between managers and employees can range from those solely based on the official employee contract (low quality leader-member exchange) to relationships considered by joint respect, trust, and mutual influence (Linden & Green, 1980; Bauer & Erdogan, 2015). Leader-member exchange focuses on the attribute of the leaders’ special relationship with their followers encouraging optimistic behaviors and attitudes (Burch & Guarana, 2014). The leader-member exchange theory examines leadership at the dyad level, and suggests leaders encourage their followers because of the distinctive relationship that occurs between the two individuals (Vidarthi, Erdogan, Arnad, Liden, & Chaudhry, 2014). Consequently, the leader-member exchange theory has not received much attention in health care even with the vast empirical foundations in other disciplines (Wong et al., 2013).

Out of the four leadership styles presented, transformational leadership has been most researched (Zhu, Newman, Miao, & Hooke, 2013). Compared to servant leadership, transformational leadership also values the importance of shared values and common goals which often become group attributes (Burch & Guarana, 2014). Descriptions of servant leadership and transformational leadership emphasize an overlap between the two styles of leadership as both styles empower workers (Dierendonck et al., 2014). Servant leadership has been viewed by many organizations as a favorable resolution to help leaders become more ethical, effective, and employee focused (Jones, 2012b).

Sun (2013) argued organizations that improve customer and employee engagement, are more aware of the needs of society and community where they conduct and manage their business. Some global organizations have utilized servant leadership concepts and principals (Parris & Peachey, 2013). Hunter et al. (2013) mentioned there are several explanations for Greenleaf's trends of servant leadership as core organizational values and why many of Fortune's magazine's 100 Best companies to work for in the United States.

Levering and Moskowitz (1998) emphasized organizations like Starbucks, TD Industries, Steak-N-Shake, and Southwest Airlines have created management techniques around servant leadership models and are reflected as top companies to work for in America (Savage & Honeycutt, 2011; Parris & Peachey, 2013). Greenleaf (2003) also provided examples of organizations that have applied servant leadership and were named Fortune magazine’s top 100 companies to be employed. McCann, Graves, and Cox (2014) explained organizations that succeed in today’s demanding environment often identify servant leadership as a model to balance the demands of the organization and its stakeholders.

The model of servant leadership revolves around addressing and identifying the needs of the followers before the leaders’ individual concerns, leading to the growth and development of the follower instead of the needs of the organization or the manager (Jones, 2012a)**.** Linden, Wayne, Zhao, and Henderson (2008) suggested servant leadership is multidimensional and at the individual level, makes contributions beyond transformational leadership and leader-member exchange to explain behaviors of community citizenship, organizational performance, and in-role performance. Linden, Wayne, Liao, and Meuser (2014) proposed a serving culture is related to store-level outcomes and individual outcomes.

By highlighting the value of serving multiple stakeholders including customers, employees, management, and communities where the organization performs allows the serving culture and follower identification or employee identification through a multilevel study design showing how servant leadership impacts organizations with serving cultures and their followers (Linden et al., 2008; Linden et al., 2014). The impact of transformational leaders within an organization can change or transform the values and norms of their workers through follower engagement (Burch & Guarana, 2014). Braun, Peus, Weisweiler, and Frey (2013) expressed the importance of acknowledging transformational leadership directly impacts trust at individual levels as well as team levels and increases job satisfaction and performance.

Kelloway, Turner, Barling, and Loughlin (2012) suggested these elements of transformational leadership affect employee trust and psychological well-being. Zhu et al. (2013) explained how transformational leadership can affect and influence trust with follower's work outcomes. Although transformational leadership theory has been widely adopted and provided important insights into the nature of leadership and health care workplace outcomes, it lacks evidence into its efficacy in terms of clinical outcomes (Hutchinson & Jackson, 2013).

Hanse et al. (2015) described how employee behavior is inclined by the leader's supportiveness and interpersonal relationships. Hanse et al. examined the style of servant leadership and how it positively influenced leader-member exchange with health care personnel. The relationships both within the personal level and organizational levels of engagement developed between patient/family advisors and medical professionals can also be related to the leader-member exchange. The relationship between patients, caregivers, family members, and the medical staff's interactions, can help to create trust between the leaders and the followers. The leader-member exchange theory looks at the different developmental exchanges between the leaders and followers.

Dimensions of servant leadership could be helpful and influential when developing a relationship based on leader-member exchanges between the health care professionals and the leader (Hanse et al., 2015). Michel and Tews (2016) suggested developing high-quality leader-member exchange relationships inspires employees to engage in behaviors such as trust and respect which help the leader, work group, or the larger organization. Ford, Wilkerson, Seers, and Moorman (2014) further explained psychological exchanges between leaders and employees profoundly associate exchange relationships. As these relationships develop, collaboration between individuals can progress from self-interest to mutual interest (Ford et al., 2014).

Zhang, Wang, and Shi (2012) stated prior research has shown positive relationships between employee work outcomes such as job satisfaction and performance and leader-member exchange with having successful work outcomes. Guan, Luo, and Peng (2013) implied future research is needed on other types of teams such as medical teams and customer service teams. The patient and family engagement model concerning patient-centeredness may suggest a way to meet the needs of health care consumers by utilizing patient/family advisors feedback as the voice of health care consumers. Working with patient/family advisors within various advisory councils encourages input from the consumer’s perspective, using traits of (servant, transactional, transformational, and leader-member exchange), to create a conceptual framework for this research.

The major theoretical propositions concerning the developmental and managerial models and processes for implementing patient and family engagement can be conceptualized through a variety of different leadership approaches which will have a more detailed explanation in Chapter 2. Servant leadership, transactional leadership, transformational leadership, and leader-member exchange help to emphasize the leader’s position in getting followers or patient/family advisors to support and serve the organization willingly and to participate vigorously in goal achievement activities concerning patient and family engagement. These leadership approaches help create awareness of patient/family advisors, valuing the importance of supportive systems that can share perceptions regarding policies and procedures within the organizational level of patient and family engagement.

Theory relates to the study approach and research questions by looking at the central research question asking patient/family advisors to describe patient and family engagement within patient family advisory councils. While the sub questions seek to answer how members of the family advisory councils change health outcomes for patients and families, what's most meaningful to patient/family advisors and how do their perceptions of health care change since working on family advisory councils. Figure 2 shows how leadership can be used within patient family advisory councils amongst leaders (medical professionals) and follower's patient/family advisors (health care consumers) interact in ways to create patient and family engagement.

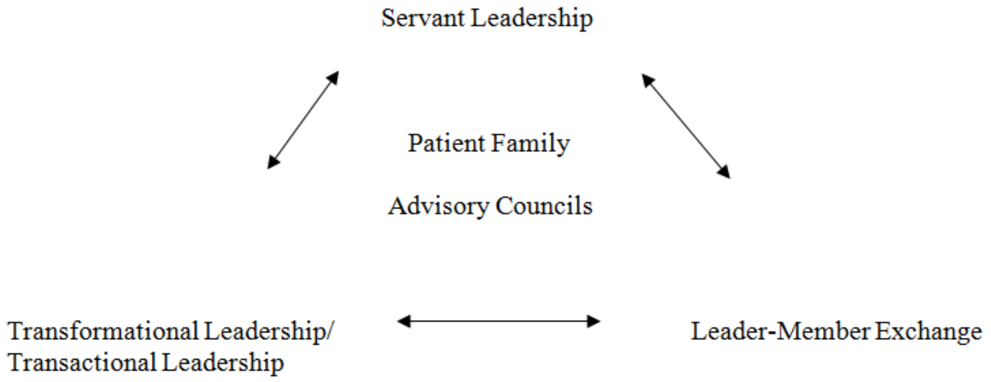


Figure 2. The conceptual framework diagram explains how leadership styles such as servant leadership, transformational/transactional leadership, and leader-member exchange encompass the various patient family advisory councils throughout the medical center.

Niles (2014) described servant leadership as the best model for healthcare organizations because it concentrates on developing trust while serving the needs of the patient and focuses on the strengths of a team. Servant leadership practiced nowadays in health care offers a distinctive opportunity to evaluate leadership behaviors and the relationships between employee satisfaction and patient satisfaction measures (McCann et al., 2014). McCann et al. (2014) expressed servant leadership behaviors may help health care organizations successfully lead society. Trastek, Hamilton, and Niles (2014) stated the United States health care system is unmanageable and shattered. Patients and families deserve the highest quality of care with lower costs (Trastek et al., 2014).

Currently, health care organizations and leaders are responsible for managing the demands and limitations of the organization they serve and the needs of their customers (Linden et al., 2014). To regain the trust of the public, the United States health care system needs to adapt and change to the needs of patients and their families (Trastek et al., 2014). Looking at change models and how they can be applied to patient-centeredness and patient and family engagement, the transformational change process that lies within the culture, creates a unified or whole systems thinking approach. This whole system thinking approach is based on partnerships which can be viewed as a transformative change in health care.

A business model based on the patient's perspective or the patient/family advisors perspective should be completely different than other business models based on what leadership thinks are the best ways to craft and respond to change. When creating models of patient and family engagement, leadership and management have the opportunity to transform the internal and external climates with the social interactions of the patient family advisory councils (Friesen et al., 2013). Guan et al. (2013) implied future research is needed on other types of teams such as medical teams and customer service teams. So, with the research, I am going to describe how patient/family advisors and medical staff work and interact together as teams on patient family advisory councils.

Nature of the Study

The nature of this study used an interpretive qualitative research phenomenology-based study as a way to get the “lived experience” and establish the essence of the patient/family advisors experiences (Reiners, 2012; Patton, 2016). The key phenomenon for study was to describe common themes associated with patient and family engagement from the perspective patient/family advisors who represent the voice of health care consumers. Patient/family advisors were identified and asked to describe their personal health care experiences and how these experiences chose them to serve within the organizational levels of engagement as patient/family advisors. The qualitative approach of phenomenology was selected as the research method because it involves interrelationships of that is applicable to the practice surrounding patient and family engagement.

The interpretive paradigm holds improvement assumptions about the social world and interpretivist assumptions about epistemology (Rossman & Rallis, 2017). Interpretive research typically tries to understand the social world as it is from the perspective of individual experience, hence an interest in subjective worldviews. The goal is to generate a thick description of the participant’s worldviews (Rossman & Rallis, 2017). Humans are viewed as creators of their worlds thus, agency in shaping the everyday world is fundamental to the paradigm (Rossman & Rallis, 2017). A thick description is described as a social action recording the meanings, circumstances, intentions, motivations, and strategies that characterize this interpretive description rather than detail that makes it thick (Schwandt, 2015).

The methodology for conducting the study consisted of a recruitment email with screening criteria, a pilot study, and semi structured interviews with open ended questions to serve as qualitative data and then reviewing and analyzing the responses to the interviews (Xie et al., 2015). Data was collected from interviews with patient/family advisors reporting high levels of patient and family engagement in an academic medical center environment, because it is believed that these patient/family advisors could provide knowledge about patient and family engagement within health care delivery systems. According to Lee and Krauss (2015), the selection of the phenomenology research method provides the most effective approach for discovering the meanings and current perceptions of patient and family engagement within these relationships.

The knowledge gained from this research may have a direct impact on the understanding of how patient/family advisors have successfully or unsuccessfully adapted to engagement within today's current health care environments. The instrumentation or methods of the interview protocols were based on a semi structured interview that uses more open-ended questions (Blom, Gustavsson, & Sundler 2013). The instrument was based on questions from the literature review. Both health care professionals and health care consumers can utilize this patient and family engagement survey. Data analysis will be based on an Interview Questionnaire (see Appendix B) and Interview Prompts (see Appendix C).

The interview questionnaire and interview prompts consisted of a conceptualization of patient and family engagement as a key goal of the interview. Next, the interviewees talked about the medical center and their experiences with patient family advisory councils. Best practices were discussed with patient/family advisors concerning patient and family engagement processes and improvements. Lastly, the closing consisted of important messages that the participant would like to take away from the interview.

Observations were used and documented from meeting minutes, advisory councils, journals, diaries, and advisory records. The nature of data was textual and consisted of interview transcripts, observation notes, documents, etc. Analyses methods included open coding which incorporated the initial coding of data into blocks, axial coding in which emerging concepts are dimensionalized in a grounded theory approach (Gale, Heath, & Cameron, 2013). Constant comparative analysis was used to compare emerging codes across participants. Thematic analysis was used to search for themes. Narrative analysis was used to analyze stories and narratives by structure, function, or oral performance.

Definitions

Patient-Centeredness

Patient-centeredness honors the whole person and family, respects individual values and choices, and ensures continuity of care and is widely acknowledged as a core value to enhance overall health outcomes, incorporating patients and caregivers as partners in healthcare (Bardes, 2012; & Barry & Edgman-Levitan, 2012).

Family

Family is defined of two or more people whom the patient would like involved in care, regardless of whether they are related biologically, emotionally, legally, or otherwise (Abraham et al., 2013; Brown et al., 2015).

Patient and Family Engagement

Patient and family engagement can be defined by actions people and individuals must do to take advantage of the benefits of their health care (Dentzer, 2013; Gruman et al., 2010). Holistic definitions of patient and family engagement expand these concepts further, unfolding patients and their families working with healthcare providers across the entire spectrum of healthcare including research (Dentzer, 2013).

Patient/family advisors

The (IPFCC) defines patient/family advisors as "patients, residents, and families who work together with health care professionals to improve health care for everyone" (Abraham et al., 2013, p.4). The expression "advisor" is used to illustrate any patient or family member who works together "with health care organizations to provide direct input and help improve the way care is planned and delivered" (Abraham et. al., 2013, p. 14). Wynn (2015) described patient advisors as "people who use their personal experiences as a lens to see how care and experiences might be improved. They are not so positive that they cannot identify opportunities to improve, nor are they so negative that they cannot move beyond their personal experiences to focus on system-level improvements" (Wynn, 2015, p. 172).

Patient Family Advisory Council

A strategy used by health care organizations to create partnerships with current or previous patients and their family members.

Assumptions

Aspects of study that are believed true include the assumption patient/family advisors would want to participate in this research and contribute to the expert body of knowledge**.** It is also assumed the strongest contributor to patient and family engagement occurs within the context of the interpersonal relationships between patients, families, and their health care providers. It is assumed that there is a relatively strong need to conduct this research.

The intent of this research is to help further the framework for patient and family engagement in health and health care organizational design, management, and governance. Literature shows a dominating theme relating patient-centeredness and patient and family engagement as the major drivers of social change, ultimately looking for ways to improve the overall patient experience. Furthermore, social change drivers show the need for an increased awareness in promoting better information, shared decisions, and health outcomes (King & Moulton, 2013).

Scope and Delimitations

The specific aspects of the research problem that are addressed in the study explore how patient/family advisors conceptualize their advisor roles and whether describing the patient/family advisors' perceptions will be beneficial to the healthcare community. Incorporating patient/family advisors into the planning, processes, procedures, programs, services, and initiatives is an organizational culture shift. The specific focus of research was chosen at an academic medical center in the Midwestern United States due to the research problem surrounding patient/family advisors.

To identify populations included such as the patient/family advisors within the Patient Family Experience Advisor Program (PFEAP), I also used evidence based research journals, books, professional conferences, and academic literature. I was able to correlate current research corresponding to the specific research topic concerning best practices of patient and family engagement from the perspectives of patient/family advisors. I decided to exclude additional patient/family advisors from other health care institutions and programs around the United States due to cost, time, funding availability, and multiple Institutional Review Board approvals.

I chose to go with a patient and family engagement model shared by Carman et al. (2013) to conceptualize patient/family advisors shared phenomenon of being involved with health care professionals within the personal level and organizational levels of patient and family engagement. Consequently, an in-depth focus of transformational leadership was used to create a framework related to servant leadership and how both health care providers as well as patients and their families use servant leadership to create transformation both personally and within a team environment throughout the organizational level of engagement.

Potential transferability could be used to disseminate and share research findings in the near future both at academic and professional conferences. Future research may ask to involve more patient/family advisors from various organizations and institutions to ask the same research questions to create more in-depth analysis. This may help to create a universal set of best practices surrounding engaging patients, families, and caregivers. Understanding the perspectives of health care consumers may improve public health among hospitals, outpatient clinics, doctors' offices across the United States.

Limitations

Limitations included only having a population from one medical institution, so the perspectives of the advisors may be limited. Limitations of the study related to design and/or methodological weakness may include issues related to transferability and dependability. In conducting the literature review, a broad selective scope was used to target points of interest for this research, which means that I have not conducted a full review of all literature in relevant areas such as shared-decision making, patient activation measures, and the concepts surrounding patient-and-family-centered care.

Furthermore, this research was conducted only within one academic medical center, a learning organization, and may not capture how other health care organizations utilize patient/family advisors. A patient-centered view of patient and family engagement can only happen if health professionals, organizations and policies (a) create clear opportunities for engagement, (b) make it clear that they welcome engagement, and (c) provide the support that people need to engage (Carman et al., 2013). Patient-centered views of engagement require health care professionals to hear and understand the values, preferences, cultural context, and potential contributions of the patients' needs (Carman et al., 2013).

Biases may consist of only including patient/family advisors within the academic medical center and only having feedback from these health care consumers, in contrast to including other patient/family advisors from rural community hospitals, nursing homes, long-term care facilities home health agencies, and community health centers. This research has made generalizations from this specific population. Measures to address limitations included acknowledging there are many other health care organizations who utilize patient/family advisors. Future research intends on addressing the limitations by conducting additional research with other health care organizations.

Significance of the Study

This phenomenological research study was discussed as a driver of positive social change, which can possibly create contributions to advance the knowledge in the discipline of management, leadership, organizational change, and health care. Supporting professional practice in answering the "so what" question. Patients, caregivers, patient groups, health care leaders, federal agencies, and communities are now both internationally and domestically calling for patient-centeredness and patient and family engagement as vital strategies for improving health delivery and outcomes (Fluerence et al., 2013; Newhouse et al., 2015). Describing the patient/family advisors perceptions can help to close the gap in incorporating patient/family advisors into the planning, processes, procedures, programs, services, and initiatives within the hospital setting.

Significance to Practice

Health care organizations who use patient/family advisors are encountering improved patient satisfaction, reimbursements, and outcomes such as decreased lengths of stay (Roseman et al. 2013). Involving patients and their families in health care systems supports treatment of the whole person (Warren, 2012). Likewise, engaging patients and families in advisory roles, health care professionals can create personalized care based on more than one model of care (IOM, 2001). Patient/family advisors can help instruct health care professionals with a true partnership of engagement on the journey of organizational change (Taloney & Flores, 2013).

Significance to Theory

This study helps to fill in the gaps in literature by providing descriptions of what is not known about patient/family advisors experiences and perceptions on their roles as advisors and their relationships with health care professionals. This study helps to link the patient’s experiences to enhance patient and family engagement within the individual level and organizational level of engagement. With the voice of the patient and their families at the center of healthcare, using the patient perspective to help improve aspects of patient and family engagement, patient satisfaction, and patient experiences (Stanbrook et al., 2012).

The research problem of patient/family advisors experiences and perceptions regarding patient and family engagement and their advisory roles was incorporated into addressing the drivers of social change by proposing and identifying opportunities for engagement and social change. Opportunities for social change describe a rationale behind creating standards or best practices for patient-centeredness and patient and family engagement. Patients and their families have ongoing opportunities to transform and engage with medical staff to create social change. Patient/family advisors can help researchers describe their rationale for engagement within the deferent levels of health care (individual, organizational and governance, and policy making).

Development in the field of management concerning the patient/family advisors perceptions on engaged health care could facilitate in the expansion of methods and tools to improve outcomes concerning patient and family engagement. The questions surrounding patient and family engagement can also help describe ways to ensure patients and families understand the role in partnering with medical staff. This partnership within the organizational level can help to make the best decision for future patients and family members. To obtain the best decision for the patient and their family, it is essential to have informed and involved patient/family advisors in the engagement processes. Herrin et al. (2015) argued patients benefit when family members play an active part in the patient's care.

Aronson, Yau, Helfaer, and Morrison (2009) found family members provided new information 46% of the time. The research participants in this study described their advisory roles in hopes to better understand patient and family engagement from the perspective of patient/family advisors. This research asked patient/family advisors how they feel about their roles in organizational and governance in areas such as advisory councils, setting agendas, public speaking, determining priorities, and partnerships. Evaluating the core values of patient-centeredness and patient and family engagement and how patient/family advisors construct and understand their subjective experiences of being part of the organizational subculture needs to be further explored. More needs to be learned from the perspectives of patients and their families.

Significance to Social Change

This research attempted to demonstrate the focus of patient/family advisors at an academic medical center in the Midwestern United States. Using patient/family advisors feedback and integrating it into the processes within management has helped to create change within the organizational structures, processes, and strategies to promote and facilitate patient and family engagement within the medical center. This research may help health care professionals better understand patient and family engagement from the perspectives of consumers within the organizational level of change management, thus creating an opportunity for positive social change within the community. Expanding this research into outpatient or ambulatory settings could also be applicable.

The relevance of future research ensures the research speaks and shapes what matters most to patients and their caregivers (Pollock, George, Fenton, Crowe, & Firkins 2014; Barello et al., 2014). Connecting the results of research to patients' individualized health care needs and making the research findings widely assessable can help transform the foundation of patient and family engagement into meaningful and essential guidance for the broad health care community (Gabriel & Normand, 2012). Hence, the long-term vision of social change involves a broad adoption of methodological standards that can increase the development, implementation, and involvement of evidence-based, patient-centered health outcomes (Gabriel & Normand, 2012).

Summary and Transition

Partnering with patients and families as active partners in health care delivery reform may be considered a potential answer to reducing health care costs while improving quality and safety, patient satisfaction, patient experience, and patient and family engagement standards. Patients who are more educated with healthcare terminology, experience, and or activated are more likely to engage in the management of their personal health care which may help to reduce or limit poor clinical outcomes, lengths of hospital stays, and overall health care costs (Barello et al., 2014; Danis & Solomon, 2013).

High levels of patient and family engagement may benefit policy makers, patient advocacy groups, community based nonprofits, health care providers, patients and their families, and other health care stake holders such as insurance companies and payers (Barello et al., 2014; Coulter, 2012). High levels of patient and family engagement can also create the partnerships with patients and their families advocating for patient and family engagement and is also a key part of the contemporary health care system within the United States (Barello et al., 2014; Coulter, 2012). Furthermore, improved understanding of patient and family engagement can help protect health care professionals, patients, and families' relationships and lead to important changes in healthcare delivery

In Chapter 2, I present the results of a literature search of current methods and activities directed toward creating best practices of patient and family engagement (both on a personal level and organizational level) from the patient/family advisors perspective as an essential precursor to creating new understanding. Chapter 3 is an explanation of how the research was conducted to gain additional information about patient and family engagement and creating best practices from the perspectives of patients and families. Chapter 4 contains the results of the interviews and analysis. Chapter 5 includes the summary, conclusion, and recommendations developed from the data.

Chapter 2: Literature Review

In this study, I focused on the continuum of engagement, which revolves around organizational design and governance of patients, families, and caregivers and their care experiences. I addressed the research problem of patient and family engagement from the perceptions of patient/family advisors who represent the overall voice of health care consumers. According to Domecq et al. (2014), research lacks of evidence concerning how patient/family advisors view their personalized health care and organizational partnerships. This led me to develop a rationale through the literature review which supports research surrounding patient and family engagement in health care.

The purpose of this research was to discover how patient/family advisors feel about their experiences with the patient family advisory councils regarding hospital quality improvement and engagement practices (Carman et al., 2013). Taking a new approach, patient/family advisors are able to relate their patient and family experiences so that important changes can be made to improve the future of patient and family engagement and the next patients experience (IPFCC, 2012). Receiving feedback from patient/family advisors may help to fill in the gap of understanding the different levels of engagement (direct care, organizational design and governance, and policy making). Incorporating patients and families' views in health care organization systems and settings can help to create a transformation within all levels of health care.

I used the multidimensional framework on patient and family engagement created by Carman et al. (2013) in conjunction with patient/family advisors and patient family advisory councils when searching the literature. Even if engagement is not likely by all patients and family members, more consumers will request greater involvement in direct care, organizational design and governance, and policy making (Hibbard & Greene, 2013). Patient and family engagement is an increasingly vital component of strategies to reform health care (Hibbard & Greene, 2013). To understand the patients' and families' ideas of patient-centeredness and patient and family engagement, researchers and health care professionals need to understand the patient and family perspective.

I examined the drivers of social change in health care settings to propose new opportunities to include patient/family advisors into the processes of patient and family engagement and patient-centeredness within the organizational level of engagement. Transforming these opportunities into research can establish transparent data, with the possibility of expanding the scholarly body of knowledge and open the doors for future research studies. I used transactional leadership, transformational leadership, servant-leadership, and leader-member exchange to synthesize literature and create grounds for the need of this study. I used servant leadership as a style of leadership, which helps organizations move beyond the tradition paternalistic approach to management (McCann et al., 2014).

Historically, the patient-physician relationship was limited to a one-way speech from medical professionals. During the 1970s, medicine shifted to toward the patient, leading to a fundamental change in the delivery of care, calling for more patient involvement and a cultural shift in how medical professionals think about patients as partners, rather than solely as recipients of care (Han, Scholle, Morton, Bechtel, &

Kessler, 2013). This cultural shift from the old paternalistic model toward the new model of transformative health care put patients first in their health care (Han et al., 2013). As models in patient-centered medicine were introduced in medical curriculum, more engagement became accepted and adopted (Han et al., 2013). Eventually the patient-physician relationship changed and participation in decision making became more common (Han et al., 2013).

Patient-centeredness revolves around the active engagement of patients and their families while also focusing on their personalized preferences and needs in the decision-making process with their health care providers (Johnson & Abraham, 2012). Patient-centeredness is accomplished by repositioning and evaluating patients and caregivers as valuable but untapped and underused partners in patient and family engagement (Ricciardi et al., 2013; Newhouse et al., 2015). Focusing on the patient first stresses the importance of understanding experiences, illnesses, and addressing the patient's needs within a complex, escalating, and fragmented healthcare system (Barry & Edgman-Levitan, 2012).

Many health care organizations use patient/family advisors and patient family advisory councils to create patient and family engagement in the inpatient and outpatient settings. Patient/family advisors have participated on performance improvement teams, served as faculty in education programs, interviewed applicants for key positions, and developed and edited patient education materials (Wynn, 2015). Understanding the patients' and families' experiences can allow researchers to learn how patient/family advisor worldviews can shape the patients' perspectives on their lives, their caregivers, and themselves.

Using patient/family advisors feedback to evaluate patient and family engagement models may help health care professionals better understand where improvements can be made and to better accommodate patient's preferences. Although many healthcare organizations have established patient/family advisor programs and patient family advisory councils to inform improvement efforts, most health care organizations do not effusively integrate the voice of patients and families into the process improvement efforts, thereby creating new standards for care for patient and family engagement.

Chapter 2 includes how patient/family advisors can help create positive social change within the organizational setting. Involving patient/family advisors within the hospital level of engagement have included establishing patient and family advisory councils, workgroups, committees, improving care systems (Rockville et al., 2012). Chapter 2 also looks to define and synthesize all the available definitions of patient and family engagement. I acknowledged the health care consumer perspective on patient and family engagement by including patients, families, caregivers, and communities at large. I also explored themes such as patient-centeredness, patient/family advisors, patient family advisory councils, patient experience, servant leadership, transactional leadership, transformational leadership, and leader-member exchange.

Literature Search Strategy

The library databases that I accessed included an academic medical center library and Walden's online library. I used the Walden library to obtain majority of the scholarly journals during the search process. Before I started the research, I created an outline to conduct background reading, searched the literature within the field, found specific resources for the research, and remained focused on the topic even as it was broadened, narrowed, or modified based on the initial research findings. The search engines I accessed included PychINFO, ERIC, ProQuest, EBSCOhost, Google Scholar**,** Medline database, and Pub Med literature database.

I used the following search terms: *patient/family advisors, patient engagement, patient and family engagement, and patient-family centered care surrounding keywords such as academic medical centers, healthcare, engagement, patient advisors, patient partners, patient experience, hospitals, academic medicine, patients, caregivers, transactional leadership, transformational leadership, servant leadership,* and *leader-member exchange*. I conducted targeted searches through journals such as Journal of the American Medical Association and an annual Health Affairs student subscription.

Furthermore**,** I conducted an iterative search to explore the key search terms of patient and family engagement, hospitals, patient-centeredness, patient activation, patient/family advisors, and to identify germane scholarship. My goal was to locate major resources on the topics of patient-centeredness as well as patient and family engagement in addition to scholarly and professional resources closely related to the patient experience and patients' perceptions. My initial search efforts were broad seeking out hundreds of potential resources.

I used a literature-based description of this qualitative study to explore the potential themes and perceptions from patient/family advisors in an academic medical center. The content of the review is drawn from using other sources that are considered acceptable peer-reviewed and otherwise sound academic literature such as books, dissertations, and conferences. Because the notion of patient-centeredness and patient and family engagement is still emerging in the field of research, there is little current research and dissertations. I have attended conferences with the (IPFCC) as well as the Patient Centered Outcomes Research Institute (PCORI) to gain a deeper understanding of these emerging concepts.

The central research question for this study was: How do patient/family advisors describe patient and family engagement within patient family advisory councils? The sub questions helped me to explain how patient/family advisors described opportunities and partnerships for engagement within the patient family advisory councils. I used the responses from the face to face interviews to cobble together a narrative of best practices of patient and family engagement from the perspective of patient/family advisors.

Conceptual Framework

I used servant leadership to describe the role of serving others, patients, families, and the community, looking from the perspectives of patient/family advisors and their roles serving on patient family advisory councils. I used transactional-transformational leadership to describe the cultural shift that occurs within the organizational level of engagement between patient/family advisors and medical staff. The cultural transformation of engagement for medical professionals, patients, and families helps to connect the idea of serving others.

I used leader-member exchange to describe the relationships between the medical staff and patient/family advisors and how each led each other to sustainable partnerships in health care and to see if the patient family advisory councils are considered beneficial to increasing patient and family engagement within the medical center. James MacGregor Burns (1978) conceptualized “leadership as either transactional or transformational” (Bass & Riggio, 2006, p. 3). Burns (1978) explained how transactional leaders such as business leaders will either offer or deny financial rewards based on the followers productivity.

Transactional leaders use social exchange, exchanging one item for an alternative to lead. Transactional leaders support the exchange process (Gunzel-Jensen, Jain, & Kjeldsen, 2016). Bass (1985) viewed both transactional and transformational leadership as positive and recommended optimal use of both the styles for maximum effectiveness. Bass and Riggio (2006) felt transformational leadership may be more effective in modern times. The transactional process of reinforcing expectancies for rewards is a vital component of the full range model of effective leadership.

A transactional leader manages inside an existing culture or system by (a) concentrating on attention to irregularities, mistakes, or deviations and taking action, and (b) trying to satisfy the existing needs of employees by concentrating on exchanges and contingent reward behavior (Bass, 1985). A transactional leader does not expect or encourage employees to exceed defined goals or to change the status quo (Gunzel-Jensen et al., 2016). Transactional leadership seems to be aligned with change focusing on benchmarking or monitoring the quality of healthcare work using clinical and organizational indicators in addition to incentivizing and controlling employee's behavior (Bass, 1985).

Transactional leadership can happen when the leader, has apparent authority and motivates followers by punishment or reward (Kumar, 2016). Gunzel-Jensen et al. (2016) expressed, transactional leadership has succeeded in supporting the give and-take approach within the health care industry. Transactional leadership is still practiced extensively in healthcare settings and is in part is embedded within the hierarchical of organizational settings (Kumar, 2016). Transactional leaders can help healthcare organizations meet financial and operational targets but have a limited role in service management (Kumar, 2016).

Bass (1985) defined the parameters of transformational leadership, suggesting specific behaviors can influence employees' reactions to change. Bass and Riggio (2006) stated leadership can happen by any person and at different levels "is the foundation of the paradigm surrounding transformational leadership" (p.2). These viewpoints originating from transformational leadership are essential to creating successful leadership and have been widely relevant to life, varying from family to work to classroom to sport and, social change (Bass & Riggio, 2006). The way teams are lead has been measured by healthcare performance, while various aspects associated with leadership styles have been strongly linked to patient outcomes (Fischer, 2016).

Transformational leaders engage followers to believe in themselves and their mission; they motivate the front line medical staff to perform beyond expectations while also inspiring growth in the culture by transforming attitudes, beliefs, and behaviors

(DiGioia, Greenhouse, Chermak, & Hayden, 2015). Allowing all partners in the healthcare team to think beyond the box and to dream of the perfect care experience for patients and families gives staff a huge opportunity create a cultural transformation, rather than incremental improvements in the way healthcare is delivered (DiGioia et al, 2015).

Many scholars have emphasized the substantial similarity between servant leadership and transformational leadership (Dierendonck et al., 2014). The explanations of servant leadership and transformational leadership highlight a significant connection between the two leadership styles (Dierendonck et al., 2014). Both servant and transformational leaders concentrate on their followers, offer leadership beyond creating goals and visions for the future (Dierendonck et al., 2014). Servant leadership (Greenleaf, 1970) is one leadership style that has become popular for several decades because it emphasizes improving organizations through empowerment and building the culture, successfully leading to increased revenue due to becoming customer-focused (Jones, 2012b).

Hayati, Charkhabi and Naami (2014) found transformational leadership had a positive and significant impact amongst hospital nurses on aspects of work engagement. Their research illustrated transformational leaders transfer enthusiasm to their followers through modeling. Shuck and Herd (2012) found transactional leadership may also contribute to the development of employee engagement along with transformational leadership, but has not been tested much. Building trust between the leader and the follower can also be related to the leader-member exchange theory. Leader-member exchange is founded on the belief that leadership exists in the quality of the association between the manager and employee (Vidarthi et al., 2014).

For more than forty years, researchers have investigated the dyadic relationship between follower and leader (Vidarthi et al., 2014). Leader-member exchange theory claims when managers offer resources which are perceived fair and beneficial, employees will perceive the relationship positively and respond through improved effort and commitment, resulting in high quality relationships (Hanse et al., 2015). Leader-member exchange theory focuses on the value of the relationship of the leader-follower, offering "a different relational perspective on how leaders influence their subordinates to become engaged" (Burch & Guarana, 2014, p. 7).

The theory of leader-member exchange distinguishes leadership as a method which focuses on the partnership between employees and leaders (Lo, Azlan, Ramayah, & Wang, 2015). Leader-member exchange relationships between managers and employees socialize subordinates into codependent roles in which personal influence can function, and synchronized work may or may not be accomplished (Ford et al., 2014). Psychological contracts between employers and employees essentially involve exchange relationships, representing an insight of how single and joint interests are considered through exchange (Ford et al., 2014).

The leader-member exchange theory ties into using patient/family advisors as patient leaders within the organizational setting of health care to enhance the consumer's voice. At times, patient/family advisors take initiative, leading council meetings, speaking at new employee orientation, or participating in workgroups and committees.

During the course of the (PFEAP) initiative, both the medical center staff and the advisors take turns leading and following within the patient family advisory councils. The social exchange between patient/family advisors and medical care professionals creates an environment of sharing information, creating a culture of trust, transparency, dignity, respect, empathy, and compassion.

The rationale to choose servant leadership as the main leadership style was used because it can be implemented differently among various organizations; each individual organization consists of a distinctive history, philosophy, and culture (Parris & Peachey, 2013). Servant leadership is grounded on common characteristics that are applicable to individuals, businesses, communities, and organizations (Baldner, 2012). Contemporary definitions of servant leadership place emphasis in “serving” and expand beyond employees to include customers, stakeholders, and investors within an organization (Linden et al., 2014). In other words, the servant-leader strives to understand and empathize with others, these leaders practice compassion, acceptance, and empathy and have been recognized for their special and unique spirits (Baldner, 2012; Frick, 2009).

Trastek et al. (2014) described servant leadership as the best model for healthcare organizations because it concentrates on developing trust while serving the needs of the patient and focuses on the strengths of a team. Building upon team support and collaboration is a characteristic of servant leadership and helps to create a positive environment between the patients, families, and health care staff (Baldner, 2012). Hunter et al. (2013) suggested servant leadership can have a positive impact on followers, by creating service climate, enhance sales behaviors and helping followers, and reduce withdrawal. The practical implications for management show how the practice of servant leadership can help with creating a culture that promotes serving others and where their follower wants to remain.

Dierendonck et al., (2014) offered considerations into the various tools through which servant leadership and transformational leadership influence followers. Dierendonck et al. assessed the environmental uncertainty as a moderator with the results of servant leadership and transformational leadership. Grounded on the conclusions of one field study and two experimental studies, Dierendonck et al. concluded, both servant leadership and transformational leadership were associated with organizational commitments and work engagement. However, the ways in which they are implemented differed. Servant leadership worked mostly through the needs of follower satisfaction, while transformational leadership operated largely through distinguished leadership effectiveness (Dierendonck et al., 2014).

Transformational leadership attempts to cultivate emotional relationships with employees and inspire enhanced values of organizational performance (Lo et al., 2015). The style of transformational leadership delivers a message of importance to the mission and creating a sense if determination and importance onto the employees (Lo et al., 2015). Transformational leaders are advocates and promoters for advanced cultures diffused with knowledge to create enhanced organizational performance (Lo et al., 2015).

Burch and Guarana (2014) compared the influence of leader-member exchange and transformational leadership behaviors on follower engagement and researched the relationship between leader-member exchange and transformational leadership theories and follower engagement. The results imply follower engagement is created by the distinctive relationship between the leader and employees'. Understanding the implications of different leadership theories on follower engagement can help leaders to understand how to establish and support follower engagement (Burch & Guarana, 2014).

The conceptual framework was based on the combination of views from health care professionals, patient/family advisors, and patient family advisory councils. Servant leadership, transactional leadership, transformational leadership, and leader-member exchange were used to focus on the dyadic relationships between the medical staff and patient/family advisors. I also synthesized literature to discuss patient and family engagement between patients, families, and health care organizations. This is important because the notion of patient-centeredness revolves around the exchange between patients, families, and the medical staff to create a better future for health care and relationships based on trust.

Patients and families consist of a diverse group of primary stakeholders in the health care system, creating challenge to improve the quality and cost of health care (Trastek et al., 2014). Looking at various stakeholders, health care consumers and health care providers are in greatest position to establish ways to improve care (Trastek et al., 2014). To create social change, health care professionals must be taught how to successfully lead patients, individuals and families within health care organizations, and various stakeholders (Trastek et al., 2014). As servant leaders, healthcare professionals may be best equipped to create changes in the organization and in the patient-provider relationship to improve the quality of care for patients (Trastek et al., 2014).

Servant leaders focus on the process of reflecting on their own self-knowledge and awareness which can lead to developing morals, ethical beliefs, and creating a moral core (Trastek et al., 2014). The moral and ethical aspects of servant leadership expect health care professionals to consider the financial, emotional, and physical needs of the patient first (Trastek et al., 2014). Bass and Riggio (2006) considered followers as the most effective cornerstone of transformational leadership or in this case, the advisor's perspectives on their commitment and attitudes toward the organization and the leaders within the organization.

Popli and Rizvi (2016) studied the drivers of employee engagement and the influence of leadership styles such as the transformational-transactional style. The study found evidence for the transformational leadership-employee engagement association but more importantly it established the transactional leadership-employee engagement association, especially during the beginning stages of career and amongst young subordinates. In summary, the importance of both transactional and transformational leadership styles helps to enable employee engagement known as a critical variable which influences many organizational outcomes (Popli & Rizvi, 2016).

Patient/family advisors and medical staff tend to also show traits and characteristics of roles within the leader-member exchange. Whereby, both medical leaders and patient/family advisors are working together to enhance levels of patient and family engagement and the patient experience within the organizational level of change. The model of leader-member exchange suggests that leaders don't use the same styles or set of behaviors consistently with all employees (Hays & Lou, 2013). As an alternative, individual exchanges or relationships develop with each member which stays somewhat steady throughout the relationship (Hays & Lou, 2013).

Vidarthi et al. (2014) research findings suggested when followers have more dual leaders; the relationships between the two leaders tend to impact employee outcomes. In other words, many followers work within organizations where everyday directions and employee evaluations come from different leaders and the various quality of those relationships affect job satisfaction and employee turnover (Vidarthi et al., 2014). Studies have shown patient family advisory councils can create transformative shifts in the paradigm of collaboration between health care professionals and consumers, creating and supporting exchanging ideas while setting expectations and clarifying needs (Friesen et al., 2013).

Patient/family advisors may feel a strong commitment and loyalty to their health care providers and organizations for various reasons. Patient/family advisors may feel they are paying it forward, or giving back, or contributing to creating change not only for others but for themselves as well. The reward of volunteering often ties the optimistic feeling of contributing to the organization and creating loyalty and commitment to the organization, transformational leadership which understands the advisors needs, stimulates and inspires the advisors level of satisfaction with their services.

The cornerstone of the true power of organizational leaders involves the degree to which leaders can influence followers. Often, power of organizational leaders is dependent upon a level of trust between the leader and the follower along with the amount of interface organizational leaders has with their followers. Ethics and values play important roles in patient and family engagement (Danis & Solomon, 2013). Patient and family engagement has been promoted to be justified ethically with evidence to suggest patient-centeredness can create improved outcomes for patients (Danis & Solomon, 2013).

Merging employee-volunteer-leader relationships in the context of the business model regarding patient-centeredness and patient and family engagement with patient/family advisors needs to be researched and further developed. Organizations can create transferability from the patients and their families to better enhance outcomes for quality and safety while innovating ways to create best practices for patient and family engagement. There is a need for an innovative approach to enhancing patients and families voice in the care processes of change. Preparing to address change techniques with patient and family engagement models may help with the transition along with creating opportunities to enhance and meet the needs of patients in the 21st century.

Literature Review

Servant Leadership

According to Robert Greenleaf (1970), the focus of servant leadership should be on serving rather than leading. Greenleaf discussed the need for a new leadership model that put serving others such as the community, customers, and employees as the number one priority. Greenleaf defined characteristics of servant leadership. These ten characteristics were critical to a successful servant leader: (a) listening (b) empathy (c) building community (d) healing (e) awareness (f) commitment to the growth of people (g) foresight (h) stewardship (i) conceptualization (j) persuasion. Spears (2004) also recognized the characteristic and qualities of servant leadership: empathy, listening, persuasion, foresight, commitment to the growth of people, healing, stewardship, awareness, conceptualization, and building community.

McCann et al. (2014) explained servant leadership is additionally characterized by the traits of empathy, self-awareness, stewardship, and being a good listener, which allows the leader to gain a better understanding of the needs of the people. Servant leaders are known for expanding their abilities while adapting their goals to the organizational objectives (McCann et al., 2014). Jones (2012b) also described many attributes of servant leaders that included trust, empowerment, acceptance, empathy, positive morale, and desire to serve others. These specific traits would become the foundation of a good leader and follower relationship per Greenleaf (1970). From this idea of servant leadership, Greenleaf promoted the objectives, ambitions, and interests of the followers to the forefront of the organization.

The ten characteristics described by Spears (2004), combined with a moral core and motivate servant leaders to help employees overcome challenges and reach their goals (Trastek et al., 2014). Trastek et al. (2014) explained many of these characteristics can help to create trusting relationships between leaders and families. Trastek et al. (2014) stated,

> A patient has a high degree of trust in the health care provider and the health care team has a high degree of mutual trust, then the trust will improve the quality of care and lower the cost of care, thus improving value (p. 380).

The sets of skills included awareness, empty, listening, persuasion, and healing all add to a trusting patient-provider relationship (Trastek et al., 2014). The characteristic of persuasion is a symbolic distinction from servant leadership compared to other leadership styles because it removes the traditional leader authority for creating unilateral decisions (Frick, 2009). Servant leaders nurture their community, those who work in businesses and other institutions (Frick, 2009). Servant leaders also practice healing of relationships, which is a powerful force for transformation and integration (Frick, 2009).

Servant leaders practice stewardship, a commitment to serving the needs of others while also emphasizing the use of openness and persuasion, rather than control (Frick, 2009). Servant leadership has been known to create atmospheres that show compassion and empathy, concepts that are also important in health care (Frick, 2009; Johnson & Abraham, 2012). Sun (2013) also viewed the approach of servant leadership by looking the servant leader's identities with engagement within both private and public areas. Sun considered the identity of servant leaders, their sense of self, and how they cognitively process information and exercise behavior while responding within the organization.

Servant leadership can help health care professionals create "positive patient outcomes by promoting change in patient health behavior" (Trastek et al., 2014, p. 380). Health care professionals such as administrators, nurses, and doctors work as a team to treat and diagnosis disease and build communities to provide high valued patient-centered care (Trastek, 2014). McCann et al. (2014) studied the amount in which rural community hospitals leaders were recognized as servant leaders and the degree of employee satisfaction within these hospitals. The research compiled 10 United States community hospitals with 219 completed surveys, revealing a correlation between servant leadership and employee satisfaction as well as Health Consumer Assessment of Healthcare Providers and Systems (HCAHPS) scores and intrinsic satisfaction (McCann et al., 2014).

Furthermore, Sun (2013) analyzed the psychological factors constituting the servant identity which is identified with “being a servant is central to one’s sense of self” (p. 546). Jones (2012b) examined the results of servant leadership between the leader-follower relations with influence on the customer in the context of employee empowerment, satisfaction, performance, and organizational culture. Jones’ (2012b) results indicated, engaging in servant leadership encourages stability with increased finances and increased productivity within the organization. Jones (2012b) additionally implied profits increased as a net result of servant leadership.

Transactional Leadership

James MacGregor Burns (1978) conceptualized transactional leaders as those who lead by way of social exchange. Transactional business leaders deny rewards for lack of productivity or reward financially for desired work outcomes (Bass & Riggio, 2006). Transactional leadership stresses the exchange or transaction that occurs between colleagues, followers, and leaders (Bass & Riggio, 2006). This transactional exchange is established when the leader discusses with others what is required and specifies the rewards and conditions others will be given if they accomplish what is expected of them (Bass & Riggio, 2006).

In reference to the model, the full range of leadership, developed by, Avolio and Bass (2001), transactional leadership occurs when the leader rewards or disciplines the follower, depending on the adequacy of the follower’s performance. Transactional leadership depends on contingent reinforcement, either positive contingent reward or the more negative active or passive forms of management-by-exception (MBE) (Bass & Riggio, 2006). Contingent reward is otherwise known as the constructive transaction and is believed to be successful in motivating others to accomplish advanced levels of performance and development (Bass & Riggio, 2006).

MBE is a corrective transaction that tends to be more unsuccessful than contingent reward or the four components of transformational leadership (Bass & Riggio, 2006). The MBE corrective transaction may be passive (MBE-P) or active (MBE-A) (Bass & Riggio, 2006). In MBE-A, the leaders organize to vigorously monitor deviances from errors, mistakes, and standards in the follower’s work and when necessary undertake corrective action (Bass & Riggio, 2006). On the other hand, MBE-P involves waiting inertly for errors, mistakes, and standards to happen and then and undertake corrective action (Bass & Riggio, 2006). MBE-A may be effective and required in certain situations, especially when safety is a principal of importance (Bass & Riggio, 2006).

Leaders sometimes must practice MBE-P when they are obligated to manage a significant number of followers who directly report to leaders (Bass & Riggio, 2006). Transactional leaders who rely on MBE, and who also draw attention to harsh corrective procedures, may in fact increase stress among their followers (Bass & Riggio, 2006).

Transactional leaders who are coercive with their threats and promises may lower the confidence of their followers who may already feel angry, stressed, victimized, and subjugated (Bass & Riggio, 2006). Transactional leaders who use their power to coerce their followers may create additional stress on their followers and to some extent can be considered the most stressful aspect of the followers work environment (Bass & Riggio, 2006).

Authoritative managers are often referenced as a major source of stress on employment (Bass & Riggio, 2006). This can become excessive when the transactional leader states, “either you do as I say or else” (Bass & Riggio, 2006, p. 62). Such leaders establish the exchange or transaction on their power to intimidate followers (Bass, 1960). Conflict is considered an important source of stress in organizations and an essential leadership task is managing the conflict and stresses that take place within the work environment (Bass & Riggio, 2006). Transactional leaders manage crisis with structures by MBE-A and can supply solutions for immediate satisfaction and needs perceived by their followers, but do not necessarily create long-term positive effectiveness in coping with stressful circumstances (Bass & Riggio, 2006).

When MBE is commonly practiced, employees work independently (Bass & Riggio, 2006). Cooperation from the followers typically depends on the organizations capability to satisfy the self-interests of each employee (Bass & Riggio, 2006). When employees do not relate with the organization, its mission, or its vision, it’s typically because the transactional organization provides extreme compensation for top management, leaving followers to question their rationale for loyalty to the institution

(Bass & Riggio, 2006). Leaders are considered merely resource allocators and negotiators in which the politics and power following the request may be as significant as the merit while risk taking and innovation is normally discouraged (Bass & Riggio, 2006).

Individual rewards to a great extent compensate concern for the larger organization (Bass & Riggio, 2006). A transactional culture focuses on implicit and explicit contractual relations (Bass & Riggio, 2006). Job descriptions are in writing, followed by statements about employment conditions, disciplinary codes, rules, regulations, and benefits (Bass & Riggio, 2006). The motivation to work is a matter of trade-offs of the follower's efforts in exchange for rewards while avoiding disciplinary actions. Commitments remain temporary, while self-interests are highlighted, and where the subordinate's rewards are contingent on their job performance (Bass & Riggio, 2006).

Transformational Leadership

Transformational leadership represents a multidimensional leadership style that inspires followers to improve work for the betterment of the organization (Dierendonck et al., 2014). Transformational leaders stimulate and inspire followers by offering a compelling vision of future changes within the organization (Bass, 1985). Transformational leaders use intellectual stimulation and challenge employees to accept innovative solutions to problems and to challenge the status quo (Bass, 1985; Bass & Avolio, 1994).

Transformational leadership examines numerous components of leader behaviors (Dierendonck et al., 2014). For instance, Bass (1985) theorized transformational leadership as having four distinctive traits; inspirational motivation (communicating and stimulation vision), idealized influence (serving as a motivating role model), intellectual stimulation (stimulating followers to think outside the box), and individual consideration (an emphasis on followers' development). Kelloway et al. (2012) suggested that the elements of transformational leadership proposed by Bass and Avolio (1994) are particularly related to employee's emotional well-being.

Inspirational motivation uses the leader's ability to motivate, inspire, and communicate expectations with images, emotional appeals, and symbols (Bass & Avolio, 1994) by providing followers with a meaningful purpose driven job, creating goals, and visions of future business (Bass, 1985). If the leader can fulfill the vision, followers may believe the leader is dependable, trustworthy, and competent (Zhu et al., 2013), by communicating clearly and generating optimism for goal achievement and vision attainment (Avolio, 1999). Leaders demonstrating inspirational motivation inspire employees to accomplish more than what was possibly believed by overcoming emotional setbacks by building confidence to undertake future problems (Kelloway et al., 2012).

Transformational leaders who offer idealized influence act as role models, displaying the type of behavior which is usually well-liked in society (Zhu et al., 2013) and have higher levels of trust with their followers (Jung & Avolio, 2000). Attributes of idealized influence refer to the followers admiring or respecting their leader (Hensworth, Multerera, & Baregheh, 2013). Leaders who demonstrate idealized influence can look beyond the organizational demands of temporary monetary outcomes, and as an alternative, focus on long-term goals of concentrating on the health of their employees (Kelloway et al., 2012).

The display of being a role model and readiness to place team goals over personal welfare create an emotional bond between the leader and their followers with increased levels of emotional trust (Zhu et al., 2013). Idealized influence happens when leaders uphold ethical standards and have a moral commitment to their followers for the betterment of the organization, instead of serving one's own interest (Kelloway et al., 2012). Intellectual stimulation allows leaders to promote and emphasize rationality and intelligence by allowing followers to express ideas, values, and beliefs (Bass, 1985).

Leaders who demonstrate intellectual stimulation help employees restructure problems, examine their individual assumptions, and handle difficulties with innovative strategies (Kelloway et al., 2012). Employees develop more confidence in developing and protecting their own interests when they are given the opportunity to create personal strategies to handle emotional and work-related road blocks (Kelloway et al., 2012). In return, the emotional bond is strengthened between the leader and their followers, leading to higher levels of emotional trust (Zhu et al., 2013). Individualized consideration portrays the extent to which leaders teach followers they sincerely are concerned for their well-being (Judge & Piccolo, 2004).

With individualized consideration, the leader gives personal support and feedback to the follower (Hensworth et al., 2013). Leader's actions are described as actively listening to concerns, mentoring, keeping communication lines open and pro-actively taking initiative to concentrate on each individual follower (Avolio, 1999). Individualized consideration recognizes and supports the employees' needs with compassion, empathy, and guidance to influence their well-being (Kelloway et al., 2012). The establishment of individualized consideration may increase levels of trust in their followers (Zhu et al., 2013). Leaders who display individualized consideration are more likely to improve follower's opinions of the leader's integrity regarding the degree they are reliable and competent, creating increased levels of trust (Zhu et al., 2013).

The growing requests of health care social systems have begun to see the importance of the patients and families' perspective. Transformational leadership may enhance the cultural change within health care systems as it relates to patient and family engagement business objectives. Braun et al. (2013) investigated relationships between transformational leadership such as trust in supervisor and team, job satisfaction, and team performance. Braun et al. findings propose transformational leadership was positively related to job satisfaction of followers' at both the individual level (job satisfaction) and the team level (team performance).

Leader-Member Exchange

Many leader-member exchange studies have shown how employee outcomes are influenced by the quality of the dyadic relationship between managers and followers (Vidarthi et al., 2014). Schermuly, Meyer, and Dammer (2013) researched innovative behavior in the workplace and examined how leader-member exchange influences innovative behavior and how the relationship is facilitated thru empowerment. When employees receive additional emotional reinforcement, and share work material, they tend to be more motivated and adopt innovative behaviors and new ideas, particularly in unclear circumstances, leading to greater levels of psychological empowerment (Schermuly et al., 2013).

Mangers and leaders who have an optimistic attitude toward the employee and innovative job responsibilities play an important role with the success of the innovative process (Schermuly et al., 2013). The theory of leader-member exchange distinguishes leadership as a method which focuses on the partnership between employees and leaders develop either a low-quality or high-quality social exchange and “is an important boundary condition to explain the effects of leader behaviors on subordinates” (Michel & Tews, 2016, p. 14). In this relationship, followers who form high-quality social exchanges tend to share information with leaders while also enhancing work performance, improvements, skills and ethics (Lo et al., 2015).

High-quality exchanges allow leaders to provide employees with emotional support and trust which is positively related to performance of the organization and supports the idea that the leader’s emotional regards are essential in the performance of the organization (Lo et al., 2015). Employees who have high quality exchanges are often referred to the “in-group” and those with low quality relationships are considered the “out-group” (Hays & Lou, 2013, p. 54). High-quality leader-member exchange employees will engage in behaviors to improve their relationships based on positive social exchanges, validating their individual identification among the leader (Michel & Tews, 2016).

High-quality relationships allow for an improved understanding of dyadic problems and allows both to tackle them, resulting in enhanced organizational performance (Lo et al., 2015). A high-quality exchange between team members and leaders has shown to have a positive impact on innovative behavior as it increases employees' psychological empowerment (Schermuly et al., 2013). On the other hand, in low-quality social exchanges leaders offer little support to motivate and prepare employees to perform their job duties and job requirements (Lo, et al., 2015).

Conversely, employees who have low quality leader-member exchange exchanges are familiar with opposed behavior and may view discussion strategies as dishonest and are driven by devious intents (Hays & Lou, 2013). For example, leaders with bad character who engage in caring behaviors could be viewed stealing employee's ideas, or perceived as selfish efforts to increase employee approval, instead of an effort to expand or initiate change (Hays & Lou, 2013). "Low-quality LMX relationships are also less likely to personally identify with the leader and adopt the leader's values and beliefs" (Michel & Tews, 2016, p, 15).

Ford et al. (2014) investigated the relationship between social exchange quality and perceived influence in both leader-member relationships and team-member relationships. Ford et al. (2014) findings suggested if an individual perceives someone as influential, the individual is more likely to change personal behaviors to adapt to the influential person, noticeably comparable to how followers act in leadership positions

(Ford et al., 2014). Relationships in which shared interests and direct interactions among individuals can also show the processes of social investment creating influence and trust and among coworkers (Ford et al., 2014).

Hanse et al. (2015) aimed to examine associations of social exchange between leader-member exchange and psychosocial factors at work amongst health care professionals. The sample consisted of 240 employees from a Swedish Nordic Multicenter with a cross-sectional questionnaire based research study (Hanse et al., 2015). Hanse et al. (2015) concluded a positive relationship with the manager (high leader-member exchange) correlates to employees becoming more interested in work meaningfulness, as medical staff gain a greater understanding of their role within the hospital (Hanse et al., 2015). Thus, the higher the quality of leader-member exchange, more medical staff experience higher job satisfaction (Hanse et al., 2015).

Patient-Centeredness

Research studies have validated the partnership approaches between patients, families, and health care professionals have resulted in greater patient satisfaction, better management of health care outcomes and resources (Abraham et al., 2013). In fact, health care organizations are seeing positive outcomes of patient-centered-care and partnerships of patients, families, and health care professionals within the organizational level of engagement to enhance health care for all (Johnson et al., 2008). In other words**,** patient/family advisors are working together with health care professionals to redesign and improve programs, practices, and policies **(**Abraham et al**.,** 2013).

In this partnership between patients, families, doctors, nurses and other health care professionals, health care is delivered based on the goals, values, beliefs, and strengths of patients and their families. Whereby patients, families, and the healthcare professionals are respected for their skills and expertise. Patient-centeredness is intended to transform both the organization and culturally shift the focus on the patients input and voice. Looking at each person individually, and providing the transformation of sick care to well care, engaging patients to better manage their health can be accomplished through patient-centered-care (Roseman et al., 2013).

The belief is if patients were individually able to manage their care, embraced healthier lifestyles, the costs of their health care would be lowered. There is strong evidence showing the effectiveness of likely strategies to create best practices for patient and family engagement whereby health care professionals and organizations seek to adapt the delivery of health care and practice approaches to allow effective engagement of patient and their families to help plan and shape the future of health care (Coulter, 2012).

Patient and Family Engagement

Patient and family engagement is becoming more recognized as the foundation of the health care system by reducing health care costs while also increasing or improving health outcomes (Barello et al., 2014; Dentzer, 2013). Patient and family engagement includes the interventions designed to increase patient activation and the resulting behaviors of the patient such as engaging at different levels of care (Carman et al., 2013). Furthermore, awareness to patient and family engagement has been validated by the increased number of both managerial and academic publications over the last decade (Barello et al., 2014).

Academic literature related to patient and family engagement includes both qualitative and quantitative empirical studies, theoretical papers, and pulls on the theoretical developments in numerous discipline sand fields such as management, nursing, medicine, psychology, education, and communication (Barello, Graffigna, Vegni, & Bosio, 2014). Barello et al. conceptualized patient and family engagement as a comprehensive model that describes the evolving roles and characteristics within the processes. Barello et al. considered the engagers to be the organization, community, health care professionals, patients, residents, caregivers, and family members.

Barello et al. (2014) also considered engaging elements such as the tools, devices, and interventions to help assist with consumer and health care provider engagement strategies. Dentzer (2013) referred to patient and engagement as a drug of the 21st century and should be included in health care. The emphasis on patient and family engagement originated from a belief that both the health care professionals and patients share an equally important in promoting the health of individuals, their families, and their communities (Coulter, 2012).

The rationale behind patient and engagement shows patients who are more informed regarding their choices may use fewer procedures such as tests and surgeries, lowering health care costs and may also have improved care experiences and health outcomes (Hibbard, Greene, & Overton, 2013; Hibbard & Greene, 2013). Thus, patient and engagement can be understood to be apparent factors in achieving the Triple Aim

(Dentzer, 2013). Patient and family engagement is an important element in evaluating strategies to reform healthcare (Hibbard & Greene, 2013).

Evidence also recommends interventions and organizational policies which encourage, direct, and support the roles of patients in managing their personal levels of health, engagement, or activation and build confidence and skills, are successful with increasing patients' activation levels (Hibbard & Greene, 2013). Engaging patients in quality improvement efforts can promote change including individual engagement in their personalized health care and improving their experiences at the organizational level within the health care system (Roseman et al., 2013).

Roseman et al. (2013) conducted a systematic review with literature regarding the effects of patient and family engagement on the delivery of health care and how those changes help to improve patient-centered care related to costs and clinical impacts. Roseman et al. examined 40 quality improvement indicatives where engaging patients in the process of service change such as revised appointment policies, improved access to health care, development of patient information materials. Patient's unique perspectives can stimulate changes in the delivery of healthcare that can improve processes for both providers and their patients. Factors influencing patient and family engagement: (a) patient **-** beliefs about patient role, health literacy**,** and education, (b) organization – policies, practices, and culture (c) society- social norms**,** regulations**,** and policy.

An academic medical center located in North Carolina, Vidant Health (VH), used patient advisors to establish patient family advisory councils, creating a system wide transformation of engagement and quality (Wynn, 2015). (VH) utilized patient/family advisors to create a system-wide cultural transformation to enhance engagement with patients and families (The North Carolina Institute of Medicine and the Duke Endowment, 2015). Patient family advisory councils were described as creating meaningful partnerships that help identify individuals with the largest stake - the patients and families they serve (The North Carolina Institute of Medicine and the Duke Endowment, 2015).

Some of the patient family advisory council accomplishments included, improvements in way-finding, achievements in a family presence policy, the patient portal MyChart, and helped review quality content for patient education materials (Johnson & Abraham, 2012). (VH) provided patient/family advisors with complete training process including background checks, confidentiality agreements, and risk-management screenings (Johnson & Abraham, 2012). Wynn (2015) described the lessons learned from (VH) as a cultural transformation with over 120 patient advisors who partnered in meaningful acts within every level of the organization.

Advisors participated on corporate level committees, interviewed potential job applicants, served on process improvement teams, were involved with safety rounds, served as faculty educators, developed and edited patient education information (Wynn, 2015). Haycock and Wahl (2013) described patient and family engagement as a strategy to help organize patient family advisory councils to create patient and family engagement into the health systems of care. Many organizations are unaware on how to establish a professional partnership with their patients and families or how to empower patients and families with equal partnership (Haycock & Wahl, 2013).

Commitment, satisfaction, and loyalty of the patient/family advisors with the medical staff's leaders can help "followers grow and develop into leaders by responding to individual followers' needs by empowering them and by aligning the objectives and goals of the individual followers, the leader, the group, and the larger organization" (Bass & Riggio, 2006, p. 3). Leaders and hospital administration could use this information to evaluate their leadership styles and clinics or offices and how it may impact the organization they lead.

Patient Activation Measure. Some studies show that patients who are activated or have the ability, willingness, and skills to manage their personalized health care, experience lower costs and better health outcomes compared to patients who are less activated patients (James, 2013). Judith Hibbard, of the University of Oregon, created the patient activation measure, a survey which scores the degree to which a patient views themselves as a manager their health and health care as a way to quantify patient and family engagement levels (James, 2013). Hibbard and Greene (2013) defined patient activation as "the skills and confidence that equips patients to become actively engaged in their health care - makes to health outcomes, costs, and patient experience" (p. 207).

The patient activation measure is a reliable and valid scale that exposes a developmental model of activation with four stages a patient must engage to activate their care: (a) having the knowledge, confidence, skills, abilities, and other resources required to take action (b) believing the role of the patient is critical (c) staying focused even during stressful periods (d) taking action to improve and maintain personalized health care (Hibbard, Stockard, Mahoney, & Tussler, 2004). Hibbard and colleagues (2004) examined the relationship between health care costs and patients' activation scores at Fairview Health Services, a health care organization in Minnesota (James, 2013).

Hibbard and colleagues (2004) analyzed more than 30,000 patients (James, 2013). Their findings suggested individuals with lower activation scores (people who have minimum confidence and skills to actively engage in their personalized health care) experienced costs averaging eight to twenty-one percent higher compared to patients with maximum activation levels, even after adjusting for health status and other factors (James, 2013). In conclusion, Hibbard and co-authors described patient activation scores are significant forecasters of health care costs (James, 2013). Evidence suggests patients who are more engaged in their healthcare have decreased healthcare expenses and improved health outcomes (Hibbard & Greene, 2013).

The Engagement Behavior Framework. The engagement behavior framework developed by Gruman et al. (2010) is a patient-centered model consisting of ten measurable expectations for an individual’s behavior, which assist individuals who seek and utilize safe care: (a) promote health (b) find safe care (c) organize health care (d) communicate with health care professionals (e) participate in treatment (f) get preventive health care (g) pay for health care (h) make good treatment decisions (i) seek health knowledge and, (j) plan for end of life.

Continuum of Patient and Family Engagement

Researchers in the discipline have approached patient and family engagement differently, how it works widely vary. Carman et al. (2013) recommended a conceptual framework of patient and family engagement taking place on three levels (James, 2013).

The conceptual model of the continuum of engagement ranges from three levels of engagement from 1- direct care, 2- organizational design, and 3- policy making (see Figure 3) (Carman et al., 2013).

This framework is not restricted to personal health behavior or within the interactions of direct care, but it can also occur within the governance and organizational design and policy making within the continuum of engagement (Carman et al., 2013). Within the continuum of engagement, the first level of patient and family engagement is direct patient care, in which patients receive information concerning their condition(s) and answer questions about their treatment preferences (James, 2013). This method of engagement allows patients and providers to make decisions together based on the patients' preferences, medical evidence, and clinical judgment (James, 2013).

Within the second level of engagement, organizational design and governance, health care organizations ask for health care consumers' participation to guarantee they are responsive to the patients' needs (James, 2013). The third level, policy making, health care consumers are involved in decision making in which communities and society make regarding laws, regulations, and policies in public health and health care (James, 2013).

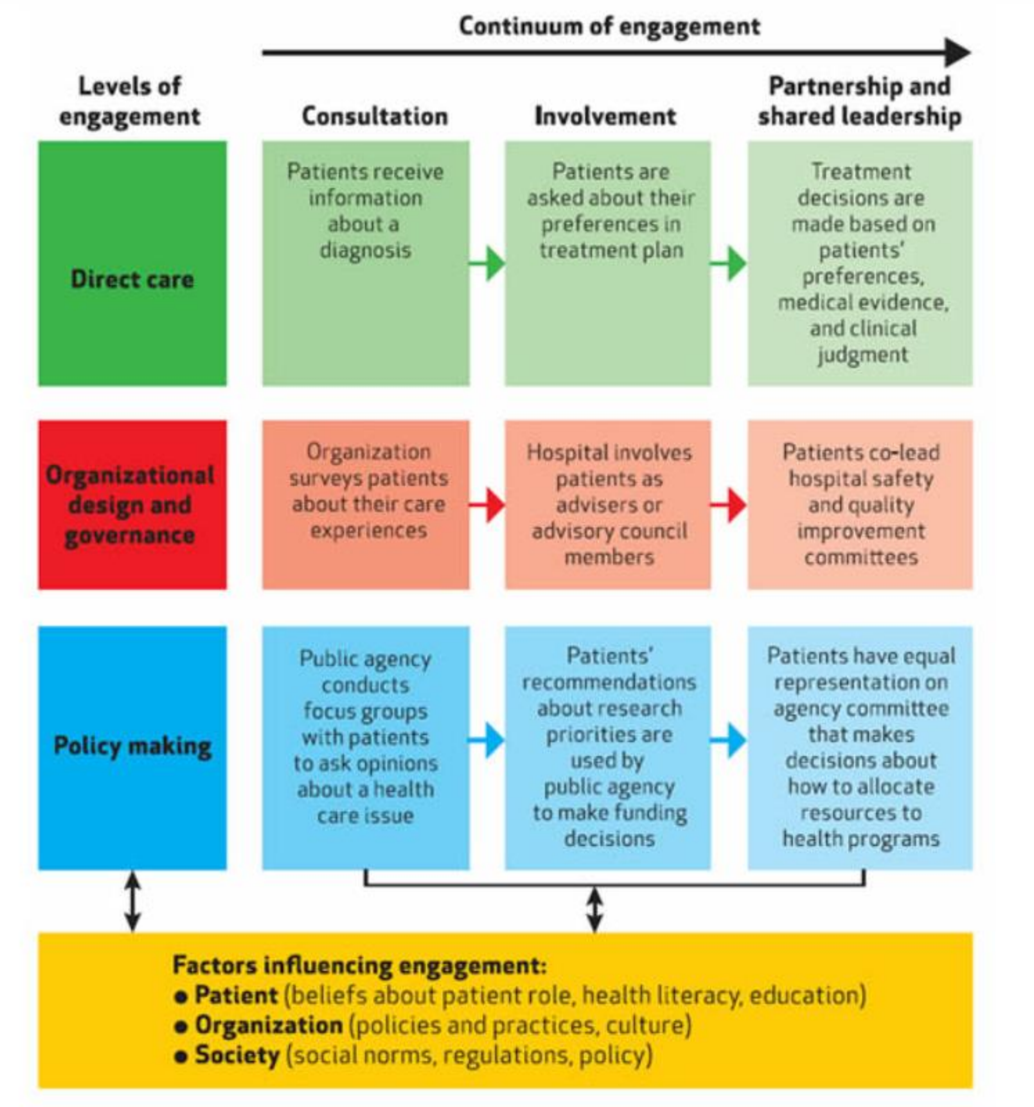


Figure 3. The continuum of engagement. Movement on the right on the continuum of engagement represents increased patient collaboration and participation. Adapted from "Patient and Family Engagement: A framework for Understand the Elements and Developing Intervention and Policies ," by K.L. Carman, P. Dardess, M. Maurer, S. Sofaer, K. Adams, C. Bechtel and J. Sweeney, 2013, *Health Affairs, 32, 2, p.* 223-231.

Levels of Engagement

This patient and family engagement model requires health care professionals to adopt behaviors, attitudes, and interventions which can support and encourage the patient and family while also designing interventions and care treatment plans that meet the needs of the individual patient and family (Carman et al., 2013). Using this model as managerial function or tool can help create partnerships between the patient, family, and the health care professionals (Hibbard & Greene, 2013). Partnership and shared leadership between healthcare professionals and patients and their families can increase the continuum of engagement to better enhance the well-being and lives of mankind (Gabriel & Normand, 2012).

Using this multidimensional framework, the research will attempt to explain and or describe how patient/family advisors feel about and their ability, confidence, and skills to partner with organizational leaders, mangers, clinicians, medical staff, to plan, evaluate, and deliver care in health care settings and organizations (Carman et al., 2013). Furthermore, the continuum of engagement ideally shows social change to incorporate families and patients into the partnership and shared leadership roles. The three levels of engagement are described in detail below.

Individual Levels of Engagement. Direct care happens when providers use consultation to help patients and families receive information. Patients who are involved in their health care are often asked about personal preferences and treatment plan. Direct care also promotes partnership and shared leadership where health care decisions are made based on patients’ needs, clinical views, and medical evidence, interventions which encourage personal levels of engagement or activation, build confidence and skills, which have been successful with increasing patients’ activation levels (Hibbard, Greene & Overton, 2013).

For example, at an individual level engaging in exercise or obtaining preventive care, Minnesota’s Courage Center, provides assistance to the most disabled and disadvantaged patients to help take better control of their health (Hibbard & Greene & Overton, 2013). These patients would seem the hardest or most difficult to engage, but this population of patients saw an increase in scores concerning the patient activation measure (Hibbard, Greene, & Overton, 2013). Leadership can influence outcomes of patients through processes by inspiring staff behavior, attitudes, or performance that may facilitate the care of patients or through procedures such as creating changes in the context of work (Wong et al., 2013).

Transformational leadership may successfully motivate patients to improve their personalized health behavior because clinicians engage and inspire patients to sustain positive health behaviors (Huynh & Sweeny, 2014). Huynh and Sweeny synthesized research on transformational leadership, patient-provider communication, and improved health behavior by introducing an innovative approach to improving and understanding the motivators of the clinicians’ success.

Paquet, Coursy, Lavoie-Tremblay, Gagon, and Maillet (2013) showed the indirect effects of leadership surrounding patient outcomes (patient’s length of hospitalization and decreased medication errors) concluded the support managers were associated with reduced nurse/patient ratios, overtime, and absenteeism. The association between positive patient safety outcomes and supported leadership styles argues the importance of leaders understanding the processes of patient care and the role healthcare professionals play in promoting better outcomes (Wong et al., 2013).

There is a positive relationship between improved patient safety outcomes and patient satisfaction and relational leadership styles showed a decrease in hospital-inquired infections, restrain use, patient mortality, and reduced medication errors (Wong et al., 2013). This expands contemporary research by contributing organizational constructs of clinician behaviors based on the transformational leadership framework (Huynh & Sweeny, 2014). The manner, frequency, and degree, which clinicians make the most of their ability to motivate patients using health literacy can be a predictor to their success in engaging patients with behaviors to change their personalized health (Koh, Brach, Harris, & Parchman, 2013; Huynh & Sweeny, 2014).

Organizational Design and Governance. Examples of new paradigms include patient and family engagement within the organizational level, indicating true partnership with patient and their families. A non-profit organization called the courage center, located in Minneapolis practices patient and family engagement with the disabled. The courage center has an engagement center which has a primary care clinic with mental health and rehabilitation services (Langel, 2013). The center is able to meet multiple needs of patients' while also increase the scores of the patient activation measure defined by Judith Hibbard (2013). Patient and family engagement combined with the health home has lowered hospitalization from 10.8 days to 3.1 days annually, a decrease in 71 percent (Langel, 2013).

Policy Making. Consultation occurs when public agencies such as (PCORI) and the (IPFCC) conduct interviews and focus groups with patients and family members to ask opinions about health care issues such as qualitative feedback (Fluerence et al., 2013). Patients' and caregivers were involved with policy making by creating recommendations about research priorities, which are used by (PCORI) to make funding decisions (Fluerence et al., 2013).

Patients have equal representation regarding partnership and shared leadership on agency committees that make decisions allocating resources to health programs and policy making (Fluerence et al., 2013). Patients and their families have been working with researchers to describe the rationale behind creating standards for patient-centeredness and patient and family engagement working with national research institutes such as (PCORI) and the National Institute of Health (Fluerence et al., 2013).

Some of the areas patients and families have been engaged included choosing study designs, prioritizing research topics, and conducting, designing, and reporting patient-centered outcomes research (Gabriel & Normand, 2012). Advisory roles occurring within the policy level include speakers at state and national levels, grant reviewers, partners in health care research, dissemination, participating at meetings and conferences, co-authors and reviewers for online, written, and audio-visual materials (Abraham et al., 2013).

Patient/family advisors

Patient/family advisors are essential partners on creating positive social change and improving health care for everyone. Patient/family advisors are viewed as experts in their personalized care experience. Patient/family advisors bring a unique perspective of health care that health care professionals simply do not have by sharing their perspectives, ideas, and experiences to help create programs, services, and resources which have the potential to meet the needs of patients and their families (Abraham et al., 2013).

Advisors know firsthand how they would like to be treated and respected as a partner in care (Abraham et al., 2013). Patient/family advisors understand how it feels when a nurse or doctor spends extra time helping them to better understand a difficult part of their care or how develop a care plan that involved their personal goals and preferences (Abraham et al., 2013). Using patient/family advisors personal healthcare experiences to engage with medical staff can be related to the continuum of engagement designed by Carman et al. (2013).

The patient/family advisors personal healthcare experiences can range from consultation, involvement, to partnership and shared leadership within each level of engagement (Carman et al., 2013). Lastly, multiple aspects affect the readiness and capability to engage patients (Carman et al., 2013). Ultimately, recognizing the various levels of patient and engagement implies a goal to always move forward on the higher levels of the continuum of engagement with patient and family advisors. Such engagement may lead to creating partnerships and relationships between patients, their families, and medical staff.

Advisor Roles in Organizational Level of Engagement. Patient/family advisors have had the opportunity to co-lead hospital quality and safety improvement efforts. Hibbard and Greene (2013) imply interventions and organizational policies directed at supporting the roles of patients in managing their health care which in return is linked to better health outcomes. Health care organizations are involving patients and family members as advisors or as advisory council members asking for the patients' perspective, helping to create an organizational culture based on patient and family engagement and shared-decision making (Barry & Edgman-Levitan, 2012). As advisors build their skills, knowledge, and confidence, they begin to serve in various advisor roles.

Advisors put forward suggestions by sharing their stories, insights, and perspectives about their health care experiences. Improvements have been made with policies, services, research and evaluation, materials and information, support programs, educational programs for other patients and families, and with the design of health care amenities, services, and facilities (Abraham et al., 2013). Advisory roles for patients and families within the organizational level consist of but are not limited to advisory councils, board members, committee members, work groups, ambassadors, recruiters for new advisors, peer educators, mentors for patients, families, faculty for medical and nursing students, and public speakers for orientation (Abraham et al., 2013).

Patient Family Advisory Council. Patient and family advisory councils can be used as a strategy to view the patient perspective. Patient family advisory councils are involved in organizational decision-making efforts as well as to participate in facility planning, participating on committees, quality improvement teams, safety policies, and the hiring of new management or staff (Rockville et al., 2012). Some states exhibit advisory councils, but many regions in the United States continue to be inexperienced with consumer advisory roles (Grob, Schlesinger, Davis, Cohen, & Lapps, 2013).

Oregon Health Care Quality Corporation has five patient advisory councils and was launched with the *Patients and Families as Leaders Program* (Roseman et al., 2013).

The leaders program included rigorous coaching, training, technical assistance, and web-based tools to create the five advisory councils. One of the advisory councils established in 2011 with Providence Medical Group, has thirteen advisors who take part in projects such as education courses, new employee orientation, and after-visit summary reports (Roseman et al., 2013). In Maine, the Aligning Forces for Quality has also established patient advisory councils. Through a twenty-six-practice pilot program, patient advisors and health care professionals are trained in transformation practices (Roseman et al., 2013).

The central research question looked to describe how patient/family advisors view patient and family engagement within patient family advisory councils. The sub questions sought a deeper understanding of how results of the patient family advisory councils can help change future outcomes for patients, what engagement strategies are most meaningful, and how have the perceptions of patient/family advisors health care changed since being involved on patient family advisory councils?

Summary and Conclusions

Partnerships between patient/family advisors and health care professionals can help to create improved outcomes, within all levels of engagement (direct care, organizational, and policy) as well as the continuum of engagement levels. Decision making can occur within all three levels of engagement described by (Carman et al., 2013). Shared or collected leadership at the organizational level between patient/family advisors and medical staff could help to decentralize the hierarchy within organizational complexity. Every family is acknowledged as being unique with their own set of traditions, values, and relationships**.**

Patients and families are partners with health care professionals and have helped change the delivery of care across numerous settings by taking a role in determining how they decide to participate in decision-making and their care (Abraham et al., 2013). The American health care system is encountering significant challenges. To respond to these problems, necessary changes are taking place within many health care settings. Hospitals, outpatient clinics, researchers, federal agencies, and long-term care facilities are examining new strategies with a recent focus on patient and family engagement, acknowledging that patients and their families have a vital role to play in their personalized health care (Coulter, 2012).

Because the changes in health care will directly impact patients and their families, advisors are viewed as important stakeholders and key allies to create change**.** Currently, there are an increasing number of health care organizations who are consistently developing ways to increase the engagement of patient and family advisors with evaluating, implementing, and developing policies and programs. Clinics, hospitals, state health agencies, long term care communities, national organizations, and the federal government are offering opportunities for advisors to partake in having a voice in influencing health care.

Within the organizational level of engagement, managers and leaders reported patient/family advisors created positive outcomes. These outcomes included increased satisfaction for patients, residents, families, and staff improvements in the healing and health of patients, residents, and families, better and more cost-effective use of health care resources (Abraham et al., 2013). Abraham et al. (2013) described benefits as serving as advisors for patients, families, and health care professionals. Some benefits for patients/ family advisors included improving changes in health care, expanding patient/family advisors skills and knowledge, and giving opportunities to share ideas and network with medical staff and other patient/family advisors (Abraham et al., 2013).

Benefits for health care professionals include the improvement of the delivery and planning of health care helps leaders continue the mission of the organization, and brings passion and meaning to help them improve their job performance (Abraham et al., 2013). Challenges to patient and family engagement include but are not limited to encouraging providers and patients to embrace engagement and achieve potential to improve health and the delivery of care (Dentzer, 2013). Additional challenges for patient and family engagement include encouraging providers and patients to embrace engagement and achieve potential to improve health and the delivery of care (Dentzer, 2013).

Bernabeo and Holmboe (2013) of the American Board of Internal Medicine explained the degree of patient and family engagement may be exaggerated by such factors as sex, education, age, and cultural differences. Specific abilities, such as having an understanding or awareness of religious beliefs or a set of language skills may be required by health care delivery systems and health care professionals to successfully engage patients and families with diverse socioeconomic status and cultural backgrounds (James, 2013).

Health care professionals may find difficulty with accepting families to serve as advisors due to organizational commitment with resources, money, time with listening and responding to patient/family advisors (Dentzer, 2013). The challenge revolves around encouraging providers and patients to support engagement and increase its potential to improve health and healthcare (Dentzer, 2013). Since patient-centeredness approaches replace the physician or institution care model, most power and authority regarding patient care in the hands of the professionals and organizations where treatment is provided (Laurance et al., 2014).

Physicians who are reluctant to change may not want to give up their traditional decision-making roles, or they may lack the training in communication needed to comply with patient centered outcomes and objectives, often complaining they don't have the time to learn or adhere to the new concepts in health care (McCann et al., 2014; Laurance et al., 2014). Healthcare professionals, delivery systems, and policy makers cannot assume all patients and family members have the same preferences, goals, or capabilities, nor can they dictate the route to achieve the goals of patient/family advisors.

There is a range within the continuum of engagement can be determined based on the participation of patient/family advisors perceptions of being advisors to help create best practices for developing and sustaining partnerships at the organizational level with patient/family advisors. The concept of patient and family engagement suggests providing meaningful value for health care organizations, providers, patients, families, and other stakeholders in health care. There are still many gaps that exist for patient and family engagement to make an impact on health care systems in the United States. Thus, the health care industry may benefit from an analysis of best practices for patient-engagement that is evidence-based from the patient family advisor perspective.

Finding out what is important to health care consumers and allowing these patient/family advisors to share information could lead to future developments in the field of management and health care. By including the patient/family advisors perceptions on their roles within the organizational level of engagement could facilitate in the development of methods and tools to improve patient-centeredness and patient and family engagement at the organizational level.

The questions surrounding patient and family engagement are important to the field of management and health care because they can help to improve, define, or explain what steps can be taken to ensure patient and family members understand the importance of their roles in partnering with medical staff to make the best decisions possible. Finding out what current patients and their family members know and want to know about their health care could be used to help evaluate and improve quality of experience and patient safety (Graffigna, Barello, & Riva, 2013). Partnerships with patient/family advisors and medical staff can help create a flow between health care professionals, patients, and their families within the organizational level of health care.

Patient and family engagement is frequently used as a canopy term to include multiple interactions patients and their families face within health care systems. Terms such as patient involvement, patient participation, and patient empowerment are often exchanged for patient and family engagement. An evidence-based clarification of patient and family engagement from the patient/family advisors perspective could enable additional empirical and theoretical interpretation of patient/family advisors perceptions associated with patient and family engagement. The possible research findings can create data for future research.

Since there is a lack of data from patient/family advisors, the initial findings are based on qualitative measures. This data could eventually be used in future research studies involving quantitative research to help validate the current research findings. Evidence from this research may also help academic institutions, learning organizations, and health care facilities find ways to incorporate patient/family advisors into teaching the whole spectrum of health care professionals, clinicians, and providers.

Understanding patient and family engagement from the perspective of patient/family advisors may also help health care organizations to enhance improved health and health care outcomes creating a transformative shift related to patients' roles in modern health care. The framework for patient and family engagement shows the need for social change within health care at all levels- individual, organizational, and policy-making.

Chapter 3: Research Method

The primary purpose of this qualitative phenomenological study was to explore and describe the lived experiences of 19 patient/family advisors working on advisory councils at a healthcare facility in the Midwestern United States. For the purpose of this research I defined the lived experiences of the reach participants as the shared phenomenon working on advisory councils. The lived experiences of these participants included their work on patient and family engagement from the patient/family advisors perspective. According to Tsianakas et al. (2012), capturing the lived experiences helps to elicit a detailed understanding of the specific meanings attached to the participant's health and personalized health care.

The secondary purpose of this study was to describe the lived experiences of patient/family advisors who serve on patient family advisory councils. I explored the potential applications of patient and family engagement and how the research design derives logically from the problem statement. The problem statement showed a lack of literature on patient and family engagement surrounding the perspectives of patients and their families. According to Xie et al. (2015) and Blom et al. (2013) using the phenomenological approach as a method may help with the understanding of improving patient and family engagement between patients, families, and medical staff.

In this chapter, I offer a detailed explanation of my research method and how I conducted the research. I explain why I chose a qualitative phenomenological research design and discuss my role as researcher, including my main responsibilities. Next, I describe the specific methodology including participant selection logic, data collection instrumentation, procedures for recruitment, participation, data collection, and data transferability, dependability, conformability, and ethical issues, and then conclude with a summary highlighting the key points in the chapter.

Research Design and Rationale

The central research question: How do patient/family advisors describe patient and family engagement within patient family advisory councils?

Research Question 1: How can the results of the patient family advisory councils change health outcomes for patients and families?

Research Question 2: What has the organization done or asked patient/family advisors to be involved in that is most meaningful to patients and families?

Research Question 3: How have patient/family advisors perceptions of health care changed since working on patient family advisory councils?

Rossman and Rallis (2017) distinguished the differences in data collection tools, processes, and techniques between quantitative and qualitative research. These scholars insisted that quantitative researchers follow specific plans because their data collection is focused in testing a certain theory while qualitative researchers do not know what theory their insights might demonstrate. Rossman suggested qualitative research uses inductive reasoning. Inductive reasoning can be utilized to create meanings out of data sets by identifying relationships and patterns to build upon a theory, rather than using deductive reasoning, which begins with theory and tests its appropriateness (Rossman & Rallis, 2017).

Neuman (2015) suggested an approach uses broad orienting concepts and a few assumptions in which theory is developed after gathering and analyzing data. According to Bloomberg and Volpe (2016) the inductive approach looks to understand particular theories, not to develop general theories. I chose the paradigm of qualitative research to theorize both deductively and inductively with first observing the empirical world of patient/family advisors and then reflected upon the participant interviews by thinking in abstract ways.

Neuman (2015) noted that qualitative researchers many face challenges as there are no systematic rules to abide by, only guiding ideologies gathered from direct experience. Experience is derived from studying with others, reading literature, and the physical doing of conducting research (Neuman, 2015). Furthermore, Bloomberg and Volpe (2016) stressed qualitative researchers have flexibility when choosing different research approaches. Rossman and Rallis (2017) specified qualitative researchers need to provide a detailed explanation of data collection, data analysis, and data presentation. Van Manen (2014) remarked researcher bias needs to be acknowledged for qualitative research.

Quantitative research was not appropriate for my study. Quantitative researchers focus on a large number of randomly selected participants using statistical measures such as the standard deviation, mean, and median, mode to deny or prove a certain hypothesis. On the other hand, qualitative researchers focus on a comparatively small number of purposely-selected research participants by observing or interviewing to explore the in-depth meaning of a phenomenon. Quantitative research was not appropriate for my study as my research focus did not quantify the lived experiences of the research participants.

A mixed-methods approach was not appropriate for my research because the focus of my research was only to explore a more in-depth meaning of the lived experiences of those participants, not to quantify them. Qualitative research was the best match to meet the design and the explorative nature of my research. Five qualitative approaches were originally considered using Leedy and Ormrod (2014) descriptions in the book, *Practical Research: Planning and Design* and Patton's (2016) *Qualitative Research and Evaluation Methods*, including, narrative research, ethnography, grounded theory, case study, and phenomenology. Ultimately, I chose phenomenology as the qualitative design.

I considered narrative research because the methodological approach stems from interpretation. The idea would be to account and capture the experiences or stories in a very small number of lives. Narrative analysis could be employed through the lens of a personal experience of certain individuals who share the same stories, which capture or interpret the texts of individual's stories (Leedy & Ormrod, 2014). Furthermore, narrative stories and research could be obtained through historical memories, in-depth interview transcripts, family stories, or life history narratives. Narrative analysis is an approach to study organizational research to conceptualize, collect, and write as a way for the researcher to capture tales of the field of management into a storyline (Patton, 2016).

Narrative approaches rely on stories to create windows of opportunity to transcend social and cultural meanings. Patton (2016) explained narrative analysis can be related to phenomenological research. Patton further argued narrative analysis is also influenced by the phenomenological approach to understanding past perceptions and experiences of phenomena. In a case study, individuals may be asked to participate to share their stories, whereas, narrative research, individuals may be invited to share their stories (Patton, 2016). Narrative research was not suited to my goal to represent a broader teachable model.

I considered ethnography because it reflects an in-depth analysis of an entire group who share a common culture within a natural setting (Leedy & Ormrod, 2014). I did not select this approach because the length of time it would take me to conduct this type of research. Ethnography research can last for months to years depending on the focus of the research regarding cultural norms, social structures, beliefs, and everyday behaviors (Leedy & Ormrod, 2014). I examined more than a cultural pattern to understanding patient and family engagement with patient/family advisors in the organizational level of health care settings.

Grounded theory begins with data and develops it into a theory (Leedy & Ormrod, 2014). The goal is to create theory using field data, which is collected from multiple stages and interpreted from the participant's point of view (Leedy & Ormrod, 2014). It may be difficult for the researcher to determine when the categories are fully developed and reach saturation. Thus, the resulting data may not correspond to the required outcome components of a central phenomenon. I did not consider grounded theory for this qualitative research design because I was not trying to develop a theory surrounding patient-centeredness and patient and family engagement.

I did not select case study because the goal of case studies is to develop descriptions that would encompass just one or a few cases (Neuman, 2015). Case studies allow for a deeper understanding by evaluating outcomes of a single case or a set of a few cases such as a program, activity, event, organization, community, geographic unit, a duration of time, or a single point in time such as critical incident to find out more about misunderstood or unknown circumstances (Patton, 2016; Neuman, 2015; Leedy & Ormrod, 2014).

Most case study research is qualitative, but it can also include the use of quantitative analysis through cross-case studies to create a mix methods approach (Rossman & Rallis, 2017; Neuman, 2015). Case study researchers focus on numerous characteristics or details within each case and each situation by examining both the surrounding situation as well as the details of each case's internal features (Neuman, 2015). Data analysis can use descriptions of the case, themes, and cross-case themes and usually involves a detailed description of the problem, the issues, context, and lesson learned. According to Rossman and Rallis (2017) and Patton (2016) despite of the unit of analysis, a qualitative case study seeks to explain that unit in detail and in-depth.

This in-depth understanding and analysis of data is typically collected by using multiple sources such as observations, interviews, documents, and artifacts (Leedy & Ormrod., 2014; Bloomberg & Volpe, 2016). Contextual details are used to describe the case setting and help provide an in-depth visualization of the case. Case studies are complex and multilayered (Rossman & Rallis, 2017). Case studies may not have clear beginning and end points and choosing boundaries that sufficiently bound the case can be difficult (Rossman & Rallis, 2017).

According to Rossman and Rallis (2017), research questions try to understand a bigger phenomenon using one instance or example of an issue, problem, or hypothesis to construct a rationalization for those events or outcomes. Because case study methodology has such a broad definition for the research focus, it can be used with many methods and associated philosophical perceptions (Mills & Birks, 2014). Bloomberg and Volpe (2016) explained an extremely interpretivist approach may decide to highlight participant observation by performing field ethnography, whereas a more realist approach might choose to conduct interviews or surveys.

I selected phenomenology because it seeks to gain an in-depth understanding of a lived phenomenon or experience. Phenomenology is a philosophy as well as a method that explores the shared essence or lived experiences related to a social phenomenon and the way individuals structure meaning. I used phenomenology to examine ways patient/family advisors comprehend, interpret, understand, and create shared experiences of patient and family engagement within the patient family advisory councils to which they give specific meaning. According to Moustakas (1994), phenomenology sets aside presuppositions, tries to eliminate prejudgments, and reaches a state transcendental openness, not threatened by the beliefs, customs, and prejudices of science.

Phenomenology can also provide an understanding of first-person reports of shared life experiences such as the concept of patient and family engagement (Moustakas, 1994). Phenomenology includes the descriptions of the conscious experiences of the participant’s perceptions (seeing, hearing), bodily actions, feelings, and judgments, making sense, remembering, and talking about the phenomenon in everyday life (Schwandt, 2015). Conducting a phenomenological study helped me to narrow in on the essence of the shared experience or descriptions of what and how participants experience being the patient or caregiver and gaining a better understanding of the desires, needs, and impressions that occur during their interactions with medical staff regarding patient and family engagement.

The notion of shared experiences allowed me to study how participants describe the phenomenon of patient family engagement, thus creating a way for me to make sense of their world through the lens of subjunctive experiences. According to Tuohy, Cooney, Dowling, Murphy, and Sixmith (2013) and Blom et al. (2013) the subjunctive experiences of the participants past involvement surrounding patient and family engagement along with the similarities among participants helped to develop a common description.

Role of the Researcher

Xu and Storr (2012) expressed the importance of qualitative researchers acting as research instruments. The researcher’s role for a phenomenological study is to bring individuals’ lived experiences into words for data collection, try to understand the experiences, categorize themes from reflected experiences, and then records their experiences in writing (Sanjari, Bahramnezhad, Fomani, Shoghi, & Cheraghi, 2014). I served as the primary data collection instrument for this study and will act as the research instrument (Maxwell, 2013).

My role was to observe monthly and quarterly advisory councils meetings, collect data, and to bring the participants life world and past experiences such as the (PFEAP), patient family advisory councils, the organization, culture, and relationships with medical staff and other patient/family advisors into words of data collection. My role was also used to analyze code, inter ret, and present data. I conducted interviews with the research participants face-to-face.

First, I had the director of the (PFEAP) email the research participants with the recruitment letter and screening criteria (see Appendix A) and informed consent to thoroughly explain the purpose, benefits, and risks associated with the study, asking for volunteers to participate in the research study. The participants who were interested in participating in the study then contacted me by either phone or email. I then followed-up with a call those who are willing to participate in the study to arrange a mutually convenient time to meet in person to conduct the interviews.

I asked the participant’s open-ended questions and used interview prompts when needed (see Appendixes B and C) during the interviews and audio recorded the face-to-face interviews. I then organized the hand-written notes I took during the interviews and assign a number to each interview note. I repeated the process 5 times for the pilot study and an additional 14 times for the full study until the data was saturated. I conducted data analysis by grouping the interview responses into categories to make sense of them and then summarize the distinct themes.

I established and maintained a professional and courteous relationship with the participants. There was no supervisor versus supervisee relationship between me and the participants, and I had no direct work relationship with any of them. Additionally, there was no instructor-student relationship between me as the researcher and the research participants. I consciously worked at maintaining a professional relationship with all participants during and after the interviews. There was no power issue to be addressed throughout the research process. The participation in the study was voluntary and did not have cohesion throughout the research process.

Maxwell (2013) explained research always has the potential to be biased by researcher subjectivity. I could possibly create a biased or flawed study if my research is driven my personal desires. Maxwell noted it is impossible to remove personal beliefs, perceptual lens, and theories of the researcher. Qualitative researchers should recognize how individual values and expectations might impact the conduct and conclusions of the research study. The impact could be either positive or negative. Maxwell stressed the importance for qualitative researchers to explain personal researcher biases and how they will manage such challenges during their research.

I managed my personal researcher bias and power relationships by keeping an open attitude during data collection and data analysis. Openness was achieved by utilizing epoche (Schwandt, 2015). Epoche originated from Husserl's phenomenology, claiming the "phenomenological attitude" was the philosophical act of pure reflection, in which the researcher suspends, or brackets the convictions, awareness, intentions, awareness, and characteristics of the natural attitude, moving from my natural attitude to the phenomenological attitude, where I recognized the true nature and meaning of the life (Schwandt, 2015).

For my study, I identified and handled my own researcher biases by being consciously aware of their existence and by using an appropriate research method such as epoche in the study. I set aside whatever personal assumptions, knowledge, and values I had and concentrated only on reflecting the authentic views of the research participants. I hold personal and professional relationships with the research site and some of the research participants. I recognize the importance of epoche to mitigate bias and data from a personal lens. I do not have supervisory or instructor relationships involving power over participants. I also addressed ethical issues related to the study including acknowledging biases such as doing the study within my own work environment. There was no conflict of interest, power differentials, or justifications for use of incentives.

Finally, my role as a researcher was to address ethical issues that may arise. I had a plan for addressing these issues and power relationships. I made efforts to protect the privacy and confidentially of the research participants, remain cognizant of other ethical issues, such as building professional researcher-participant relationships and gaining informed consent from the research participants. I also made sure to fully explain the risks as well as the benefits of joining this research study to all 19 participants.

Methodology

Participant Selection Logic

The participants or population for my study were 19 patient/family advisors volunteering at an academic medical center in the Midwestern United States. I used a purposeful sampling strategy to collect data through face-to-face interviews. Research participants shared the common phenomenon of participating in a patient family advisory council as a patient family advisor. Participant characteristics varied in terms age, years of experience with the patient family advisory council, the type of patient family advisory council, and participant's personal health care experiences.

I wrote a letter to the director of the Department of Patient and Family Centered Care to gain permission to conduct my research at this site. I asked permission to have access to the facility's (PFEAP). Recruitment and participant selection for the research study participants was conducted through a series of two phases of research (phase one, the pilot study and phase two, the full study). This helped to select participants who reported having specific experiences volunteering as a patient family advisor and serving as a patient family advisory council member (Englander, 2012). The research purpose in this phenomenological study was to describe and explore the lived experiences of those participants volunteering as patient/family advisors.

Those who participated in patient family advisory councils within the (PFEAP) and met the criteria were invited to participate in the study. Thus, criterion sampling was used for the research when I selected the participants. To begin, I recruited five participants for the pilot study. After the pilot study, I recruited another 14 participants for the full study for a total of 19 participants because I anticipated no new information would continue to emerge after I completed the interviews. I remained open and flexible to adjust the sample size number until I reached data saturation, meaning no new information has emerged after the additional 14 interviews were completed.

Approaching from a health care perspective, Walker (2012) argued data saturation should be a required standard for data collection. Walker explained data saturation can be used as a tool to confirm if enough data has been collected to support the study. I used a few different data collection instruments which included memoing, interview protocols, recruitment and screening emails, audio-tapes, field journals, interviews with open-ended and developmental questions, on-site visits, participant observation of the various patient family advisory councils, and program documents.

Developmental analysis and cultural analysis were conducted to establish sufficiency of data collection instruments and to answer the research questions (Maxwell, 2013). Data collection included the relationship I established with the research participants of the study, the research site, and participant selection. I had the director first email 30 individuals with the informed consent forms to explain the purpose of the study. Upon receiving the completed and signed informed consent forms via email from the participants and after anticipated excluding those who do not return my original email, I called each participant to schedule a mutually convenient time to meet for the research interview.

In the first phase, the pilot study, I contacted the first five individuals by phone or email who replied to the original email and those who met the criteria and expressed interest to join the study. During the face-to-face interviews, I asked each participant the previously crafted interview questions as specified in Appendixes B and C. After the pilot study, for the second phase, I contacted the remaining 14 participants to conduct the actual interviews.

According to Moustakas (1994), epoche derives from the Greek word to refrain from judgment, or abstain from the everyday way of looking at things. From the perspective of epoche, the idea of epoche allows me to put aside my personal assumptions made in the sciences ad in everyday life, concentrating on the intrinsic nature of phenomenology and the conscious acts such remembering or perceiving (Schwandt, 2015). Using epoche, I set aside my own personal views to analyze the participants’ responses with objectivity. I gained a better understanding of the phenomenon from the participants’ perspective about their lived experience while providing theory-based explanations for the phenomenon.

Using epoche as a technique, I conducted long interviews by observing the participants body language and facial expressions during the face-to-face interview. I took notes during the interview with research participants and audio-recorded the participants’ answers to each interview question. I repeated this process 19 times until I gathered enough data from all 19 research participants. Once I determined there were no new themes emerging from the 19 participants, I concluded I had reached data saturation. I then started to organize, read, categorize, and hand-code all the collected data to find emerging themes and patterns from the face-to-face interviews.

Reflexivity was used methodologically to acknowledge through self-reflection my own biases, preferences, and theoretical predisposition and recognizes that I am part of the social phenomenon, context, and setting to I seek to understand. Being reflexive allowed me to analytically inspect the entire research process, including reflecting how I established a social network of research participants in this study (Schwandt 2015). Reflexivity helped me examine my theoretical and personal commitments, serving as resources for developing interpretations, generating specific data, and for behaving in particular ways concerning the participants (Schwandt, 2015). Reflexivity was critical for creating the validity of account of the social phenomena (Schwandt, 2015).

Instrumentation

This study utilized a semi structured interview guide as the data collection instrument. A pilot test was conducted using the interview guide with five patient/family advisors prior to data collection. I planned to submit an amended interview guide if needed. Specifically, the director sent out the recruitment letter and screening criteria (see Appendix A) and informed consent forms to the potential participants by email that explained the purpose of the research study as well as the risks and benefits associated with this study.

Those who were interested in the study then contacted me by phone or email. I then followed- up with those individuals who expressed interest to join the study with an email or phone call within five business days later to schedule a mutually convenient time for the face-to-face interview. Reaching out to the participants via phone helped with scheduling the actual interviews. I was able to conduct long interviews using the research questions and interview guide (see Appendixes B and C) and observed the participants' nonverbal language.

The interview questions were open-ended and explored how the participants perceived their lived experiences of patient and family engagement individually and within their membership of the various patient family advisory councils and how servant leadership and transformational leadership may affect their participant and enjoyment. All the interview questions were derived from the original research questions so that the interviewees' responses would be relevant to the central research question of the study. I expected the interviewees' replies to the open-ended interview questions to yield sufficient data to depict the emerging themes regarding their lived experiences with patient and family engagement.

I used a purposeful sample of 19 participants to join the research study. The sampling strategy of choice was a purposive strategy or a theoretical (non-probability sampling) technique (Schwandt, 2015). I chose purposeful sampling to better help me select information-rich cases, with the hope to bring forth insight and understanding of the phenomenon of patient and family engagement (Bloomberg & Volpe, 2016). This purposeful sampling strategy contained certain persons, settings, and activities to obtain information that can't be gained from other sampling choices and can provide me with the information I need to answer my research questions (Maxwell, 2013).

The sample was emblematic, meaning it was drawn choosing the participant for their relevance to the research question, analytical framework, explanation, or account in the research (Schwandt, 2015). Relevance may include choosing a participant because there may be a good reason to believe their prior knowledge and perception is critical in understanding the concept of patient and family engagement (Schwandt, 2015). Participant's knowledge may be unique, deviant, typical, extreme, or particularly revelatory for creating awareness on patient engagement (Schwandt, 2015).

"A purposive strategy employs emblematic sampling - choosing case or incident because it is extreme or deviant, typical or average, or emerging or novel and secures variation among the participants" (Schwandt, 2015, p. 278). The goals of this purposive sample was to achieve a representation or typicality of the patient family advisory councils setting and activities selected and to capture the heterogeneity of the sample population, ensuring my conclusions represent the population and criteria on which participant selection is based (Maxwell, 2013).

I intended to make necessary adjustments to the sample size as needed to make sure data saturation occurred before I concluded my data collection. I remained flexible and prudent in my use of sample size and made sure no new information emerged from the selected 19 participants before I stopped gathering data. I intended to increase my sample size and recruit more participants if there new were new themes or information emerging after I completed all 19 interviews. I made sure I reached data saturation before I ended my data collection.

Pilot Study

According to Maxell (2013), qualitative researchers should be aware of two important implications which lack logical connections. First, Maxwell suggested qualitative researchers should anticipate how research participant understand the interview questions, and how they would likely respond. Maxwell encouraged qualitative researchers to imagine themselves as participants and envision how researchers would react to the interview questions individually. Second, Maxwell reasoned qualitative researchers should pilot test the interview instructions and questions to see if they are clear and understandable and to plan for revisions if necessary.

In order to clarify if my dissertation instructions and questions were understandable and clear from bias, I carried out a face-to-face pilot study with five individuals before I actually started the main study. These five individuals were included in the final research study and their responses are included in the final report. I did not have to make any changes to the interviews instructions and the interview questions, as nothing was confusing or unclear from the pilot participants'. I focused on my pilot study in the discussion section. Furthermore, this study was approved through the Institutional Review Board (IRB) of Walden University IRB number 03-06-17-0055846 on March 6, 2017 and the Office of Responsible Research approval number 2016E0756 where the academic medical center is located.

The goal of this research was to collect data to construct descriptions of actions and behaviors described by the research participants. Protection and confidentiality of the participants occur with the use of pseudonyms**.** Ethical issues were considered by establishing beforehand who has the final say with the research study's content and to the time and number of interviews involved. Participants were required to read and sign an informed consent to be included in the research study (Schwandt, 2015).

Procedures for Recruitment, Participation, and Data Collection

Access to observing interactions between patient/family advisors and medical staff was granted through observer-participant within the various patient family advisory councils throughout the medical center. Qualitative data collections were created with different methods including direct observation trough the patient and family advisory councils and semi structured interviews (Schwandt, 2015). Challenges such as confidentiality of the councils, or patient/family advisors, alongside the possible interruption of the expected dynamics of the interactions may arise.

One of the desired outcomes was to verify perceptions of patient and family engagement by identifying the specific skills, knowledge, behaviors, and communication tactics transferrable to other healthcare settings and organizations. I conducted the study to examine and define common behaviors and characteristics that are important in describing patient/family advisors perspectives with patient and family engagement.

The inclusion criteria for which participant selection consisted of individuals falling within any of the following protected categories were screened out of the interview process, elderly individuals (75+), pregnant women, emotionally/mentally disabled individuals, at least 18 years of age, individuals who do not use English as their primary language, economically disadvantaged individuals, or residents of a facility like assisted living or a nursing home.

Participants were solicited by e-mail from the director. Each participant received a letter seeking his or her approval to participate and consent to participate. After the completion of the participation agreement, an appointment was made with each interview participant. The director sent out my initial research invitation with a letter (see Appendix A) and the informed via email to individuals to explain the purpose, criteria, and the benefits and risks associated to my study.

I then asked the participants to email their responses to me or call me with their intention to join within five calendar days. Once I heard back from the first 20 people who wanted to join the study, I then contacted the interested patient/family advisors to schedule an in-depth, semi structured interview face-to-face. Once the appointment was scheduled, I prepared for the actual interviews. I had all the necessary tools ready such as the voice recorders, interview questions on a sheet of paper, pens, loose paper, and a folder to hold all the paper in place.

I took notes and memos during the face-to-face. Data from each interview was audio taped supplemented by field notes and transcriptions. Guiding questions helped to explore the individual's understanding of patient and family engagement and patient-centeredness. Interviews were audio recorded, transcribed, and thematically analyzed. I also hand-coded the interviews and independently reviewed the transcripts and worked inductively to draw out themes from the data, establish a coding framework which was subsequently used to analyze individually assigned transcripts (Gale et al., 2013). This process ensured inter-rater reliability with the qualitative data analysis and results.

Data collection was an important component of the research process and there was substantial effort needed by myself as the researcher to accurately reflect the viewpoints of the research participants (Schwandt, 2015). Data collection took place within the academic medical center and included observations to make context of the patients' and families experiences visible and provoked questions for conversations. Observation provided a powerful and direct way of learning about patient/family advisors behavior in the context in which this occurs.

Observation also helped me draw inferences about patient and family engagement that I couldn't obtain by relying solely on interview transcripts as data. For example, watching the way patient/family advisors respond or engage within the patient family advisory councils provided a much better understanding of the patient/family advisors actual views about patient and family engagement and patient-centered-care than what the patient/family advisors mentioned with their interviews (Maxwell, 2013).

The duration of data collection events consisted of six months which allowed me to make plans for cancelations and make-up interview times. Furthermore, repeated data collection allowed me to review the data and discover gaps. The data from conversations and interviews was audio recorded and transcribed. Field notes from two observational sessions and 19 transcribed conversations and interviews provided text for the analysis (Schwandt, 2015). Schwandt (2015) explained transcription as a way to record and prepare the participants own words and create text of what the participant said during the interview, from handwritten notes, and audio recordings.

A field journal, a bounded notebook was used in the field I as recorded personal notes, observational notes, ideas, sketches, lists of terms, etc. It was used for jotting notes-key words, phrases, and quotes that I will later use as memory aids for writing up the field notes (Schwandt, 2015). The field notes were considered data on which I based claims about meaning and understanding. Field notes included documentation from my journal, interviews, transcripts, observations, conversations, copies of documents, diagrams, charts, audio tapes, and descriptions of events within the patient family advisory councils (Schwandt, 2015).

I also held informal interviews with advisory council members within the organizational level and were held within conference rooms and lecture halls around the medical center. All participants were observed on two difference occasions for one to two hours depending on the length of the advisory councils. The conversations with the patient/family advisors were informal and lasted no longer than five minutes, depending on the advisors' availability. Interviews with the patient family advisor participants were more formal, held in a quiet office room in the medical center that was reserved for each specific interviewee.

Individuals participated in one face-to-face interview. The interview sessions were scheduled for ninety minutes and started broad and progressed to more specific as the interview progressed. These broad questions began the interview and allowed the research participant a chance to relax. Interview prompts were used in the form of questions inviting the respondents to elaborate. The interviews were followed up with a thank-you letter and a $5 gift card to either Starbucks or Wendy's.

It was important I did not bring final closing because there was an opportunity for more communication. After concluding my data analysis, I held a one hour focus group with majority of the research participant to discuss the research findings. The participants, program director, and I met at the medical center in a conference room and went over the research questions, themes, and subthemes. All participants unanimously agreed on the conclusion of my research.

The director was also available for patient/family advisors who needed support during the interview phase, so that a comfortable interview could take place. It was also important to create an opportunity for participants to give voice to the health care experiences, so the conversations were held in an open and unstructured manner. With the use of open-ended questions, the conversations and interviews focused on the broad scope of the research study and on the narratives of the advisors' experiences of patient and family engagement within the organizational level in the medical center.

The follow-up plan if recruitment resulted in too few participants consisted of all eligible participants within the (PFEAP). To date, there were roughly 60 patient/family advisors who qualified for this specific research study. My intent was to obtain an accurate understanding of what each participant really would like to convey. The participants exited the interview by me acknowledging and thanking them for their time and effort in participating in the reach study and receive a $5 gift card for participating.

There was no cohesion involved with the participants and the data collection process. I made it clear to the participants that joining this research study was totally voluntary. I also made it clear they could withdrawal from the study at any time with no fear of retaliation. I had no direct supervisor versus supervisee or instructor versus student relationship with any of the participants, thus removing any issue for possible conflict of interest or power concern from the study.

Furthermore, the director of the (PFEAP) at had no influence or coercion on who would join the study. The purpose of the director was to give permission for me to conduct my research at this site, send out the initial recruitment email invitations to participate in the study. This was the only reason I contacted the program director. The senior leader had no knowledge to who joined the study. The participants contacted me if they were interested in participating.

I made it clear to the participants that I would not disclose any information to anyone who joined my study. I did not know who the patient family e advisors were before they contacted me. This way, participants concerns for privacy were relieved of any form of cohesion from the program director, or pressure. Before I began my interviews, I made sure all participants identified information such as name, email address, or phone number and was removed in the data collection and analysis process. I protected the confidentiality of the participants by assigning a number to each participant before I conducted the interviews.

The information with each participants name and number was recorded on a separate sheet of paper, which has been locked in a safe and secured drawer at my home office. Only I have access to this piece of paper. The paper with the participants' confidential information on it will stay in the secured drawer for five years after the completion of my research. Audio files and transcripts will be stored separately in a separate file from the participants' contact information to reduce the risk.

I informed the participants about the follow-up procedure during the initial face-to-face interviews. I informed the participants that I planned to follow up with a focus group to confirm and validate my interpretation of the meanings of each of their answers. After five years, all the information will be destroyed. There is minimal risk of breach of confidentiality. To minimize this risk, all participant contact information (collected for the purposes of conducting the interview) and interview data (the audio file and transcript) will be stored separately and there will be no link between participant contact information and project ID.

Data Analysis Plan

Data analysis was based on interpretive phenomenology by describing the meaning of their experiences through emerging themes (Reiners, 2012). The development of structural and textual descriptions was done through interpretive analysis (Cooney, Dowling, Murphy, & Smith, 2012; Rossman & Rallis, 2017). I searched for common patterns stimulated from the patient/family advisors specific experiences (Reiners, 2012). I provided a thick description of data by describing the participant's social intentions, circumstances, strategies, meanings, and motivations that characterize an interpretive characteristic of description (Schwandt, 2015).

Data were analyzed through the codes that were assigned to the phrases. Data analysis used an interpretive phenomenological analysis, an approach to analyzing first person, detailed, in-depth accounts of experiences drawn from hermeneutics (Schwandt, 2015). Interpretation began as soon as the text was available from the data collection and continued until the final interpretation and articulation. A coding system was used after the first interview and allowed for the interpretive process to involve an analysis of concepts and themes from interviews that were related to the literature search strategies for patient-centeredness and patient and family engagement frameworks. These were used as guides toward the determination of codes.

Coding was considered the main categorizing strategy. Coding was involved with the process of analyzing large volumes of data produced from my field notes, interview transcripts, etc. (Gale at al., 2013). Coding helped to disaggregate data by breaking data down into segments to identify or name those segments using a category or code. Coding required a constant comparison and contrast between the data segments (Schwandt, 2015).

Organizational coded categories were broad issues or areas that I established prior to my observations and interviews, or were easily anticipated. Organizational categories functions as “bins” for sorting data for further analysis. They were useful chapter or section headings in presenting my results, but they did not help with making sense of what was going on (Maxwell, 2013). Substantive categories were primarily descriptive and included description of participant’s concepts and beliefs (Maxwell, 2013). Theoretical categories place coded data into a more general theory or form and inductively developed theory (Maxwell, 2013).

Interpretation began with the close analysis of one case that conveyed a strong pattern of meanings. The analysis process consisted of reading and writing to fully interpret, then moved to other cases to explore, compare and contrast to the first case. The whole text was read across cases for common themes that emerged to develop themes and subthemes. Finally, exemplars were searched for and developed throughout the descriptive process and were used to discover qualitative distinctions (Matua & Van, 2015).

Analytic methods were used to apply codes to the textual interview transcripts by reflecting on observation and tracked the coded observations to identify patterns and similarities. Over a period of time, I expected the codes would change due to the field experience of the researcher. According to Miles, Huberman, and Saldana (2014) maintaining definitions and codes helps to connect concepts. I also maintained definitions of codes along with names of codes to help associate concepts when reviewing the coding architecture

I used Atlas.ti software for the PC Windows environment as a text-based database program that allows coding for text materials. Atlas.ti helped to create a systematic way to track and identify coding and the relationship patterns including the strength of the relationships and directionality (Miles et al., 2014). Each phrase with text was assigned a code or even several codes to each phrase or concept. Data was sorted into groups based on the individual codes and were categorized by heading and subheadings for textual descriptions.

Codes were continuously evaluated and refined during the process of moving from data collection to data analysis using the constant comparative method (Miles et al., 2014). Attributes were identified specific to each category to help clarify the themes that could contribute to the development of a description. If further interviews were needed, I addressed the question topics to understand the behaviors and characteristics that lead to creating patient and family engagement opportunities.

I was able to conduct the interviews concurrently with the initial coding of the responses. This gave an opportunity to refine the questions and add more probing where needed to find commonalities and patterns to identify generalizations while seeking for themes and constructs. I was able to compare and contrast the context within each category while also examining the characteristics of each identified attribute to better identify the relationships between categories and subcategories.

This occurred in several sequential steps, movement from data collection and coding. The research also used memoing to track information and ideas through the coding development and analysis stages. There was no context-and cultural specific issues related to the specific population of patient/family advisors while developing the instrument. There were no historical or legal documents used as a source of data which demonstrate the reputability of the sources.

Issues of Trustworthiness

Credibility

Trustworthiness was a criterion for judging the quality of qualitative inquiry. Lincoln and Guba (1985) suggested qualitative research's trustworthiness is enhanced through its credibility, transferability, dependability, and conformability. Lincoln and Guba also recommended strategies to maintain and establish the trustworthiness of qualitative research. Furthermore, a qualitative study cannot be transferable unless it is credible; likewise, a qualitative study cannot be credible unless it is dependable.

Credibility was considered parallel to internal validity and addresses my inquiry and provides assurance of the fit between the participant's life ways and my reconstruction and representation of the same (Schwandt, 2015). Issues of trustworthiness or credibility will be implemented with guidelines within the process of naturalistic inquiry and will be used to replace positivist standards for establishing trustworthiness using internal and external validity, reliability, and objectivity. Member checking and peer debriefing have been defined as most appropriate for credibility (Schwandt, 2015).

Trustworthiness is credible and usable. For a study to be trustworthy, it must be more than reliable and valid. It must be ethically conducted with sensitivity to power dynamics. Attention to methodological matters (sampling, design, and methods), ethical issues, and political dynamics should be consistently addressed throughout the project and be evident in the final product. This determines the integrity of the project. Integrity also implies soundness of moral principle, the ethical dimension that constitutes the second element of trustworthiness (Rossman & Rallis, 2017).

Rigor was established with engaging the study participants. Furthermore, the research findings were discussed with other researchers such as the Principal Investigator who over saw my research studies and data analysis. Rigor poses significant questions, linking to theory, using methods for direct empirical investigation, and providing a coherent chain of reasoning. Rigor seeks to explain if someone else can understand the study.

Relying on multiple methods for collecting data enhances the complexity of what I learned in the field. I documented the process of gathering, analyzing, and interpreting the data. I also established my perspective and make my process transparent with a natural history of inquiry with a journal using analytic memos. The journal documented the intellectual odyssey of the study and helped establish rigor to readers and potential users (Rossman & Rallis, 2017). Janesick (2015) and Rossman and Rallis (2017) mentioned several strategies for ensuring creditability and rigor.

These strategies include a) triangulation – multiple sources of data, multiple points in time, or a variety of methods used to build upon the picture that I am investigating, b) being there – prolonged engagement, being present for a long period in the setting and spending a substantial amount of time with the participants helped ensure I had more than a snapshot of the phenomenon, c) participant validation – member checks, take emerging finings back to the participants for them to elaborate, correct, extend, and argue about can be done with interview transcripts as a method for eliciting further information with emerging analysis, d) community of practice – engage in critical sustained discussions with colleagues in a setting of trust so emerging ideas can be shared, e) judging integrity and value of qualitative studies (truth, value. rigor, and usefulness) are important characteristics when designing a study.

Triangulation helped to reduce the risk that my conclusion will reflect the systematic biases or limitations of a specific source or method, and allowed me to gain a broader understanding of the issues I am investigating. Triangulation includes using multiple sources of data (the administrative staff, the patient/family advisors, my own notes and journals, and center records. Data from staff was collected through journals, formal and informal interviews, and participation in patient family advisory councils. These multiple sources and methods give creditability to the conclusions rather than only using one source or method (Maxwell, 2013; Janesick. 2015).

Triangulation was used as a procedure to establish criterion of validity has been met. I made inferences from data, claiming that a particular set of data support a particular definition, theme, assertion, hypothesis, or claim. Triangulation was used as a means of checking the integrity of those inferences. It involved the use of multiple data sources, multiple investigators, multiple theoretical perspectives, and multiple methods.

The central point was to examine a conclusion from more than one vantage point. Strategies such as bracketing, member checks, and triangulation helped to protect research from invalidity (Maxwell, 2013). I compared early and late phases of fieldwork, from different patient/family advisors, from different patient family advisory councils, data from observations of patient/family advisors interactions with data from interviews with each respondent and so on (Schwandt, 2015).

Reflexivity, known as the relationship existing between me and the research participants and our reflections constitute a phenomenon that is central to understanding the practice of qualitative research. Reflexivity in the setting began with me. As I observed and interviewed research participants, I tried to react to the participant’s words and actions through the triggering hunches, thoughts, and understanding of the setting and the participants. I generated constructs or identity patterns drawn from the theoretical orientation and cultural knowledge to explain and describe the actions I observed or words I heard - in which I sought to make sense. These constructs began as unexamined reflexes in reaction to what I saw or heard.

Reflexivity also involved the research participants and how the participants reacted to me. My presence became part of their social world and they adjusted their actions accordingly. The more I appeared to be like members of their social world, and the longer I stay in it, the less my presence affected their everyday routines within the patient family advisory councils. I became an integral part of the social world. The way the participants reacted to me became part of their repertoire and their reoccurring actions. As I reflected on my initial reactions, they grew into an examined and rigorous representation of my complex perspective.

Transferability

Content validity was established by triangulation of sources, methods, and theories. In which I searched for discrepant evidence in comparison with other programs in literature. Measurement validity refers to whether the data I have accurately represented what it is supposed to reflect. Establishing validity such as triangulation, member checking, and providing fieldwork evidence helped to make a case for a credible and plausible account to say the findings are certain and true (Schwandt, 2015). Content validity was sought by finding patient/family advisors within the medical academic using purposeful sampling method.

The purposeful sampling method was used to show individuals who have accomplished and established engagement partnerships with medical staff were identified to ensure the accuracy in what it was intended to describe. The naturalistic equivalent of external validity provided for the extent to which the results can be applied to other populations. Transferability which was parallel to external validity helped to deal with the issue of generalization in terms of case-to-case transfer (Schwandt, 2015). Transferability was concerned with my responsibility for providing readers with enough information on the study so they could establish the degree of similarity of findings between the case studies and the transferred cases (Schwandt, 2015).

As part of the interview questions, respondents were asked the degree to which their responses were specific and reflective to their current academic medical center organizational setting, in comparison to their experiences in other health care settings. The advisors’ perspectives of the degree to which they saw their descriptions as being applicable to other settings were included in the report to allow readers to gain a better understanding on how to better determine the generalizability of the conclusions to other health care settings.

Dependability

Reliability helped to establish the truth of the interpretation in the fieldwork by using methods for recording my field notes, analyzing transcripts, and conducting inter-rater checks on categorization, coding, and results, thus establishing dependability through documentation of procedures for interpreting and generating the data. Dependability was considered parallel to reliability and focused on the process of responsibility to ensure the process was logical, documented, and traceable (Schwandt, 2015). Reliability was a matter of producing dependable evidence and the methods used to make the claim about the meaning of this evidence was an issue of validity (Schwandt, 2015).

Confirmability

Member-checking was accomplished by sending the interview participants a summary of their personal interviews and a conclusion of the main research findings (Dirksen et al., 2013). I used member checking of the data interpretation of transcript review to help with the validity, confirmability/trustworthiness. This helped to confirm the respondent’s validation to feedback on the research findings to assure they are valid and meet the criterion of confirmability or trustworthiness (Schwandt, 2015).

Confirmability can be viewed parallel to objectivity and is concerned with establishing and linking assertions findings, and interpretations to the data themselves in a willingly and obvious way (Schwandt, 2015). Auditing has been emphasized as a useful procedure for establishing both dependability and conformability (Schwandt, 2015).

Ethical Procedures

The research study was used as an agreement to gain access to participants and approved from the patient experience department and the Institutional Review Board within the university medical center in the Midwestern, United States. Institutional permissions included; Walden University IRB number 03-06-17-0055846 on March 6, 2017 and the Office of Responsible Research approval number 2016E0756 where the academic medical center is located. According to Schwandt (2015), ethical issues such as informed consent, avoidance of harm/risk or deception, treating others as an end, never as a means, no broken promises, or lack of confidentiality are associated with the relationship between the researcher and the research participants.

I was objective and explained my ethical obligations as researcher to all research participants in terms of a contract, a written agreement between me and the researched. The content explained the purpose of the research study, the anticipated length and extent of the participant’s involvement, the procedures I employed as the researcher, assurances of confidentiality, the potential risks/benefits to subjects and a means whereby research participants found further information. The terms of the contract included voluntary participation specifies no penalty for withdrawal from the study (Schwandt, 2015).

All participants were provided written informed consent. Informed consent is considered an ethical requirement as the research participants have the right to know they are being researched, the right to know the risks and benefits, the right to be fully informed about the nature and purpose of the research, the right to withdrawal from participation at any time (Schwandt, 2015). Informed consent reflects moral principle of respect for persons, treating them as ends not means (Schwandt, 2015). Throughout the data collection process, I made sure that the patient/family advisors best interests and well-being had a priority over the research needs. The patient/family advisors were also informed they could ask me to stop the interviews at any time.

Summary

I have justified and described why I selected a qualitative research method with a phenomenological approach based on my research purpose and interest. I have also noted the inappropriateness of other qualitative research designs including, narrative, grounded theory, ethnography and case study. The qualitative phenomenological approach allowed me to collect data related to the research participants lived experiences with patient and family engagement. With the qualitative method, I was able to describe, understand, explore, and interpret the phenomenon related to the participants lived experiences with patient and family engagement in a health care organization in the mid-western United States.

This qualitative proposal aimed to conduct face-to-face interviews with a purposeful sample of 19 participants that explored the participants’ lived experiences with patient and family engagement. The goal of this qualitative phenomenological study was to identify the important patterns and themes from the responses of the participants via face-to-face interviews. I was diligent when taking notes during the interviews and recorded every interview. I organized, made sense, hand-coded, and used software to manage the data to identify the important themes related to the research questions from the participant’s responses to the interview questions. I have presented the descriptions of the research findings with the detailed data analysis in Chapter 4 and the conclusions in Chapter 5.

Chapter 4: Results

The purpose of this qualitative phenomenological research study was to describe and explore the lived experiences, perceptions, and meanings patient/family advisors associate with the concept of patient and family engagement. To better understand the patient/family advisors' experiences, I presented this central research question: How do patient/family advisors describe patient and family engagement within patient family advisory councils? I also included three sub questions to this study:

1. How can the results of the patient family advisory councils change health outcomes for patients and families?
2. What has the organization done or asked patient/family advisors to be involved in that is most meaningful to patients and families?
3. How have patient/family advisors perceptions of health care changed since working on patient family advisory councils?

Within Chapter 4, I reflect upon the procedures of data analysis and the corresponding data from interviewing 19 patient/family advisors. I also discuss the objectives of the study and findings of the pilot study. I provide a description of the research setting, demographic details of the participants, details of the data collection process, data analysis techniques, determining evidence of trustworthiness of the data, and lastly, the study results.

Pilot Study

The pilot study consisted of face-to-face interviews with five patient/family advisors who participated on patient family advisory councils throughout the medical center. I selected participants using a purposive sample which identified the qualifying criteria. I conducted the phenomenological interviews within a private office at the medical center. The participants signed informed consent forms and were exposed to the same measures of the interview protocol. I explained to the participants they could quit the interview at any time without any reason or reprimand. Participants received a $5 gift card to either Starbucks or Wendy's.

The interviews were conducted between March 17th and March 28th, 2017. Interviews for the pilot study lasted between 28 minutes and 46 minutes. Participants confirmed the time frame for the interviews was appropriate. They also agreed the interview questions were clear, easy to understand, and believed the interview questions would create meaningful information for this study. The results of the pilot study were critical because they helped determine the effectiveness of the interview questions.

I did not alter the interview questions after the pilot study. I did not have to make changes in the instrumentation or the data analysis strategies. The results from the pilot study helped me to be more confident as a researcher and gave me a clear understanding on how to approach the future interviews. Like the participants of the study, I maintained the privacy of pilot study participants and ensured all details were held confidential throughout the whole study.

Research Setting

When a participant indicated interest to participate in the study, I confirmed a private office room at the medical center for the interview. I permitted the participant to choose the day and time for their convenience. I conducted all interviews in a private office at the medical center. I did not conduct interviews in a clinical area of the medical center which may have affected clinical interactions or regularly scheduled appointments.

Before each interview, I spent time with each participant to build rapport and to help them relax and feel comfortable to participate. Before having the participants signs the consent form, I provided an ample amount of time for each participant to clarify any doubts of moving forward with the interview. Interviews were recorded with two different audio recording devices so that no information would be lost while recording. One audio recorder was placed close to the participant and the other close to me. Interviews were scheduled for 60 to 90 minutes and were recorded with the permission of the participants.

None of the participants acknowledged any ongoing organizational or personal circumstances that may have affected their experiences. All participants indicated that their past health care experiences did play a part in building their current patient family advisory council roles and capabilities while shaping their current experience as a patient/family advisor. The subjects did not have any personal or organizational conditions that influenced the participants or their experiences at the time of study or the interpretation of the study results. There have not been any organizational changes in personnel, budget cuts, or other trauma.

Demographics

The participants of the study were recruited by the program director who oversees and facilitates the (PFEAP) and through purposive sampling. To begin, the program director sent an email inviting eligible patient/family advisors to participate in the study, listing the inclusion criteria to be eligible to participate. I initially received responses from five participants to participate in the pilot study. I numbered these respondents sequentially: Participant 1 (P1) through Participant 5 (P5).

After the pilot study, I continued numbering the respondents sequentially: Participant 6 (P6) through Participant 19 (P19). I began the study with requesting participants read and sign the consent forms. After I received consent forms, the participants were then asked to answer the interview questions which were formally approved by the Institutional Review Board at Walden University and the office of responsible research at the academic medical center. These questions were:

- What do you think it is meant by patient and family engagement?
- What are the most important components of patient and family engagement?
- What is the ultimate goal of patient and family engagement?
- How, if at all, does patient and family engagement relate to patient-and-family-centered-care? Is it the same? Different?
- How would you describe that state of patient and family engagement within the patient family advisory councils - where is it now and where does it need to go? What can be done to make it happen?
- What behaviors have health care professionals shown to support patient and family engagement that were most meaningful to you?
- What elements of organizational culture facilitated or challenged your personalized patient and family engagement? Hospital leadership? Policies procedures? Team work?

- What resources were made available to you or your family member? (I.e. financial, staff expertise)?
- What type of information (if any) from the patient family advisory councils has helped you to be more engaged in your own health care?
- Do you feel more informed or more comfortable when participating in your personalized health care since working within a patient family advisory council?
- What are your expected or hoped health outcomes through the patient family advisory councils?
- What are the best ways to engage patients and families at the organizational level to transform patient family advisory councils? Who is the best person to deliver the information?
- How can aspects of leadership bring patients, families, and health care professionals together around a common goal?
- How can leadership be applied to transform the culture of patient and family engagement?

Demographics of the Participant Sample

The demographics of the participant sample are provided in Figure 4 (age) and Figure 5 (gender). All participants involved in the study were volunteers of the medical center but also serve as patient/family advisors with the (PFEAP) who combined, participated in five different patient family advisory councils throughout the medical center. Five participants participated in the pilot study, with an additional 14 participants who participated in the full study. The ages ranged from 30-74.

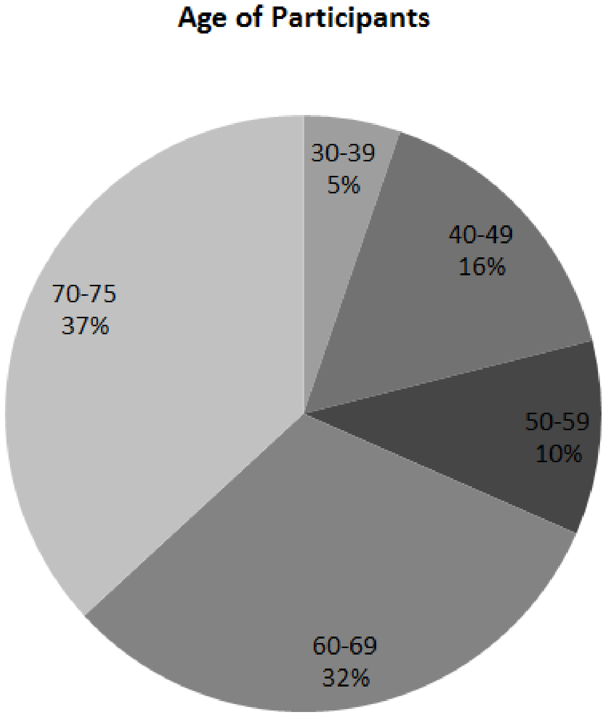


Figure 4. Age ranges of participants included in this study.

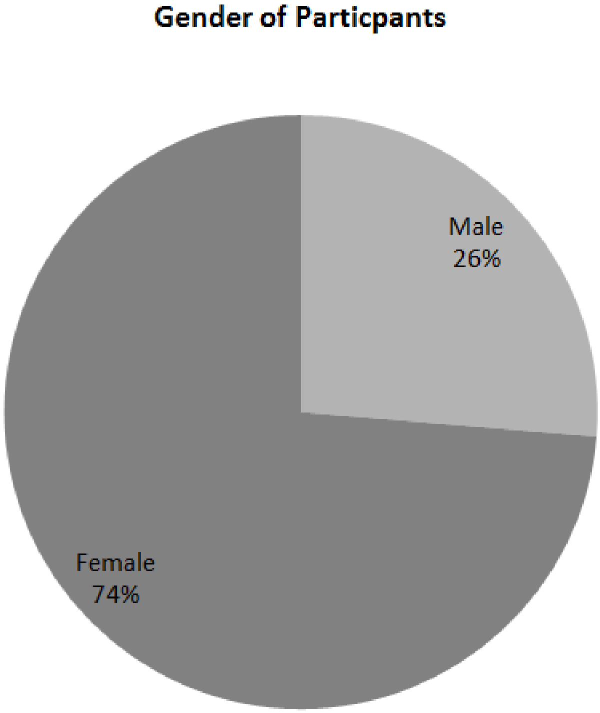


Figure 5. Gender of participants included in this study.

With regard to number of years of participating on one of the five patient family advisory councils, one (5%) participants (P7) participated on the council for less than 1 year, four (21%) participants (P1, P11, P12, P15) have participated for the entire length of the councils and the same four (21%) participants have participated on two different patient family advisory councils within the organization.

Table 1

Years Participating on Patient Family Advisory Council

Participants	Advisory Council	Years on Council	Advisory Council	Years on Council
Participant 1	Oncology	6	System-wide	7
Participant 2	System-wide	2		
Participant 3	East	1		
Participant 4	Behavioral	4		
Participant 5	Behavioral	4		
Participant 6	Oncology	3		
Participant 7	System-wide	3 months		
Participant 8	Oncology	3		
Participant 9	Oncology	1		
Participant 10	System-wide	1		
Participant 11	System-wide	7	Oncology	7
Participant 12	System-wide	7	Oncology	7
Participant 13	East	1		
Participant 14	Maternity	1.5		
Participant 15	Oncology	7	System-wide	7
Participant 16	Maternity	4		
Participant 17	Oncology	4		
Participant 18	Ambulatory	1	System-wide	2
Participant 19	System-wide	2		

Note. The data presented in Table 1 compared and contrasted the mixture in patient family advisory council members in the study by council membership, years of experiences, and number of councils participated.

The diversity in participant characteristics enhanced the trustworthiness of my data. The range of length serving on a patient family advisory council ranged from 3 months of participation to a maximum of 7 years of participation from the patient/family advisors. Overall, having a mixture of five different patient family advisory councils to compare and contrast experiences of the patient/family advisors allowed my research to be credible, transferable, and dependable.

Data Collection

I collected data through semi structured in-depth interviews. Semi structured interviews helped enhance the participation of the patient/family advisors and to clarify their doubts, thus helping to uncover the participants' philosophies and thoughts. The study was piloted with five participants, P1 to P5 from March 17th and March 28th, 2017. After the pilot was completed, I conducted interviews with P6 through P19 from March 18th, 2017 to May 25th, 2017. I interviewed these participants over the course of 10 weeks, depending on the availability and participant's schedule.

When a research participant showed interest to participate in the study, I finalized the venue for the interview according to the convenience of the participants. I conducted all interviews in private rooms of the academic medical center to avoid interruptions and to clearly audio record the interviews. Before each interview, I spent time with each participant to build rapport and to make the subjects feel comfortable. In advance to signing the consent form, I provided an opportunity for the participants to clarify all doubts. After asking the participants for permission, I recorded all interviews on two audio recording devices so that no information was lost in the recording. One audio recorder was placed close to me and the other close to the participant.

Each interview began with an open-ended predetermined lead question about demographic information. This allowed time for the transition for the participants to talk about their perceptions of patient family engagement within the patient family advisory councils. As the topic of the phenomenon progressed, the participants were prompted to talk specifically about certain experiences. Participants were encouraged to discuss their experience of the patient family advisory councils within the medical center and to reflect on their roles as patient/family advisors.

I had the interviews transcribed by the Midwestern University’s transcribing department to permit rigorous analysis. A confidentiality statement signed by the representative of this department can be found in Appendix D. The transcripts and audio files were identified only by a unique project ID created for this study and the link between project ID and contact information will not be maintained. All data will be stored in a safe location on the box and only accessible to me.

The data collection procedure was precisely as initially planned and presented in Chapter 3. I did not come across any unusual circumstances during data collection process. All participants were very open and eager to talk about their personal health care experiences in addition to their experiences within the patient family advisory councils. I chose open-ended questions to bring to light the responses from participants about their experiences in health care. For example, I asked questions such as the following:

- What do you think it means for patients to participate or engage in their healthcare?
- What type of resources do you think patients need to help them engage in their healthcare?
- What would help patients feel confident bout engaging in their healthcare?
- What makes patients willing to engage in their healthcare?
- What types of capabilities do patients need to engage in their healthcare?
- What else do you think about when considering patients engaging in their healthcare?

The steps of this phenomenological methodology included identifying the nature of lived experience through the literature review of the phenomenon, conducting an investigation through data analysis and bracketing of knowledge, phenomenological reflection and phenomenological writing (Van Manen, 2014). I captured the participant's' phenomenological reflections and writing as data collection as a way of bracketing my experiences. I followed the participant's stories to gain a deeper understanding of the phenomenon, themes, and dimensions in order to understand their lived experiences as patient/family advisors.

Common themes evolved from the participant stories which described the aspects of the phenomena and answered how patient/family advisors describe patient and family engagement within patient family advisory councils**.** In line with a semi structured approach, the contents of the interviews were in a particular sequence. When a certain topic was not addressed freely, I prompted participants to address it. Throughout the interviews, I restated the thoughts patient/family advisors shared with me so that I could verify the accuracy of the content.

I used communication techniques such as open-ended questions, rephrasing, summarizing, and probing as a way to capture each topic in greater depth. At the end of each interview, I provided every participant the opportunity to add any additional thoughts or comments. I hired a professional transcribing company to translate the audiotaped interviews for thematic analysis. Throughout the process of interviewing, I kept a reflective journal.

The reflective journal was used as documentation for the field notes as a way to capture the experiences and reflections of my study. The recorded notes were written during and directly after each interview. I purposely allotted time to record these notes after the interview when the conversation was still on in my mind. I recorded general notes such as the setting and the environment of each interview, comments on the participants' appearance, and the nonverbal communication during the interviews, my impressions of how the interview evolved, and my preliminary interpretations of emerging themes.

The interviews lasted for an average of 54 minutes. Although there were a couple outliers in which the interviews lasted a minimum of 28 minutes to a maximum of 136 minutes. P15 spent over one hour and five minutes in the interview. The shortest interviews lasted 28 minutes with P5 from the pilot study in addition to P19.

P6 and P7, a married couple, conducted the face-to-face interview together taking one hour an twenty one minutes to complete the interview. P11 and P12, also a married couple conducted the face-to-face interview together taking one hour and thirty six minutes. Both sets of these participants both served on the patient family advisory councils together. I recognize this may be considered out of the norm. I allowed this to happen due to the request of the participants wanting to take the interviews together. This may potentially skew the data and create member bias.

Data Analysis

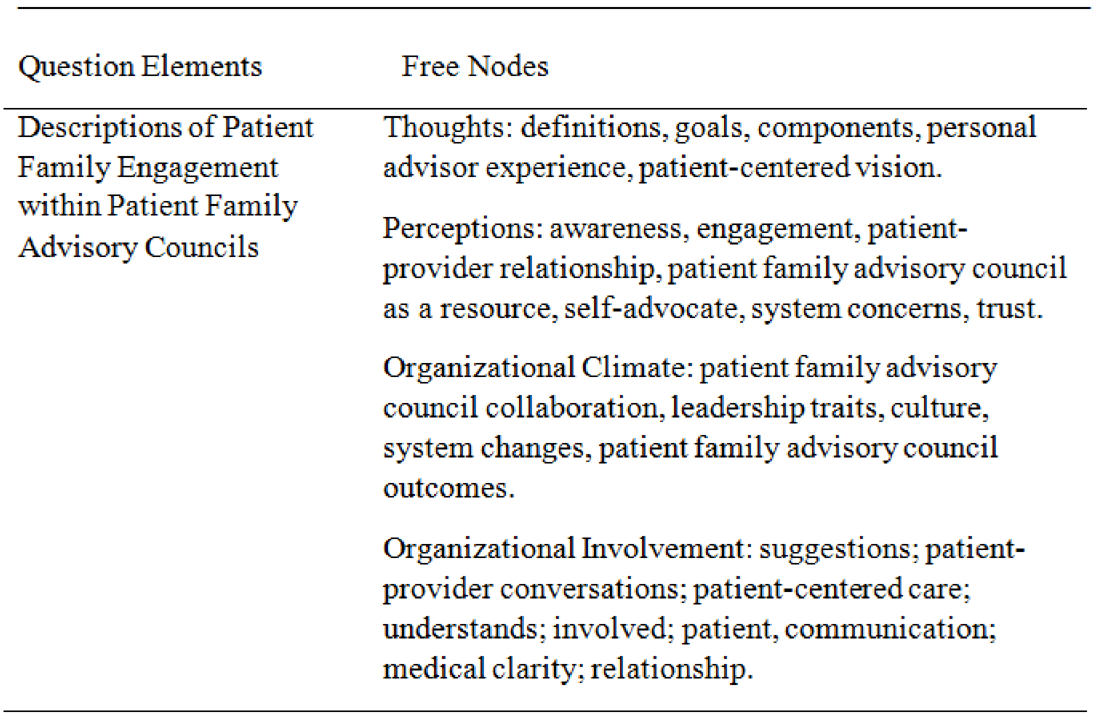
Once the audio recorded interviews were finished, the field notes and interviews were transcribed using a Word document and then entered into Atlas.ti, a qualitative software program. Atlas.ti is a CAQDAS program computer assisted analysis that helps to sort, categorize, and analyze the data. Atlas.ti helped to rapidly sort phrases and data into frequent words and was used to facilitate developing the themes to report the data. For example, Atlas.ti assisted to capture trends of repeated phrases or words in the interview data. Atlas.ti was used to import the transcribed interviews and tag sections of the qualitative codes and sub codes to identify themes and to later pull out example quotes related to those items.

Key words relevant of the study included, organizational involvement, experience, health outcomes, and resources appeared often during the interviews. Atlas.ti helped me to sort through the data I collected and to note the frequency of phrases and words, ultimately to develop a theme or category system. Atlas.ti was used to sort the collected interview data into themes and categories. The data became continuous, resulting in numerous layers of analysis instantly as the data were entered into the software program.

For this research study, the themes and categories were created by using free nodes which were organized surrounding the central research question. The question asked: How do patient/family advisors describe patient and family engagement within patient family advisory councils? I created a folder to represent the participant's responses at the medical center. During coding, each interview was entered as a separate free node (see Table 2).

Table 2

Beginning Coding of Free Nodes



Question Elements	Free Nodes
Descriptions of Patient Family Engagement within Patient Family Advisory Councils	Thoughts: definitions, goals, components, personal advisor experience, patient-centered vision. Perceptions: awareness, engagement, patient-provider relationship, patient family advisory council as a resource, self-advocate, system concerns, trust. Organizational Climate: patient family advisory council collaboration, leadership traits, culture, system changes, patient family advisory council outcomes. Organizational Involvement: suggestions; patient-provider conversations; patient-centered care; understands; involved; patient, communication; medical clarity; relationship.

Note. The data was categorized so any words or phrases referring to the nodes were coded under the free nodes. I continued this process until all data from the participants were sorted and assigned to a node.

After the first round of data review, I examined the data two additional rounds. On the second round, I added personal memos or notes to the interview data from the first two rounds of data review. This helped to refresh my memory regarding impressions I formed throughout the course of the face-to-face interviews. For example, as I began to sort the data, I began to note the similarities and differences in types of experiences that were associated between the five patient family advisory councils.

The participants, although serving on different councils and having different diseases and health care experiences, were able to provide their lived experiences both on a personal level of being a patient, family or caregiver, but within the organizational level as participating as a member of a patient family advisory council. The third and final round of analysis reviewed the data to ensure all potential categories were collected. Using the qualitative software helped to rapidly arrange and sort through the data and helped to create the justification for saturation in the data capturing the participants' lived experiences.

Figure 6 shows the sorting that was used in the qualitative software that resulted in trees of frequently repeated words or phrases. Words and key phrases analysis uncovered five essential themes: (a) descriptions of patient and family engagement, (b) organizational efforts most meaningful to patient/family advisors, (c) patient/family advisors perceptions since working on a patient family advisory council, (d) and (e) patient/family advisors perceptions on elements of the patient experience.

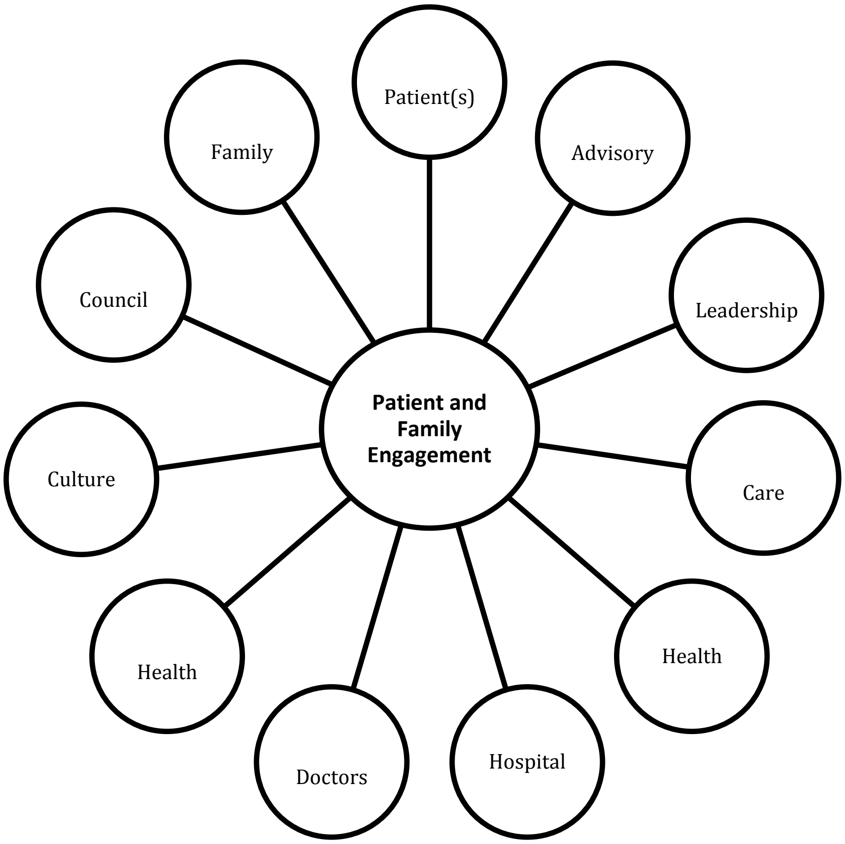


Figure 6. Tree node of most frequently used words throughout participant interviews.

Moving Inductively From Coded Units to Larger Themes

The phenomenological reflections granted me the opportunity to **c**onduct a thematic analysis to establish the existential themes. In fact, the phenomenological reflection along with phenomenological writing began during data collection. The interpretation and descriptions of the findings evolved as the themes emerged from the analysis, and from the logs that included the words and feelings from the participants' responses. My coding process consisted of several iterations.

Conducting thematic analysis. The thematic analysis involved three methods that were highlighted by Van Manen (2014), which included a holistic discriminatory approach and an in-depth or sentence-by-sentence analysis. First, all transcripts were interpreted as a group to gain a holistic understanding. I then used the discriminatory approach to review all transcripts and highlighted all expressions, texts, and judgments that contributed meaning to the phenomenon of the study. Lastly, I read the transcript again line by line thinking about the meanings hidden in the text.

To grasp the expressions of the participants, the interviews were classified or coded with thematic headings (Van Manen, 2014). Patterns emerged from the codes, but were analyzed several times. The data analysis process included an assessment of the data. This was done by evaluating emergent patterns and creating processes to link and connect the data to patterns and themes (Table 3).

Table 3

Implementation Coding Dictionary

Codes	Abbreviation	Definitions	Examples/Key Words
Personal background	Personal	Background information on participants	Age, gender, years on council, membership
Thoughts on PFE & PCC	Thoughts	Thoughts on PFE & how it relates to PCC	Thoughts, components, goals of PFE, relation to PCC
Patient-centered care	PCC	Thoughts about PCC	Critical component of PFE, care, experience, people, center, partner
Patient family engagement	Engagement	Thought about PFE	Communication, heath care, provider

Table 3 (continued).

PFAC goals	Goals	Mentions goals of PFAC	Facilitate, engagement, improve, health
Patient-provider communication	Communication	Conversations with staff	Patient, family, caregiver, provider
Institutional collaboration	Collaboration	Ways PFAs collaborate	Input, build, together, change, staff, university
Patient experience	Experience	PFAs share experience	Personal, health, PFAC, improve
Learn about health care	Learn	Importance of learning	Education, suggestions, implementation
Environment	Environment	Culture of the medical center	Direction, signage, interactions
Organizational involvement	Culture	Involvement with PFACs	Professionals, behaviors, climate
Provider efforts	Provider	Provider effort to engage	Partners, involvement
Communication	Communication	Conversations with PFAC	Clear communication, staff, providers, patient
Organizational efforts	Organization	Involvement with PFAC	Leadership, culture, partnership
Perceptions	Perceptions	Perceptions of health care	Comfortable, self-advocate, engagement
PFAC resource	Resources	Elements of resources	Knowledge gained, cognizant, perspective

Note. Table 3 shows emergent patterns connecting codes to definitions and patterns/themes. PFE = patient family engagement. PFAC = Patient family advisory council. PFAs = Patient /family advisors. PCC = Patient-centered care.

After I completed the initial coding process of all the participants' transcripts, themes were coded, citing the participants' interpretations that emerged from the analysis. Afterwards, I analyzed the codes and identified relationships between the codes using my understanding that resulted from the literature review and grouped them accordingly. Bazeley and Jackson (2013) suggested a large numbers of codes specifying the significance of grouping or merging them together. The next phase included clustering the codes into numerous themes. The process of clustering resulted in five thematic clusters that integrated thematic headings and sub headings.

As a result, I marked illustrative themes, organized conversions and gathered thematic interpretations from the data. Bazeley and Jackson (2013) recommended organizing nodes into categories and subcategories with fewer than ten categories. Miles et al. (2014) recommended taking the loose chunks of meaning and reconfiguring as necessary the central themes. Reviewing the actual recordings of the interviews and transcripts multiple times allowed me to verify the themes and data, which ultimately portrayed an accurate description of the participants' lived experiences.

With the last step, I interpreted the data by a final review of all the transcripts, using the themes that evolved as headings and reconstructing participants' narrations listed under these thematic headings. Interpretations of the findings was undertaken by reading, writing, reviewing, and clarifying the meanings, then going back to the literature, reflecting and reordering of the themes to capture the essence of the lived experiences of the participants'.

Emergent Findings

Once all the transcripts were coded, I compared all codes across all participants' in the Atlas.ti program. During the comparison, I made note of similar associations and combined them, maintaining each participant's meaningful phrases. The interpretations distinctive to one participant were also included in this file, and those that were similar were merged, creating the first list of themes for comparison. These topics were typically much shorter in phrases and captured the meaning of the participants' comments in a few words. In creating themes, I tried to capture the essence of the participants' meaning on both in the interpretative and semantic level.

Themes were separated by examining the context of the participants' experience, and how the participants' phrased what they conveyed. An iterative process emerged with naming themes, moving back and forth between my words to the participants words and then from individual participants' to the sum of all the participants' voices. Phenomenological depictions were created with stories to represent the essence of the phenomenon of the study. Imaginative variation was used to search and create meaning to each theme. This helped to distinguish each theme was unique to the individual experiences of every patient family advisor involved in the patient family advisory councils.

Interpreting Lived Experiences

As themes emerged, I began to write with personal logs and reflective notes. The description portrayed a rigorous organization which presented the participants' lived experiences. To begin the analysis, I first created a summary using the narrative of each participant. Next, I described the experiences to capture the essence of the participants' lived experiences. As the themes emerged, I used paper to connect ideas and themes that were similar and combined them. I captured interpretations and included quotes that made the story clear and included quotes to capture the essence of the participants' lived experiences.

Discrepant Cases

There were no discrepant cases in this phenomenological study.

Evidence of Trustworthiness

Credibility

Evidence of trustworthiness must be documented to strengthen the validity of a qualitative study. Using rigorous methods helped to support the importance of this qualitative study, specifically when looking to reproduce the setting of qualitative data. Credibility, transferability, dependability, and confirmability help to strengthen trustworthiness of a study (Ravitch & Carl, 2016; Patton 2016).

A qualitative study cannot be credible unless it is dependable. Similarly, a qualitative study cannot be transferable unless it is credible. Credibility was considered a counterpart to internal validity, addressed my inquiry and provided reassurance of the fit between the participant's life ways and my reconstruction of their experiences (Schwandt, 2015). Issues of trustworthiness or credibility was used and applied with guidelines for the practice of naturalistic inquiry and was used to replace positivist standards for establishing trustworthiness using internal and external validity, reliability, and objectivity.

Member checking and peer debriefing have been characterized as most suitable for credibility (Schwandt, 2015). Member checking and saturation were used to confirm creditability. Each of the 19 participants were invited to a focus group and given the chance to look over or change their comments if desired. Member-checking gave research participants the opportunity to have a say in the final approval of the research findings in this study.

There were many commonalities with the participant's, thus helping to enhance the creditability of this research. Ravitch and Carl (2016) suggested saturation happens when frequent themes arise within the samples of participants. Utilizing common themes throughout the analysis also helped to validate the participant's health care experiences amongst each other and helped to validate the shared experiences of the phenomenon being studied. The comparisons helped me determine I had reached saturation with the 19 participants.

Transferability

Miles et al. (2014) recommended variability with participant selection should include rich, thick descriptions, consistent with other studies, admission of limitations in sample selection, and dialogue of my perspectives on the transferability of the data. Transferability was an important metric in this study and indicates practical implications for further research aimed toward practitioners, health care workers, patients, families, caregivers, and the community as a broader whole. The analysis of my study in each of domain is further discussed in depth below.

Variability in participant selection. Variability in the participant selection included the four dimensions, age, gender, patient family advisory council membership, numbers of years of participating, and various health care conditions. Having more variability with participant selection increases the likelihood for this study to be utilized with numerous environments. Transferability was developed by incorporating variations in gender, representation of multiple patient family advisory councils, a wide range age and of years of experience, and undertook varying health care conditions into account.

Rich, thick description. Producing rich, thick descriptions of interviews was a key method used in this study. Maxwell (2013) suggested researchers utilize the entire interview transcripts to produce rich, thick descriptions. Furthermore, creating repetitive open-ended questions can help to produce rich, thick descriptions. Some examples of the open-ended questions used in the interviews included the following.

- Regarding _____, could you tell me more about that experience?
- I’d like to hear more about ____?
- What else can you tell me about your experience?
- What was that like for you?
- Could you share both your positive and negative experiences?

I continued using open-ended questioning until the participants told me they had nothing else to say or until the participants started to repeat themselves. For example, I asked participants, “Is there anything else about that question most meaningful to you at the advisory councils? Is there anything else you would like to add?” One participant replied, “Yeah, I think mine the most meaningful part is that there’s validity in what we’re saying and what they’re doing and the feedback it proves understanding. Its validity.”

Consistency with other studies. Transferability can be enhanced when the characteristics of a study are consistent or comparable with other studies. The research findings in this study are comparable to other studies and the descriptions of patient and family engagement. The tangible experiences of my participants portrayed unique characteristics; in general the categories of the experiences described by the patient/family advisors in this study were similar with the patient/family advisors experiences found in existing journal articles and research studies.

Limitation in sample selection. Transferability can be limited by having small sample selections particularly if commonalities occur among participants’ in the sample. Diverse sampling can facilitate broader understanding to other situations (Miles, et. al., 2014). The participants’ varied in gender, age, patient family advisory council participation, years of experience, and health care conditions. This variation reduced the potential limitation of transferability due to sample selection. The absence presence of such limitation is described below.

Gender consisted of five males and 14 females. It could not be determined whether transferability would be limited. Although more females participated in this study than males, I did not notice any differences with the experiences between genders. Participants in my study represented five patient family advisory councils: system-wide, oncology, behavioral health, east, and maternity. While it was not possible to interview all the participants from all patient family advisory councils in this study, having interviewed multiple participants from each patient family advisory council gave a range to help determine the transferability of this study.

With respect to the number of patient family advisory councils, the participants fell into two categories: participated in only one patient family advisory council or they participated in one or more patient family advisory councils. The range of years of patient family advisory council participation went from three months to seven years. The number of years of experience participating on two or more patient family advisory councils varied from one year to seven years I included the experience of patient/family advisor with only a few months of participating on a patient family advisory council which helps to minimize the limitations to this study.

P2, a newer council member, who had only been on the patient family advisory council for three months and attended only two patient family advisory councils meetings indicated,

> I understand that a lot of the people serving on that committee have stories to tell and have wonderful stories to tell and experiences to share, and definitely have opinions, and hopefully our input does go back to the right people, and it really does make a difference.

Transferability of the data. Having consistent similarities of rich, thick descriptions which describe the phenomenon of patient and family engagement by numerous participants indicates other patient/family advisors within these patient family advisory councils are likely to have similar experiences. Including a wide variety of participants can also help to enhance transferability. The sample selection may have minor limitations with only including one organization. This research study reflects existing research and is consistent with other published research concerning patient and family engagement.

Organizations can create transferability from the patients and their families to better enhance outcomes for quality and safety while innovating ways to create best practices for patient and family engagement. There is a need for an advanced approach to enhancing patients and families voice in the care processes of change. Preparing to address methods of change with patient and family engagement models may help with the transition along with creating opportunities to enhance and meet the needs of patients in the 21st century.

Dependability

Accomplishing dependability depends significantly on the structure of organizing the project and the completion of data. Since the data being drawn from the participants is unknown prior to conducting face-to-face interviews, the process for collecting data can be and rigorously applied. Miles et al. (2014) suggested the requests for collecting data need to be consistent. My data collection process followed the proposed Institutional Review Board application and included having the director of the (PFEAP) conduct participant screening and outreach.

I received consents, conducted the interviews, and hosted a focus group for member-checking. I also created a process to track each participant. This included keeping a record of the dates of all indicated steps for every participant as recommended by Patton (2016). As well as audio recording the interviews, I also took notes during the interviews to help in the review of my data. I have included all of my coding notes within the audit trail. As mentioned in Chapter 3, the audit trail allows other researchers to have a strong understanding of the processes needed to replicate my research study.

Confirmability

To improve conformability, I needed to recognize my own biases and make a conscious effort to minimize them. Ravitch and Carl (2016) implied even though researcher biases may exist, it is imperative the researcher must try to minimize the effect with research by being aware of personal biases throughout the research process. Patton (2016) advised keeping an open mind during interviews and data analysis can help to facilitate a reduction in bias.

Moustakas (1994) explained the importance of bracketing personal experiences which can help the researcher by comparing and contrasting them with those of the interview participants. Bracketing resulted in me recognizing some of the interview responses related with my own personal experiences whereas other responses disclosed different experiences which did not relate to my own experiences.

Study Results

In the following section, I describe the presentation of the results of the study as themes derived from the personal experiences of 19 Patient/family advisors who were involved in the translation of evidence into practice. Then, I highlight the core essence of the study as a result of the phenomenological reflection. My overall aim in this phenomenological study was to interpret and reveal the patient/family advisors lived experiences of the complex phenomenon of describing patient and family engagement within patient family advisory councils and how this has helped to improve the patient experience, quality measures and health outcomes.

19 patient/family advisors or 42% of eligible participants completed the face-to-face interviews. Preliminary data suggests various patient/family advisors do feel more confident about engaging with their personalized health care since participating with patient family advisory councils. Patients and families believe communication is the key to successful partnerships. Patient/family advisors want to have an equal voice in their healthcare but at times still feel intimidated to speak up to their healthcare provider.

Patient/family advisors perceptions and feedback might help expand scholarly literature, research methods, and tools to better understand patient and family engagement from the consumer's perspective. This qualitative research may possibly help healthcare professionals identify what matters most to patients and their families. The patient family advisory councils have helped to create better patient experiences and improve health outcomes for future patients and families. Furthermore, patient family advisory council members have stated they have more confidence in their personal health care since participating on the various councils.

The central research question asked, how do patient/family advisors describe patient and family engagement within the patient family advisory councils? Five themes emerged. When a code was assigned to a highlighted portion of the transcribed interview text, Atlas.ti counted the assignment as mention. I focused on themes that had 10 or more occurrences and sub themes that consisted of five or more occurrences. There could many reasons for the differences in frequency of each theme, taking into consideration my coding choices and my ability to describe these certain themes in more extensive ways. Below, I describe these themes in greater detail and provide example quotations.

Themes

Theme 1: Descriptions of patient and family engagement

The first theme of responses surrounds descriptions of patient and family engagement. 14 out of the 19 participants described patient and family engagement from the perspective of the advisor. Five participants identified ways engagement takes places within the patient family advisory councils, 10 participants identified “communication” as a major component of engagement, and nine participants reported the importance of including the “family” or “friends” in respects to engagement.

P3 stated patient and family engagement, “is a process of communication between family, patient, and all, and healthcare providers. I guess healthcare provider is a broad term. It’s part of the institution.” P16 described patient and family engagement as, “a holistic approach to meeting the patients’ needs and also engaging their families because the support person is so important and they need to be included, they need to be communicated with.” P4 stated advisors have **“**the ability to give feedback that will actually be received and heard in the administration.” P2 described engagement within the patient family advisory council as,

> Education, feedback, observations, suggestions on our part...Engagement to me feels like communication is taking place…with an open mind and trying to put

> that in action with your experiences with the patient, really are keeping that viewpoint. Again how does this affect the patient?

P9 explained the patient family advisory council takes “the viewpoint of the patient into consideration.” P13 described patient family advisory council attendees to consist of doctors, nurses, supervisors and patients. P14 shared, “nurses in particular… seem to be looking for ways to improve the experience of being a patient.” P17 felt council members were “able to express things that would be necessary for patients in the future in the present and the future so their care is exceptionally better.” P18 described patient and family engagement within the patient family advisory council,

> Everyone being good communicators and again that’s with parties both the provider but also the family and the patient and an atmosphere of total candor… I feel some of the things they talk about the, on the committee directly affects the patient but it also you know kind of speaks to the family component as well. For example, when they talked about the physician and nurse rounding…The patient and family take responsibility they take some of the responsibility for being informed and for raising questions that should be asked and are active participants in their care, so it’s a joint project both between the patient and the family and the provider.

A second common category of responses relates to communication. Regarding communication, patient/family advisors identified communication as a vital component of being engaged in their personalized health care and being able to ask questions. P12 and 19 stated communication is the key to engagement. P4, P5, and P7 expressed communication between the patient and the provider should be patient centered whereby patients have a role in shared-decision making. P4 stated, “The patient being able to communicate back to the doctor, a conversation as opposed to a doctor dictating.”

P5 expressed the patient and provider should have, “Two way communication not just reading a patient or a guest or a family member with the insincere hello. But trying to be helpful, letting them know that you’re there to help them, if you have any questions, and they always teach us.” P7 expressed the importance of including the family in the communication process from the advisor perspective, “sometimes doctors and nurses may not understand how important that communication is for a family member and will be quick with instruction or thought and maybe not even allow you to be in the room or be around the patient.”

P14 and P16 discussed communication from their maternity experiences from serving on the patient family advisory councils to their personal experience of labor and delivery. P14 said doctors deliver babies “a dozen times in a day” but most people will deliver a baby a “handful of times” and how important it is for patients and families to be communicated with during this experience. P16 shares how at the maternity council she was,

> Often asked what did your spouse, or partner, or husband, or whoever was with you, what did they need? Did they, were they asked if they have questions. Did they feel that they were involved, did they have something to eat, did they know where to park?

A third common category of responses related to the importance of including the family, caregivers or friends. Participants identified common attributes in which others may be involved or engaged with the patients' health care. P8 stated it may be necessary to involve others in the patients care in "a possibly life threatening situation, or certainly a serious situation, so that they are aware as much as can be possible what's going on with the patient." P15 further explained the importance of involving the family during a patient-provider encounter, "when the doctors come in and maybe the patient can't think of something but the family member might think of something." P19 expressed, "Having the family involved in the patient care in whatever capacity that may be." P7 explained sometimes family members, caregivers, or friends are the only person in the patient's life to understand, "making arrangements from what happens next or listening to diagnosis, having direct input into if the patient isn't able to talk, or a direct input into what's going to be happening in the process, recovery, and their future."

Theme 2: Provider and organizational efforts most meaningful to patient/family advisors

The second theme of responses surrounds provider and organizational efforts most meaningful to patient/family advisors. Eight of the 19 participants (P6, P7, P8, P10, P12, P14, P15, and P17) discussed the advisors perspective. Two common categories emerged from the participants, providers' behaviors, and organizational efforts.

The first common theme of responses of provider's behaviors, three participants (P6, P7, and P17) discussed ways provider's behaviors can help to support patient and family engagement. These behaviors included the importance of involving the family/caregiver, clearly communicating to patient and families in ways they can understand, and recognizing patients may have different levels of engagement within their personalized health care. P7 described a personalized encounter with a provider and the importance of having clear communication,

> There have been times that [spouse] been with me and I thought I understood what that doctor had told me. Afterwards we were talking about it and he said, I don't think he said that, I think he said this, and I was like oh yea I never thought of that.

P6 stated, “And if you’re not, who is your advocate?” P17 expressed the importance of the caregiver’s perspective,

> because there are things you are going to see as a caregiver or as a patient that you would not necessarily see as a provider and I can say that because I am a provider and I was also a caregiver for my daughter so, there were things that I could see from a family perspective that I would not have seen from a provider.

The second common theme of responses indicated the importance of incorporating a team based culture. Seven of the 19 (P6, P7, P8, P10, P12, P14, and P15) participants discussed the importance of incorporating a team based culture into the patient family advisory councils whereby patients and families have the opportunity to be considered partners in health care. Participants discussed the importance of creating a team-based culture within the patient family advisory councils. P15 expressed,

> The other thing I’ve noticed is that it’s much more team-they emphasize the team. When I had my outpatient surgeries, everybody came in which was wonderful.

> Every nurse, every doctor, the anesthesiologist, everybody introduced themselves, told me what they did, asked me if I had any questions. It was- it's so much more team-centered now.

P7 stated, "We are always given the opportunity in our advisory council to bring up topics." P6 expressed there is "a unanimous consensus in the group" of patient family advisory council members to ask questions after a topic has been presented. P6 also stated,

> I think at the meetings it's amazing how many times when a presenter comes in there's almost a unanimous consensus in the group when they pose questions after they communicated to us a topic. It could be issues in the parking lot, it could be issues about the doctor not or the doctor showing up to bedside one a day with the nurses in terms of rounds and how it's done. It could be in terms of almost remembering some of the topics. Some of the docs will cop out and say its ok not to have people skills and I started saying you really need to have a certain protocol and people skills. We will teach and help you and we will rate you on your performance and improvement. And that's powerful stuff, that's the only reason why I go to advisory meetings is because of those kinds of things.

Participants feel comfortable to engage with medical staff at the patient family advisory council meetings. P14 stated "a lot of what we are doing is talking about ways to better the communication between medical professionals and patients." Since participating on the patient family advisory councils P10 became "more cognizant" of the culture.

Participants P8 and P12 stated a patient-centered culture helps to foster engagement with patients and families personally and within the patient family advisory councils. P8 stated the patient family advisory council "group is instrumental… the patient-centeredness and the training of the staff to say this is the caliber of people we want...That culture, it, from the day you walk through the door, that culture is enforced." P12 expressed the importance of partnership and engagement, "the patient and the families and the hospital and the caregivers and the staff and to make their experience positive."

Theme 3: Patient/family advisors perceptions about patient family advisory councils

The third theme of responses helped to confirm patient/family advisors personal perceptions of health care have changed since working on a patient family advisory council. 12 out of the 19 participants (P1, P2, P3, P4, P5, P6, P7, P8, P9, P10, P12, and P15) described their personal perspective as a patient/family advisor. Three common categories emerged. Participants discussed having more awareness and appreciation of how health care works, having a better sense of empowerment with their patient-provider relationship, and identifying the patient family advisory council as a resource.

The first common category of responses, participants (P4, P5, P8, P9, P10, and P15) reported being more aware and having a better appreciation of the changes in the organizational culture and the daily operations of the medical center since working on the patient family advisory council. P4 stated, "I think the more you interact with health care professionals, the more comfortable you always feel. So the fact that we're in there and we see the upper administration, and there's nurses on the committee." P5 expressed having a “better understanding of the university hospital system, all the different departments.” P10 stated, “I take more notice of how care is provided.” P9 stated the patient family advisory council has made her more aware and she also has a greater appreciation for the institution. P8 expressed, ‘‘The advisory council has made me more aware of other people’s jobs.” P15 stated,

> So oh yeah it’s definitely being on the council is without a doubt a learning experience…Everybody has to understand how the patient feels. Ok are they physically, how sick are they, where are they mentally like in other words am I getting better and I dying I mean what is going on with me and so they have to let the patient talk about that however it’s going to come out. Ok and I think it’s most important whoever else is there, I’m going to say generically the family, that the family has to listen and they have to let the patient speak.

The second common category of responses, participants (P1, P3, P6, and P7) discussed attributes of feeling more empowered and more comfortable interacting with health care providers since working on the patient family advisory council. P6 discussed the importance of being a self-advocate. P1 identified as being a caregiver and learned to be an advocate herself “and for others yeah out in the real world.” P7 expressed sometimes having to follow-up with a provider after an encounter and feels “frustrated that I didn’t go back and speak at the moment but I’m just not there yet**.**” P3 stated,

> The council, in fact, might even be able, it opens your eyes to, these are the things that I should know, I should be aware of, and I think it makes you a better advocate for yourself…It opens up communications between you and your

> professional care person, whether it’s a doctor or a nurse or the nurse practitioner. It opens up a new dialogue with them, too, which you may get to a different level than you were prior to being on that council…All that does is open up your eyes and enlighten you to ask more questions and advocate in a greater manner for yourself and for someone else if you are helping them.

The third common category of responses, participants (P2, P8, and P12) identified the patient family advisory councils as a personal resource. P8 discussed having “a greater sphere of resources… because of the advisory committee.” P2 stated, “I know I have that resource to fall back on, [PFAC] you know at the same time I feel bad for those who don’t.” P12 discussed working with leadership from the patient family advisory council to help correct an error within an electronic personal medical record that was in the electronic health record.

Theme 4: Patient family advisory council efforts to change health outcomes for future patients and families

The fourth theme of responses identified ways in which the patient family advisory councils have helped to improve health outcomes for future patients and families. 16 of the 19 participants (P1, P2, P3, P4, P5, P6, P8, P9, P11, P12, P13, P14, P15, P16, P17, and P19) discussed ways they have been involved with improving health outcomes. Three common responses emerged, improving the patient experience, improvement efforts, and improvement examples including cleanliness and noise initiatives.

Participants (P2, P3, P5, P9, P11, P12, P13, P15, and P16) identified ways of improving the patient's experience. P3 discussed how the patient family advisory councils bring together "families and patients with professionals" as a group to improve the "varying experiences." P5 stated the "overall quality of service to patients and families. That there is a positive experience for people." P15 discussed the importance of having "a good relationship between hospital staff and patients who are in the hospital." P2 expressed "comfort outcomes, not to be scared of being in the hospital" especially for elderly patients. P11 stated,

> Your focused on how can you make that experience the best it can be whether that's wayfinding, whether that's connecting them with the right people, whether it just a listening you know maybe even a possible compliant kind of thing, not necessarily saying you know we see it we hear it we feel it but your saying you know what emphatically we know what you are saying.

P9 explained "we're trying to make it better for everybody" while P13 stated, "Better health, better health for all of us." P12 stated,

> If you look at the big picture the fact that we have been on for a number of years, one of the most gratifying thing is some of the things we talked about a very long time ago years ago are now being implemented and its extremely rewarding…To have the patients and the families have the best experience possible while they're under our care…So in the meantime I think the culture of welcoming and caring and trying to focus on the patient and the family and how we can best make their experience one that they want to come back and they feel confident that they're

> going to be well taken care ….So I guess for me I would like to believe that the impact that has been made with the doctors and the leadership staff understands there's a bigger role than just a patient walking through the door, you're diagnosing what you think is wrong with them and sending them back out the door kind of scenario. Versus the person coming in describing to you and the dialogue that takes place to make sure that you identify as best as you can with what's wrong with me or if there's nothing wrong kind of thing. I guess my hope for the future that becomes a major part of this.

P14 discussed ways to improve health outcomes for "Healthy mom, healthy baby." P16 discussed the topic of wellness, "People come to the medical center to be treated for something specific, but ideally we don't want to have them come back you know we want people to go and be well." P17 explained, "Just better care and good care." P19 stated "the overall best care for the patient involved and that's you know from the physical piece to the mental piece you know to the entire whole."

Participants (P1, P5, P6, P7, P8, P11, P14, P16 and P18) discussed ways in which the patient family advisory councils have helped to create improvements throughout the organization based on patient advisors recommendations. P1 expressed,

> I expect my input, I expect to get good information and I expect our as a council our response to make a difference. I have the full expectation that if we are really adamant on something that there will be a change. And but as the council, we also realize the change has to come slowly, but we are always encouraged that there is change and it's a positive change going forward. It always seems to be the patient

> at the center. Which to me is the key…With a hope that this is going to make an impression and that this will help change things in the future, not for us but of the next patient and the next family and the next one and the next one. It's like paying it forward.

P5 discussed their role while volunteering at the hospital and feels the patient family advisory councils have helped create more awareness around "customer service and a connection." P16 expressed,

> I mean wellness it seems culturally wellness is very foundational here at the medical center you know I work here, I've been a patient here and I volunteer here and it's just all through out and so as I talked about earlier just wellness of the patient being so multidimensional and that patient support, work being important and being recognized and the realization that we need to support those who support the patient.

P6 stated the oncology patient family advisory council discussed ways to eliminate their problems during "the transition" of moving cancer patients from the old hospital to the new hospital. P8 expressed,

> The committee that I'm on…. that committee is the conduit for the emotional upkeep, the, you know, the, the support of, the support of the families and the patients. I also took, when I started volunteering, I took the position from early on that I was volunteering not just to help the patients and their families, but also to the staff. Because the staff, a lot of times, I can't understand why they would get weary.

P14 explained the maternity patient family advisory council worked on topics such as anxiety mapping,

> From the moment you're like Oh, I guess it's time to go to the hospital. To the time that you are being discharged, where are all the points that you might feel anxiety and how can we better communicate about that and how can we train our anesthesiologist staff or nursing staff or housekeeping staff? What are all the touch points?

Three of the 19 participants (P6, P7, and P18) shared examples of ongoing discussions around the topic of cleanliness at patient family advisory council meetings. P6 expressed remembering the topic of cleanliness being discussed frequently, “It seems like a no brainer, but apparently it is a struggle and we work on it.” P7 shared leadership has created a long-term focus on improving cleanliness and how staff can better communicate with patients so they have a better understanding of what has been cleaned. P18 expressed cleanliness was “a conscious initiative” and was also “impressed at the attention at a fairly little detail level to things being done the right way.”

Participants (P6, P11, and P18) discussed ways in which the patient family advisory councils have helped to encourage medical staff to help decrease the noise levels around the medical center with ongoing discussions within the patient family advisory councils. P18 shared having conversations with staff to as ways to be mindful of “noise levels in the hospital.”

P11 shared an example of initiatives regarding a restful design that evaluated alarms to see which alarms could be toned down to decrease the noise level of the overhead alarms as well as the mechanical aspect of placement of the alarms, "do they need to be there?" P6 stated, "Noise, quietness and when you to go to sleep, do you really need to have your blood pressure and all those things checked 8 times a night? Or in your situation or your condition would twice or once be enough?"

Theme 5: Patient/family advisor perceptions on elements of the patient-provider relationship

The fifth theme of responses surrounds factors patients want in a patient-provider relationship. Eight of the 19 participants (P2, P3, P5, P6, P7, P9, P15, and P18) describe their perceptions surrounding their relationships with providers, awareness surrounding MyChart, and challenges they have faced within the health care system. Participants (P3, P5, P7, P9 and P15) stated they value their relationship with health care providers. Participants value providers' professional opinion and validated the importance of establishing a relationship with the patient and family.

P7 described providers who attend the patient family advisory council as "compassionate." P9 stated**,** "Some things are new and are coming down the pipe so I want his opinion on it. I really value my doctor; he really values me because he knows I'm a self-advocate." P5 discussed the importance of providers communicating with patients and family members,

> When a patient or family member comes in, then how is that going to be different or better of an experience for them? I know its cliché, but I know communication

> always seems to be, you know, is key for a lot of things. And, just, people want to feel they're informed. And their questions are being answered, they know, they feel comfortable asking questions. They don't feel like they're being ignored and that whoever they see or wherever they go in the hospital, um, it's all a fairly positive experience.

P15 expressed, "They each have to understand where each other is coming from." P3 felt the patient family advisory council has helped enhance the patient-provider relationship**,**

> Especially at the level of being on a family care [patient family advisory council], and it might be somewhere embedded in there, but someone, I think it takes, for a lack of a better, it takes the awe, A-W-E, out of that is a doctor, oh, that is a nurse, oh, I don't know any better, oh I think it allows you to see them as a human being first, and the only reason that they're an expert is because they've studied that field. Well, I've got just as much invested in mine, it's just in a different area. So if you came into mine, you'd probably be, like. So I, I think to get a better understanding of, hey that is just a regular guy, too. And really, they're just human, and you can talk to them.

Participants (P2, P15, and P18) expressed the importance of having awareness of using MyChart and how this tool can better engage patients in their personalized health care. P2 mentioned how frustrating it can be when providers do not use MyChart messaging. P15 mentioned MyChart being discussed at a patient family advisory council and how they have become more familiar and engaged with the tool since being involved in the system-wide discussions. P18 discussed being involved as a partner research, a study surrounding MyChart Bedside for the inpatient settings.

Participants *(*P2, P6, and P9) identified potential challenges for patients in the health care system. P2 stated “the amount of time you have to wait to see a specialist” describing the wait time to be over three months. P6 identified challenges with providers not having the patients’ medical records and provided an example of a personal health care encounter, “And he messes up my meds, he says well it’s about time to, it’s about time to get you blood work done. I said I already had it sent to you by the internist.”

P9 discussed the topic of providers not spending enough time with the patient. “I did have a doctor by the way that I fired…That was not a good relationship, just couldn’t see eye to eye.” P2 stated a concern when scheduling appointments across multi-disciplinary teams. “I had to call four different ones to get the earliest one… I don’t think it’s necessary to make four different calls to find which location can see me the soonest.”

Summary

There are numerous factors which affect the translation of evidence to practice for management and health care professionals in the health care setting. The patient/family advisors perceptions surrounding patient and family engagement and patient family advisory councils present a method to include both health care consumers and professionals to better understand ways to improve the overall patient experience and the relationships between patients, providers, and medical staff. Although there is growing research in the field of patient family advisory councils and patient and family engagement, there still remain many gaps in the knowledge transfer to apply in clinical settings.

Viewed from a conceptual framework of the patient and family engagement from the health care consumers' perspective, certain findings emerged that confirmed and extended existing literature. The aim of this phenomenological study was to describe and interprets the patient/family advisors lived experiences with the complex phenomenon of implementing and sustaining patient family advisory councils within the inpatient and outpatient settings.

This was an attempt to better understand the nature of experiences patient/family advisors encounter working to help change future outcomes for patients and families. I assessed these experiences to be highly trustworthy based on my adherence to process, consistency of experiences across the group, and variability in my participant pool. The following chapter includes my interpretation of the findings of mu research, limitations to my study, recommendations for future work, and implications for positive social change and for practice.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this phenomenological study was to describe the lived experiences of patient/family advisors working within patient family advisory councils in an academic medical center in the Midwestern United States. I conducted this study to capture the voices of health care consumers and how they describe patient and family engagement both within their personal level of health care and within the organizational level working within various patient family advisory councils. This research helped me gain a better understanding of patient/family advisors' perceptions on elements of the patient experience as it relates to patient and family engagement.

I chose a hermeneutic approach and analyzed the data using an interpretive phenomenology-based study. I discovered the lived world experiences of patient/family advisors involved working with patient family advisory councils and their lived experiences of patient and family engagement. This enabled me to examine the patient family advisory council members lived experiences by highlighting the insights of their philosophies and reactions from their perception.

The purpose of this study was to describe common themes associated with patient and family engagement from the perspective patient/family advisors who represent the voice of health care consumers. I asked patient/family advisors to describe their personal health care experiences and how these experiences brought them to participate in the patient family advisory councils. I selected a qualitative phenomenological approach as the research method since it encompasses interrelationships.

In the following section, I discuss the findings, the limitations to the study, implications for further research and practice, implications for positive social change, methodological, theoretical and empirical implications, and recommendations for practice.

Interpretation of Findings

The findings of the study showed that patient and family engagement is still an evolving concept in health care. I investigated the experiences of patient/family advisors working on patient family advisory councils with health care professionals in the hospital setting using phenomenology as the methodology. This research approach confirmed even though patient/family advisors may have some similar experiences to participating in patient family advisory councils, they too have unique individual experiences worth further investigating.

The main themes developed with the data analysis from the interview data have shown similar commonalities among current research on patient family engagement and patient family advisory councils. The distinctions of the patient/family advisors experiences transpired when comparing and contrasting their experiences to those found in current research. There were five major themes that are discussed further below.

Theme 1: Patient/family advisors' descriptions of patient and family engagement within the patient family advisory councils

Theme 2: Organizational efforts most meaningful to patient/family advisors

Theme 3: Patient/family advisors' perceptions since working on a patient family advisory council

Theme 4: Patient family advisory council efforts to change health outcomes for future patients and families

Theme 5: Patient/family advisors' perceptions on elements of the patient experience

Theme 1: Patient/family advisors' descriptions of patient and family engagement within the patient family advisory councils

The first theme of the study confirmed participant's views on patient and family engagement and the significance of patient and family engagement within the patient family advisory councils. There were three common categories noted from the patient/family advisors. A first common category of responses described patient and family engagement within the patient family advisory councils. Participants recognized patients and families value the approach in which they receive feedback from the patient family advisory council. Examples include ways in which leadership and management actively listens to the patient/family advisors' concerns, the ability to give advice, and encourages understanding between patients, families, and staff.

The second common category of responses discussed the topic of communication. Participants acknowledged communication as a vital component of being engaged within their personalized health care. Participants discussed ways in which the patient family advisory councils have helped them become more comfortable communicating with providers. Communication is an important factor to improving health outcomes for future patient and families. When communication occurs, patient/family advisors felt they were more engaged in their health care and it is easier to ask questions.

The third common category of responses confirmed the importance of including the family, caregivers or friends within the patient-provider relationship. Participants shared the importance of having others involved in the patient provider relationship. Some patients rely on others to help with the provider encounter. Whether the patient encounter be a regularly scheduled appointment or a life threating situation, participants valued having family, caregivers, or friends involved.

The first theme confirmed the importance that patient/family advisors placed on patient and family engagement. It signified that the participants have understanding about the phenomenon. This finding indicates the need to improve the knowledge surrounding patient/family advisors, patient and family engagement, and patient family advisory councils, including evidence translation, tools, and frameworks. Medical knowledge from patients and family members may be limited and patients likely trust safety protocols will safeguard them from injury (Berman, 2016). Similar to this research, Peikes et al. (2016) confirmed patient family advisory council members' participation varied with providing feedback.

These common categories are supported in the literature. For example, communication was found to be a critical component of the patient family advisory councils and the patient-provider relationship. The quality or types of communication can be a helpful lens for understanding the extent in which patients and families want to be engaged in their personalized health care (Cene, Johnson, Wells, Baker, & Turchi, 2016). Some council members were described as active participants within the patient family advisory council meetings while other members stated they were not as comfortable expressing their complaints or concerns in front of medical staff (Peikes et al., 2016).

Peikes et al. (2016) discussed how patient family advisory council members rely on the medical staff to set the meeting agenda and tone of the council. They found that patient family advisory council members may be concerned about making unreasonable demands and try to avoid burdening the medical staff. Patients and families prefer experiences that are pleasant, comfortable, and respect their time (Berman, 2016). Patients and families want to be respected and listened to as an individual, not just patient number 12 (Berman, 2016).

Theme 2: Organizational efforts most meaningful to patient/family advisors

The second theme of responses confirmed provider and organizational efforts that were most meaningful to patient/family advisors. Examples of provider behaviors that support patient and family engagement include the importance of involving the family and/or caregiver, creating clear communication with patients, and recognizing the different levels of engagement patients may have. Examples of organizational efforts that support patient and family engagement include giving patient/family advisors the opportunity to bring up topics for the patient family advisory councils, creating a team emphasized culture, and helping to enhance the quality of care.

According to Swartwout, Drenkard, McGuinn, Grant, and El-Zein (2016), this theme articulates the necessity of a harmonizing shift in thinking how the role of the provider affects the patient’s health care journey for both provider and institutional efforts. Instead of the provider serving only as the expert clinician of care, a new role of advocate, partner, navigator, and coach is warranted (Swartwout et al., 2016). Swartwout et al. identified key behaviors for providers to embrace effective collaboration, team work, communicate with respect to guarantee the patient is the center care, and participate in the exchanges of information with patients.

To be able to completely incorporate these changes into practice, these competencies should be considered within the design of health care systems (Swartwout et al., 2016). Health care professionals should consider everyone involved, counting the patient as an equal partner in care by including the patient as a respected team member (Swartwout et al., 2016).

Theme 3: Patient/family advisors' perceptions since working on a patient family advisory council

The third theme confirmed changes in patient/family advisors' personal perceptions of health care since being a member of the patient family advisory council. Three common categories of responses emerged: participants acknowledged being more aware how health care works, having better sense of empowerment with their patient-provider relationship, and identifying the patient family advisory council as a resource.

A first common category of responses confirmed how the patient family advisory councils have helped participants to gain a better appreciation and understanding of the culture and daily operations of the organization as a whole. They felt better able to navigate the system themselves as well as to provide guidance and support to others.

In the second common category of responses, participants discussed the having a better sense of empowerment. Patient/family advisors feel more comfortable engaging with their personal patient-provider encounters since working on the patient family advisory councils. Participants also acknowledged the patient family advisory councils have made them more aware of how health care works and with the changes occurring within the health care system. Participants expressed the patient family advisory councils have helped to create a positive impact culturally on the patient-provider relationship.

In the third common category of responses, participants identified having the patient family advisory council as a resource. By participating on patient family advisory councils, patient/family advisors often have more resources available for their health care. This finding highlights the importance of health care institutions in supporting patients, families, and communities with improved health care to create partnerships with patients and families.

Partnerships between healthcare systems and patient family advisory councils can range from restructuring and planning to providing services and assessing overall health outcomes (Linblad et al., 2017). Overcoming the challenges of health care can be accomplished by creating a culture surrounded by a shared understanding of what still needs to be improved and how health care services can be utilized to positively influence and improve health outcomes (Linblad et al., 2017).

Theme 4: Patient family advisory council efforts to change health outcomes for future patients and families

The fourth theme illustrated the importance of the patient family advisory council efforts to improve health outcomes for future patients and families. This theme confirmed the relationship between leadership styles and focus on improvement efforts. For example, transformation and transactional leaders sought to make improvements within the organization, servant leaders helped to focus on the patient experience, and the leader-member exchange was incorporated as a way to hear the patient's voice.

Three common concepts emerged in this theme: participants viewed the role of the patient and family advisory council as a means to improve the patient experience, ways in which improvement efforts could improve health outcomes and examples of improvement initiatives in which participants had been involved. The first set of common responses from participants included patient family advisory council goals as a way to help the patient experience. Patient/family advisors discussed ways in which they have a better understanding of the health system and they also see themselves as self-advocates.

The second set of common responses, participants discussed how the patient family advisory councils have helped to improve health outcomes shows there has been somewhat of a positive impact on the advisor within their own personalized health care. The third theme of common responses, patient family advisory council actions and improvement examples, patient/family advisors gave real world examples of ways the patient family advisory council has helped create improvements within the organization.

For example, patient/family advisors have helped develop a new cancer hospital from being included in the blue print stages of the hospital design, to taking tours of the building while under construction, and helping move cancer patients into the new building on opening day. Patient/family advisors discussed ways they have been involved with MyChart Bedside, a research study that involved some of the patient/family advisors of the medical center. MyChart Bedside is a tablet-based application that was developed as a way to engage patients in their medical care. Cene et al. (2016) noted online portals and personal health records have also been used as tools to foster patient and family engagement.

The fourth theme confirmed the results of the patient family advisory councils have helped changed health outcomes for future patients and families. I was able to incorporate the thoughts pertaining to the impact on the patient/family advisors' personal experiences, hospital leadership and the patient family advisory councils.

Transformational and transactional leadership styles were discussed goals of the patient family advisory council as ways to improve experience and health outcomes throughout the medical center. Servant leadership was recognized as a way to focus on the overall patient experience and the impact it patient family advisory council has had on each individual patient family advisor. Leader-member exchange was associated with communication whereby since working within the patient family advisory councils, patient/family advisors have felt more engaged in their own health care and they found it easier to ask questions to provider and medical staff.

The patient family advisory councils have been a tool in which the patient/family advisors' voices have been seen as a way for the medical center leadership to create positive changes and health outcomes for future patients and families. Bogue and Mohr (2017) discussed metrics used to assess advancement toward the aim of improving communication between the health care professionals, patients, and families. Bogue and Mohr provided an example of how improved communication with family involvement helped to reduce the length of a hospital stay by one day and also cut costs associated with the length of stay in the PICU at Riley Hospital for Children (Bogue & Mohr, 2017).

Theme 5: Patient/family advisors' perceptions on elements of the patient experience

The fifth theme identified patient/family advisors' perceptions about important elements of the patient experience, including factors patients want in a patient-provider relationship. Patient/family advisors stated it is important to for providers to show attributes such as compassion and empathy, they value their provider's professional opinion while they also encourage a relationship with the family. An additional subtheme identified challenges for patients in health care systems. Patient/family advisors discussed challenges such as the wait time to see a specialist, scheduling appointments across multi-disciplinary teams, and creating awareness regarding the tool MyChart.

Patient/family advisors also expressed the importance of training and engaging staff to know the importance of having the patient-provider relationship. Providers are trained to solve problems independently and quickly and may find collaborating with patients and families challenging (Cunningham & Walton, 2016). It is important to help health care providers understand collaborating with patient/family advisors can help to improve the patient and family experience.

Berman (2016) research involved the viewpoint of being a long-term patient and the importance of having a relationship with the health care staff. Berman further explained when the health care team shows characteristics such as respect and compassion, it is easier for patients to form a personal connection or bond. Increased literature publications support the valuable role families play in health care (Cene et al., 2016).

Many of times, family members will go with patients to medical visits and will participate in the medical visit by communicating with the provider and are specific ways families demonstrate (Cene et al., 2016). Some studies have associated family accompaniment with increased patient satisfaction with the care and counseling they receive from health care providers (Cene et al., 2016). Furthermore, patient family advisory council members identified challenges for patients within health care systems.

Berman (2016) identified challenges such as wait times, poor interpersonal skills of staff, poor communication regarding wait times, and a lack of customer service when scheduling appointments or having to leave voice messages. Lack of communication and/or poor communication skills can leave patients feeling frustrated and dissatisfied with their care (Berman, 2016). Berman (2016) and Peikes et al. (2016) verified this finding by sharing, majority patients have said the wait times are directly tied to patient satisfaction and the overall patient experience.

Patient family advisory council discussions about wait times have included topics about how long it takes for patients to secure appointments and how long it can take to see the doctor once in the office or exam room, and how long it can take to learn about test results (Peikes et al., 2016). Berman (2016) pointed out understaffed offices can have adverse effects on the overall patient experience. Understaffing can cause many problems with the office flow, while short staffing can lead to employee burnout which can directly affect the patient experience and potentially patient safety (Berman, 2016).

Limitations of the Study

The limitations to this study were minor. My process followed closely to all of the intended procedures as outlined in Chapter 1 of my proposal. I did not have to deviate from the original proposed plan to accomplish trustworthiness of the study. One limitation was the result of having a small sample size. Another limitation for patient/family advisor involvement in general is the issue of recruiting and facilitating involvement participants who represent the vulnerable populations, and variety participants who represent different levels of socio-economic status (Tapp, Derkowski, Calvert, Welch, & Spencer, 2017). Including patient/family advisors from a variety of backgrounds is important to consider, researchers should have patients who represent the vulnerable populations their study hopes to address (Tapp et al., 2017).

As is the case in qualitative research of this type, generalizing from this study could be challenging (Arieli & Tamir, 2018). Additional research should be carried out on other social, ethnic and national groups to learn the extent to which this study's findings are related to the organizational setting or the cultural experiences of the participants, and whether they are applicable to individuals from other groups and other health care organizations (Arieli & Tamir, 2018). This study only represents the patient/family advisors perspectives and does not capture the perspective of health care professionals. Future research is needed to involve health care staff, managers, leaders, and professionals (Arieli & Tamir, 2018).

Saturation was accomplished and helped to confirm the trustworthiness of this study. Although my sample did not include multiple organizations and patient family advisory councils outside of the medical center, sufficient data is supported or is available for anyone using this research to decide if the transferability of this study is applicable to their personal use. Another limitation was the lack of newer (PFEAP) participants. The average length of patient family advisory council membership was three years.

My study did not include many experiences of patient/family advisors with less than one year of experience being a patient family advisory council member. Patient/family advisors with less experience participating in patient family advisory councils may have the opportunity to learn from more experienced patient/family advisors and the experience of these newer patient/family advisors may be also transferable to their own personal health care experiences.

Recommendations

This study suggests several approaches for further research as well as recommendations for healthcare systems. This study included just one healthcare system. Future studies could expand the number of healthcare systems and include additional perspectives from healthcare system leaders to provide a deeper understanding of this topic. A review of the literature reinforces patients and families are powerful partners to change and evaluate the delivery of health care services (Cunningham & Walton, 2016). Peikes et al. (2016) study confirmed patient family advisory councils can be used as an essential tool for health care organizations and practices to involve patients and families in improvement efforts surrounding the delivery of health care to meet the needs of future patients and families.

Furthermore, Peikes et al. (2016) explained patient family advisory councils may also provide health care professionals with ways to gain a deeper understanding into issues at hand and get immediate, open-ended responses and feedback covering a variety of topics relating to the patient experience and ways to improve it. Using the Hibbard and Green model, additional research could seek to understand how patient and family advisory councils can best fit into the engagement continuum. For example, this research could also expand the awareness surrounding best practices of patient and family engagement to help health care professionals, patients, families, caregivers, and communities. Existing research often takes the clinical perspective of patient and family engagement and may have several disadvantages.

Studies do not discuss how health care consumers discuss patient and family engagement and what that looks like with the care continuum model by Hibbard et al. (2013). Looking at patient and family engagement from the individual level to the organizational level, Johnson et al. (2016) explained the outpatient settings otherwise known as ambulatory care that are currently creating partnerships with patients and family members in quality improvement efforts have reported positive benefits such as patient empowerment and better interactions with patients, families, staff, and providers.

Patients and families fill distinctive roles within the continuum of partnership, driven by the nature of required involvement of the organization (Haines, Kelly, Fitzgerald, Skinner, & Iwashyna, 2017). Three levels of partnership can be distinguished, transactional, transitional, and transformational engagement (Haines et al., 2017). One particular example of transitional partnership is seeking user insights regarding processes of care (Haines et al., 2017). Patient and family engagement needs to be genuine, ensure powerful and constructive voices are represented, and representation of the local population to avoid tokenistic engagement (Haines et al., 2017).

Engaging consumers who have had positive experiences compared to engaging consumers who have had negative experiences can be challenging (Haines et al., 2017). Health care consumers who have had negative experiences may present valuable insights resulting in greater opportunities for innovation and improvement (Haines et al., 2017). Future research could also explore the impact of patient family advisory councils on quality improvement efforts in the inpatient and ambulatory settings. Creating potential patient/family quality improvement partnerships within the ambulatory care settings is lacking in a research focus and could improve our understanding of how best to leverage such partnerships (Johnson et al., 2016).

Other studies discussed how strategic organizational advantages can be gained by working alongside patient/family advisors and patient family advisory councils to have better communications with providers and organizational managers and leaders. As patient family advisory councils in ambulatory settings continue to grow, this research could examine any strategic advantages through the enabling of a growing patient family advisory council programs. Taking what we have learned from the from hospital or inpatient setting and expanding the patient family advisory councils into ambulatory or outpatient settings can help create mechanisms to help identify challenges, improve outcomes with the cultural transformation for practice redesign (Johnson et al., 2016).

Finally, scholarly literature confirmed there is a national effort forming to expand patient family advisory council cohorts, demonstrating the achievability of patient and family engagement even with the sickest patients in hospitals (Haines et al., 2017). Although patient and family engagement can be a challenging undertaking, there are many opportunities to seek meaningful engagement strategies that can lead to transformative change in the way organizations establish their practice and educational activities (Haines et al., 2017). Health care staff must be willing, open, and committed to seeking opportunities for partnership in order to make continued improvements based on the perspectives of patients and families (Haines et al., 2017).

Recommendations for healthcare systems

When forming a patient family advisory council, it is vital to create processes and procedures to reach out to diverse patients and families, involve more than one patient and family member of different gender, age, socioeconomic status, and health care experience to enhance the diversity of viewpoints (Haines et al., 2017). It is important to manage and recognize barriers such as financial limitations, the inability to get time away from work, non-English speaking backgrounds, and caregiving responsibilities (Haines et al., 2017). Patients and families schedules are different than clinician's schedules and needs to be considered when scheduling patient family advisory council meetings.

For example, if the patients and families have caregiving or work related responsibilities, these need to be considered the same as not scheduling a meeting with a surgeon while in surgery. Efforts should be made to pay for parking; otherwise this could be a barrier to participating. Patients and families want to know that action is being taken based on their participation (Haines et al., 2017). For example, if asked to review patient and family information for usability, participation may only be meaningful to patient family advisory council members if their feedback is incorporated into the changes and they are made aware of the modifications (Haines et al., 2017).

Practice challenges can include the uncertainty of patient partnerships as well as staff and organizational uncertainty about how to include patients and families with quality improvement efforts (Johnson et al., 2016). Practices may have concerns about ensuring representative voices and burdening patients (Johnson et al., 2016). Challenges to include patient/family advisors are increased with the increased requirements in health care, whereby clinics and practices may not even consider patient partnerships as a goal due to the lack of limited resources (Johnson et al., 2016).

Opportunities to help enhance clinical partnerships with patients and families within ambulatory setting largely depend on the efforts made by the organization. Providing orientation to patient/family advisors can help organizations identify guidelines for engagement while creating awareness of valuing these partnerships with shared purpose can help patient/family advisors feel valued and involved (Johnson et al., 2016).

Addressing ground rules and confidentiality with patient/family advisors supports trusted communication with a productive and open discussion (Johnson et al., 2016).

Implications

Despite the theoretical importance of patient and family engagement and policy recommendations that patient and family engagement occurs within all levels across the health care system, there is a lack of evidence supporting the effectiveness with quality improvement efforts (Cene et al., 2016). Studies have shown there are many advantages of researching to understand the implications and importance of engaging patients in their personalized health care to help improve health outcomes, costs, and quality (Kohler et al., 2017). Some health care organizations struggle when finding ways to be more engaging with patients and families.

Numerous shifts in health care academia need to take place to transform the educational system to focus more on patient and family engagement strategies and techniques such as incorporating patients and families into the expansion of health education (Swartwout et al., 2016). A shift within the health care organization is required to ensure patients and families will be more engaged in their decision-making capabilities about their personalized health care (Kohler et al., 2017). Creating curriculum for inter-professionals in health care could help teach the importance of engaging patients and families, using the approach for coordinating care of patients by a collaborative team of health care providers (Swartwout et al., 2016). This may be applicable for pre-licensure, graduate programs, and ongoing continuing education (Swartwout et al., 2016).

Positive Social Change on the Individual Level

This study could create positive social change on the individual level by disseminating information from this study to help other patient/family advisors, patient family advisory councils, and organizations reflect upon their own experiences. Benefits to individuals and families show they are more engaged in their personalized health care after being involved or participating on a patient family advisory council. Working with patient family advisory councils has shown to help improve the overall patient experience, patient satisfaction, and has been found to build trusting partnerships between patients, families, and health care professionals.

This study helps to create a better understanding of health care consumer perspective regarding patient and family engagement. This research can be used as a resource or tool for patients, families, organizations, and society. As previously indicated, newer patient and family engagement managers, leaders, and professionals could also benefit from the research findings in this study. Finucane et al. (2018) argued patient stories frequently have increased validity because the patient’s voice and experiences are portrayed as more engaging and holistic approaches to patient and family engagement.

Positive Social Change on the Family Level

Positive social change on the family level expresses the importance of communication with the patient and family. Involving the family in the communication process and making resources readily available to help the patient and family can create better health outcomes and also improve health care experiences. This provides better family relationships with providers and organizations creating more trusting relationships and the eagerness of patients understanding how to better engage in their health care and benefits both the organization and the consumers of health care. Having the opportunity to fully implement family centered care can help organizations to enhance family integrated care. Studies have shown fully supported and integrated families can help with quality improvement efforts (Celenza, Zayack, Buss-Frank, & Horbar, 2017).

Positive Social Changes on the Organization Level

Patient and family engagement in practice improvement can involve providing feedback through focus groups or surveys, participating in quality improvement activities, patient family advisory councils, or practice redesign (Cene et al., 2016). Organizations can better understand the patient experience firsthand and how they can improve by gaining knowledge from the patient/family advisors of how they view patient and family engagement within the health care system (Bookout, Staffileno, & Budzinsky, 2016). Furthermore, partnering with patient/family advisors and patient family advisory councils has created an understanding to the perceptions and delivery of care which have been related to positively improving outcomes (Bookout et al., 2016).

Bookout et al. (2016) also argued this process can motivate health care professionals to consider patients individual preferences while putting patients and their families in the center of the delivery of health care. To ensure further progress, it is also beneficial to include education on these topics continues to reach across the educational continuum – from health care undergraduate students to medical residents, to health care providers and physicians (Jirasevijinda, 2017). Health care professionals can create a partnership that effectively serves to improve health care experiences of patients and their families (Celenza et al., 2017).

Positive Social Change on the Society/Policy Level

One of the major benefits of creating a patient family advisory council is to improve health outcomes and the patient experience for individual organizations and communities. When evaluating positive social change within societies and creating policies, these can happen within the boundaries of individual organizations. Health care is a diverse and ever evolving field, using the patient's voice to share research findings at conferences allowing disseminating research findings to the broader community as a whole.

Including patients and their families on decisions surrounding health care has created an important focus on patient and family engagement and patient and family centered care. Patients have assumed responsibility for engagement and their efforts to contribute toward shared decision making, health care delivery and policy reform, and the increased awareness of established guidelines for clinical practice (Duffett, 2017). Acknowledging the patient and family perspective has been associated with positive clinical outcomes (Duffett, 2017).

Meaningful and active engagement with patients, their families, and caregivers combined with health research has shown health care consumers have an abundance of information and knowledge stemming from personal experiences such as living with a chronic medical condition (Duffett, 2017). There is quite more to learn surrounding best practices for patient and family engagement and the impact it has on scholarly research

(Duffett, 2017). By appreciating and considering the experiences of patients and families, initial outcomes are favorable while future research may increase the overall acceptance of patient and family engagement (Duffett, 2017).

The development of theory with patient and family engagement in health care may progress with the increased understanding (Higgins, Larson, & Schnall, 2017). The notion of patient and family engagement may also help to develop curriculum for health care professionals about the actions and behaviors that may help teach patients how to manage their personalized health care needs (Higgins et al., 2017). Furthermore, the practice, policy, and theory behind executing patient and family engagement within health care institutions deserves acknowledgement (Higgins et al., 2017).

Methodological, Theoretical, and Empirical Findings

The methodological findings from this research shows patient family engagement within patient family advisory councils creates a distinctive relational and situational context for leaders and managers, confirming that relationships exists between patient family advisory councils and health care professionals alike which is credible acknowledgement for future research. For example, my research participants shared numerous experiences which are consistent with existing research on patient family engagement, patient/family advisors and patient family advisory councils.

Expanding the knowledge in the area of patient and family engagement and patient family advisory council s could focus on how professional relationships change when working with patient/family advisors and patient family advisory councils. Furthermore, health care workers can learn how to adopt best practices for patient and family engagement when working with patient/family advisors and patient family advisory councils. Improving the communication skills of health care professionals between patients and families could help resolve challenges with the patient populations at large.

Recommendations for Practice

Recommendations for practice include recognizing the importance of the patient-provider relationship. Patient/family advisors valued the professional opinion of their provider, they encourage compassion and empathy from all health care workers, and they value the family relationships with providers and health recommendations. The second recommendation would be to acknowledge challenges patient/family advisors have encountered in the practice setting. Patient/family advisors have expressed the concern for the wait time for specialists, often having to wait three to six months to see a specialist. Scheduling appointments across multi-disciplinary teams can be very challenging and overwhelming for patients to do on their own, and creating awareness of MyChart.

As health care organizations seek new ways to enhance the patient experience, patient family advisory councils have been utilized as an influential approach or fundamental strategy to creating a culture that values patient-and-family-centered care (Cunningham & Walton, 2016). Patient family advisory councils have emerged as an effective strategy to help create culture change and quality improvements within organizations (Cunningham & Walton, 2016). The patient voice is fundamental to improving the experiences of health care and can help organizations such as hospitals, primary care, and private practices enhance patient satisfaction, safety, health outcomes, and quality of care (Cunningham & Walton, 2016). Integrating patient family advisory councils into the organizational culture can create new opportunities for communication among patients, providers, families (Cunningham & Walton, 2016).

Conclusions

As health care continues to develop, patient and family engagement techniques continue to evolve, constructing this study on patient/family advisors and patient family advisory councils is timely and pertinent. This phenomenological study of patient and family engagement has shaped a body of knowledge regarding the experiences of patient/family advisors and patient family advisory councils which can be utilized for further research and understanding of this topic. This research presented the experiences of patient/family advisors, working on patient family advisory councils with health care professionals, providers, managers, and leaders and signals the unique experiences of these individuals which warrant additional investigation.

In addition to researching the individual experiences of patient/family advisors and their perceptions with patient family advisory councils and medical staff, incorporating best practices from the patient and family perspective might inform health care organizations on ways to improve the overall patient experience with patient/family advisors and patient family advisory councils. There is a further need for a meaningful discussion concerning the distinctive ways doctors, providers and patients perceive the importance and meaning of medical encounters and patient and family engagement strategies (Arieli & Tamir, 2018).

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Appendix A: Recruitment Letter and Screening Criteria

Subject: Invitation to participate in a study of patient/ family advisors

Dear patient/family advisor,

I am conducting a research study to for my doctoral dissertation to understand the experiences and thoughts of Patient/family advisors on the topic of patient/family advisors participating in advisory councils and how it relates to patient and family engagement. Patient and family engagement specifically identifies with the patient's and caregivers experiences, describing the importance of patients and families being actively involved in the process of their care.

As a patient/family advisor, you have been selected to participate in this study. There will be two phases to this research study. The first phase will involve 6-7 participants. The second phase will include an additional 20 participants. To be considered for this study, you must meet a set of inclusion criteria below. I am specifically looking for Patient/family advisors who meet these criteria:

- Who are at least18 years of age
- Have participated in a patient family advisory council within the last 12 months
- Are aged 75 and under
- Use English as primary language
- Are not pregnant
- Free from mental/emotional disabilities
- Are not considered economically disadvantaged
- Does not live in a long-term care facility like assisted living or a nursing home

Your participation is voluntary. A decision not to participate will not affect your medical care or your standing with the Patient and Family Experience Advisor Program or [redacted] or its affiliates. You may skip any questions you do not feel comfortable answering. Your responses will be anonymous and available only to the research team. Only aggregate results will be analyzed, summarized and presented in any reports from this study.

If you have any questions about this project, please contact [redacted]. For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact [redacted].

To participate, please contact [redacted]so you can set up a time to meet face-to-face. The interview will last between 60-90 minutes and will be held at a room within the [redacted]. To compensate you for your time and effort, you will receive a $5 gift card to Starbucks or Wendy’s.

Thank You

Appendix B: Interview Questions

The central research question: How do patient/family advisors describe patient and family engagement?

1. What do you think it is meant by patient and family engagement?

2. What are the most important components of patient and family engagement?

3. What is the ultimate goal of patient and family engagement?

4. How, if at all, does patient and family engagement relate to patient-and family-centered care? Is it the same? Different?

(Sub Question 1): What has the organization done or asked patient/family advisors to be involved in that is most meaningful to patients and families?

5. How would you describe that state of patient and family engagement within the patient family advisory councils - where is it now and where does it need to go? What can be done to make it happen?

6. What behaviors have health care professionals shown to support patient and family engagement that were most meaningful to you?

7. What elements of organizational culture facilitated or challenged your personalized patient and family engagement? Hospital leadership? Policies procedures? Team work?

8. What resources were made available to you or your family member? (I.e. financial, staff expertise)?

(Sub Question 2): How have patient/family advisors perceptions of health care changed since working on patient family advisory councils?

9. What type of information (if any) from the patient family advisory councils has helped you to be more engaged in your own health care?

10. Do you feel more informed or more comfortable when participating in your personalized health care since working within a patient family advisory council?

(Sub Question 3): How can the results of the patient family advisory councils change health outcomes for patients and families?

11. What are your expected or hoped health outcomes through the patient family advisory councils?

12. What are the best ways to engage patients and families at the organizational level to transform patient family advisory councils? Who is the best person to deliver the information?

13. How can aspects of leadership bring patients, families, and health care professionals together around a common goal?

14. How can leadership be applied to transform the culture of patient and family engagement?

Appendix C: Interview Prompts

- What do you think it means for patients to participate or engage in their healthcare?
- What type of resources do you think patients need to help them engage in their healthcare?
- What would help patients feel confident bout engaging in their healthcare?
- What makes patients willing to engage in their healthcare?
- What types of capabilities do patients need to engage in their healthcare?
- What else do you think about when considering patients engaging in their healthcare?

Appendix D: Confidentiality Agreement

Dear Ms. Cortney Forward,

This letter is to formally acknowledge a formal confidentiality agreement made by [redacted] [redacted]. This confidentiality agreement recognizes all data must be kept confidential concerning the status of files generated by the service provided to you by [redacted] in transcribing xx minutes of audio materials (job number 122).

When in operation [redacted] policies are that all material related to a job is confidential and only made available to the client who arranged the work or to those the client designated in writing. Since closing its operations all records are in a secure archive and are subject to the university and units applicable records retention policy.

If I can be of further assistance please let me know.

[redacted]