

NURSE PERCEPTIONS OF ENGAGING LOW- INCOME DEPRESSED MOTHERS IN A  
MENTAL HEALTH INTERVENTION

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## **ABSTRACT**

**MAUREEN J. BAKER: Nurse Perceptions of Engaging Low-Income Depressed Mothers in a Mental Health Intervention**  
(Under the direction of Linda Beeber)

The U.S. health care system is in the midst of major transformation, requiring a shift from the traditional patient and provider roles to a more collaborative partnership. Patient engagement has been identified as both a goal and strategy to lower health care costs and improve health outcomes. However, there is a lack of consensus and clarity in identifying patient engagement as a concept, and more importantly, how the process of patient engagement occurs between patient and providers. For this reason, there is an urgent need to understand the underlying and crucial components of effective patient engagement to inform both patients and providers as to the expectations and responsibilities of their new relationship and roles as active collaborators in care.

A mixed methods exploratory design was used to gain a comprehensive understanding of patient engagement. Guided by the Interactive Care Model, a directed content analysis was used to analyze three hundred nursing narratives, written by advanced practice mental health nurses describing in detail how they engaged low-income depressed mothers in a mental health and parenting intervention. Quantitative analysis was then employed to examine how nursing engagement strategies were employed in the three phases of the nurse-mother interpersonal relationship and in response to various levels of mothers' engagement.

The Interactive Care Model was validated by the nursing narrative data and captured the process of patient engagement with a traditionally underserved population. The key process

components and partnership roles of the ICM were found to be fluid, dynamic, with different components operating at different intensities and frequencies depending upon the phase of the mother-nurse relationship and level of mother's engagement. Engagement skills and strategies were significantly limited when mothers were minimally engaged- underscoring the importance of the effort and time spent in the orientation phase to gain some degree of patient engagement. Demographic differences between the nurses and the mothers, built in power inequalities and dynamics, and reflective practice, were not addressed in the ICM and should be added to enrich the model and to enhance patient engagement.

Keywords: *directed content analysis, Interactive Care Model, patient engagement, patient centered care*

To Brian Baker

My husband, my best friend, my rock and tireless supporter- you are the definition of an honorable man. Thank you for your constant encouragement and patience. I could have never done this without you.

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My beloved parents who taught me to take one day at a time and have a little fun in the process

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## **LIST OF ABBREVIATIONS**

ANOVA	Analysis of Variance
ICM	Interactive Care Model
IPR	Interpersonal Relationship
PE	Patient Engagement
QSEN	Quality and Safety Education for Nurses Initiative
SDM	Shared Decision Making

## **CHAPTER 1**

### **INTRODUCTION AND CONCEPTUAL FRAMEWORK**

The U.S. health care system is in the midst of major transformation. The Patient Protection and Affordable Care Act (PPACA; 2010) is landmark legislation, passed with the intent to increase the quality, accessibility, and affordability of health care for all Americans (Blumenthal & Collins, 2014; Deville & Novick, 2011; Hofer, Abraham, & Moscovice, 2011; Huntington, Covington, Center, Covington, & Manchikanti, 2011; Oechsner & Schaler-Haynes, 2010; Rosenbaum, 2011). A cornerstone of the law is to improve access to quality health care for those populations who have been previously left out of the health care system (Koh & Sebilus, 2010; Somers, & Mahadevan, 2010). By proactively driving preventative health care out into communities, overall population health outcomes are expected to improve, and the unsustainable costs of the current system are projected to decrease (Axelrod, Millman, & Abecassis, 2010; Casey, D., Tully, K., & Michel, A. 2015; Shi & Singh, 2014). However, genuine transformation requires more than just policy changes from the top down (Dougherty & Conway, 2008; Hillestad et al., 2005). To change the current health care paradigm, and to realize the full intentions of the PPACA, care delivery at the direct care level must undergo its own fundamental metamorphosis (Leape et al., 2009).

One way of conceptualizing this fundamental change has been organized under the concept of patient engagement (Barello, Graffigna, Vegni & Bosio, 2014; Dentzer, 2013; Hibbard, Stickard, Mahoney & Tusler, 2004). Patient engagement refers to a collaborative



relationship between patients and health care providers, as they work together to promote and support active patient involvement in their health and health care (Coulter, 2011). Health care providers are well-known experts regarding diseases, treatments, and procedures. However, it is the patient who has intimate knowledge regarding their bodies, values, personal circumstances, and reality (Coulter, Parsons, & Askham, 2008). By partnering together, and by combining and balancing patients' and providers' individual knowledge and perspectives, patient care can be better planned and implemented (Conway et al., 2006).

For patients to actively engage in their health care, a fundamental shift in the traditional roles and relationships between patients and providers is necessary (Bernabeo & Holmboe, 2013; Carman et al., 2013; Coulter, 2012; Gruman et al., 2010; Ricciardi, Mostashari, Murphy, Daniel, & Siminerio, 2013). Health care providers need to shift from being sole decision makers and providers of care to *partners in care*. Providers need to transform the environment and employ strategies to facilitate patient's access, understanding, and use of existing services and tools to manage their illness (Barello, Graffigna, & Vegni, 2012; Frosch, May, Rendle, Tietbojl, & Elwin, 2012; Knox-Houtsinger, 2013). Likewise, patients will need to shift from being traditional recipients of care to becoming active and engaged members of the health care team and in the self-management of their health care (Drenkard, 2014).

Patient engagement has been touted as having considerable potential and promise (Laurence et al., 2014; Kisch, 2012). Patients who actively engage in their health and health care have better health care experiences, better health outcomes, and lower healthcare costs (Greener, Hibbard, Sacks, Overton, & Parrotta, 2015; Kidd, Lawrence, Booth, Rowat, & Russell, 2015; Hibbard & Greene, 2013; Koh, Brach, Harris & Parchman, 2013; Tzeng, 2014). Conversely, patients who are not actively engaged in their health care often have poorer health outcomes and

incur higher average health care costs (Agency for Healthcare Research and Quality, 2004, 2011; Hibbard, Greene, & Overton, 2013). Therefore, patient engagement is vital to the success of the PPACA, in reaching the triple aim of better patient care experiences, improved health outcomes, and containment of health care expenditures (Alliance for Health Reform, 2011; Barello, Graffigna & Vegni, 2012; Berwick, Nolan, & Whittington, 2008; Center for Advancing Health, 2010; Coulter, 2002; Crawford et al., 2002; Drenkard & Wright, 2014; Forbat et al., 2009).

However, there remains a substantial lack of consensus and conceptual clarity as to what patient engagement is, what the crucial components of patient engagement are, and most importantly, how the components of patient engagement are operationalized regarding patient-provider interpersonal relationships and interactions (Barrello et al., 2014). Furthermore, the PPACA has expanded health care access for approximately 32 million Americans, many who are low-income and historically underserved (Russell, 2014). Thus, now more than ever, there is an urgent need to understand the crucial, interpersonal, interactive process components of effective patient engagement within the patient-provider relationship at the direct care level. With this understanding, individuals previously left out of the health care system can be reached and connected with health care services. In understanding the essence of patient engagement, patients and providers can execute the behaviors that exemplify actively engaged partners in care. Moreover, knowledge about the process of patient engagement can direct health care dollars and efforts towards the provisions of more efficient and effective health care services.

The purpose of this study was to elucidate the process underlying patient engagement and to determine how the crucial components of patient engagement were operationalized in the patient-nurse interpersonal relationship and interactions with an underserved population using a pre-existing data set. This study explored and examined advanced practice nurses' perceptions of

the interpersonal skills and strategies used to engage low-income mothers with depressive symptoms in a mental health intervention. Specific engagement skills and strategies acted as the vehicle in which nurses gained entry, and established and maintained an interpersonal relationship with the mothers. The interpersonal relationship was critical to deliver the psycho-behavioral intervention in an attempt to improve mothers' depressive symptoms. Additionally, the study assessed the usefulness of the Interactive Care Model as a patient engagement framework. Outcomes from this study add to the limited body of knowledge on patient engagement practices by adding empirical evidence to support this new patient engagement framework in clinical practice with a historically challenging population. Outcomes from the analysis of the nursing narratives demonstrate what was captured by the ICM and what was not.

### **The Interactive Care Model**

Patient engagement is an evolving concept and dynamic process that is steeped in complexity (Barello, Graffigna, & Vegni, 2012; Gruman et al., 2010; Schoen et al., 2011). At the fundamental core of patient engagement is the provider-patient relationship (Beach & Inui, 2006; Drenkard, Swartout, Deyo, & O'Neil, 2015; Greene & Hibbard, 2012; Swartout Drenkard, McGuinn, Grant, & El-Zein, 2016). However, most of the existing patient engagement frameworks tend to focus heavily on the technological aspects of patient engagement or engagement at the organizational system and policy levels (Carman et al., 2013; Holden et al., 2013; Timbie, Damberg, Schneider, & Bell, 2012).

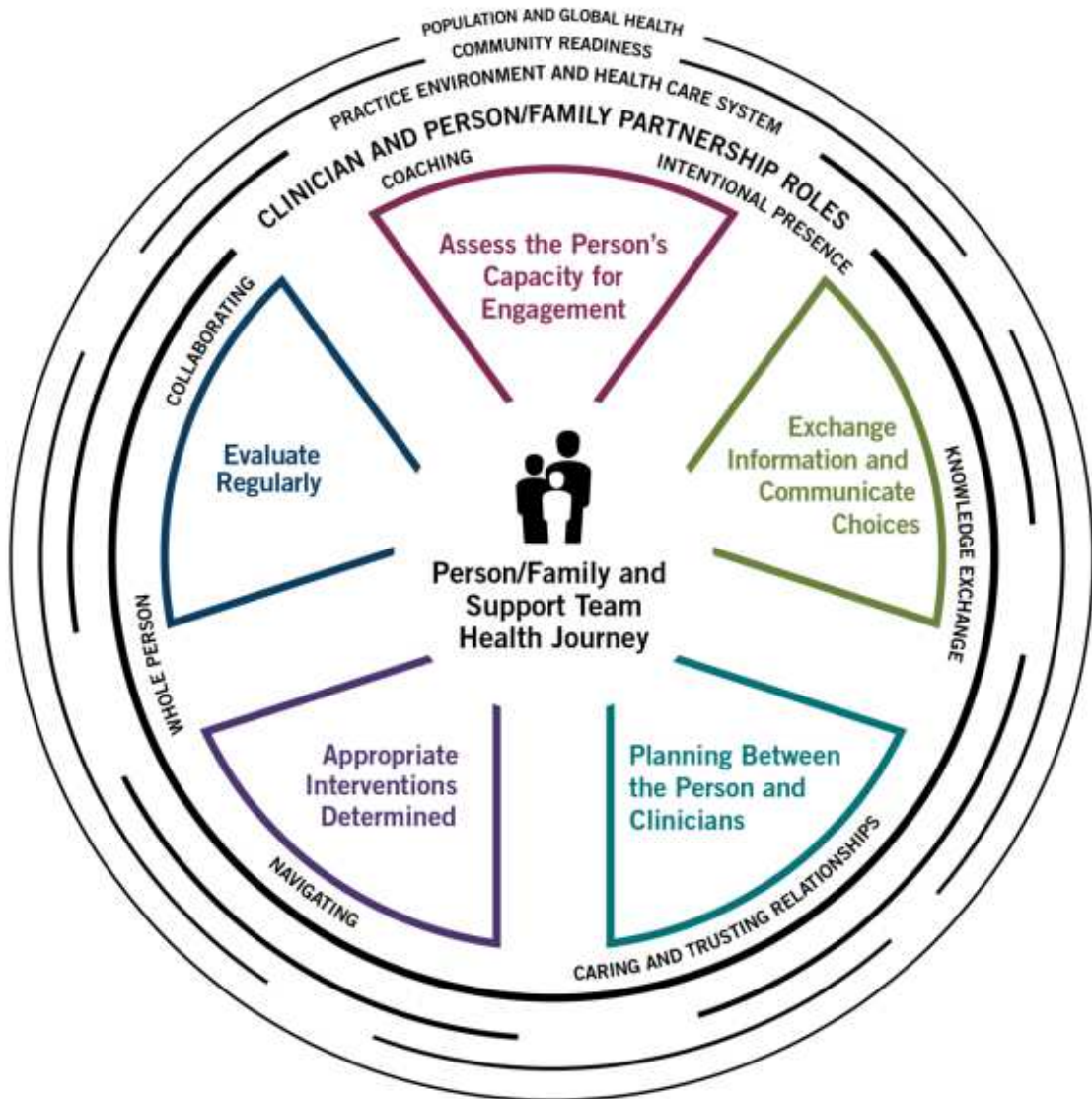
The Interactive Care Model (ICM; 2015) is a new patient engagement framework that addresses the fundamental and interpersonal interactions between patient and provider at the direct care level (Drenkard et al., 2015). Moreover, the ICM takes into account the changing roles of both patient and provide necessary for the PPACA goals to be realized (Bernabeo &

Holmboe, 2013; Drenkard et al., 2015). As a health care delivery process model, the ICM has great potential in capturing the essence of patient engagement at the direct care level. Applicable to all care settings and clinicians, the ICM outlines, describes and explains the interpersonal steps and strategies necessary to engage patients more fully in their healthcare management (Drenkard et al., 2015; Swartout et al., 2016).

The ICM is centered on the vital interpersonal relationship between person, family, and providers (Drenkard et al., 2015). Surrounding this fundamental core are five bi-directional key phases that demonstrate the interactions required for the patient and provider partnership to develop and for engagement to progress (i.e. assessing a person's capacity for engagement, exchanging information and communicating choices, planning between person and providers, determining appropriate interventions, and evaluating regularly; Drenkard et al., 2015; Swartout, 2016; Swartout, Drenkard, McGuinn, Grant & El Zein, 2016). Woven throughout these interactions and exchanges, are various partnership roles that help facilitate the engagement process (i.e. coaching, intentional presence, knowledge exchange, caring and trusting relationships, navigating, whole person, collaborating; Drenkard et al., 2015). Based upon systems theory, the ICM posits external influences in the broader practice environments (i.e. health care system, community resources and readiness, and population and global health) impact the person, family, and provider relationship (Drenkard et al., 2015). However, as important as the external influences, is the momentum for care transformation created at the direct care level via the interpersonal relationship between patient and provider, which has the great potential to ripple out and significantly impact the broader practice environments (Swartout et al., 2016).

The underlying drivers of the ICM are: patients' right to autonomy, financial reform, and communication between people and their care providers (Drenkard et al., 2015; Swartout et al., 2016). First and widely accepted, is the moral notion that each person has the right to be autonomous and self-directed (Kant, Wood, & Schneewind, 2002). Respecting the ethical principle of autonomy, patients make their own decisions about which health care interventions they will or will not receive (Drenkard et al., 2015; Entwistle, Carter, Cribb, & McCaffery, 2010). Patient education by the provider can inform and help patients arrive at their decision (i.e. shared decision-making) but in no way should the decision be coerced (Institute of Medicine, 2006). Second, as consumers of health care, patients can weigh the financial costs and benefits as to how to attain optimal health (Drenkard et al., 2015; Milenson & Macri, 2012). Patients report wanting to know information about their health cost data, and what their out of pocket expenses for the entire health care episode will entail, versus only the costs for specific procedures or services, or nothing at all (Drenkard et al., 2015; Yegian et al., 2013). Finally, communication and information exchange are quickly and continuously evolving. Thus, patients and families have an unprecedented opportunity to take an active role in accessing and monitoring their health information (Drenkard et al., 2015). See Figure 1 for the Interactive Care Model.

Figure 1.1 The Interactive Care Model



As mentioned, the five key encounters of the ICM are as follows: assessing a person's capacity for engagement, exchanging information, planning, determining interventions and regularly evaluating (Drenkard et al., 2015) and will now be discussed in more detail.

## **Five Key Processes of the Interactive Care Model**

The Interactive Care Model has five distinct key processes described as (a) assessing a persons capacity for engagement, (b) exchanging information and communication choices, (c) planning, (d) determining appropriate interventions, and (e) evaluate regularly. Drenkard et al., (2015) provided a thorough and systematic description of these processes and related engagement concepts. Each of these key processes are discussed, with specific reference to their meaning in patient engagement.

**Assessing a Person's Capacity For Engagement.** *"A holistic person engagement measure of the factors that influence a person's engagement in his or her health care"* (Drenkard et al., 2015, p.505). A comprehensive assessment of a person's capacity for engagement is the first step towards patient engagement (Cronenwett, Sherwood, & Gelmon, 2009; Drenkard et al., 2015; Swartout 2016). Eight domains that impact a person's capacity to engage include: preferences based upon cultural values, health literacy, activation/motivation, disease burden, psychosocial support, preventative health strategies, involvement in safety, and technology use for health care (Coulter, 2012; Drenkard et al., 2015; Gruman et al., 2010; Koh, Brach, Harris, & Parchman, 2013; 2012; Swartout, 2016; Wolever, 2011). Knowledge about each of these domains positions providers to meet patients where they are, regarding their health care management and sets a benchmark for where to begin the engagement, how to translate health care information, and how to proceed with future interactions (Dentzer, 2006; Drenkard, 2015). In assessing a person's capacity for engagement, interventions and education can be tailored to each patient for greater success in engaging them in their care (Hibbard & Greene, 2013; Titler, 2008). The Patient Engagement Index, a measurement of a person's level of engagement, desire and capacity to engage has been developed and is currently is being piloted

in several health care practices (O’Neil, personal communication May 23, 2016; Swartout, 2015).

Patients vary considerably regarding how much they are engaged in their health and health care (Hibbard & Cunningham, 2008; Tu & Hargraves, 2003). Patients often feel overwhelmed, especially when they lack having the knowledge or confidence in managing and navigating their journey within the health care system and thus, are often less engaged in their care (Dixon, Hibbard, & Tusler, 2009; Hibbard & Mahoney, 2010). According to the Center for Advancing Health (2010), two-thirds of all Americans describe themselves as having passive attitudes toward their own health and lack the necessary knowledge and self-confidence to actively participate in their healthcare journey. Likewise, in 2007, the Center for Studying Health System Change found 59% of the U.S. adult population lack some or most of the necessary knowledge, confidence, skill, ability, and/or willingness to be highly engaged in managing and navigating their health and health care (Hibbard & Cunningham, 2010; Tu & Hargraves, 2003).

Patient engagement relies on and begins with a patient’s ability to obtain, process, communicate and understand basic health information (Baker, 2006). Alarming, over a third of adults in the United States – approximately 77 million people- have difficulty with common health tasks like following directions on a prescription drug label, or adhering to an immunizations schedule using a standardized chart (e.g. health literacy; Gibbons, Lowry, & Quinn, 2011; Kutner et al., 2006). Therefore, assessing a person’s health literacy is a vital component of the key process of assessing a person’s capacity for engagement.

**Exchange Information and Communicate Choices.** *“Decisions are made based on the patient’s values, beliefs, and preferences with the use of decision aids”* (Cronenwett et al., 2009; Drenkard et al., 2015, p. 505). Although the providers have clinical knowledge and expertise, the



patient's knowledge of their values, care goals, preferences, and circumstances are what drive engagement (Drenkard, 2015; Swartout et al., 2016). A care partnership can develop when information is exchanged from the perspectives of both patient and provider, and choices are communicated considering the patient's values, beliefs, and preferences (Teutsch, 2003). From this exchange, providers can then tailor education, resources, care, and offer health care alternatives to fit the genuine needs of the individual. Shared decision-making is a collaborative process involving patient and providers making health care decisions together as they consider the best clinical evidence available, and the patient's values and preferences (Informed Medical Decisions Foundation, 2016; Stacey, et al., 2011). Shared decision making has been linked to patient's enhanced quality of life, reduced symptoms, and lower litigation rates (Hack, Degner, Watson, & Sinha, 2006; Hibbard & Greene, 2013; Legare et al., 2010; Kiesler & Auerbach, 2006)

Decision aids (i.e. educational booklets, skill sheets, DVDs, interactive tools) can help communicate health care information and help foster patient's better understanding of their condition, the associated risks, improve adherence to prescribed treatments, and improve self-care behaviors (Coulter, 2012; O'Connor, Légaré, & Stacey, 2003; Woolf et al., 2005). The use of such aids promotes a climate in which shared decision-making can transpire.

Positioning the patient at the center of care is highly consistent with the Quality and Safety Education for Nurses (QSEN) competencies. Patient centered care recognizes the patient as the source of control and as full partner in providing compassionate and coordinated care based on respect for patient's preferences, values, and needs (Cronenwett, Sherwood & Gelmon, 2007).

**Planning between People and Clinicians.** *“The person and clinician collaboratively develop a person-centered, holistic plan based on person-specific needs, preferences, and resources” (Drenkard et al., 2015, p. 505).* The ICM was designed to be a roadmap and guide for including patients and families in developing and setting mutually agreed upon goal and plans of care (Drenkard et al., 2015). Patients involved in the planning of their care, often gain a sense of accountability and engagement (Anderson & Funnell, 2010; Drenkard, 2015; Rutter, Manley, Weaver, Crawford, & Fulop, 2004). Understanding the whole patient and their reality, within the context of their living environment, support systems, daily routines, and expectations are critical to effective and sustained patient engagement (Drenkard et al., 2015; Wanless, 2004)

Providers consider the information gleaned from the previous process components (capacity to engage, health literacy, preferences, values, beliefs, circumstances, resources), and together, with the patient, determine mutually agreed upon goals and aspirations to create an effective health care management plan (Drenkard et al., 2015). When providers and patients take an aspiration-based approach, holistically considering the patient and their specific needs, care becomes patient-centered versus disease centered (Drenkard 2015; Gerteis, 2003; Reynolds, 2009). Research has shown patient-centered care improves health status, disease outcomes, and quality of life (Epstein, Fiscella, Lesser, & Stange, 2010; Oates & Weston, 2000).

**Determine Appropriate Interventions.** *“Jointly determine tools resources, education, technology, and support advance the person in their care journey” (Drenkard et al., 2015, p. 505).* Education is the foundational strategy to teach patients how to self-manage and enhance their health (Corbett, 1999; Drenkard et al., 2015; Herber, Schnepf, & Rieger, 2008; Ryan & Sawin, 2009). Tailored to the patients level of health literacy, engagement desire, and engagement readiness, patients are taught how to be proactive and engaged in managing their

health care, and in navigating the complex and at times overwhelming health care system (Drenkard et al., 2015; Gruman et al., 2010; Koh, Brach, Harris, & Parchamn, 2013). A proactive approach includes patients learning how to be engaged patients (i.e. identify health issues, knowing when to consult a provider, track medication usage, make appointments, join support groups; Rajibiun, 2007). Patient and providers jointly determine what tools, resources, education, technology, and support are needed to influence and advance the patient towards his healthcare self- management and attainment of their health care goals (Drenkard et al., 2015).

**Evaluate Regularly.** *“Continuous evaluation of patient’s engagement and clinical outcomes assists in further coaching the person to reach his ideal health” (Drenkard et al., 2015, p. 505).* Regular evaluations are essential to determine the effectiveness of care interventions (Campbell, Fitzpatrick, Haines, & Kinmonth, 2000). By evaluating the person’s engagement on a continuum, the most effective strategies for engagement and care can be determined (Drenkard et al., 2015) and least effective ones modified. Recurring evaluations of engagement and outcomes help the person and provider track success and modify interventions as needed (Reisinger, Bush, Colom, Agan & Battjes, 2003). Outcomes can be at the individual level (i.e. weight, blood pressure, depression score) or the system level (i.e. hospitalizations, emergency room visits, disease prevalence).

### **Seven Provider, Person-Family Partnership Roles**

In addition to the five key encounters, the ICM outlines seven partnership roles for the provider, person, and family that are necessary for genuine person and family centered care to transpire.

**Intentional presence.** Intentional presence means being emotionally present to another person, or being there by conveying availability and a willingness to share feelings

(Drenkard et al., 2015; Swanson, 1991). Intentional presence conveys to the patient and family that they are not alone, they have support, and that they are important (Drenkard et al., 2015, Watson, 2002). For person and provider, the simple act of genuinely being present, taking the time and attention to be fully aware and open to healing builds trust and sets the environment for open exchange of knowledge, information, and ideas (Drenkard et al., 2015; Watson, 2002).

**Knowledge exchange.** Knowledge exchange entails information collection between the clinician and patient, recognizing the valuable expertise of both (Drenkard, 2015). Both bring unique information and perspective to the interaction (Bensing, 2000). As such, clinicians bring expert clinical knowledge whereas patients bring the expertise in their symptoms, care goals, and reactions to current circumstances (Bernabeo & Holmboe, 2012; Drenakrd et al., 2015; Friedberg, van Busum, Wexler, Bowen, & Schneider, 2013). The level of knowledge and understanding patient's bring to interactions with providers can range from highly competent to completely unaware (Friedberg et al., 2013). Providers can help patients navigate through the knowledge exchange process by matching instruction with health literacy levels and describe the associated risks and benefits of the differing treatment and care options (Baker, 2006; Drenkard et al., 2015).

**Caring and Trusting Relationship.** A caring and trusting relationship between provider and patient sets the foundation for care transformation and patient self-management (Epstein et al., 2011; Hall, Dugan, Zheng, and & Mishra, 2001). A transpersonal relationship goes beyond the physical interaction in the clinical setting and addresses the person's physical, emotional, and spiritual needs to promote well-being (Drenkard et al., 2015; Watson, 2006). The absence or presence of trust in the patient-provider relationship can have significant consequences as a person who is trusting of a provider is more likely to seek care, comply with recommendations,

and return for follow-up versus an individual who has little trust in the provider and health care system (Roter, 2000; Thom, Hall, & Pawlson, 2004).

**Collaborating.** Bernabeo and Holmboe (2013) define collaboration as a “true partnership, valuing expertise, power, respect on all sides and recognizing and accepting separate and combined spheres of activity and responsibility” (p.7). In the new health care paradigm, clinicians no longer “do for” but rather “do with” and “partner with” the patient to achieve their health goals (Carman et al., 2013; Bernabeo & Holmboe, 2013; Pelletier & Stichler, 2014; Reid & Peterson, 2008; Roseman et al., 2013). Collaborating entails clinicians and patients working together to discover the best options for the patient, considering what matters most to the patient, and within the context of the patient as being part of a family and the larger community (Swartout et al., 2016).

**Navigating.** To transform care at the interpersonal level, providers need to partner with patients, and ensure they understand how the health care system works, what resources and services are available to them, and when and how to seek out and access such services (Drenkard et al., 2015). For example, patient navigators and advocates have historically worked with and addressed cancer patients with multi-faceted needs and the medically underserved to help them along the challenging health care continuum (Freeman, Muth, & Kerner, 1994; Natale-Pereira, Enard, Nevarez, & Jones, 2011; Shockney, 2010; Wells et al., 2008). Services provided include: researching the disease, handling insurance problems, finding doctors, understanding treatment and care options, accompanying patients to visits, serving as coach and quarterback of their health care team, mobilizing resources, and managing medical paperwork. (Freeman, Muth, & Kerner, 1994; Natale-Pereira, Enard, Nevarez, & Jones, 2011; Shockney, 2010; Wells et al.,

2008). The partnership role of navigator is extremely valuable as a strategy to promote person and family centered care (Ferrante, Cohen, & Crosson, 2010).

**Whole Person.** A holistic approach that addresses the social determinants of health and all the facets of care is necessary for health self-management (Drenkard et al., 2015). Alternative therapies (i.e., herbal medicine, massage, megavitamins, self-help groups, folk remedies, energy healing, and homeopathy) are now more generally accepted as being effective and complimentary in promoting healing and health (Maizes, Rakel, & Niemiec, 2009).

**Coaching.** Coaching by providers is actively supporting a patient in attaining improved health through lifestyle and behavior adjustments (Butterworth, 2010; Grant, 2003). Coaching has been shown to be effective in preventing patient's exacerbations of chronic illness and supporting lifestyle change (Coulter, 2008; Huffman, 2007; Wolever et al., 2011). As coach, clinicians can help motivate patients to develop and maintain positive health behaviors and self-management skills. For patients, feeling they have the support and encouragement of a professional who has vast experience with these situations brings reassurance and a certain comfort within a maze of uncertainty.

### **Statement of the Problem**

As the PPACA moves health care delivery out into the communities, patients and providers must shift their traditional responsibilities and roles to become active partners and collaborators in care. However, there is a lack of clarity and consensus as to how this active partnership and collaboration are successfully operationalized in practice. The purpose of this dissertation proposal was to examine the strategies described by advanced practice mental health nurses used to engage a historically underserved population.

Specifically, this research examined nursing narratives from an existing data set, Reducing Symptoms of Depression in Low-Income Mothers (HILDA; RO1), a randomized depressive symptoms and parenting enhancement intervention (Beeber, Holditch-Davis, Belyea, Funk & Canuso, 2004; Beeber et al., 2010). Depressive symptoms are a known obstacle to patient engagement (O'Kearney, Kang, Christensen, & Griffiths, 2009; Thota et al., 2012). Engagement skills and strategies were the vehicles in which the advanced practice nurses gained rapport with the mothers and made it possible to deliver the mental health intervention. How the engagement skills and strategies opened the door for intervention delivery was examined as well as the mother's engagement levels throughout the intervention.

This research was exploratory and descriptive. Given the lack of previous research that examines patient engagement at the direct care level, I concentrated the analysis on the crucial interpersonal relationship between patient, family, and provider. The research questions were designed to identify the crucial components of patient engagement and the ICM that were represented in the nursing narratives, and those that were not.

In the parent study (HILDA), advanced practice mental health nurses described how they engaged low-income, depressed mothers in the community in a mental health intervention. Using a purposive stratified sample of nursing narratives from the HILDA study, the following questions were examined:

1. How do nurses perceive the engagement process with a historically underserved population in a mental health intervention?
2. How do nurse's description of the engagement skills and strategies that they used vary across the three phases of the nurse-patient relationship (i.e. orientation, working, and terminations phases)?

3. How do nurse's description of their engagement skills and strategies differ between mothers with adherence levels (i.e. highly engaged, fluctuating engagement, and minimally engaged)

4. What is the relationship between the level of mother's engagement and the length of time spent in the beginning (orientation) phase of nurse-patient relationship prior to problem-specific (working) phase?

5. What is the relationship between nurse descriptions of engagement skills and strategies employed and mothers level of engagement?

This study examined the complex concept of patient engagement, and looked specifically at a historically underserved and disengaged population. As the science of patient engagement is beginning to develop, the perceptions of nurses in the engagement process have not been extensively examined. This study described and illuminated patient engagement skills and strategies described by advanced practice nurses in an attempt to gather empirical evidence to support and enrich a promising patient engagement process model, the Interactive Care Model (ICM).

While the existing literature on the importance of patient engagement and technologies is rapidly growing, less research has been conducted examining the core components and process of patient engagement at the interpersonal level. This study represented a first step towards trying to advance the science of patient engagement, by using the ICM to guide the inquiry.



## Definition of terms

The following list provides definitions of terms used frequently throughout this study.

*Adherence.* The extent to which a person's behavior - taking medication, following a diet, and/or executing lifestyle changes --- corresponds with agreed recommendations from a health care provider (Vrjens et al., 2012).

*Caring and trusting relationship.* A relationship that is based on mutual respect and trust, nurturing of faith and hope, sensitive to self and others, and assists with physical, emotional, and spiritual needs of the other (Watson, 2006).

*Coaching.* Coaching suggests teaching and training to continually improve oneself in any capacity; including improving one's health and circumstances (Watson, 2006).

*Collaborating.* Collaborating is working together, respecting and valuing each other's expertise and responsibilities in the care partnership (Cronenwett et al., 2009).

*Culture.* Culture is the characteristics and knowledge of a particular group of people, defined by language, religion, cuisine, social habits, music and arts (Zimmerman, 2015).

*Health care transparency.* Transparency in healthcare refers to the free, uninhibited availability, accessibility, and sharing of health information such as clinical outcomes, physician licensing, malpractice cases, and patient satisfaction responses (Leape et al., 2009).

*Knowledge exchange.* Knowledge exchange is the process of gathering information from person, family, and provider. Information may include health conditions, symptoms, feelings, personal circumstances, health care goals, risks and benefits of potential treatments and care choices.

*Navigating.* Navigating involves helping others find their way within the health care system and broader health care environments, helping others understand how the system works,

when to seek services, what services are available, and how to access them. Patient- individuals or persons who use health care services

*Providers/Clinicians.* Health care providers, practitioners, clinicians, nurses, doctors

*Patient-centered care.* Care that is respectful and responsive to individual patient preferences, needs, and values and ensures the patient values guide all decisions (Cronenwett et al., 2009; Institute of Medicine, 2001, p. 6)

*Patient and family engagement.* A set of behaviors by patients, family members and health professionals and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the health care team and collaborative partnerships with providers and provider organizations (Maurer, Dardess, Carman, Frazier, & Smeeding, 2014, p. 10).

*Patient activation.* Patient activation is patients' willingness and ability to take independent actions to manage their health and care (Hibbard & Greene, 2013, p. 207).

*Self-care management.* - Self-care management is the practice of activities that individuals initiate and perform on their behalf in maintaining life, health and well-being (Orem, 1991).

*Shared decision-making(SDM).* SDM is a process which clinicians and patients work together to make decisions and select tests, treatment and care plans based on the best clinical evidence, balanced with the risks and expected outcomes, and patient preferences and values (Cronenwett et al., 2009; Informed Medical Decision Making, 2013).

*Underserved.* Underserved populations are individuals or groups whose demographic, geographic, or economic characteristics prevent access and usage of health care services (Weitz, 2000).

*Whole Person.* The whole person includes a person's body, mind, spirit, and emotions. Imbalances within the whole person can impact one's healing and health. Conventional medication and alternative therapies can be used to promote healing and health (Stuckey & Noble, 2010).

### **Significance of the study to nursing**

Patient engagement is one of the core tenets of PPACA and health care reform (Carman et al., 2013; Milenson & Macri, 2012; Schoen, Doty, Robertson & Collins, 2011). However, the concept and process of patient engagement have yet to be well defined and operationalized. The outcomes from this research add empirical evidence to the existing body knowledge by examining: the crucial components of patient engagement, what patient engagement looks like, and how engagement is operationalized in clinical practice. Having a better understanding of the science behind patient engagement can help realize the intentions of the PPACA if implemented on a large scale.

Registered nurses are the largest group of healthcare professionals in the country with 3,963,844 holding active licenses (Kaiser Family Foundation, 2016) and are indispensable figures on the front lines of health care delivery. Spending the majority of their time interacting with patients and families (Buerhaus, Staiger, & Auerbach, 2009), nurses have the opportunity and capability to lead the charge in transforming the existing health care paradigm. When armed with a thorough understanding of what patient engagement is and what skills and strategies are both essential and effective in engaging and maintaining patients in their health care, nurses can have a significant impact on the health care system and health care delivery at large. At every patient and family encounter, nursing care can be streamlined and delivered efficiently and

effectively, while continually enhancing patient engagement at every turn. Underserved populations, described as individuals or groups whose demographic, geographic, or economic characteristics prevent access and usage of health care services (Weitz, 2000) can be reached more effectively and helped to enter and actively participate in the health care and health care research arenas. Future generations of providers and practitioners will have essential engagement skills and strategies seamlessly woven into their education and ultimately, their clinical practice for shared engagement and decision-making.

Sometimes, to move forward, we must look back and assess the foundation from which we are jumping. By examining the foundational basics of the patient-provider relationship and the process of facilitating patient's active engagement in one's health care, nursing can lead the charge and pilot the health care paradigm transformation from the traditional model, to one that is truly person and family centered.

At a time when more Americans than ever have access to health care services synchronized with the ultra access technology has given us to both information and people, and pressure to demonstrate patient's improved health outcomes, the popularity and focus of engaging patient's in their health and healthcare has reemerged. Although touted as a new patient engagement model, elements of the ICM have been represented in the health care literature for decades. Mirrored in both Peplau's 1948 Interpersonal Theory of Relations and Quality and Safety Education for Nurses (Cronenwett et al., 2007) patient and family centered care competencies, prioritizing and engaging patients in their care has long been a core responsibility of nursing practice. As such, the timing for a refreshed and updated model in this new era of patient engagement may be ideal in making what is old, new again.

Beeber et al.'s (2013) RCT intervention was theoretically driven by Hildegard Peplau's Theory of Interpersonal Relations (1948). Notable, key phases and partnership roles in the ICM parallel and mirror phases of the nurse-patient relationship and nursing's role in Peplau's theory. As such, data from Beeber's study offered a prime opportunity for a secondary analysis in applying a new model to the nurse's engagement activities and relationship construction practiced.

## CHAPTER 2

### PATIENT ENGAGEMENT

#### **Background**

The concept of patient engagement has slowly evolved. Rooted in the civil rights and advocacy movements of the 1960's and 1970's, patient engagement emerged when attitudes about personal rights were in question. The concept of patient engagement shifted in the 1980's to emphasize the patient's legal right to information about their health and treatment options (Deccache & Aujoulat, 2001). In the 1990's, the advent of the Internet facilitated patient's access to information regarding health promoting behaviors, treatments, and healthcare options (Hoving Visser, Mullen, & van den Bore, 2010). Today, patients are positioned at the center of healthcare delivery and are both encouraged and expected to play an unprecedented, pivotal role in their health care. However, despite being a term now widely used by healthcare providers, healthcare reform activists, analysts, insurers, pundits, and technology vendors, the meaning of patient engagement remains vague and imprecise (Worden, 2015). Clarity regarding the meaning of patient engagement, related concepts, and conceptual framework is essential to fully understand what engagement is, and more importantly, how the process of engagement is executed efficiently and effectively.

**Derivation of terms.** As a noun, the word patient means one who receives medical attention, care, or treatment (American Heritage Dictionary, 2014). The term is derived from the Latin *patiens*, which means to endure. As an adjective, patient means calmness while enduring pain, difficulty, provocation, or annoyance (American Heritage Dictionary, 2014). The word *patient* denotes a sick individual, especially when waiting or under the care and treatment of a

physician or surgeon (Merriam-Webster Dictionary, 2015). Many of these characterizations have a certain passivity and a neediness embedded within them, contributing to the traditionally paternalistic, provider-centered health care paradigm (Hoving et al., 2010; Novack, et al., 1979; Oken, 1961). Thus, prompting some to suggest replacing the term patient with *health consumer* or *client* (which do not denote illness), to buffer the implied power imbalance (Hibbard & Greene, 2013).

Conversely, the term *engagement* refers to the action of engaging; the state of being engaged; or the condition of being in gear (American Heritage Dictionary, 2014). The term, first used in 1515, is derived from the Middle French *engagier*, and the Old French term *engager*, meaning to pledge or under pledge respectively. Engagement is defined as an emotional involvement or commitment (Merriam-Webster Dictionary, 2015). A person is considered engaged when they are involved in doing something in which they have significant interest. Engagement is considered an obligation or agreement as well as an encounter, conflict or battle (American Heritage Dictionary, 2014).

Combined together as patient engagement, a contradiction of sorts exists. Patients are in a position of vulnerability while simultaneously expected to be actively participating and doing something about their circumstance.

Definitions from health care research. The health care research literature has varied definitions and descriptions of patient engagement (Barnsteiner, Disch & Walton, 2014; Coulter, 2010; Drenkard & Wright, 2014; Greene, Hibbard, Sacks, Overton, & Parrotta 2015; Gruman et al., 2010; Jarousse, 2011; Rosenthal, Fernandopulle, Song, & Landon, 2004; Rowe, 2013; Young et al., 2007). Existing definitions and descriptions vary in terms of addressing the questions: what is patient engagement, who is involved, how is it done, and how is it measured?

Additionally, descriptors differ regarding what level of engagement is addressed (i.e. direct care, organizational design and governance, or policy-making levels; Carman et al., 2013). For this analysis, I strategically concentrated on the relationship between the patient and provider at the direct care level to avoid the conceptual broadness that accompanies the other levels (Barello, Graffigna, Vegni & Bosio, 2013). Moreover, a real understanding of patient engagement at the direct care level will set a solid foundation for the other levels of patient engagement to build upon. In an extensive review of the literature, there was no consensus on the unitary concept of patient engagement. At the direct care level, patient engagement is often described and explained in terms of relationships, stakeholders, responsibilities, and measurements. Table 1 demonstrates the multi-dimensionality of patient engagement as a concept.



**Table 2.1. Different definitions/descriptions of patient engagement (PE)**

Context	Roles	Description/Definition	Considerations
Relationship	Provider-patient	Patient engagement is a true partnership between care providers and patients and families (Drenkard & Wright, 2014, p. 96).	The description ignores the inherent power imbalance between provider (having intimate information on patient) and patient (not having same info about provider).
	Patient-provider	Patient engagement is the “relationship between patients and healthcare providers as they work together to promote and support active patient and public involvement in health and healthcare and to strengthen their influence on healthcare decisions” (Coulter, 2012, p. 10).	A managerial complexity exists when a patient has multiple providers.
Stakeholders	Patients	Becoming engaged in their health care is empowering and allows patients to get and stay healthy (Barnsteiner, Disch & Walton, 2014; Jarousse, 211; Rowe, 2013).	Patient engagement exists on continuum ranging from passive to active partner in care.
	Providers	Financial stake in patient engagement exists as reimbursements often depend on patient outcomes and value of prescribed care (Rosenthal, Fernandopulle, Song, & Landon, (2004).	What is driving engagement? Dollars? Outcomes? Both?
	Families	Families create and maintain the practical everyday environment which influences patient’s journeys to achieving their health care goals (Gruman et al., 2010).	Families are affected emotionally, socially, and financially in terms of patient health care outcomes.
Responsibilities	Patient	Patients are responsible for being involved in their care, actively processing information, deciding how best to fit care into their lives, and acting on those decisions, in order to achieve the best health benefit (Gruman et al., 2010)	Sometimes impaired or lack resources to take on this role
	Provider	Providers assess patient’s level of engagement and capacity to engage	One size does not fit all- engagement takes time. Time =Money
Measurements	Patient Activation Measure	The measure is scored on a scale from 0 to 100. Four levels of activation have been identified, which range and progress from being passive with regard to one's health to being proactive(Young et al., 2007). Patient activation levels are often the independent variable. Level 1 (score of 0.0-47.0) suggests that a person may not yet understand that the patient's role is important. Level 2 (47.1- 55.1) indicates that a person lacks the confidence and knowledge to take action. Level 3 (55.2- 72.4) indicates that a person is beginning to engage in recommended health behaviors. And level 4 (72.5-100) indicates that a person is proactive about health and engages in many recommended health	Relies on Self report data Patient activation refers to a patient’s knowledge, skills, ability, and willingness to manage his or her own health and care. Patient engagement is a broader concept that combines patient activation with interventions designed to increase activation and promote positive patient behavior” (James, 2013).

		behaviors. (Greene, Hibbard, Sacks, Overton, & Parrotta 2015 ; Young et al., 2007)	
	Patient Health Engagement Scale	A tool to measure PE accounts for the emotional aspects of diagnosis and how a medical diagnosis impacts a person's daily life. Four levels of engagement include- blackout, arousal, adhesion and eudemonic reconfiguration (think-feel-act) (Graffigna, Barelo, Bonanomi, & Lozza, 2015)	Further validation in practice is needed
	Health confidence measure	How confident are you that you can control and manage most of your health problems (Carpinello, Knight, Markowitz, F & Pease, (2000) p.9)? 10 point scale	1- low confidence 10-high confidence Determine patient's level of engagement and develops and individualized approach to managing care
	Patient Engagement Index (PEI)	The PEI assesses and measures a person's level of engagement and capacity to engage in their healthcare (Swartout, 2015).	Undergoing psychometric testing at present.

## **Patient Provider Relationships**

Although there has been various, and at times conflicting, descriptions of patient engagement, the crux is the patient and provider relationship (Drenkard et al., 2015; Legare et al., 2008; Weston, 2001). The patient-provider relationship provides a basis for genuine engagement, collaboration, and partnering to be established and fostered (Roter, 2000). The quality of the patient-provider relationship has been shown to be directly associated with patient outcomes. In a cross-sectional study of 1,743 patients with HIV, the association between the patient's perception of "*being known as a person*" by their provider and patient's receipt of and adherence to antiviral therapy was examined (Beach, Keruly, & Moore, 2006). Patients who perceived their providers *knew them as a person* were more likely to receive the antiviral therapy ( $p < .001$ ), maintain adherence ( $p = .007$ ), and have undetectable serum HIV RNA ( $p < .001$ ).

**Patient factors that affect the patient-provider relationship.** Before delving into the empirical evidence concerning patient engagement, it is important to note and consider patient and provider factors that affect their fundamental relationship. In addition to one's knowledge, attitudes, and beliefs, personal values vastly influence patient's motivation, willingness, and ability to establish and maintain a relationship with their provider (Corey, 2015; Cronenwett et al., 2009; Shim, 2010). Four important factors that impact a person's capacity for engaging are their cultural values, socio-economic status, health literacy and their activation/motivation (Coulter, 2012; Drenkard et al., 2015; Gruman et al., 2010; Koh, Brach, Harris, & Parchman, 2013; Martin, 2012; Wolever, 2011).

**Cultural values.** Cultural values vastly influence patient's health and engagement in their health care. Specifically, cultural values influence a person's perceptions of health, illness and death, their beliefs about disease causation, approaches to health promotion, their experience

and expression of illness and pain, where to seek help, and the types of preferred treatment (Kleinman, Eisenberg, & Good, 1978; Kodjo, 2009;). Culture is defined as the integrated pattern of human behavior that includes thoughts, communications, actions, customs, beliefs, values, and institutions of a racial, ethnic, religious, or social group (Cross, Bazron, Dennis, & Isaacs, 1989). As such, culture and cultural values provide context and are relevant to everyone's relationship with their providers, especially for ethnic minorities who are often in a race discordant relationship with their providers (Institute of Medicine, 2003).

Differences in patient-provider communication behaviors in race concordant relationships versus race discordant relationships were found by Cooper's et al. 2003 study. The cohort study of 252 patients (142 African American (AA), 110 Caucasian) and 31 providers (18AA, 13 Caucasian) found visits between race concordant patients and providers were longer, patients had a higher rating of patient care, and physicians were perceived and rated as more participatory than race discordant pairs (Cooper et al., 2003).

Additionally, cultural differences can impact patients' attitudes towards their health care and health care providers. Consider the Asian culture, where great emphasis and high value is placed upon family connections as a major source of identity and protection against the hardships of life (Fulgini, Tseng, & Lam, 1999; Ying, Coombs, & Lee, 1999). It is not unlikely for a person of Asian descent to defer to the elders in their family over the advice of healthcare providers (V. Yeh, personal communication, May 15, 2015). African Americans traditionally have had a distrust of health care research and the health care system at large based upon a discriminatory history marked with racial tones of experimentation, the sickle cell screening initiative, family planning/involuntary sterilization, and the Tuskegee experiments (Dovidio et al., 2008; Gamble, 1993; Harris, Gorelick, Samuels, & Bempong, 1996).

The association between socio-cultural factors and patient provider communication and related racial differences was examined in 2014 by Song et al., in a study of 1854 men with prostate cancer. The researchers found Caucasian American men had significantly greater mean scores of interpersonal treatment ( $p < .01$ ), communication regarding their prostate ( $p < .001$ ), and physician trust ( $p < .001$ ) when compared with African Americans. In comparison, Caucasians had lower mean scores of religious beliefs and perceived racism ( $p < .001$ ). In both African American and Caucasian men, better interpersonal communication between provider and patients was associated with patients having a higher trust in their physicians and less perceived racism (Song et al., 2014). Thus, socio-cultural considerations, such as developing greater trust-enhancing behaviors and delivering respectful and equal treatment should be considered in facilitating patient and provider communication during health care interactions (Song et al., 2014).

**Socio-economic factors.** In addition to many socio-cultural factors, affordability can be a significant barrier to gaining access to providers. Those patients with a low socioeconomic status may lack both health care insurance and/ or geographical access to care (Burge, Lucero, Rassam, & Schade, 2000; Jerant, von Friederichs-Fitzwater & Moore, 2005; Nam, Chesla, Stotts, Kroon & Janson, 2011; Potosky, Breen, Graubard, & Parsons, 1998). Other pathways in which socio-economic status can affect patient engagement include: competing financial demands, childcare issues, language barriers, immigration issues, limited education and communication proficiency (Hinton & Ernest, 2010). In a systematic review of 12 original research studies and meta-analyses, Willems et al. (2005) found patients with lower socio-economic status received less positive social and emotionally supportive statements, less information giving, less direction and less participatory consulting style from their provider than patients of higher socioeconomic

status. Not mentioned or measured in these studies was the patient's desire and interest to gain information versus patient's ability or limited ability to express themselves. Moreover, the effective use of language is foundational for patient provider communication and relationship building. Lack of language proficiency acts as a major barrier for many ethnic minorities in the United States and significantly hinders the navigation of mainstream health services (Nam et al., 2011).

**Health Literacy.** Health literacy is the ability to read, understand, and act upon health information to protect, maintain, or enhance a person's health (Peerson & Sanderson, 2009; Zarcadoolas, Pleasant, & Greer, 2009). Health literacy is fundamental to enhancing patient engagement, enabling patients to take in their health information, make sense of it, and express their preferences (Nielsen-Bohlman, Panzer, & Kindig, 2004). Vulnerable populations include those with low-income levels or limited English proficiency, the elderly, and mentally ill, who may face engagement challenges due to low health literacy or mental deterioration (Carman et al., 2013; Rivadeneyra, Elderkin-Thompson, Silver & Waitzkin, 2000). In order to improve the health of disadvantaged populations and address existing health inequities, improving health literacy is essential (Coulter & Ellins, 2007). In a systematic review, Berkman et al., (2004) noted lower levels of health literacy were consistently associated with increased hospitalization and emergency room usage, lower usage of preventative services like mammography, flu vaccine usage, poorer ability to interpret labels and health messages, and ability to take prescribed medication correctly.

Conversely, health literacy can breed a certain empowerment in the form of patients having a voice or a say in their health care. Genuine power exists in patients, families, and patient representatives having a voice in their health care (Davidson et al., 2009; Quennell,

2001). Voice is an expression of words and thoughts, and as such, signifies contribution, involvement, and engagement (Tannen, 2007). The Nursing Alliance for Quality Nursing (NAQN) acknowledged the importance of voice, but also recognized the significance of having the knowledge, skills, confidence, and will to express that voice in making competent well-informed decisions about their health and healthcare (Sofaer & Schumann, 2013).

Several interventions have been effective in building health literacy, promoting patients active involvement in health care decisions, and educating patients how to effectively manage chronic conditions (Coulter, Parson, & Askham, 2008). Electronic, web-based, or printed materials that meet the language and literacy needs of the patient, function as decision aids and supplements to clinical consultations. These materials can increase patient knowledge about their illness and treatment and decrease feelings of uncertainty (Center for Advancing Health, 2010; Coulter et al., 2008; Mishel, 1984. Stacey, Samant, & Bennett, 2008; Stacey et al., 2011)

**Activation/motivation.** Activation refers to the competencies (knowledge and skills) needed, as well as the willingness and ability to use those competencies to manage one's health care (Hibbard & Greene, 2013). Hibbard and Greene (2013) have done extensive work on measuring patient activation with the Patient Activation Measure (PAM), a single measure of one's knowledge, skills, beliefs, and confidence in managing their health and health care (Greene & Hibbard, 2012). The PAM examines 13 patient outcomes in the four areas of prevention, unhealthy behaviors, clinical indicators, and cost utilization. In a sample of 25,047 patients patient activation was strongly related to a broad range of health-related outcomes suggesting improving patients activation can improve health care outcomes (Hibbard & Greene, 2013).

Depressive symptoms are well-known obstacles to activation and motivation needed to engage in and manage one's health and health care (Berardi et al., 2005; Kravitz et al., 2013;

Lotifi Flyckt, Krakau, Mårtensson, & Nilsson, 2010; Simon, Fleck, Lucas & Bushnell, 2004; Unitzer et al., 2002). Feelings of hopelessness and helplessness, decreased energy, and difficulty making decisions-intrinsic to depression, impede individuals from seeking out and engaging in critical mental health services (Beeber et al., 2007; Goldberg, Brintnell, & Goldberg, 2002). Depression has been projected to affect 16 percent of the US adult population, with fewer than half receiving treatment (Young, Klap, Sherbourne, & Wells, 2001), and one fourth of the cases going undiagnosed (Barbui & Tanslela, 2006). A 2010 study by Epstein et al. used focus groups to explore adult patient's (n= 116) experiences before and after seeking depression treatment and found patients with depressive symptoms encounter difficulty in: recognizing something is wrong, finding words to describe their distress, and in looking for meaning in what they are feeling. Hence, targeting individuals who suffer from depressive symptoms provides both a challenge and prime opportunity to test patient engagement skills and strategies.

**Provider Factors that Affect the Patient Provider Relationship.** Patients and providers vary considerably in their perceptions, knowledge, and attitudes, which can lead to possible confusion, misinterpretation, and potentially poorer patient health outcomes (Anderson, Fitzgerald, & Gorenflo, 1993). Understanding some of the provider factors that impact care can lead to an improvement in establishing the patient-provider relationship.

***Training/Education in Communication.*** Active listening, soliciting information, providing support and establishing agreement are the essence of patient and provider communication and collaboration (Beckman, Markakis, Suchman, 1994). A patient centered approach (versus the traditional provider centered approach) can enhance patient's disclosure of information and problems and can enhance both communication and the patient provider relationship (Roter & Hall, 2004). Perhaps the most important part of the patient provider



interaction is the medical interview, where the provider gathers information, begins to relationship build, and educates the patient. However, providers differ in their interview ability, skill, and effectiveness (Barrier, Li, & Jensen, 2003) based upon their training and prior experience. Interestingly, studies have shown a positive association between poor communication and malpractice claims (Levinson, Roter, Mullooly, Dull, & Frankel, 1997; Stewart et al., 1999; Wallace, Lowry, Smith, & Fahey, 2013). Communication problems most commonly mentioned include: inadequate explanations of diagnosis and potential treatments and options, as well as patients feeling their voices and inputs were ignored (Beckman et al., 1994).

**Time.** In order to build and maintain a therapeutic relationship between patient and provider, adequate time is required. Stewart et al. (1999) posited effective provider communication (and thus patient provider relationship building) was largely a function of *time available* for the patient consultation. Time has been identified as both a barrier and facilitator of effective communication and in building a therapeutic patient and provider relationships (Hemsley, Balandin, & Worrall, 2012). As a facilitator, Robbins et al. (1993) found 100 randomly assigned patients in an academic family medical practice were most satisfied with their relationship with their provider when they had time to discuss both health education ( $p < .001$ ) and the effects of specific therapeutic interventions ( $p < .01$ ). Providers who saw a high volume of patients per day had less time to perform valuable preventative services than providers who saw a lower volume of patients (Gross, Zyzanski, Borawski, Cebul, & Stange, 1998). Researchers calculated the time needed for providers to meet all of the U.S. Preventative Services Task Force (USPTF) recommendations and found it would take an average of 1773 hours of annually, or 7.4 hours per day to fully satisfy the USPTF recommendations (Yarnall, Pollak, Østbye, Krause, & Michener, 2003). Time constraints limit the ability of providers to

provide complete patient care and can negatively impact relationship building, patient outcomes, and costs (Devlin, & Arneill, 2003; Ha & Longnecker, 2010).

**Shared decision-making.** One of the many areas where provider training and time constraints have an impact involves shared decision-making. Shared decision-making is a collaborative process involving patient and providers making health care decisions together as they consider the best clinical evidence available, and the patients values and preferences (Informed Medical Decisions Foundation, 2016; Stacey, et al., 2011). Although clinicians are experts concerning disease, tests and treatments, patients are experts regarding their bodies, their values, their goals, and their circumstances (Coulter et al., 2008). Ideally, in shared decision-making, the patient and provider together, arrive at the optimal plan of care for the patient. Both patient and health care providers consider and discuss the patient's condition, treatment options including benefits and risks of each, and patient preferences, unique concerns, inputs and wishes to reach and implement an agreed upon treatment plan (Makoul & Clayman, 2006). Shared decision making has been linked to patient's enhanced quality of life, reduced symptoms, and lower litigation rates (Hack, Degner, Watson, & Sinha, 2006; Hibbard & Greene, 2013; Kiesler & Auerbach, 2006; Legare et al., 2010). For shared decision-making and ultimately patient engagement to effectively occur, there must be a patient and provider relationship that considers patient's values, socioeconomic status, health literacy and activation/motivation. Additional influences of successful engagement include provider's communication proficiency and time availability. Interestingly, the Center for Medicaid Services is beginning to call for evidence for shared decision-making in lung cancer screening as a pre-requisite for reimbursement (Centers for Medicare & Medicaid Services, 2015). However, several of the existing shared decision-

making scales have been validated in only small samples, and often use the measurement scales developers in the testing process (Simon, Andreas, & Harter, 2007).

In summary, an important determinant of gaining entry into the health care system and maintaining active engagement in one's health care is the initiation and quality of the relationship between the patient and his/her health care providers (Willems De Maesschalck, Deveugele, Derese, & De Maeseneer, 2005). Shared decision-making, the embodiment of patient engagement and effective patient provider communication, is highly influenced by a myriad of factors that can either block or facilitate this crucial patient and provider relationship. In discussing the various patient and provider factors that impact the patient and provider relationship, the various layers to patient engagement begin to unfold.

### **Significance of Patient Engagement to Healthcare**

**Active patient engagement and healthcare outcomes.** Several studies have shown positive correlations between patients who actively engage in their health and health care and better health care experiences, better health outcomes, and lower healthcare costs. Greene, Hibbard, Sacks, Overton, & Parrotta (2015) found that after controlling for age, sex, income and a number of chronic conditions, highly engaged patients had better clinical, behavioral, and cost reduction outcomes compared to those who were less engaged ( $n_1 = 32,060$ ,  $n_2 = 10,957$ ). Specifically, those more engaged in their health care had better cholesterol and triglyceride levels, were nonsmokers, and were less likely to be obese. More engaged patients were more likely than less engaged patients to have obtained cancer screening tests (e.g. pap smears, mammography), and were significantly less likely to be hospitalized or had recently visited the

emergency department. Additionally the authors reported that more engaged patients had health care costs projected to be 8 percent lower than those who were less engaged.

However, the Greene et al., 2015 study had several limitations. The study sample was taken from 44 primary care clinics as part of one large health care system in Minnesota, with 60-64% of the sample identified as females over the age of 50 years old. Additionally, although the Patient Activation Measure (PAM) has been deemed reliable and valid, it ultimately remains a self-report measure of the patient's perception of their involvement in their health and healthcare and could be skewed by patient's lack of disclosure about unhealthy behaviors and practices. Because of the self-report nature of the data and the homogeneity of the sample, Greene's et al. conclusions that increased engagement as measured by the PAM were correlated with enhanced future health related outcomes and decreased health costs, are limited in generalizability.

Similarly, Fowles et al., 2009 study (n=625) found highly engaged patients to be twice as likely to prepare questions in advance of a visit to the doctor; to know about treatment guidelines for their condition; and to seek out health information, including comparisons of the quality of health care providers than those less engaged. However, again in Fowles' et al. study, the majority of participants were women (87%), with an average age 45, were white (90%), and 44% of the sample, had at least a four-year college degree. These results raise a question: was this sample more engaged, or simply more equipped with the necessary resources like income and education that naturally breed and facilitate patient engagement?

A qualitative study by Kangovi (2014; n=65) examined the disparity faced by high-risk, less engaged groups. In-depth interviews were conducted with low-income recently discharged stroke victims to explore and understand the perceptions health care needs, barriers, and preferences of a high-risk patient sample. Patients reported preferring a provider with whom they

could relate, tailored support addressing their specific needs and goals, and post discharge support for psychosocial, financial, and follow up issues that may impair recovery. The identified recommendations and themes from the participants in the Kangovi et al. study speak to the very advantages (i.e. resources, education) those in the previous study came into the health care experience with- advantages that were essential and that were already built in to their care experience.

Reinforcement of Kangovi's findings can be found in the Hibbard and Cunningham (2008) study that found engagement levels to differ considerably across socioeconomic and health characteristics. Based upon the 2007 Health Tracking Household Survey, a nationally representative telephonic survey (n=17,800), engagement was particularly low for people with low socio-economic status, less education, Medicaid enrollees, and those who self-reported having a poor health status. Conversely, those who were younger, well-educated, and had higher engagement levels reported having their medical needs met and had support from providers to self manage their chronic conditions. Less engaged patients were found to be three times more likely to have their medical needs unmet and twice as likely to delay medical care, compared with more engaged patients (Hibbard & Cunningham, 2008).

Multiple studies have shown that when controlling for chronic conditions and socio-economic backgrounds, more engaged patients are still more likely to self-monitor their health care at home (i.e. keeping a blood glucose diary, performing regular exercise) and obtain regular care for chronic conditions (i.e. foot exams for diabetes, eye examinations; Greene & Hibbard, 2012; Hibbard Mahoney Stick & Tusler, 2005; Lorig et al., 2010; Rask et al., 2010; Rogvi et al., 2012; Wolever et al., 2011). Although many of these studies had small sample sizes which limited generalizability, correlations between more engaged patients, better self care behaviors,

and better health outcomes was recurrent and clear. It is not as clear whether active engagement preceded better health, or whether better health preceded active engagement. Finally, the evidence base for patient engagement is limited. Studies are based upon participants who indeed decided to engage in the research study at some level. There is limited knowledge and understanding as to the narratives of those people who *choose not* to engage in both research studies and health care services.

### **Interventions to Promote Patient-Provider Relationships**

**Interventions to engage patients.** Interestingly, Hibbard et al., 2005 study found activation levels (a patient's knowledge, skills, ability, and willingness to manage his or her own health and care) could be changed over time. In a randomized control trial (RCT), 479 patients with chronic disease were randomized to the control group (which received nothing) or the intervention group, which received 6 weekly sessions of the Chronic Disease Self-Management Program (CDSMP). The CDSMP is a community workshop for people with different chronic health problems, addressing issues involving problem solving, exercise and nutrition regimens, medication use, and effective communication. Principal findings from the longitudinal study using the PAM, included positive changes after participating in the 6-week CDSM program. At six weeks, the intervention group scored significantly higher on the PAM than those of the control group ( $p < .001$ ) accompanied positive changes in several self-management behaviors (i.e. exercising regularly, managing stress, monitoring fat intake, blood pressure, glucose, taking diabetic medication as prescribed). However, the reported changes in self-management behavior and activation had a very small sample size and significant statistical power issues. In addition, when both groups were surveyed 6 months out, differences in patient activation between the intervention and control group declined, with the control group gaining in activation as time

passed ( $p=0.127$ ). This suggests activation levels can indeed change and can take different trajectories. Moreover, something else other than the CDSMP was improving activation among the control group over time, indicating perhaps a type of testing bias. Another result of this same study was a small to moderate negative correlation in 9 of the 18 self-management behaviors between depressive symptoms and improvements in activation scores. Thus, encouraging patient engagement and activation may also address existing depressive symptoms (Hibbard et al., 2005).

In a similar education intervention, Bozic and colleagues (2013) conducted an RCT ( $n=123$ ) to examine the impact of decision aids and coaching in informed decision making. Informed decision-making was defined as scoring above 50% on a previously validated knowledge survey (Sepucha et al., 2011) for patients with osteoarthritis. The control group received usual care and the intervention group received video educational materials, risk-benefit brochures, visit with health coach and audio recordings of health coaching visits. Knowledge and decision-making were measured pre and post intervention. The intervention group were 58.3% more likely to make an informed decision about orthopedic surgery than those in the control group (33.3%), and reported having increased confidence and ability to ask questions and participate in the decision making process. A limitation was the small study sample from two orthopedic practices in California that limited its generalizability.

In another educational intervention, Wolever et al. (2011) ( $n=56$ ) analyzed the effectiveness of a 3-day immersive individualized diabetes coaching intervention, which provided instruction and linked behavioral goals to patients' values and personal vision of health. Using this integrative model, patient's self-reported improved medication adherence, patient engagement and behavior, perception of illness, psychosocial measures, and A1C. These studies,

although limited in the depth and variety of the engagement skillsets described, suggest patient engagement is teachable and a learnable skill.

In a mixed methods study, Kidd, Lawrence, Booth, Rowat, & Russell, (2015) used the assessment of patients and their capacity to engage, motivational interviewing, goal elicitation, goal setting, and self-management advice to underpin the design and development of a tailored, person-centered, self-management support programs for stroke survivors (n=26). The PAM, a well-known and validated measure of patient knowledge, skill and confidence to self-manage ones health and health care (Hibbard et al., 2007) was used to assess stroke survivor's readiness for self -management. Interesting to note, while 85% of participants scored high on the PAM, individual narratives from qualitative interviews with stroke survivors suggested participants *did not* feel they had the confidence and knowledge to self-manage their care in times of stress, illness or anxiety (Kidd et al., 2015), highlighting that the PAM score alone does not tell the entire activation tale within this population. Components of the developed program were perceived as feasible and acceptable to both stroke survivors and nurses (Kidd et al., 2015) but the study had several limitations. The small sample size limited generalizability, and suffered from selection bias as the majority of the small sample were males stroke survivors, between 1 and 6 months post stroke incident, who did not have any severe cognitive, communicative and/or visual impairments (Kidd et al., 2015). Thus, the question arises, “how can we tailor and truly center care if patients are not, or physically or emotionally cannot, engage in the care partnership?”

**Interventions to promote relationships with the underserved.** Studies reviewed thus far link patient engagement with improved outcomes in those patients capable of proactively seeking care or capable of learning how to become more actively engage in their health and



health care. However, these studies do not address populations that face significant barriers to patient engagement. To date, clinicaltrials.gov reports 109 completed, active, or currently recruiting for general patient engagement studies and 127 studies focused on patient engagement of underserved or at risk populations. Historically underserved populations like those with mental illness, cognitive issues, or those who live in poverty are often shut out from health care services and research (Morse, 2000; Park, Turnbull, & Turnbull, 2002). Multiple barriers to health care services often feed a vicious downward spiral leaving those at the highest risk for certain illnesses often with limited access to quality health care (Smedley, Smith, & Nelson, 2003; U.S. Department of Health and Human Services, 2003). For example, low-income depressed mothers are up to four times more likely to suffer from depressive symptoms than women in higher income classes, and are three times less likely to engage in mental health treatment [Bhui et al., 2013; Ertel, Rich-Edwards, & Koenen, 2011; Gaynes et al., 2005; Grote, Zuckoff, Swartz, Bledsoe & Geibel, 2007; Knitzer, Teberge, & Johnson, 2008; Lennon, Blome, & English, 2001; Minkovitz, Strobino, & Scharfstein, 2005; U.S. Dept. Health and Human Services, 2014).

Barriers to seeking treatment include societal stigma of seeking mental health treatment, limited access to services, and financial barriers to mental health care (Beeber et al., 2007). In addition, feelings of hopelessness and helplessness, decreased energy, and difficulty making decisions-intrinsic to depression, further impede mothers from seeking out and engaging in critical mental health services. Moreover, constant stressors in their lives paired with lack of engagement in mental health care can trigger a worsening of their depressive symptoms, leading to difficulty in bonding with their infants, decreased sensitivity to their infant/child's cues, and inconsistently responding to their infant/child's needs (Beeber et al., 2007, 2013; Richter, 2004).

Hence, mother's depression and disconnection can negatively affect the crucial development and welfare of the child/ren under her care (Brauner & Stephens, 2006 ; Cooper, Masi, & Vick, 2009; McDaniel & Lowenstein, 2013). The double generational impact highlights the critical need to connect those in need of care with crucial treatment and services.

An examination of how to engage the historically underserved in mental health care provides an ideal backdrop to examine patient engagement, as mental health care and treatment require deliberate and sustained engagement. Much more is required in mental health care than a one-stop visit for antibiotics for an acute infection. Decisions to seek mental health services are often followed by a conscious effort and deliberate action to stay involved, and maintain involvement and participation in both treatment and follow-up (Interian, Lewis-Fernandez & Dixon, 2013). For mental health outcomes to be maximized, patient's continual and active engagement is required. If we can identify the specific skills and strategies providers use to engage the disengaged in sustained engagement at the patient and provider relationship level, a patient engagement conceptual foundation can be laid to support and enhance *all levels* of engagement in the patient engagement spectrum. Meaning, if we can identify what it takes to initiate and sustain engagement in a historically underserved, at risk population, those strategies can be adjusted and tempered to build patient provider relationships and engagement for all individuals and families. Interventions to improve mental health care engagement among underserved populations will now be explored.

Collaborative care has shown promise in reaching and helping hard to reach populations. In one RCT (n=387) predominantly Hispanic (96.5%) diabetic patients with depression were followed for 18 months. The intervention group received comprehensive collaborative care management for depression that was sensitive to participant's linguistic, cultural and economic

factors. Collaborative care management provided psycho-education to dispel treatment misconceptions, reduce stigma, and enhance therapeutic alliances between patients and providers (Ell et al., 2010). Problem solving therapy, medication therapy, first line treatment choice, telephonic support for treatment response, adherence and relapse prevention, and system navigation help were provided to participants in the intervention group for 12 months. The control group received usual, standard clinic care with educational pamphlets and a community resource list provision (Ell et al., 2010). The intervention group who received the socio-culturally adapted collaborative depression care, resulted in significant improvements in their depressive symptoms, emotional and physical functioning outcomes and lower diabetes pain symptoms when compared with the control group ( $p = .001$ ). Interestingly, there was no intervention effect on Hemoglobin A1C values or self care management outcomes (measured by a Summary of Diabetes Self-Care Activities Questionnaire). In addition, this study failed to measure patient's engagement capacity leaving the question of whether social-culturally adapted care had a true impact on patient engagement proper. Thus, begging the question, did participants in the intervention group have better outcomes because of the additional attention and care, or did they have better outcomes because their capacity for engagement improved? The study alluded to a care algorithm but failed to go into much detail as to the training, or skills and strategies used by providers to adapt the mental health care program.

The concept of collaborative care was also explored by Miranda et al., (2003) in a RCT quality improvement intervention with 267 women with depression, recruited from with county-run Women, Infants, and Children food subsidy programs and Title X family planning clinics. Title X clinics provide contraceptive service, counseling, and reproductive health services to low-income women (Gold, 2001). Participants who received 8 weeks of manual-guided

cognitive behavior therapy via telephonic monitoring and adherence encouragement had better outcomes than the usual care group. Ethnically diverse providers delivered culturally sensitive and linguistically appropriate materials to address common barriers to mental health care faced by Latinos and African American women. Outreach was part of the intervention and included provision of childcare and transportation when needed and provider encouragement to adhere to selected treatments (Miranda et al., 2003). Results showed an increase in mental health care engagement and improvement in depressive symptoms as per Hamilton Depression Scale as a result of the collaborative care (Miranda et al., 2003). Although encouraging, Miranda et al. did not discuss in any detail as to *how the nurses* engaged and kept the mothers engaged in the intervention. Patient engagement as a behavior was not quantified or measured, leaving the readers with an all too familiar question- do these interventions improve participant's patient engagement as a skillset to be implemented in the future or do providers going above and beyond to engage patients have only short term benefits on engagement outcomes? Studies reviewed thus far are limited in measuring engagement as a behavioral construct and tracking behaviors over time. In addition, the existing literature provides sparse detail as to the skills and strategies used by the providers to engage participants.

Telephonic care management plus telephonic cognitive behavioral psychotherapy was found superior to telephonic case management alone in improving antidepressant use among 600 primary care patients beginning antidepressant treatment for depression (Simon et al., 2004). The telephone program integrated care management and structured cognitive-behavioral psychotherapy to significantly improved satisfaction and clinical outcomes. Findings from all of three of these studies suggest actively reaching out with tailored, purposeful, and sustained effort improves patient's access to and motivation to engage in treatment. Bringing the treatment to the

people and helping them engage in care is an effective way to overcome barriers to care. As mentioned, a substantial gap in the patient engagement evidence base exists in terms of measuring specific patient engagement behaviors, tracing engagement over time, and a significant lack of detail and description as to provider training and what engagement skills and strategies they implemented.

Going above and beyond to reach certain populations can certainly be low tech. Mailing reminder letters and following-up with phone calls made an impact in an RCT (n=113) involving African Americans with either depression (39%), substance abuse (39%), or both (22%). Participants in the usual care group received either a follow up letter reminding them of a mental health appointment, whereas the intervention group received the same plus 1-2 brief telephonic motivational interview calls. Seventy percent of the intervention group versus 32% of the control group engaged in at least one mental health treatment appointment ( $p < .001$ ) and attended more than three appointments versus the usual care less than two appointments ( $p = .008$ ; Zanjani et al., 2008).

As important as bringing health care to those most in need, is involving the families who support those patients. Engagement interventions for schizophrenia have examined engagement of families for those patients who are at times are incapable of engaging themselves. Kopelowicz et al., (2012) adopted multi-family groups (MFG's) to address crucial medication adherence among Mexican Americans diagnosed with schizophrenia. In the RCT (n=174 patients) MFG's consisting of 5-8 family members were coached to utilize problem solving and to address medication adherence barriers and beliefs about schizophrenia and treatment. A sociocultural approach was used in assessing family's attitudes, norms, and perceived resources

toward schizophrenia and treatment. Compared to the control group, the intervention group that received culturally adapted, multifamily group therapy had a significant increase in medication adherence ( $p = .003$ ) and decrease in hospitalization for Spanish speaking Mexican Americans with schizophrenia ( $p = .04$ ; Kopelowicz et al., 2012).

Similarly, Villegan et al. (2008) found weekly cognitive adaptive training (CAT) and pharm-CAT visits with environmental supports (notes, signs alarms, pill containers, checklists) efficacious for improving overall functioning, increased medication adherence, and time to relapse compared with usual care ( $n = 120$ ). [CAT customizes environmental, cognitive and behavioral supports to sidestep deficits in cognitive functioning and improved community adaptation for persons with schizophrenia (Donahoe, 2006)]. Studies reviewed in this section highlight the importance of meeting participants where they are on the health engagement spectrum, and in delivering simple, deliberate, and tailored interventions versus a broad roller approach when attempting to enhance engagement of underserved populations.

**Interventions to Promote Provider Relationship with Patients.** Examining studies from the sole perspective of the patient ignores the vital other half of the patient engagement equation. Both patients and health care providers have essential roles for patient engagement to be successful (Mallinson, Rajabiun & Coleman, 2007). To better understand cultural values, health providers have used strategies like culturally adapting therapies, employing ethnographic and motivational interviewing (Channon, Smith, & Gregory, 2003), using culturally sensitive and linguistically competent providers, extending hours of health care operations to accommodate varying lifestyles and workforce demands, and establishing accessible venues in

non-traditional settings (e.g. wellness buses; Kahler, 2014; U.S. Department of Health and Human Services(USHHS), 2006, 2013).

In addition, to gain access and trust, health facilities have employed peers, or near peers with caring and non-judgmental approaches (U.S. HHS, 2013). In addition, health system navigators, outreach workers, case managers, and promotoras have all been utilized to promote active engagement behaviors for at risk populations (U.S. HHS, 2013). However, most of these strategies focus on gaining initial contact and access to care, but fail to describe the specific skills and strategies needed to sustain engagement of vulnerable and underserved populations.

Most evidence on provider engagement strategies involve shared decision- making (Legare & Witteman, 2013). Shared decision-making, a crux of patient centered care (Weston, 2001), occurs when the provider and patient discuss health care options, benefits, risks, while considering the patients values preferences, and circumstances in jointly coming to a health care decision (Hoffmann, et al., 2014). However, much like patient engagement, there is limited and somewhat conflicting evidence supporting its effectiveness.

Associations between patient engagement in HIV care and specific patient and provider communication and relationship factors was examined in a 2013 study by Flickinger et al. (n=1363.) Observational methods were used to track appointment adherence in an urban academic medical clinic and self-report data from patients via a computer-assisted self-interviewing survey instrument. Patients were more likely to keep appointments when they felt that their providers treated them with dignity and respect, listened to them, explained information to them in ways they could understand, and got to know them as a person. Interestingly, the domain of *“being involved in decisions about their care as much as they wanted”* was not

associated with appointment adherence. Although this observational study was limited in addressing the reasons behind patient's failure to keep appointments and was representative of only a single clinic setting, being involved in decision-making stood out as the one and only domain *not* associated with appointment adherence. Thus perhaps suggesting some patients may not desire an active role in making decisions regarding their HIV care (Stevenson, Cox, Britten, & Dundar, 2004), consistent with the traditional medical model, where the patient passively accepts the proposal of the provider (Couet et al., 2015; Longo, 2005). The assessment of how much involvement patient's desire is often lacking in most studies, with Flickinger's study having no exception.

A multicenter parallel cluster RCT was done by Legare et al., (2010) to test the effect of DECISION + 2, a shared-decision making training program for providers, on the patients use of antibiotics for acute respiratory infections (URI's) after provider consultation. One hundred sixty two providers were given one month to complete DECISION +2, a 2-hour online tutorial that addressed shared decision making, diagnostic probabilities of upper respiratory infections, treatment of URI's, effective communication skills conveying risks and benefits of treatment, and the promotion of active patient participation (Legare et al., 2010). As part of the program, an interactive workshop was included for providers to practice skills learned including use of decision support tools. Post intervention, patients who had providers trained in DECISION+2 were less likely (27.2%) than patients in the control group (52.2%) to use antibiotics. Sixty seven percent of the patients in the intervention group reported having an active role in their care decision process compared to 49% in the control group ( $Z=3.9$ ,  $p<0.0001$ ). Interestingly, there was again no assessment of, or option offered, for patients to decide how much involvement or participation they wanted in the care decision process – an important extraneous factor that was



not considered. Although there was some loss to follow up and many other extraneous factors that could influence provider communication were not controlled for, this study suggests providers can be trained in engaging patients in shared decision-making and enhance their decision-making skills (Legare, et al., 2010).

In the field of dentistry, an RCT by Johnson (2006) tested the use of a decision aid, the Endodontic Decision Board (EndoDB) and its impact on patient knowledge, patient satisfaction with decision-making process, and patient anxiety. The one page- EndoDB helped to clarify treatment alternatives, risks, benefits, prognosis, and costs when root canal and dental extractions were indicated. Patients in the intervention group (n=32) demonstrated a significant increase in knowledge compared to the usual care group (n=35,  $p < .03$ ), but there were no differences between the group's satisfaction or anxiety ( $p > .05$ ). Important to note, no indices of the researcher developed one-page questionnaire used to assess patient knowledge, satisfaction, and anxiety self-reported outcomes were reported, and therefore calls into question the reliability and validity of both the measures used and its results.

In 2004, Elwyn et al. conducted a cluster-randomized trial with crossover with 20 general practitioners who were trained in shared decision making skills and the use of risk communication aids with simulated patients in 2 workshops. Risk communication refers to the discussion of the risks and benefits of the proposed treatment or care options. The second intervention group received the same training but in reverse order, with risk communication training first, followed by shared decision making skills training. The aim of the study was to test which intervention (separately and then combined together) would improve clinician's ability to engage patients in their health care decision-making (Elwyn et al., 2004). Independent, trained

and blinded raters used a validated OPTION scale to assess levels of patient involvement and analyzed the nature of risk information discussed in clinical consultations with patients with known chronic conditions (e.g. atrial fibrillation, prostatism, menorrhagia, menopausal symptoms) via audio taped discussions. Observing Patient Involvement in Decision Making (OPTION) is one of the first measures designed to measure the extent to which health care providers involve patients in decision making from a third party perspective (Couet et al., 2013; Elwyn et al., 2003; Elwyn et al., 2005). The score on the OPTION is derived from the observer rating the health care providers level of expertise on 12 patient involving behaviors throughout the consultation via audio recorded tapes (Couet et al., 2013). Clinicians who received the intervention training had a significant increase in patient involvement after risk communication training ( $p=0.001$ ) and after shared decision-making development ( $p=0.001$ ). Those clinicians who received the risk communication training followed by skill development workshops had a 7.7 % increase in the patient's involvement in decision making that was not seen in the clinicians who received skills before risk communication training. However, the study failed to compare interventions to a pure control group, so the changes seen in the providers may not necessarily be because of the intervention training, limiting the ability to draw any conclusions (Glick, 1974).

A cluster- randomized study tested the efficacy of 12-hour shared decision-making and decision aid training of physicians ( $n=44$  physicians) with oncology patients (Harter et al., 2015) with the inclusion of a control group ( $n=42$  physicians). The intervention group received shared decision and decision aid training and the control group did not. No differences were found at the patient level- between the intervention group and control group in terms of patient's confidence and satisfaction with their decision-making process. Confidence and satisfaction were measured

with Satisfaction with Decision Scale (Holmes-Rovner et al., 1996) and Decisional Conflict Scale (calculated as confidence in decision; Connor, 2005), both self-report scales. However, physicians in the intervention group were more competent (as measured by the shared decision-making questionnaire (SDM-Q-9; Kriston et al., 2010) and third party observation (OPTION;  $p < 0.05$ ). Researchers set a generous alpha level of 0.10 and reported patients treated by the intervention group of physicians' experienced lower anxiety and depression scores immediately after consultation ( $p < 0.10$ ). Remarkably, three months later the results were indeed significant ( $p < 0.01$ ). However, the small sample size of both patients and providers significantly limit the generalizability of these results.

A systematic review of eleven RCT's comparing the effects of shared decision making (SDM) interventions compared with non-SDM on patient satisfaction, treatment adherence, health status, and quality of life was conducted by Joosten et al., 2008. Methodological quality was assessed by two independent reviewers using criteria issued by the Cochrane Back Review Group and was deemed high, and included either three or all four of shared decision making key characteristics:

1. physician and patient are involved
2. both parties share information
3. both parties take steps to build a consensus about the preferred treatment
4. an agreement is reached on the treatment to implement (Charles, Gafni, & Whelan, 1997).

The results of the studies were mixed. Five RCTS showed no differences in studies with shared decision-making interventions and control groups (Gattellari, Butow & Tattersall, 2001; Edwards et al., 2004; Murray et al., 2001; Ruland, White, Stevens, Fancuillo, & Khilani, 2003),

one RCT showed no short term effects but positive long terms effects, and five studies (two in mental health) reported positive effects of shared decision- making on outcomes of satisfaction, well being and knowledge. An important conclusion highlighted the need to examine the process of shared decision-making in order to assess whether the shared decision-making intervention was of poor quality or was lacking in methodological rigor. Moreover, examining the process of shared decision-making would illuminate its essential ingredients (Joosten et al., 2008).

More recently, Couet et al., 2013 conducted a systematic review of studies to assess and summarize the extent to which providers involve patients in the decision-making process during consultations. Literature was searched between 2001 and 2012 including studies that reported having used the previously described Observing Patient Involvement in Decision Making instrument (OPTION). Only descriptive analysis was performed on the 33 total studies reviewed. Provider behaviors that were most consistently observed in over 69% of the studies reviewed were: *identifying the problem, providing opportunities for questions and indicating need to review or defer treatment options*. Alarming, the provider behaviors that were consistently observed the least were: *eliciting patients preferred involvement* (0/18 studies) and *assessing their preferred approach* (observed once out of the 18 studies reviewed). However, the authors self-disclosed the incompleteness and “fuzziness” of the data reviewed preventing any statistical testing or modeling attempts for more precise estimates.

Although shared decision making is being highly promoted with the intent to improve the health of patients while controlling costs (et al., 2011), evidence to support its effectiveness is quite mixed or flawed with design errors. Moreover, none of the reviewed intervention studies went into much detail as to the essential elements of the shared decision process or training making it especially difficult to assess the quality of the shared decision- making intervention.

As mentioned earlier, mixed results can be a result of an ineffective intervention or a poorly executed intervention. Rigorous study is needed to shed light on the process of shared-decision making, and its crucial components, in order to understand what shared decision making truly entails; this would clarify the meaning and implementation for both patients and providers.

## **Conclusion**

In summary, this chapter has covered defining the conceptual broadness and complexity of patient engagement and the myriad of factors that affect engagement's crucial patient-provider relationship. Interventions to improve patient engagement via the patient-provider relationship focused on patients, providers, and historically underserved populations were reviewed and examined.

An extensive appraisal of the patient engagement literature was presented. Key findings included the patient factors: cultural values, socioeconomic status, health literacy and activation/motivation levels as having a substantial impact the crucial patient-provider relationship. In addition, provider training and experience in communication, time constraints, and shared decision-making are factors that significantly impact if and how the patient provider relationship is both established and maintained. In examining the various patient and provider factors that impact the foundational patient-provider relationship in which patient engagement is built upon, it becomes clearer why it is so difficult to define and operationalize patient engagement and specify its application to practice.

Studies reviewed demonstrated engagement behaviors are teachable and learnable, but the long-term effects of engagement education and resultant health practices remain unclear. Therefore, it is essential to consider and gauge a patient's level of engagement and capacity to engage (including cultural values, socio-economic status (SES), health literacy,

activation/motivation) before and during interactions with health care providers in order to improve both the effectiveness and efficiency of care delivery. Moreover, provider studies that focus on specific skills and strategies used to develop a relationship, assess engagement levels, engage patients, and maintain engagement are lacking.

Although seemingly intuitive and generally accepted, the connection between increased engagement and improved outcomes is not strongly supported by clear scientific evidence. Homogenous and small sample sized studies suggest a clear association between active patient engagement and better health care outcomes and lower costs. However, the directional causality as to whether better health precedes engagement or whether engagement precedes better health care outcomes is less clear. Further investigation into the empirical evidence revealed patients who were actively engaged in their healthcare had embedded resources (i.e. education, health literacy, accessibility to ample resources, positive role modeling), which naturally help create an engagement advantage or ease in establishing a working relationship with their providers. Moreover, the existing research is limited to those participants who choose to participate in the research versus vulnerable populations that remain on the outskirts of both research and health care at large.

Interventions that helped to guide, support, and teach patient engagement activities and patient provider relationship building skills had some success but were limited in the variety and specificity of the engagement skills and strategies employed. Interventions that promote patient engagement and patient provider relationship construction with underserved populations include collaborative care management enhanced with socio-cultural adaptations. Although shown to be effective, the literature is lacking in precise detail and rich description as to how providers were trained and specifically how they adapted their interpersonal practice to enhance the patient-

provider relationship and participant engagement. Questions remain as to whether participant engagement behaviors improved- leading to improved outcomes, or if the improved outcomes were a direct outcome of the additional time, attention, and support received. Interventions to enhance and promote provider relationships with patients primarily focused on shared decision-making interventions. The assessment and measurement of patients' desire and preferred approach of shared decision-making was seldom mentioned and often lacking in the studies reviewed, as was specific detail and description of the essential elements of shared decision making or provider training curriculum.

Lack of measurement of participant engagement factors and capacity paired with a lack of detail about provider training leaves a substantial gap in the patient engagement literature and evidence base. Moreover, theoretical underpinnings were seldom mentioned in the studies reviewed, and no formal patient engagement framework was used or described. In order to advance the science, a patient engagement framework with the essential ingredients and formula of patient-provider relationships and patient engagement needs to set a foundation in which the science and research can be built upon and guided.

A back to basics approach is necessary to examine the process of patient engagement using a conceptual framework to illuminate the essential elements of: *how* the patient- provider relationship is established, *how* it develops and is maintained, and *what* explicit skills and strategies are required to foster and enhance the patient-provider relationship and patient engagement.

A key focus of this study is the inclusion of the Interactive Care Model. This study helped to elucidate the essential elements of patient engagement using the Interactive Care Model as the lens through which to examine both the patient-provider relationship and patient

engagement. To address the gap in understanding patient engagement in a vulnerable population, this study specifically focused on how mental health nurses richly described the skills and strategies used to engage and develop a therapeutic relationship with a historically underserved and disengaged population- low income depressed mothers, in a mental health intervention. By grounding the study in the ICM, the study addressed the three major components of engagement 1) *what relationship building and patient engagement entails*, 2) *how patient-provider relationships are initiated and maintained*, and 3) *how relationship building and patient engagement are executed in clinical practice*. Additionally, the perceptions of the providers as to *how* they engaged a traditionally underserved population, and subsequent outcomes of specific engagement skills and strategies were examined. The study also showed important elements of the Interactive Care model that were missing, and thus added new perspectives and insights to potentially further advance the science of patient engagement.



Table 2.2 Evidence Tables of Reviewed Studies

<u>Authors/Year</u>	<u>Sample</u>	<u>Study design</u> <u>Variables</u>	<u>Measure used / Outcome</u>	<u>Limitations</u>
Greene, Hibbard, Sacks, Overton, Parrotta 2015	Group 1 (n=32,060) Group 2 (n=10,957)	Longitudinal observational study primary care patients at, forty-four primary care clinics in Minnesota. IV- patient activation DV- 13 health related outcomes in areas of clinical indicators Healthy behaviors Preventative screening Avoid costly utilizations	PAM / After age, sex, number of chronic conditions, and income were controlled for, more activated patients had normal HDL, serum triglycerides, and PHQ-9; more likely to be nonsmokers; and non-obese, obtain cancer screening tests (Pap smears and mammography), decreased hospitalization or ED visit two years after the Patient Activation Measure level was collected. Furthermore, patients at higher levels (3 or 4) had projected costs that were 8 percent lower than those at level 1 and 13 percent lower than those at level 2 (Exhibit 2).	Non-generalizable. Homogeneous population. 60-64% female Sample not entirely representative of all Fairview health system patients: They were somewhat older, had higher chronic illness burden, and resided in lower-income ZIP codes. Outcomes could be influenced by another unmeasured factor that was related to both the Patient Activation Measure level and the outcomes.
Fowles et al 2009	N=625 employees from large health care system and airline Industry Employed population with health risks	Secondary analysis of RCT controlling for age, gender and race IV- engaging in healthy behaviors, seeking health information and readiness-to-change. -	PAM In separate multivariate analyses controlling for age, gender and race (Table 4), PAM scores were positively related to engaging in some healthy behaviors, including exercise, eating breakfast, eating fruits and vegetables, but not to having a personal physician or nurse practitioner. For measures of health information-seeking, PAM was directly related to recognizing reliable Web sites for health information, reading medical resource books, subscribing to health magazines or newsletters, knowing where to find comparative	Most participants were women (87%) and white (90%), with an average age of 45 years. 44% having at least a four-year college degree. PAM scores were directly related to some demographic characteristics (higher education, higher income and being married). The scores were not related to age, gender or race.

			information about hospital quality, and knowing about health plan choices. The PAM score was directly related to readiness-to-change to live a healthier lifestyle	
Kangovi 2014	Sixty-five low-income, recently hospitalized patients	Modified ground theory- in-depth semi-structured interviews to explore perceptions of hospitalization and discharge, barriers to recovery, and ideas for improving the post-hospital transition. Qualitative PAR study in order to engage high-risk patients and understand their needs and preferences	Five key themes patients wished to establish a relationship with healthcare personnel to whom they could relate. Second, patients suggested tailoring support to their needs and goals. Third, patient goals were misaligned with those of the inpatient team. Fourth, patients lacked post-discharge support for predominantly psychosocial or financial issues that undermined recovery. Finally, patients faced numerous barriers in obtaining post-hospital primary care.	Small sample size, which limits generalizability.
Hibbard & Cunningham	2008		Activation levels differ considerably across  Socioeconomic and health status characteristics Status characteristics.	Because activation levels are linked to important outcomes, such as Seeking care, seeking information and health behaviors, and because it is a changeable attribute, it is a potentially important lever for change.
Rogvi et al., 2012	2045 pts with diabetes	cross-sectional study used a survey and record review to assess aspects potentially associated with glycemic control: (1) socio-demographic factors (age, gender and education); (2) clinical conditions (recorded duration of diabetes and presence of other chronic diseases); (3) lifestyle indicators (self-management behaviors and latest measured BMI); (4) patient activation, assessment of care and diabetes-related emotional distress;	Problem Areas in Diabetes scale to assess emotional distress PAM/ Lower patient activation and more diabetes-related distress were associated with poor glycemic control.	The cross-sectional design limits the ability to draw causal conclusions. Another limitation is our relatively low response rate of 54% and the fact that non-respondents differed significantly from respondents. This raises the issue of selection bias. Furthermore, the patients treated at the Steno Diabetes Centre, in general, had severe diabetes and many patients had diabetes complications, other chronic

		and (5) knowledge about target HbA <sub>1c</sub> .		diseases, poor glycemic control and low educational level. These factors may limit the generalizability of our results to patients with these characteristics. Another limitation is the self-reported information on behavior. However, these variables are very often self-reported and, as such, are comparable to most other studies.
Rask et al., 2010	N= 287 Mostly African American females who were uninsured	<p>Cohort study</p> <p>Oral interviews were used to assess each patient's socioeconomic background, health status, medical history, and self-management behaviors.</p> <p>cross-sectional comparison of activation scores and other self-reported behaviors to assess concurrent validity.</p>	<p>PAM</p> <p>Patients reporting weekly foot exams, regular exercise had</p> <p>Pts reporting significant checks, recommended eye exams and regular exercise had significant higher mean PAM scores</p> <p>Higher activation levels as measured by the PAM survey were associated with higher rates of healthy behaviors and less difficulty managing diabetes care</p>	the study sample was recruited from a public hospital diabetes clinic and thus may not be generalizable to other populations.
	56 patients with type 2 diabetes	56 patients with type 2 diabetes	ASK-20, Morisky Adherence Scale, Patient Activation Measure (PAM-13), Appraisal of Diabetes Scale, Interpersonal Support Evaluation List (ISEL-12), Perceived Stress Scale (PSS-4), and Short-Form Health Survey (SF-12). The Benefit-Finding Scale-Pre and post-intervention assessments measured	First randomized controlled trial to analyze the effectiveness of an individualized diabetes coaching intervention that, in addition to providing education, targets internal motivation by linking behavioral goals to patients' values and personal vision of health. Improvements were observed in

			medication adherence, exercise frequency, patient engagement, psychosocial variables, and A1C.	self-reported medication adherence, patient engagement and behavior, perception of illness, psychosocial measures, and A1C.
Kidd, Lawrence, Booth, Rowat, & Russell, 2015	26 stroke survivors, between 3 and 12 months post stroke and 16 stroke nurses, from across three NHS Boards in Scotland.	Mixed methods  ‘tailored self- management action plan,’ designed in a booklet format (included as supplementary material), and created by nurses and stroke survivors working in partnership using a structured self-management assessment questionnaire (The PAM) and a process of goal-setting	Interviews PAM tailored and personalized approach offered by the use of the goal-setting, underpinned by motivational interviewing, was perceived as particularly valuable by both stroke survivors and stroke nurses, and was feasible in the context of nurses practice in supporting self-management. The emphasis on the goals being patient-initiated and patient-articulated, being personally meaningful and often outside of the traditional realm of health services, as well as the process of documenting and recording these in an explicit and systematic manner, provided a valuable structure to delivery of self-management support and engaging individuals in meaningful self-management.	Small sample of stroke survivors, the majority of whom were between 1 and 6 months post stroke, male and who did not experience any particularly severe cognitive, communicative and/ or visual impairments. Furthermore, participants in the evaluation phase were selected by nurses, which may have introduced a degree of selection bias. The findings from the study sample are, therefore, by no means generalizable

## **CHAPTER 3**

### **METHODOLOGY**

Public Law 111-148- the Patient Protection and Affordable Care Act (PPACA) (2010) identifies and emphasizes patient engagement as a key component of quality in transforming health care delivery systems (Doherty, 2010; Stone & Hoffman, 2010). A cornerstone of the law is to improve access to quality health care for underserved populations. Patient engagement holds promise in terms of reducing disparities, reducing costs, and improving outcomes (Hawkins & Groves, 2011; Koh, Graham, & Glied, 2011; Lillie-Branton & Hoffman, 2013); however, patient engagement at the direct care level has not been studied systematically to identify, describe, and clarify its key concepts and operationalization of the concepts in clinical practice. Direct care refers to the provision of health care services requiring some degree of personal interaction between patient and health care provider (Medical Dictionary for the Health Professions and Nursing, 2012). Whereas some engagement frameworks have taken a broad systems or policy approach to engagement (Bechtel & Ness, 2010; Carman et al., 2013; Koh, Brach, Harris, & Parchamn, 2013), an in-depth examination of the specific process of engagement between patient and provider is lacking.

Thus, there is a timely need to know and understand what skills and strategies exemplify and demonstrate patient engagement at the direct care level and how these

skills and strategies are used in order to implement effective systems of care. Moreover, gaining clarity about the process of patient engagement with vulnerable and at-risk populations has the potential to illuminate and inform the necessary changes for both health care providers and the health care system to change and advance the current health and illness care paradigm.

The purpose of this study was to examine retrospectively the specialized, relationship-based strategies used by advanced practice mental health nurses to engage and retain high-risk mothers in a mental health care intervention. Data were collected from using nursing narrative data from the Reducing Depressive Symptoms in Low Income Mothers (HILDA; NIH R01MH065524), a randomized controlled trial carried out from 2004-2010. “High risk” refers to the increased likelihood of mothers’ experiencing depressive symptoms based upon a combination of genetic, physical, psychological, and environmental risk factors (Piccinelli & Wilkinson, 2000; Risch et al., 2009). Specifically, mothers in the original study had low socio-economic status and histories of facing significant life stressors, traumatic events, disturbances in interpersonal relationships, and limited social supports. Nurses who were part of the study intervention, strived to establish an interpersonal connection with the mothers, creating a context in which mother’s depressive symptoms, parenting skills, and life challenges were addressed (Beeber et al. 2013). The nurse role is critical in establishing and sustaining the therapeutic milieu (Peplau, 1952) in which collaborative nurse-patient partnerships form and thrive, to thus foster and improve patient engagement, patient care,

healing, and optimum health.

### **Nature of the nurse role in the nurse-patient relationship**

The nurse-patient relationship is central to nursing care throughout the spectrum of health, illness, healing, and recovery (Hagerty & Patusky, 2003; Peplau 1952; Sheldon, 2009), as the relationship is the basis for a care partnership to commence. Established by a conscious commitment by the nurse to care for the patient, the relationship embodies a mutual agreement to work together for the patient's benefit. In using a patient-centered approach, the nurse and patient establish and agree upon the structure and purpose of their partnership to address and meet the patient's needs (Anderson & Funnell, 2005; Cronenwett et al., 2009; Johnson et al., 2008).

The purpose of the nurse-patient relationship is to support the patient, promote healing, and support or enhance functioning (Sheldon, 2009). Practicing within professional, legal, ethical and personal boundaries, the nurse respects the individuality of each patient and strives to understand their respective response to health challenges (American Nurses Association (ANA), 2015). Patients differ in their responses to health and illness and ways of adapting to health challenges, requiring the nurse to be non-judgmental and accepting of them as human beings. Additionally, the nurse needs to respectfully take into account patient's symptoms, feelings, values and beliefs and work in collaboration with the patient to achieve care goals (Griffith, 2012; Sheldon, 2009). By integrating fundamental concepts of intentionality, respect, empathy, trust, genuineness,

and confidentiality into communications and interactions with patients, an effective nurse-patient relationship can be established and maintained (Sheldon, 2009).

**Intentionality.** Defined as a consciousness or awareness directed towards another (Watson, 1999, 2002), the philosophical concept of intentionality involves the projection of awareness with purpose and efficacy toward action, expectation, belief, volition, and even the unconscious (Pilkington, 2005; Quinn, 1996; Schlitz, 1996;). Intentionality in nursing practice focuses on and is mindful of the patient connection, and in promoting physical, psychological, and spiritual healing (Herbst, Swengros, & Kinney, 2010).

**Respect.** Described as “unconditional positive regard” (Rogers, 1961, p.283), respect is the ability to accept another’s beliefs despite one’s personal feelings without negatively judging their basic worth (Milton, 2005; Sheldon, 2009). By suspending judgment and acknowledging patient’s unique experiences in responding, adapting, and coping with health challenges, nurses demonstrate respect for the patient as a fellow unique human being (Sheldon, 2009).

**Empathy.** Empathy is “educated compassion” or the intellectual understanding of a person’s emotional state (Sheldon, 2009, p. 57). Empathy stems from a desire to understand the patient experience from the patient perspective, and allows the nurse to recognize patient concerns and feelings to inform compassionate care (Sheldon, 2009).

**Trust.** Involving confidence and reliance, the concept of trust denotes becoming



vulnerable and dependent on another person's intentions and motivations (Mosby's Medical Dictionary, 2009). Foundational to all interpersonal relationships, the development of trust is a basic, primal human need (Freud, 1912). As one of nursing's intangible assets and core values, trust between nurse and patient generates a context in which personal, sensitive, and relevant information can be shared (Rutherford, 2014). Having trust in the nurse and in the nurse patient relationship can often help quell patient's feelings of vulnerability and uncertainty (Bell & Duffy, 2008).

**Confidentiality.** Confidentiality is the ethical principle undergirding the information a patient shares with their health care provider. Confidentiality implies that information is private and that there are specific limitations as to how and when information may be disclosed to a third party (Dorland's Medical Dictionary for Health Care Consumers, 2007). Nurses have a moral and legal responsibility to keep patient information confidential, with the exception of cases with suspected abuse, crime, or threat of harm to self or others (ANA, 2015; Cochran, 1999). Knowledge of nurse's responsibility of confidentiality can facilitate patient trust and open communication.

Hildegard Peplau (1952), a pioneer in nursing theory development, described the nurse-patient relationship as "a significant, therapeutic, interpersonal process . . . that makes health possible" (p. 205). In her landmark book, *Interpersonal Relations in Nursing: A Conceptual Frame of Reference for Psychodynamic Nursing*, Peplau's central focus was the planned, professional, reciprocal, and therapeutic relationship between the

nurse and patient as the basis and context for which professional nursing occurs (Black, 2016; Peplau, 1952). Different from a social relationship, the therapeutic relationship formed between nurse and patient is patient-centered, health focused, goal-oriented, and is delineated by clear professional boundaries (Dean, 2016; Peternelj-Taylor, & Yonge, 2003; Sheldon, 2009). Peplau's theory notably shifted the focus from what nurses *do to and for* patients, to what nurses *do with* patients, thus envisioning nursing as an interactive and collaborative process between nurse and patient (George, 1990; Peplau, 1997; Sheldon, 2009).

Often the most consistent health care provider in many patients' lives, the nurse bears great responsibility in providing communication that is professional, honest, empathetic, and knowledgeable while protecting patients' dignity, autonomy, and privacy (Alfaro-LeFevre, 2009; ANA, 2001; Arnold & Boggs, 2015; Sheldon, 2009). Peplau referred to the nurse's *therapeutic use of self* as the use of one's genuine personality and communication skills to assist patients in achieving health (Beeber, 2000; Peplau, 1952). Integrating genuine personality and self into practice, allows for a sense of authenticity and shared humanity to develop and often humanizes the patient's health care experience (Cornelius-White & Motschnig, 2012; Sheldon, 2009).

### **Phases of the Nurse-Patient Relationship**

Essentially unscripted, the nurse-patient relationship is "unique in both process and outcome", however the relationship has structure supported by three distinct and

recurring phases: the orientation phase, working or exploitation phase, and termination phase (Peplau, 1952, p. 17). The orientation phase is characterized by the introduction of the nurse, including professional status, purpose, nature, and time available for the patient, essential patient and health information is collected, and the nurse and patient begin to get to know one another as individuals (Peplau, 1997; Sheldon, 2009). During this phase, the nurse's behavior and reactions have great potential in signaling receptiveness and interest in the patient (Peplau, 1997). A successful orientation phase is characterized by the formation of mutual trust between nurse and patient, the patient divulging his or her needs and problems, and both nurse and patient agreeing to work on addressing the needs or problems together during an estimated timeframe to accomplish established health care goals (Black, 2016; Hagerty & Patusky, 2003).

The exploitation, or working phase, involves the patient and nurse exploring, understanding and dealing with the patient's underlying problems or issues (Peplau, 1991). Focused on patient reactions to their health problem or issue, the nurse strives to help the patient understand himself or herself and the necessary modifications required to achieve his/her health care goals. A patient may regress in reaction to the arduous stresses of making and sustaining behavioral changes (Black, 2016). Thus, the nurse is required to practice patience and self-awareness, in order to actively listen and effectively communicate with patients to help facilitate necessary change and growth (Sheldon, 2009).

Finally, the resolution, or termination phase occurs when a patient's needs have been met and there is no longer a need for or dependence on the nurse. The relationship ends as previously planned, ideally, with both patient and nurse having grown and changed in positive ways. Phases of the nurse patient relationship were clearly and widely represented in the pilot study, using a conventional content analysis of the HILDA/original study data, described later in this chapter.

### **Original Study**

The purpose of the original HILDA study, named in honor of Hildegard "Hilda" Peplau, was to help mothers manage their depressive symptoms and life issues, increase their social supports, and help them enact effective parenting techniques (Beeber et al., 2013). Using a combination of evidence based treatment for depression, Interpersonal Psychotherapy (IPT), and a symptom-specific parenting component, advanced practice psychiatric mental health nurses sought to reduce mother's depressive symptoms and improve interaction with their child(ren; Beeber et al., 2013). The intervention study used IPT focused on the mother's interpersonal issues that factored into the genesis and maintenance of their psychological distress (Stuart & Robinson, 2012), with the goal of symptom resolution and improved interpersonal functioning (Beeber et al., 2013). The intervention was delivered in the homes of low-income mothers of infants and toddlers who were enrolled in the Early Head Start Program, a federal child enrichment program that provides early, intensive, comprehensive and continuous child development and

family support services to pregnant women, low-income infants, toddlers and their families (Head Start, 2013). Mothers eligible for participating in the original intervention study had scored 16 or above on the Center for Epidemiological Studies Depression Scale (CES-D), indicative of the presence of significant depressive symptoms (American Psychological Association, 2016).

Advanced practice mental health nurses delivered the IPT intervention at the mother's home, meeting face to face with the mothers for the first 10 sessions, followed by five booster telephone calls, and concluding with a final face to face meeting. After every session, the nurses recorded narrative notes, providing detailed data and unique perspectives regarding the home setting and atmosphere, interactions and specific exchanges with the mothers and family, and interpersonal skills, strategies, and techniques employed to establish a relationship, engage, and retain the mothers in the intervention (Beeber et al., 2013).

As described in chapter 2, many studies measure engagement success based upon outcomes like depression, medication adherence, or patient satisfaction. However, studies that measure patient engagement per se are notably lacking in the existing patient engagement literature thus begging the question: do outcomes improve because patient engagement levels improved, or do outcomes improve because the patient receives extra attention and support during the intervention? In the original study, nurses assigned adherence ratings for each session, a one-item ordinal rating indicating the nurse's

perceptions of how well the mother was following through with the mutually agreed upon health strategies and suggestions from the previous visit. The adherence ratings offer a unique measure of mother's engagement in the intervention. Based upon a 5 point Likert scale the adherence ratings were described as follows- 0= not at all engaged, 1= engaged very little, 2= somewhat engaged, 3= engaged well, and 4=engaged very well. During weekly reflective supervisory meetings with the research team leadership, nurses discussed specific criteria for the assigned rating to ensure consistency in their assigned ratings. However, the adherence ratings capture a partial, incomplete view of patient engagement, limited to the view of the nurse. A conceptual misfit of sorts exists as the nurse holds a position of power in assigning an adherence rating to the mother- not indicative of the collaborative partnership between nurse and patient. As such, for the proposed study, the adherence ratings can only serve as a proxy for the mother's level of engagement. Ranging from 0 (not at all) to 4 (very well), the adherence ratings offer a moment-to-moment snapshot of each weekly session as well as adherence over the 5 months duration of the original intervention, providing significant opportunity to examine nurse's responses to mother's varying engagement levels.

In addition to assigning weekly adherence ratings, the nurses (again unilaterally), indicated the phase of the interpersonal relationship between nurse and mother (i.e. orientation, working, termination). The identification of whether the relationship with the mother was in orientation or working phase allows for the analysis of when the

movement from orientation phase occurred for each nurse-mother dyad and examines differences in the length of the orientation phase.

Whereas the original HILDA randomized control study examined the pre and post intervention changes in mother's depressive symptoms and coping abilities, the nurse's description of engagement skills and strategies used to develop the nurse-patient relationship and subsequent adherence ratings have yet to be closely examined. Therefore, the HILDA data afforded a unique opportunity to (1) examine specific nurse-patient relationship building and engagement skills and strategies from the unique perspective of the mental health nurse, (2) examine how engagement skills and strategies were employed in response to mothers' varying levels of engagement as measured by the adherence ratings, and (3) examine how the length of the orientation phase impacts the nurse's ratings of the mother's adherence.

### **The Interactive Care Model as an Analytical Framework**

Clinical and patient engagement experts, researchers, and industry thought leaders at the O'Neil Center of the Get Well Network Inc., based in Bethesda, MD developed the Interactive Care Model (ICM) in response to the lack of conceptual structure and guidance for patient engagement in the current health care paradigm. Informed by input from clinicians and patients from several major health systems, the purpose of the ICM is to advance the science of patient and family engagement by outlining a process of how to fully engage patients in their health care (Drenkard, Swartwout, Deyo & O'Neil, 2015).

The model, unlike other patient engagement frameworks, was created with the specific intention and focus on the current, fundamental, and evolving patient and provider roles and relationships required to reach the triple aim of better care, better outcomes, and lowered costs (Berwick, Nolan, Whittington, 2008; Drenkard et al., 2015).

The Interactive Care Model provides a useful framework for analyzing the perceptions of nurses who aimed to establish a relationship with and engage low-income depressed mothers in a mental health and parenting intervention. The model describes actions providers can take to help patients and their families become more engaged in the management of their health (Drenkard et al., 2015). The ICM has five distinctive process components or key phases of care delivery: (a) a comprehensive assessment of a person's capacity for engaging in their health and health care, (b) information exchange and communication of choices, (c) development of a strong patient-provider partnership to create plans, (d) implementation of mutually determined, suitable behavioral, technological, and clinical interventions, (e) regular evaluation of patient's engagement level and clinical outcomes to revise the plan to achieve optimal health (Drenkard et al., 2015, p.506). Nurse's perceptions as to the manner and degree in which they engage low-income depressed mothers in the mental health intervention were explained as a function of these five process components.

**Assessing person's capacity for engagement.** Determining a person's capacity for active participation in their health care is a critical first step for successful patient



engagement. A person's capacity for engagement is highly influenced by their social, cognitive and emotional capacity to engage (Bandura, 2005). Additionally, factors often tied with socio-economic status, like availability and access to necessary resources (e.g. finances, time, health literacy) impact engagement, as does a person's emotional and physical energy and motivation to engage (Coventry, Fisher, Kenning, Bee, & Bower, 2014; Drenkard et al., 2015). Cognitive capacity for engagement can range from difficulty receiving simple health information to actively partnering with the health care team, setting goals, making shared decisions and proactively managing their care (Carman et al., 2010; Drenkard et al., 2015). Therefore, *determining* a person's capacity for engagement sets a starting point and reference for communication, education, and tailored interactions to begin (Drenkard et al., 2015).

Assessing mothers' capacity for engagement begins in the orientation phase and continues throughout the intervention. Mothers facing significant barriers to engagement may take longer in the orientation phase compared to mothers without such barriers.

**Information exchange and communication of choices.** This phase of care delivery addresses the clinical expertise of the health care provider as well as the patient's expertise in terms of their values, preferences, health goals, and beliefs (Drenkard et al., 2015). Ideally, an open discussion will ensue resulting in both parties having a sound understanding of what choices are best for the patient (Drenkard et al., 2015) A pre-requisite for vital information exchange is health literacy, the degree to which individuals have the capacity to obtain, process, and understand basic health information and services

needed to make an informed health care decisions (Sorenson et al., 2013). Cultural differences, limited education, lower income levels, non-native English speaking, and compromised health status have been shown to negatively influence a person's degree of health literacy and ability to engage in health care decision- making (Alegria et al., 2008; Arora & McHorney, 2000; Bernabeo, & Holmboe, 2013; Cabassa, Lester , & Zayas, 2007; Levinson , Kao , Kuby , & Thisted, 2005; National Center for Education Statistics, 2006). Many mothers in the original study had limited education and, all had low socio-economic status, and diminished energy and motivation secondary to their depressive symptoms, impacting their ability to exchange information, actively partner in discussing their health, and in making decisions (Beeber et al., 2013). Thus, a central task for the nurses was to adjust their communication, education, and engagement styles to meet mother' unique needs and various engagement levels (Drenkard et al., 2015).

**Development of a strong patient-provider partnership to create plans.** The patient-provider relationship has and continues to be the keystone of health care (Duclos et al., 2005; Goold & Lipkin, 1999; Jennings, Heiner, Loan, Hemman, & Swanson 2005; Kukla, Matthias, Salyers,& Eliacin, 2015). The ICM's third phase of care delivery highlights the importance of the trusting bond between provider-patients that allows for effective information exchange, planning, and utilization of existing resources to take place. However, low-income mothers may feel distrust and be skeptical of the health care system and providers and their ability to understand their fears and realities of daily life

(Beeber et al., 2004; Belsky, 1984; Knitzer, Theberge & Johnson, 2008; Mowbray et al., 2000). Moreover, the same depressive symptoms that blunt mother's interaction with her infants or toddlers (Beeber, Holditch-Davis, Belyea, Funk & Canuso, 2004;; Bugental & Happaney, 2004; Bugental, Martorell, & Barraza, 2003 Laurant & Ablow, 2012) may blunt their active participation as a health care team member and interactions with the mental health nurse.

**Implementation of mutually determined, suitable behavioral, technological, and clinical interventions.** This phase of the ICM involves the patient and provider jointly determining the interventions needed in order to maximize the patient's health (Drenkard, 2015). For example, teaching a patient about the early identification of symptoms and health issues, self-management strategies, and when to consult their provider empowers the patient to become proactive in his or her health care (Drenkard et al., 2015). Interventions also include education, peer support groups, engagement reminders, and symptom tracking tools for certain disease pathways (Drenkard et al., 2015). Together, patient and providers choose and implement mutually agreed upon behavioral, clinical or technological interventions that help support and educate the patient in taking an active role in their health and healthcare (Drenkard et al., 2015). Part of this phase involves a focus on the utilization of mobile technologies and other creative technologies used to empower patients to access and take charge of managing their health and health care (Drenkard et al., 2015). Recall that interventions need to match a person's

level of engagement and readiness to engage and manage their self and health care (Drenkard et al., 2015).

In the original study, many mothers' low-income status interfered with access to web-based technologies (Beeber et al., 2013). As such, nurses used simple, laminated skill sheets, tailored to the mother's literacy levels to help them with their depressive symptoms and help them navigate the health care system and community resources. Skill sheets provided prescribed mental health education and short action plans for times when the mothers were feeling particularly down or frustrated. Skill sheets were often mounted to the kitchen refrigerator for the mother's quick and frequent reference.

**Regular evaluation of patient's engagement level and clinical outcomes.** The final phase of the ICM framework involves evaluation of engagement levels and clinical outcomes to determine the effectiveness of the delivered interventions. Interventions cannot be deemed successful unless mother's engagement level and clinical outcomes can be measured and tracked (Porteny & Watkins, 2015). By evaluating mother's engagement levels via the adherence ratings, nurse's engagement styles and interventions can be modified and care ultimately enhanced.

### **Pilot study**

Seidman (1998) recommended researchers build a pilot project to test their research design in order to gauge their own ability to conduct studies and to come to terms with practicalities. An advantage of conducting a pilot study is that it may give

advanced warning about where a main project might fail (Van Teijlingen, & Hundley, 2002). In preparation for the proposed study, a non-published pilot study using an inductive categorical approach was performed to determine if and what identifiable, substantive patient engagement skills and strategies existed within the narrative notes (Mayring, 2000). Conventional content analysis was intentionally chosen to describe the phenomena of nurse's perceptions of engaging low-income depressed mothers *without applying the ICM* to the narrative prematurely. Thus, the data in the narratives was able to emerge on its own, with no preconceived interpretations or prejudice (Hseih & Shannon, 2005; Kondracki & Wellman, 2002).

The research question for the pilot study was:

*What skills and strategies did advanced practice mental health nurses report using to engage low-income depressed mothers in a mental health intervention?*

After reviewing each of the 114 narrative cases (the intervention arm of Beeber's original study), three distinct patterns were identified from the nursing narratives and adherence ratings data. In tracking the nurses' ratings of the mother's adherence throughout the intervention, each set of narrative notes was assigned to one of 3 groups meeting the following criteria: (1) mothers who were engaged from the start and stayed highly engaged (adherence ratings were 3-4 and remained throughout), (2) mothers whose engagement fluctuated throughout the intervention (ratings fluctuated from 0-4 throughout the intervention), and (3) mothers who were minimally engaged (ratings never went above 0-2) or dropped out of the intervention early. A complete set of narrative notes (10

narrative notes from one nurse-mother dyad) was purposefully selected for the pilot study based upon mother's fluctuating adherence rating and data richness from a highly skilled, experienced, and practice savvy, advanced practiced mental health nurse who facilitated the full ten visits of the home-based intervention. In the particular case selected, the mother had been repeatedly avoiding contact with nurses from the study (e.g. not answering phone calls, not calling back, not answering the door). Challenging circumstances in the home and an ongoing child protective service investigation called for the deliberate and finessed sensitivity of an expert mental health nurse. The nurse's vast clinical expertise and experience proved crucial in her being able to keep her composure and focus while delivering the intervention in the midst of unpredictable and often-challenging home situations. By deliberately examining an extreme case, different and divergent nuanced views (Drisko & Maschi, 2015) of barriers encountered and engagement skills and strategies used to overcome barriers were identified. In Vivo coding was used as the coding method to honor and prioritize the nurse's voice (Miles, Huberman & Saldana, 2013).

Results of the pilot study indicated the nurse's narrative notes were rich with patient engagement skills and strategies. See Table 3 for themes and coding scheme. Of the 35 codes assigned to the data, *social rituals*, *mother's story*, and *coaching* stood out among the others in both frequency and robust representation of the broader themes of orientation, knowledge exchange, and therapeutic work. Themes discovered were

illustrative of Peplau's three phases of the nurse patient relationship- orientation, working, and exploitation phases.

Table 3.1 **Themes and Coding Scheme from Pilot Study**

<u>Orientation Theme</u>	<u>Knowledge Exchange Theme</u>	<u>Therapeutic Working Theme</u>
SOCIAL RITUALS	Mother--→ Nurse	Nurse offers suggestions and works
Rapport Building	“HER” STORY	on skills with the mother
Taking in context	History	Mother centric
Persistence (nurse)	Feelings	Role play
	Thoughts	Practice together
	Symptoms	Mother centric and tailored
Establishing trust	Nurse -→ Mother	Collaboration
Establishing boundaries	Teaching	Shared decision making
Time keeping	Questioning	Navigating
Signing agreement/contract	Suggesting	Planning
Relationship building	Modeling	COACHING
Using Humor	Reflecting out loud	Goal setting
		Practicing, role playing
Planning	Planning	Evaluating
Nurse reflection	Nurse reflection	Nurse reflection

**Social Rituals.** Simple social rituals such as calling ahead of time, apologizing when late, small talk or “chatting”, introductions with family present in the home, the use of light humor, touring the house, and walking a guest to the front door were described in the nurse’s narratives. Although seemingly insignificant, the social rituals seemed to offer a preview to the give and take nature of engagement in the intervention. Also of interest was the nurse’s decision to include these aspects in her notes, evidence that she thought these rituals were significant: “I called 30 minutes before appointment on Thursday – mom said she had a program at child’s school and asked to reschedule which we did for the next day.” The nurse’s prioritization of the mother’s needs, values, and preferences, indirectly communicate her commitment to the shared goal of improving the mother’s mental health and parenting skills.

**Knowledge Exchange.** In order for the nurse to meet the mother where she was, considering her contextual reality, a significant amount of knowledge and information exchange was required. While the nurse had valuable expertise and knowledge about mental health and effective parenting techniques, it is the mother who is expert on “her story”, her day to day struggles, her feelings, and her current circumstances. From the data, two types of knowledge exchange emerged. The first was somatic in nature, describing the mother’s recent thoughts, feelings, and fears. The second was more contextual in terms of relationships within the mother’s family, and her deeply personal history of abuse, rape, and neglect. For the nurse, both sets of information were



described as being extraordinarily valuable and complementary in tailoring care accordingly.

The nurse reported using “active listening” and “purposeful silence” to allow time for the mother to verbalize her story. Thus demonstrating respect for the value of the mother’s story, knowledge, and interpretations.

She (mother) described at length that the case (child protective services) was officially closed, but that in her mind, she was misunderstood. Charges were for neglect for her (not adequately dressing, feeding, taking kids for health care) and abuse by husband (she said it was wrestling in fun, not hurtful, but child reported that father had hurt him). Mother expressed anger at being reported by EHS teacher. Felt like she was being watched whenever she came to the center.

The nurse conveyed using the mother’s story (“her story”), in both its content and delivery, to gauge her level of and capacity for engagement in the mental health and parenting intervention. The nurse later reflects upon an exchange after the mother gives the nurse her cell phone number:

I felt so touched and in touch with this scared and suspicious woman – really felt what a big step it was for her to reach out given her expectations that she would get put down as had always been the case in the past.

**Coaching.** The In Vivo codes: *Encouraged, guided, praised, modeled, suggested, commented, noted, celebrated progress*, led to the process code of coaching.

Coaching refers to the support nurses use to enhance mother’s development and improvement in her mental health, parenting skills, and wellness goals. Coaching was demonstrated in the nurse’s practice as described: “I praised her and noted that

making connections such as these would stay with her long after I am no longer working with her.”

As coach, the nurse described guiding the interpersonal exchanges, by reading and responding to the mother’s verbal and non-verbal cues. The nurse clearly reports defining what the goals of the intervention are, and through knowledge exchange, notes the mother’s values, strengths, and motivations- and weaves these into encouraging guidance and direction. Coaching was highly represented in the narratives, in terms of mental health coaching, life coaching, parenting coaching, and marriage coaching.

In his 2010 Yale Medical School Graduation Address, Don Berwick reminded new doctors that it is *the health care providers* who are guests in the hospital and the patients who are at home and should be treated as such. The home-based delivery of this intervention partially upset the traditional power differential that exists in the hospital or provider office between provider and patient, and was an appropriate backdrop to practice genuine patient and family centered care. The nurse reported using mother-centric, encouraging, and supportive engagement strategies to read and adapt to challenging situations to engage the mother.

### **Research questions**

The pairing of highly skilled and observant mental health nurses, specially trained in interpersonal communication and self-regulation with underserved, disengaged, and depressed mothers, presents substantial opportunity to detect the crucial components and

logistics of patient engagement. The Interactive Care Model will be used as the conceptual framework as a means to view and interpret nurse-mother interactions. In the proposed study, the following questions will be addressed:

- a) How do nurses describe their perceptions of how they engaged a historically underserved and disengaged population in a mental health intervention?
- b) How do nurse's description of the engagement skills and strategies that they used vary across phases of the nurse-patient relationship?
- c) How do nurse's description of engagement skills and strategies used differ among mothers with varying adherence levels (highly engaged, fluctuating engagement, minimally engaged)?
- d) Is there a relationship between the level of mother's engagement and the length of time spent in the beginning (orientation) phase of nurse-patient relationship prior to problem-specific (working) phase?
- e) Is there a relationship between nurse descriptions of engagement skills and strategies employed and mothers level of engagement as measured by the adherence ratings?

## **Methods**

This study used a sequential exploratory mixed methods design. First, a directed content analysis (Hsieh & Shannon, 2005) using the Interactive Care Model was used to illuminate the key components of the ICM. Directed content analysis is a qualitative

method used to support, validate, or conceptually extend an existing framework or theory and add further clarification about the constructs and their interconnections (Hsieh & Shannon, 2005). The goal of this methodology is to identify significant themes and categories within the narrative data, and provide rich and thick descriptions of the social reality created by those themes and categories as they are lived out (Zhang & Wildemuth, 2010). Results of qualitative content analysis can support the development of new theories and models, as well as validate existing theories (Zhang & Wildemuth, 2010).

The ICM shows promise as an analytical framework for engaging a historically disengaged population in their health and health care management. Five key patient and provider exchanges and seven patient-provider partnership roles from the Interactive Care Model (ICM) will be used as coding categories. Table 3 and Table 4 contain codes and operational definitions. Narrative data that does not fit into the ICM framework categories will be examined and new categories or codes may be developed. Newly identified codes or categories may contradict or support, refine, and extend the ICM (Hsieh & Shannon, 2005). Hence, this research was both inductive and deductive in nature.

Table 3.2 Patient Engagement Key Process Components and Definitions based on the ICM

<b><u>Patient Engagement</u></b> <b><u>ICM Key Process</u></b> <b><u>Components</u></b>	<b><u>Operational Definition</u></b>
Assessing a person's capacity for engagement	By considering factors that influence a person's engagement, providers gauge a person's ability and capacity to engage in care and drive efforts to increase engagement levels.
Exchange information Communicate Choices	In taking a person's capacity to engage in their care into account, a discussion opens between the patient and clinicians exchange information so as to truly understand what is important to the patient including patient values, beliefs, needs, and preferences. This stage also includes the use of decision aids that can be tailored to the individual to convey health care choices that are available.
Planning Between People and Clinicians	Provider and patient collaboratively develop a person centered; holistic plan based upon patients needs, preferences, and resources. Health care goals and aspirations of the health care process are jointly determined.
Determine appropriate Intervention	Appropriate interventions are matched with a person's level of engagement and readiness to own his/her self-care management.  Tools, resources, education, and technology are determined and chosen by both provider and person to support and advance the person in his or her health care journey.

Evaluate Regularly	<p>Continuous evaluation of a person's level of engagement and clinical outcomes assist the provider to further coach the person to reach his or her health goals.</p> <p>Evaluating regularly determines effectiveness of care.</p>
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Table 3.3 Patient Engagement Partnership Roles and Definitions based on ICM

Model Component	Definition
Knowledge exchange	<p>Data are gathered between clinician and person.</p> <p>Knowledge about health conditions and symptoms, care goals and response to their circumstances is shared. Clinicians help person navigate knowledge exchange and discuss potential risks and benefits of care choices.</p>
Caring and trusting relationship	A transpersonal relationship assists in the exchange to enhance self-care.
Collaborating	A true partnership is one that values expertise, power, respect on all sides and recognizes and accepts separate and combined spheres of activity and responsibility (ref). Clinician and persons act as equals. Clinicians no longer “do for” but rather “partner with” person to achieve optimal health.
Navigating	Providers partner with people to ensure they know how system works, when to seek services, what services are available, and how to access them. They can also help navigate care options and serve as an advocate.
Whole Person	<p>A holistic approach is taken into account when addressing all aspects of care and social determinants.</p> <p>By using historically alternative therapies (e.g. diet, yoga, meditation, relaxation techniques) health and healing and health are promoted.</p>
Coaching	Activities that encourage people to continually improve themselves in any capacity.

	People can coach clinician on individual circumstances.
Intentional Presence	The practice of intentionality is being fully present with those to serve and to build trust. Both sides are fully aware, with a consciousness to heal, allowing for open communication (Watson, 2002).

\*\*\* All codes and definitions re taken from Drenkard et al., 2015 Interactive Care Model\*\*\*\*\*

Following the qualitative method, additional quantitative data (phases of the interpersonal relationship and levels of mother's engagement) were analyzed to supplement the narrative data. Analysis of variance and post hoc testes were used to analyze quantitative data that were collected by the nurses who wrote the narratives. By employing both qualitative and quantitative methods sequentially, I was able to capitalize on the strengths of the particular strengths of each method to gain a comprehensive understanding of patient engagement. Please see Figure 3.1

Figure 3.1 Sequential Exploratory Mixed Methods Design



Of the sixteen advanced practice mental health nurses who delivered the intervention, fifteen were white and one was African American. Nurses were well-educated, middle class women who were retired or held part or full time jobs outside the

research study (Beeber et al., 2013). As per their specialized mental health training, the advanced practice nurses employed expert skills in reading mother's and families verbal and non-verbal cues, monitoring themselves, and implementing a deliberate interpersonal process with the mothers. Hence, the nurses had unique opportunity as engagement historians, recounting and describing their perceptions of the process of engaging the mothers in the intervention.

Nurses were trained to take note of the physical and social atmosphere of the home, including interruptions by and exchanges with other family members present. Nurses recorded their own thoughts, feelings, and reflections during and after the visits, and most relevant to this proposed study, the interpersonal skills and strategies used to develop therapeutic nurse patient relationship and engage, and retain the mother in the IPT intervention. Nurses completed their narrative accounts within 48 hours of the home visit, to ensure accuracy and richness of the data (Hubbard, Beeber, & Eves, 2015).

Based upon findings from the pilot study, nursing narrative data were organized in three groups based on variations in adherence ratings patterns (i.e. highly engaged, fluctuating engagement, minimally engaged). From each group, 10 narrative cases, 30 cases in total were purposefully selected and analyzed for this study. In taking a stratified purposeful sample of cases with varying adherence ratings, the intention was to capture information rich cases related to patient engagement and examine the variations in engagement skills, strategies, and outcomes (Palinkas et al., 2015; Patton, 2002).

Comparison and maximum variation sampling are time-honored, classic ways to assess



for similarities and differences, and to test conclusions (Miles, Huberman & Saldana, 2014).

### **Setting**

Nurses travelled to the mother's homes in low-income neighborhoods and communities located in the northeastern and southeastern regions of the United States. Housing was often substandard or overcrowded with all of the participants having household incomes below federal poverty level. Mean age of the mothers was 26.6 years old, typically unmarried and, on average, had three children between 1 and 5 years old (Beeber et al., 2013). By visiting mothers in the home setting, nurses gained intimate access to the mothers, her children, family, and significant others and were granted unique opportunity to witness the multitude of disruptions, struggles, and stressors mothers contended with daily (Beeber et al., 2007). Making initial contact and keeping scheduled appointments were recognized as barriers to accessing and visiting the mothers regularly (Beeber et al., 2007). Once connected, nurse and mother often sat at the kitchen table of the home, often interrupted by children and extended family members living in the house. Nurses often capitalized on the interruptions by children and family as opportunities to teach and coach the mother in effective communication and parenting skills.

### **Protection of Human Subjects**

The original HILDA study was approved by institutional review board (IRB) for

the protection of the rights of human subjects. This study using secondary data was reviewed by the Office of Human Research Ethics, and was determined to not constitute human subjects research as defined under federal regulations [45 CFR 46.102 (d or f) and 21 CFR 56.102(c)(e)(l)], and thus, did not require IRB approval.

### **Quality Checks**

In the HILDA study, a mental health and parenting intervention, advanced practice mental health nurses wrote their narrative notes describing the engagement process during each home visit, 48 hours after each visit, usually taking between 1-2 hours to complete. To ensure confirmability, a few days following each session with the mother, the nurse, PI and Co-I reviewed the narrative notes and debriefed to confirm the nurse's verbal and narrative accounts of the engagement skills and strategies matched and were accurately represented in the notes (i.e. phase of the interpersonal relationship, adherence ratings). Team meetings and training sessions ensured nurses were consistently and effectively implementing specific relationship- based engagement skills and strategies to engage the mothers, consistently delivering the IPT intervention, and recording all significant and relevant narrative data. Thus, the careful control of original study data collection procedures ensures credibility of the data for the proposed research. Each set of narrative notes were de-identified, and coded by nurse's last initial and case numbers.

## **Procedures**

The following steps were followed in conducting the directed content analysis. First, key concepts of the ICM were identified as initial coding categories (Hsieh & Shannon, 2005; Potter & Levine-Donnerstein, 1999) and operational definitions were determined. In consulting with the ICM creator, Karen Drenkard, PhD, in the coding development and refinement process, credibility of the research was ensured by reducing possible bias from a single researcher (Zhang & Wildemuth, 2010).

A codebook was developed, and included explicit theoretical based definitions examples, and coding rules for each category, ensuring there was a clear delineation as to what would be coded as a category and what would not (Mayring, 2005). Detailed documentation of data handling and coding schema can enable other researchers to determine the transferability of the criteria to other populations or situational contexts (Zhang & Wildemuth, p.8). To achieve the most neutral and unbiased results possible, an audit trail and confirmability audit process were implemented with a qualitative methodological expert, Dr. Beth Black, PhD, to increase the accuracy of the predetermined categories and definitions (Hsieh & Shannon, 2005; Lincoln & Guba, 1985). Inter-coder reliability is of particular importance in searching for sources of error or misinterpretation (Mayring, 2014). In establishing a transparent coding process and inter-coder verification, dependability can be established. In weekly meetings with Dr. Beth Black, PhD, ambiguity of word meanings, category definitions and coding

procedures were addressed, discussed, and resolved.

Since the goal of the directed content analysis research is to capture instances of patient engagement, each of the 30 narrative sets was read and text that appears to represent an aspect of patient engagement was highlighted. Once completed, all highlighted passages were coded using the predetermined ICM codes. Text that did not fit into any of the existing categories were given a new code (Hseih & Shannon, 2005). By using the selected strategy of initially highlighting without coding, the intention was to avoid bias and increase trustworthiness. Study findings describe and report the incidence of codes that represent the five phases of patient engagement and seven partnership roles derived from the ICM and the incidence of newly identified patient engagement skills, strategies, or partnership roles.

Using an exploratory sequential mixed methods design, nursing narratives were analyzed using the ICM coding scheme. These findings informed the subsequent quantitative analysis of adherence ratings and trends (Fetters, Curry, & Creswell, 2013; Mayring, 2014; Onuegbuzie, Bustamante, and Nelson, 2010). Analysis was conducted with the assistance of MAXQDA 2012 software program. The software uses a *code and retrieve* process and has several data management features such as the ability to multi-color code, create memos, retrieve coded segments, and creative code mapping. The code mapping feature allowed for the organization and condensing of numerous initial codes into more manageable categories. In addition, the software contains several visual

organization tools like the Code Matrix Browser, Code Relation Browser, and Text Portrait options that generate images of coding trends and patterns (Humble, 2009).

Narrative data from the nurses were analyzed individually for conceptual evidence congruent with the five phases and seven partnership role codes of the Interactive Care Model. A second pass with the data followed, noting nurse generated engagement strategies. These were strategies identified by the nurse in her narrative as to the what strategies she was employing to engage and retain the mother in the intervention. Narratives were organized based upon variations in adherence ratings (i.e. highly engaged, fluctuating engagement, minimally engaged). Within and across case comparisons examined similarities and differences in skills and strategies used to engage high-risk mothers in the mental health intervention. By examining within and across cases, the intention was to “put flesh on the bones of constructs and their relationships” (Miles, Huberman, & Saldana, 2015, p. 32).

In following Mayring’s procedure for qualitative content analysis, narrative data relevant to the research questions were determined. Second, the purpose of data collection and specific details as to the rigor of data collection was determined. The third step was to describe the data as to its collection, transcription, and any existing threats to its content. Next, a determination of what needed to be interpreted from the narrative data was made. Selected portions of the data were linked to the ICM and research

questions. Finally, passages from the narratives highly salient to the conceptual framework were defined, coded, and assigned to a coding category (Mayring, 2014).

Of Mayring's nine distinct analytical techniques for qualitative content analysis, two were used in this research: summarizing and explication techniques. In an attempt to reduce the narrative data into its core aspects while preserving its essential content, the analytical technique of *summarizing* was applied. *Summarizing content analysis* includes: paraphrasing relevant passages in the data, reducing less relevant passages, deleting duplicates, generalizing relevant passages to the level of abstraction, reducing paraphrases to keep substantial content, reducing again to bundle and summarize paraphrases and thus, yield interpretations of the data. Still reflective of the original material, summarizing repackaged the data on a higher level of abstraction (Flick, 2002; Mayring, 1983, p.57). After reducing the material using the summarizing content analysis, the explication technique was then employed to interpret, explain, and clarify “ambiguous or contradictory” passages of the text in an effort to increase understanding (Flick, 2002, p.191; Mayring, 2014, p.62). By using narrow context analysis, cues from the text were used to clarify meanings within the narrative data, whereas wide context analysis seeks meaning from sources outside the text (Flick, 2002). Data reduction and clarification of summarizing and explicative content analysis techniques are ways to improve clarity and reduce ambiguities (Flick, 2002). Used mainly to analyze subjective viewpoints (i.e. nurses perspectives), reduction and clarification techniques fit well when using an a priori framework (i.e. ICM) across numerous cases (Flick, 2002). Mayring

(2002) recommends using qualitative content analysis in cases of conceptual or theory-guided text analysis, such as this study, and not in cases of explorative interpretation of material (Kohlbacker, 2006). As a purely descriptive method, content analysis describes what exists in the text, but may not reveal the underlying motives of the observed phenomena. Analysis is sometimes limited by the availability of materials and observed trends may not be an accurate reflection of reality, just as catastrophic events receive more coverage in the media than less dramatic events (Nisbet & Lewinstein, 2002).

### **Data Collection and Management**

Sets of narrative notes were extracted from existing original study files and were placed in password protected Word files. Definitions of the five key phases (assessing a person's capacity for engagement, information exchange and communication, planning, determining appropriate interventions, regular evaluation,) and seven partnership roles (intentional presence, knowledge exchange, caring and trusting relationship, collaborating, navigating, whole person, and coaching) of patient engagement were developed, discussed, and refined with the creator of the ICM, Dr. Karen Drenkard. To establish dependability and consistency, narrative notes were coded according to the categorical definitions, reviewed, and audited with qualitative expert, Dr. Beth Black in weekly meetings. Consistency checks of the study process and the internal coherence of the research data was ongoing. Narrative data identified as engagement but not appropriate for the pre-determined categories was highlighted and discussed.

## **Data Analysis**

Research question 1 was addressed using a directed content analysis with the Interactive Care Model as the conceptual framework. The core-coding scheme consisted of the five key processes and seven patient-provider partnership roles from the ICM. However, additional coding categories were allowed to emerge from the data. Visual representations (e.g. charts, graphs, tables) were created to group the textual data into the engagement categories, and to determine the relationship between and among categories. Descriptive data (e.g. mother-nurse dyad identification number, session number, engagement codes, phase of mother-nurse relationship, and mothers adherence rating) were captured in a tabular and pictorial matrix. Matrices were analyzed for relationships between codes and for codes that co-occurred. Adherence ratings were graphed and grouped for similarities in scores and variation. Text portraits of each document were created to visually represent the frequency engagement codes assigned within a narrative note. Text portraits allowed for quick visualization and assessment of similarities and differences in engagement patterns between all of the cases and sets of specific cases. Together, all the visualization tools provided by MAXQDA helped display how nurses described the skills and strategies used to engage low-income mothers in a mental health intervention.

For research question 2, coded segments were quantified, tabulated, and analyzed for trends and patterns. Engagement codes were compared across each phase of the



mother-nurse relationship (orientation, working, termination). One-way ANOVA was used to assess for statistical differences between engagement strategies used in the three different phases of the mother-nurse interpersonal relationship. A Tukey post-hoc test was ran to determine which groups were statistically significant from the others.

For research question 3, frequency of adherence ratings were examined and used to group mothers into engagement categories (minimal, fluctuating, highly engaged). Engagement strategies employed by nurses were then examined across these three groups. A one-way ANOVA was used to determine if there were differences in engagement strategies employed with mothers who had varying levels of engagement. A post-hoc Tukey test was then run to determine which groups were significantly different than the others.

For research question 4, the time each group (minimal, fluctuating, highly engaged) spent in the orientation phase was calculated and compared.

For research question 5, individual weekly adherence ratings were examined in relation to the nurse generated engagement strategies employed. Joint displays were used to integrate the engagement codes with phases of the mother nurse relationship and engagement levels. An array was built using the qualitative data as one dimension (coded segments) and quantitative data (phases of the mother-nurse relationship and engagement level) as the *other dimension*. For example, for the specific code of COACHING, a table displayed how many times coaching was represented in each phase of the mother-nurse

relationship and for each level of engagement, allowing for data comparison.

Additionally, for research question 2 through 5, the mixed methods function in MAXQDA (i.e. typology tables, cross tables) were used to determine if there was a relationship between:

a) length of time spent in the beginning (orientation) phase of nurse-patient relationship prior to problem-specific (working) phase and mother's level of engagement, and

b) engagement skills and strategies used and mother's engagement levels.

#### Summary

In conclusion, this chapter has presented the methodology for addressing the design and sampling, human subject protection, and data analysis procedures for the secondary analysis. Directed content analysis was used to examine how advanced practice mental health nurses described interpersonal skills and strategies used to engage low-income depressed mothers of toddlers and infants in a mental health intervention. The Interactive Care Model, a process model for patient engagement, guided the analysis. Nursing narrative data from 30 mother-nurse dyads were purposefully selected to examine major variations in engagement skills and strategies, phases of the mother-nurse relationship, and mother's engagement levels. Using MAXQDA software program, the exploratory sequential mixed methods study design allowed me to describe specific engagement skills and strategies used to engage these mothers and examine how

engagement strategies varied across phases of the mother-nurse relationship and across interactions with mothers with varying engagement levels.

## **CHAPTER 4**

### **FINDINGS**

In keeping with the mixed methods design of the study, this chapter is organized in qualitative and quantitative sections respectively. The logic behind choosing a sequential exploratory approach (Creswell, 1994,2013) was to first illuminate the concepts of the Interactive Care Model (ICM) in nursing practice using directed content analysis, a qualitative approach. Following the qualitative analysis, quantitative data were then examined to address the timing and flow of patient engagement in terms of interpersonal relationships and mothers' engagement levels. Employing qualitative and quantitative approaches sequentially, capitalized on the particular strengths of each method to address and gain a comprehensive understanding of patient engagement (Creswell, 1994, 2013).

In my first pass with the data, I concentrated my coding on the ICM only, performing a directed content analysis and found validation for the ICM as the concepts in the model were supported by the data. I then went through the data a second time, identifying specific nurse-generated codes used to flesh out the ICM categories.

In the first section of this chapter, I addressed the first research question and examined how each of the ICM's five key processes and seven person and provider partnership roles are represented in nurses' descriptions of how they engaged mothers in

a mental health intervention (RQ1). In the qualitative section of the chapter, “in-text” and blocked segments indicate direct quotes taken from the nursing narrative data. Under each ICM component, specific nurse generated relationship-based engagement strategies (denoted by nurse-generated), were selected to specifically demonstrate and exemplify how the ICM was operationalized in nursing practice, thus adding depth and detail to the engagement framework. Jointly, the ICM components and nurse-generated engagement strategies served to demonstrate how nurses established and fostered therapeutic interpersonal relationships with mothers, which were essential and foundational to engaging and retaining the mothers in the intervention.

Following the qualitative section, the quantitative section addresses the remaining four research questions. These questions explored differences among engagement practices, phases of the interpersonal relationship, and mothers’ levels of engagement, in addition to correlations between times spent in the orientation phase and mothers’ level of engagement.

### **Demographic Differences Between Nurses and Mothers**

Before addressing nurses’ perceptions of engaging mothers in a mental health intervention, understanding the demographic differences between the two groups of women was contextually important. Differences were found between nurses (n=16) and mothers (n=30) when comparing age, education, and ethnicity data. Fifteen of the sixteen

advanced practice mental health nurses were white; their average age was 53, and all had formal advanced education (19 years or more).

In contrast, mothers in the study were largely African American (23/30), with an average age of 26 (range 15-44), having an average of 12 years of education (range from 6-19 years). Table 4.1 includes but is not limited to demographic data of the purposeful sample (10 cases drawn from each group: 1) minimally, 2) fluctuating, and 3) highly engaged n=30) from this study and total sample of mothers from the parent study.

Table 4.1  
*Demographic and Other Data on Current Study (n=30) and Hilda Study Participants (n=251)*

<b>Demographic Variable</b>	<b>Current Study (n)</b>	<b>Current Study (%)</b>	<b>Hilda Study (n)</b>	<b>HILDA Study (%)</b>
Northeast Region	10	33.3	87	34.7
Southeast Region	20	66.7	164	65.3
White	7	23.3	64	25.5
Black	23	76.6	156	62.2
Latino	0		8	3.2
Married	10	33.3	53	21.1
Exposure to violence	9	30	35	14.1
Child health disability	9	30	139	55.4
Employed	16	53.3	109	43.6

Most nurse-mother meetings were held in the kitchens, living rooms, and bedrooms of the mothers' residences. However, one mother lived with her infant in the Salvation Army homeless shelter; two nurse-mother dyads met in local coffee shops; and one dyad met in the nurse's car, which served as a private space and escape from the many distractions in the home setting.

### **Directed Content Analysis of the ICM Processes and Partnership Roles and Nurses' Perceptions of Engaging Mothers in a Mental Health Intervention**

*Research Question 1: How do nurses perceive the engagement process with a historically underserved and disengaged population in a mental health intervention?*

Data were analyzed across 470 total text documents and included: linear descriptive nursing narrative notes, mother-child observations, Depressive Symptom Inventories, and Support System Inventories. Immediately following each meeting or interaction with the mothers, the nurses wrote detailed narrative notes describing their interactions with the mothers, verbal exchanges, and the skills and strategies used to engage the mothers in the mental health and parenting intervention.

Each of the five key processes and seven clinician and person/family partnership roles of the Interactive Care Model will now be addressed. In addition to the ICM processes and partnership roles, nurse-generated engagement strategies will also be described (denoted by nurse-generated) in context of the ICM. Findings from the data also include concepts that were not captured in the ICM. Table 4.2 is a summary of key findings and displays how the specific nurse generated engagement strategies align with

the five key processes of the ICM as well as the engagement strategies that were found to be extraneous to the ICM.

Table 4.2

*Summary of Key Findings ICM Processes, Nurse Generated Engagement Practices, and Data Extraneous to the ICM Processes*

<u>Key Process of Interactive Care Model</u>	<u>Nurse Narrative Data</u>	<u>Data Not Fitting the ICM</u> <u>Categories</u>
Assessing a person's capacity for engagement	<ul style="list-style-type: none"> <li>• Pre-engagement contact</li> <li>• Flexible, accommodating scheduling</li> <li>• Social conversation</li> <li>• Assessment Circles</li> <li>• Health literacy</li> <li>• Disease burden</li> <li>• Psychosocial support</li> <li>• Activation/motivation</li> </ul>	<ul style="list-style-type: none"> <li>• Demographic differences between provider and client</li> <li>• Reflective Practice</li> <li>• Power Dynamics</li> <li>• Phases/Timing of engagement</li> </ul>
Exchanging Information/Communicating Choices	<ul style="list-style-type: none"> <li>• Mother's history</li> <li>• Competing demands</li> <li>• Intentional presence</li> <li>• Listening</li> <li>• Silence</li> <li>• Disclosing limitations</li> <li>• Anticipatory warnings</li> <li>• Exploration</li> </ul>	
Planning	<ul style="list-style-type: none"> <li>• Contracts</li> <li>• Mutually developed and agreed upon goal setting</li> </ul>	
Determining Appropriate Interventions	<ul style="list-style-type: none"> <li>• Skill sheets</li> <li>• Cognitive Reframing</li> <li>• Problem solving</li> <li>• Refocus/redirect</li> <li>• Confrontation</li> <li>• Summarizing</li> </ul>	



Evaluate Regularly

- Depressive Symptom Inventory
- Mothers' self report
- Nurse assessment

### **Five Processes of the Interactive Care Model**

**Assessing a person's capacity for engagement.** Assessing a person's capacity for engagement occurs when providers consider the influential factors that impact a person's engagement in his or her health care, and then gauge a person's ability to engage in their health and health care (Drenkard et al., 2015). Nursing narratives were marked by frequent references to assessing the mothers' capacity for engagement. Factors associated with capacity for engagement include: the external environment surrounding the mothers' home, the mother's physical and mental health, the mothers' health literacy, available psychosocial support, and the mothers' activation and motivation for meeting with the nurse and participating in the intervention.

***Pre-engagement phone call.*** Nurses' preliminary assessments of the mothers' capacity to engage began prior to their first face-to-face meeting. An initial pre-engagement phone call to the mother was crucial for establishing contact, reacquainting the mothers with the HILDA project and their participation in the project, and arranging a date and time for their in-person meeting. Nurses contacted mothers once again, the night before or day of the scheduled visit to confirm the meeting, time, and place. However, unreliable or discontinued phone service paired with the mothers' demanding and often-

unpredictable schedules created significant barriers to establishing and maintaining contact with some of the mothers. Nurses circumvented logistical telephonic obstacles using persistent and varied strategies to contact them, such as calling at different times of day, leaving messages that included the nurse's personal cell phone number for the mother to call back, visiting Early Head Start locations when the mother and child were scheduled to be there, or driving by a mother's house for what one nurse described as an "ambush- unannounced visit." One nurse specifically recounts the use of multiple engagement strategies:

I called at 1215 and she did not answer. I left a message that I'd call back. I called back at 1300. Still no answer. Left a message for mom to call me. Sent mom a note to remind her of the calls, asking her to call me at a time that's convenient for her, and telling her I'd keep trying to reach her.

Importantly, when the nurses left phone messages or in-person messages with the family members, she would identify herself as "the nurse working with Early Head Start," protecting the mothers' confidentiality and avoiding potential stigma associated with the mental health aspect of the intervention. Several nurses described multiple, persistent and diligent attempts for contact and connection were often met with unanswered phone calls, inconsistent callbacks, frequent messaging, frequent rescheduling, and subsequently concluded with mothers' nonattendance/absence. One nurse described the pre-engagement period feeling like a "cat and mouse chase."

Conversely, other nurses described a "comfortable relationship developing on the

phone” or “building rapport” with some mothers who called to schedule or reschedule “due to illness or child care issues.” Nurses used phone calls such as these to express caring and concern for the well being of the mothers and their children, and often empathized with the mothers’ competing demands. Therefore, nursing perceptions of the pre-engagement period differed based upon the mothers’ receptiveness and responsiveness to scheduling the initial meeting.

In addition to the pre-engagement phone calls, when opportunities for face-to-face contact were missed, the nurses often left “thoughtful hand written notes” for the mothers at their homes, expressing the nurse’s concern, desire and intention to meet, paired with some encouraging words or a small gift (e.g. hand lotion, square of chocolate). Despite the mothers’ frequent rescheduling, running late, or forgetting meetings altogether, the nurses remained flexible and accommodating, noting the mothers’ significant lack of resources (e.g. lack of child care, transportation, and/or psychosocial support). Nurses acknowledged the mothers’ competing demands and were flexible in accommodating the unpredictable and challenging nature of raising young children. One nurse described calling to reschedule a missed appointment and as the nurse and the mother were talking, mother’s “4 year old poured a container of orange juice in the fish tank.”

***Social conversation (nurse generated).*** Social conversation is a kind of speech that happens informally, symmetrical, and for the purpose of establishing and maintaining a social connection (Slade & Thornbury, 2005). Nurses entered the mothers’ homes as guests, and described social conversation and social rituals as “routine.”

Mothers invited the nurses to enter and sit down, and they exchanged social conversation (e.g. heat wave, traffic, TV show). Nurses purposefully started with light conversation before transitioning to the more serious topics of the mothers' depressive symptoms and circumstances. One nurse described her rationale for using social conversation: "She is very difficult to engage with, so starting with more social conversation is sometimes helpful in engaging her."

Similarly, social conversations were opportunities to engage the family members and establish an initial connection. As a visitor, one nurse reported being "friendly" with others living in the home, including spouses, significant others, children, extended family and even the family pet. One nurse noted that social conversation created "icebreaker" opportunities to relate and connect with the mother through "something neutral" and "different from the intervention", such as the family's pet or the weather.

***Assessment (ICM and nurse generated).*** Assessment was a skill and strategy highly represented in the nursing narratives and captured by the ICM and nurse generated engagement practices. In their notes, the nurses commented on the physical appearance of the mothers' neighborhood and house, neighborhood safety, and outdoor space for children to play. A typical description of a mother's home and neighborhood was:

The visit occurred on the first floor of a two family home in a lower class, but comfortable neighborhood on the outskirts of the city. The kids have a nice back lawn to play in and Mom can watch them from the window. The rooms are small and comfortable, and rather messy, but clean.

However, in contrast, several nurses described the mothers' neighborhoods as being "tough," "dangerous," and noted "safety being an issue." One extreme case is described below:

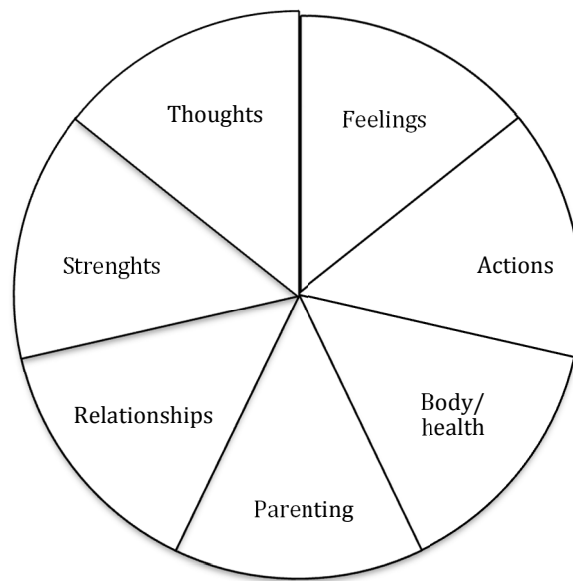
As I (nurse) turned into the street and was about to turn the corner there were flashing cop car lights so I took a different direction, and soon passed another car-unmarked, from which a SWAT team got out and went into a house, guns drawn. This is truly a challenging neighborhood in which to live, especially with a sick infant.

In addition to neighborhood safety, the nurses commented on the mothers' appearances (e.g. dressed versus pajamas), interactions with the nurse (conversational vs. quiet), degree of attentiveness to their children, or presence of others in the home. Furthermore, the nurses noted their perceptions of the mothers' overall willingness and interest to engage in the intervention, and assigned adherence ratings based on the nurse's perceptions of how well the mothers followed through with the strategies and suggestions from the previous visit.

***Assessment circles (nurse generated).*** An additional strategy in which the nurses determined the mothers' capacity for engagement was the use of assessment circles, a simple visual tool used to address, document, and track the mothers' depressive symptoms. Organized into seven segments labeled thoughts, feelings, actions, body/health, relationships, parenting and strengths; assessment circles facilitated and

focused dialogue between the nurse and the mother on the mothers' depressive symptoms and most pressing life issues (Figure 1).

**Figure 4.1.** The assessment circle



Typically, the nurses used assessment circles to begin and focus conversation with the mothers about the mothers' mental health and parenting concerns. Then, using mothers' exact words, the nurse or the mother would write the responses in the appropriate section of the circle (Beeber et al., 2007). The graphic organization of the circle, paired with the mothers' own words was intended to make the mothers' depressive symptoms visual, concrete, and real to her (Beeber, Canuso, & Bledsoe, 2007). Thus the assessment circles provided a foundation and basic structure to assess the mothers' capacity for engaging in the intervention.

***Health literacy (ICM).*** Health literacy is defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate decisions (Berkman, Davis, & McCormack, 2010). Health literacy affects people's ability to navigate the healthcare system (e.g. filling out complex forms, seeking out and locating providers and services) and when sharing personal information (e.g. health history) with providers (U.S. Department of Health and Health Care Services (USHHS), 2000). Persons with limited health literacy often lack knowledge or have misinformation about the nature and causes of health issues and diseases and may not understand the relationship between lifestyle factors on several health care outcomes (Schillinger et al., 2003).

When working on the assessment circle with the mothers, the nurses assessed the mothers' health literacy during conversation about their depressive symptoms. In assessing the mothers' health literacy, nurses used the "mothers' own words" and terminology to encourage and navigate suitable, therapeutic discussions. The 30 mothers in this sample demonstrated a broad range of health literacy. For example, one nurse took note of a mother with a particularly high health literacy level when the mother "readily stated" having a "depression and anxiety disorder . . . with some PTSD." Conversely, another nurse noted one mother "could not find the words" or "could not answer" when asked to describe her feelings. In response to varying levels of health literacy, the nurses expressed understanding, encouragement, and support, and gave the mothers both the time and space to collect, organize, and verbalize their thoughts into words.

***Psychosocial support (ICM).*** Visiting mothers in the intimate home setting allowed opportunity for the nurses to gain insight as to the mothers' physical (e.g. holes in the living room chair), environmental (e.g. open spaces for children to play) and relational (e.g. family members interjecting or eavesdropping) contexts. The nurses assessed safety issues in the home, directly observed mother-child interactions, and gauged her psychosocial support (or lack thereof) from friends or family present in the home. Although some mothers described having no social support system, others had a strong family and communal support system, created by bartering with neighbors for needed services (e.g. childcare, transportation, computer use).

Psychosocial support assessments provided information to facilitate the planning and development of appropriate interventions for each mother and the incorporation or deliberate exclusion of family members in her care plan. For example, when referring to his wife's depression, one husband stated to the nurse, "When she wants to end it all, I remind her that she has these kids and she'd better not leave them." Although the context and intentions of the husband's comments are unclear (a limitation of using secondary data) the nurse noted his comments when assessing the mother's capacity for engagement and in planning care options.

***Activation/motivation (ICM).*** Activation is having the knowledge, skills and confidence to take on the role of managing one's health and health care (Hibbard & Cunningham, 2008; Hibbard, Mahoney, Stockard & Tusler, 2005). Motivation is described as an individual's degree of willingness to exert and maintain effort towards



health and health care goals (Franco, Bennett, Kanfer, 2002). Because a person's activation and motivation underlie most health behaviors (Hibbard, 2016), the mothers' activation and motivation were assessed early and often, and used as a benchmark for future visits and planning. Nurses noted the mothers' motivation to engage was often evident in first few moments upon meeting. For example, some mothers met the nurse at the door or front porch, smiling, waving, welcoming the nurse in, and proudly displaying their completed homework for the week. Conversely, one nurse speculated that a mother was so exhausted and emotionally depleted, she did not answer the door, and did not leave her bed throughout the entire visit. Nurses wrote they deliberately "matched mother's energy to participate," so as to avoid "turning the mother off completely." Nurses engaged mothers with lower motivation differently, using a lower energetic approach, than mothers who were more motivated to participate in the project.

***Disease burden (ICM).*** Nursing narratives were marked by frequent references to the mothers' depressive symptom burden. Physical assessment skills were used weekly to identify and appraise the mothers' physical, emotional, cognitive and/or behavioral signs of depression. Nurses took note of mothers' verbal cues, for instance, when one mother said: "I'm (mother) never happy for some reason", as well as non-verbal cues "All this time she (mother) was looking down, no eye contact and facial expression flat" when assessing her depressive symptoms. Additionally, the nurses completed a formal Depressive Symptoms Inventory in the initial visit, at 6 weeks and at 12 weeks to assess mothers for major depressive disorders and dysthymias, suicidal intentions, depressive

cognitions, and energy level based upon DSM IV-R criteria (Beeber et al., 2013). Nurses were alert to recognize any potential danger or possible impending crises. Specific protocols and procedures were in place should the nurses need to refer the mothers to a crisis center.

To summarize, assessing the mothers' capacity for engagement was a complex endeavor requiring proactive, persistent effort and accommodating flexibility. Nurses employed traditional and non-traditional strategies to establish contact and connection with mothers, a crucial first step to patient engagement. Meeting face-to-face in a non-clinical context afforded insight to the factors influencing the mothers' capacity to engage, such as her home environment, activation/motivation, health literacy, disease burden, and psychosocial supports.

**Exchanging information and Communicating Choices (ICM).** Exchanging information and communicating choices, the second key process of the Interactive Care Model, entails the illumination of the mothers' values, beliefs and preferences prior to making decisions about their health and health (Drenkard et al., 2015). Exchanging information and communicating choices were evident in the nursing narratives and critical to engaging the mothers in the mental health and parenting intervention. Nurses began dialogue with the mothers in an effort to establish an understanding of their life and health goals, preferences, and values. One nurse compared the exchange of knowledge to assembling pieces of a jigsaw puzzle:

I thought that I had a few more pieces of the jigsaw puzzle about Mom and her life. I won't be able to put it together in the time we have, but I appreciated being able to add a few more pieces to the picture.

Mothers often led the dialogue, sharing difficult histories of significant loss and hardship (e.g. rape, reoccurring violence, racism, incarceration, HIV, death, abortions, paternity issues, giving up children, abandonment). Mothers' personal stories and experiences provided important historical information, helping to illuminate her present values, beliefs, and subsequent preferences.

As Mom spoke about the rape, I suddenly understood why this paternity test is even more loaded than usual for her. Even though she displayed no emotion about this she was willing to talk about it and I was glad. I listened, asked a few questions, and at the end of the story said that I was very sorry that she had to go through that. We explored some options about getting that guy's DNA but Mom said that it didn't matter as she was prepared to raise her baby on her own anyway.

Intentional presence and active listening skills were highly salient throughout the narratives as nurses tried to understand the mothers' reality. Accordingly, nurses "deliberately" and "intentionally listened" to understand a mother's reality, and were honest and forthcoming in recognizing their own limitations. For example, when talking with one mother living in a homeless shelter with her small infant, the nurse wrote: "I

said, with a very sincere look on my face that I did not pretend to know what her life was like. Mom looked directly at me for the first time when I said that.”

The nurse’s self-disclosure of having limited knowledge and understanding of mothers’ reality, presented opportunity for the mother to inform and exchange information about her daily life challenges.

A substantial component of the ICM’s exchanging information phase/communicating choices process was listening to the mothers’ stories, their realities, and their words in an effort to understand their circumstances and preferences for care. Nurses often used silence as an engagement strategy noting the mothers needed “time to collect, organize, and reflect on her thoughts” and “time to engage.”

Early stages of shared decision-making were exemplified during this phase as the nurses and the mothers discussed viable options towards: feasible and actionable change, risks and benefits of actions versus inaction, thus setting the stage for collaboratively sharing in the decision-making process. For example, nurse- mother dyads addressed complex issues and topics related to having multiple sexual partners, wanting to divorce an incarcerated spouse, facing eviction or Child Protective Services (CPS) investigations, being unemployed, and resolving child support issues. Often, these complex issues presented opportunity for the nurses to communicate choices: “I suggested [the mother] had two choices: she could continue believing life is awful because she deserves better, resulting in bitterness and anger or she could use her life experiences, good and bad, for growth.”

At times, nurses described the mothers as “frozen” in states of inaction, after the mothers described themselves as feeling “confused” or “scared of making a mistake.”

Her confusion was related to her fear of making a mistake, thus immobilizing her action. As we explored options for her along with the notion that all she could do was make the best choice she could and if it was not the right choice for her, that was ok but the important concept was to make some choice.

Exchanging information and communicating choices initiated the process of shared decision-making as nurses encouraged, supported, and helped mothers take an initial step towards purposeful action.

***Anticipatory warnings (nurse-generated).*** When communicating choices, the nurses used anticipatory warnings to underscore potential consequences that could occur as a result of the mother’s actions or inactions. Described as “gentle warnings,” the nurses used anticipatory warnings to cite possible unintentional negative consequences that might occur as a result of the mothers’ actions or inactions. For example, one nurse described working with a mother who was threatening to engage in physical violence after feeling “pushed around” by a peer. In addressing the crime of “physical assault” with the mother, the nurse also introduced the “very serious consequence of landing in jail and being forced to leave her infant.”

Anticipatory warnings were employed to help guide mothers to consider and weigh potential positive and negative outcomes, another central aspect of the shared decision-making process.

***Competing demands (nurse generated).*** Nurses frequently described imbalances between the mothers' intense and competing demands and lack of available resources. Nurses routinely asked about the mothers' current life challenges and the mothers responded with a barrage of energy depleting demands and stressors. One mother described her life as "feeling like it is just one thing after another." Limited financial resources, lack of transportation, reliance on government assistance programs, threats from bill collectors and landlords, incarcerated family members or spouses, inconsistent, minimal, or non-existent child support collectively left the mothers feeling "sad," "frustrated," "rejected," and "having no control." Nurses empathized with the mothers' plights and used the competing demands to direct dialogue toward problem solving issues that could be immediately addressed and potentially improved.

***Exploration (nurse generated).*** Exploration involved the nurses examining the subjects and themes shared by the mothers to gain a deeper understanding of their experiences and reality. Exploration was highly represented in the nursing narratives as nurses sought to hear and understand the mothers' genuine voices and their unique thoughts and feelings. Nurses asked about the mothers' thoughts, feelings, and rationales, recognizing the mothers' expertise and authority regarding their experiences, emotions, perceptions and intimate thoughts. Again, speaking with the mother living in the

homeless shelter, the nurse recounted a conversation about the mother having issues with the supervisor.

[The mother] quickly said to me, 'I mean you no disrespect, but the fact that [the supervisor] is Caucasian is causing a lot of us problems here.' I said, 'tell me', with a very concerned look on my face. As I listened to [the mother] I realized that I was clueless about what it must be like to be African American in a Caucasian culture. I backed off of my interpretation, and encouraged Mom to go on.

Conversely, nurses made judgments as to when to refrain from exploration and follow-up.

I was so struck by this admission of vulnerability from this tough street-wise fighter. [This mother] never admits to depression or sadness, only frustration, and she beats people up to solve problems. I had never heard [this mother] use the word 'scared' before. I knew better than to explore the feeling with her, as that would turn her right off. I explained that the children's father could also be involved in helping her by working with this information. She shrugged her shoulders. I was uncertain as to what that meant, however decided it was best to not explore her response at this time.

Overall, the process of exchanging information revealed valuable information in terms of understanding the mothers' life circumstances, embedded values, preferences and beliefs that impact and inform their past, present, and future health and life choices.

**Planning (ICM).** Planning, the third key process of the Interactive Care Model involves the nurses and the mothers collaboratively developing a mother-centric holistic plan based on the mothers' specific needs, preferences, and resources (Drenkard et al., 2015). Planning was woven throughout the nursing narratives. Beginning with the initial pre-engagement phone call and continuing throughout the intervention, nurses tried to collaborate with mothers in developing a plan for the mothers' mental health wellness and parenting proficiency.

At times, planning between the nurses and the mothers was routine and simple, like setting and agreeing to a time and date for subsequent meetings. And at other times, planning was unpredictable and complicated. For example, formulating a plan for one mother to regain custody of her children required strategic design in terms of dealing with Child Protective Services and proposing parenting solutions and behavioral alternatives to reflexive physical violence. Notably, nurses did not set goals for mothers each week, but rather: "helped [the mother] set goals for herself."

Each meeting, co-created plans were agreed upon and written down on paper, a visual and tangible record of consensus used for reference at future meetings. At times, planning was difficult. The mothers often refuted suggested plans citing their lack of financial resources and multiple hardships. However, the nurses responded by adapting plans by suggesting and helping the mothers set small, attainable goals for the week. For example, the nurses suggested "list cutting," "practice saying no," and "expressing her (mothers) true feelings," "trying a breathing exercise," "walking up and down the block



once,” “listening to music,” or “journaling” requiring zero financial cost, only the mothers’ focus, time, and intention. Nurses often referred to plans as “homework for the week”, and verified plans were acceptable and agreeable to the mothers. For example, when one mother reported having difficulty falling and staying asleep, the nurse and mother together developed the following specific plan:

[Mother’s] homework for the week is to notice when she is having trouble getting to sleep, allow herself to get up, check the children, check the doors once, then back to bed, block the thoughts, substitute a positive image (which we worked on), do several deep breaths, then focus on the image until she goes to sleep.

Nurses often tempered plans and expectations accordingly to correspond with the mothers’ circumstances and capacities to engage. Sometimes planning between one particular mother and her nurse involved intentionally planning for no plans at all:

[The mother] looked relieved. She said, ‘What do you want me to do for next time?’ I looked at this woman who had worked 98 hours straight to provide her children with a wonderful Christmas, was entertaining and providing for a house full of company, had helped her sister deliver her first baby, and was so depressed and exhausted she could barely keep her eyes open. I said, ‘you do not have to do one single thing, except let me in the door. You have already done more than enough.

***Contract (nurse generated).*** A contract is defined as a written or spoken agreement between two or more parties (Burton, 2007). Introduced by the nurses early

and signed by both the nurses and the mothers, simple informal contracts served to document and clarify expectations of the intervention (e.g. number of meetings, rescheduling protocols). The nurses and the mothers agreed to meet on a regular basis, for 10 face-to-face visits, 5 phone calls, and conclude with a final termination visit. Thus, contracts served as tangible evidence of the agreed upon mental model, or shared understanding of expectations between the mother and the nurse. A copy was provided for the mothers, concretizing the established agreement. In addition, to encourage honest exchanges, directness, and disclosure when one mother's safety was an issue, one nurse drafted a less formal contract:

I finished by wishing that we could be honest and share with each other when any discomfort arises so that there is no need for suspicion or secrets. I asked her to make a contract with me to try and be honest and direct with each other about this.

To summarize, the nurses and the mothers collaboratively planned and arrived at mutually determined and agreed upon goals and outcomes of the intervention. Contracts and verbal agreements between nurses and mothers helped concretize and re-enforce expectations of accountability and engagement in the intervention.

**Determining Appropriate Interventions (ICM).** Determining appropriate interventions is the fourth key process of the ICM and is described as the implementation of using jointly determined tools, resources, education, technology and support to

advance the mothers in her self-care journey (Drenkard et al., 2015). In the parent study, the nurses and the mothers worked on skill sheets, one-page worksheets targeted to help with behavioral change focused on the source of mother's interpersonal problem areas. See Table 4.3. Skill sheets were visual and concrete resources used to facilitate discussion with mothers and help initiate actionable behavioral change.

Table 4.3 View Sheet of Selected Project Skill Sheet

<u>Interpersonal Problem Area</u>	<u>Skill Sheet</u>	<u>Description</u>
Symptom Management	Beating the Blues	Get to know your worst symptoms
	Good & Bad Comforts	Sex, food, drugs & alcohol; making them safer & alternatives
	Oh No! They're Back!	Knowing the triggers; early symptoms; danger zones
Role Transitions	Solving Life Problems	Breaking big problems into smaller ones
	Talking to My Helpers	□ How to talk to teachers, childcare providers, social services providers, lawyers and other helpers
Role Disputes	Let's Talk	Talking about tough issues
	Staying Calm Under Pressure	Keeping your head; pressure- busters; knowing when to call time out
	Breaking Bad Patterns□	Stopping negative patterns and putting others in their place
Interpersonal Patterns	Reaching Out	How can I reach out to others when I am feeling so bad? Here are ways to do that
Grief/Loss	Confronting Loss	Building strengths around the empty places
	Getting Back Up When Somebody Lets You Down	Troubles in your closest relationships can bring you down. Here are some ways to solve them

Skill sheets were used to address and attempt to resolve issues mothers identified as difficult. Together, the nurses and the mothers worked on the skills sheets to address problems like: difficulty separating from spouse (Getting Back Up When Someone Lets You Down), communicating with an Early Head Start (EHS) director (Resolving Disputes), and parenting rambunctious young boys (Know Yourself, Know Your Child; Breaking Bad Patterns). Skill sheets provided structure for the mental health and parenting interventions, simultaneously facilitating engagement while delivering education and support. Not always exclusive for mothers, significant others would sometimes join in the sessions and as a group, the three would focus on topics specific to couples, communication, and parenting strategies.

***Cognitive Reframing (nurse generated).*** Cognitive reframing is a psychological technique used to identify and dispute irrational or maladaptive thoughts, and offering a different and more positive way to think about or view the event, idea, concept, or emotion (McLeod, 2015). Reframing involved repackaging what the mothers perceived as a negative into something more positive. For example, one mother described herself as “crazy” and shared that she has “chased down her older son in crack houses, brandishing weapons at times and dragged him home.” The nurse re-framed mother’s behavior “as being motivated out of a protective instinct rather than her term ‘crazy’.” In another example, when a mother shared that she “did what she had to do and supported herself as strip dancer” the nurse supported the mother for her “strength, steadfastness, and survival skills.”

Mothers often shared feeling plagued with worry, fear, and guilt of “not being good enough mothers.” In response to their anxieties, nurses recognized, reframed, and reminded them of everything they do for their family, how hard they work, and how well they were doing. As

such, cognitive reframing offered mothers an alternate viewpoint of what was positive amongst the negatives in her life.

***Problem Solving (nurse generated).*** Nurses used problem solving as a strategy to help the mothers find solutions for their most immediate and challenging problems and issues. After guiding the mothers to differentiate between problems they had power to control and those they did not, the nurses and the mothers worked together to “brainstorm” possible solutions and ways to execute them most effectively.

For example, when one particularly overwhelmed mother was having trouble with her mischievous toddler, the nurse and the mother developed a behavior chart and reward system. When faced with the inability to afford medications for her and children, the nurses and the mother immediately contacted a medication assistance program. When struggling to manage time between school, work, and family obligations, the nurse and the mother worked on time management and scheduling techniques. However, most problem solving between nurse and mothers were seldom quick or easy fixes. For example, one mother shared she was directly involved in a criminal event stating: “an off-duty cop shot [an intruder]who had a knife and was trying to stab her boyfriend and get into their apartment.”

Unable to move from the violent neighborhood, the nurse and the mother “brainstormed” possible solutions, finally deciding the mother would take her young children and stay with relatives over the weekends when violence occurred more frequently.

Throughout the intervention, maintaining the mothers’ attention and focus on problem solving was a challenge because the mothers were distracted by the needs of her children, family or friends in the home, or the television. The following four strategies: refocus/redirect,

confrontation, suggestion, and summarization helped to keep the mothers engaged and on task, serving to facilitate and advance the work of the intervention.

***Refocus/Redirect (nurse generated).*** Amidst multiple distractions and interruptions in the home paired with some mothers' short attention spans and low-levels of engagement, the nurses often worked to redirect the mothers' focus back to the topics and issues at hand. of mothers' depressive symptom burden, the nurses deliberately avoided overwhelming them. For example, when trying to refocus a very withdrawn mother to the Reaching Out skills sheet, a nurse suggested the mother try and pay attention to her child "just once this week" and later commented in her narrative note, her intentions: "I did not want to pressure this very beleaguered mother."

In another example, one nurse described using confrontation as a means to clarify parts of a discussion: "[Mother's] last statement made me wonder if I had misunderstood that Mom had directly confronted her father about the sexual abuse. So I asked her this, to be sure we were on the same page." When the mothers got sidetracked or when the mothers' "venting became unproductive," the nurses would redirect the conversation and shift the discussion to address behavioral change and improvement.

***Confrontation (nurse generated).*** Confrontation was used by the nurses to express confusion about inconsistencies, in the spirit of understanding the mothers better; to ultimately help them identify root causes of their stressors (Beeber et al., 2007). Nurses used tempered confrontation to advance the discussion with the mothers and their respective engagement levels. Confrontation was also used when a nurse did not have one mother's attention, noting "At this point I stopped and told mom that I didn't think we were getting anywhere, that she was

distracted by her son's activity and I was having a hard time concentrating because of the noise from the TV.”

Although a guest in the mothers’ home, the nurses used confrontation to help the mothers focus, and address their pressing life issues.

***Suggestion (nurse generated).*** Known to influence thoughts and behaviors in different ways (Michael, Gary, Kirsch, 2012), deliberate suggestion was used to express an idea, plan or thought into the dyad’s shared space. Once a suggestion was put forth, the mothers could choose to ignore, accept, or reject it. As opposed to the nurse telling or deciding for the mothers, suggestion allowed for the nurses to address sensitive and difficult themes in a manner limiting judgment or pressure:

I suggested that perhaps she had been left on her own too early and too much, and that the rape and the later abuse by her former partner had added to her sense that she was on her own in a dangerous world.

However, suggestions were not always considered or accepted. “Her lack of resources and mistrust of others plus her anger and frustration seemed a volatile combination to me. When I suggested she talk to her family worker at Peace (social support agency), she proceeded to refuse.” Notably, when a mother refused suggestion, her nurse refrained from belaboring the idea.

***Summarizing (nurse generated).*** Summarizing, the act of condensing the major themes of a session, areas of concern for the mother, or evidence of progress over several sessions was used in verbal and written forms (Beeber et al., 2007). By communicating what the nurse believed she was hearing from one mother, and requesting the mothers’ confirmation, the nurse acknowledged the mothers’ overwhelming responsibilities.



She was not looking at me so I was compelled to say, ‘OK, let’s see if I have this right.

You have almost no support systems, your friends come to you for advice, your work involves taking care of other people with severe needs and you are raising 3 children.’

Summaries provided the mothers with an alternate perspective and translation to her life circumstances, often highlighting her strengths and commitment to her children versus her limitations and struggle with life difficulties. Moreover, summative final letters written by the nurses to the mothers broadly recapped the highlights of each visit, including nurse-mother collaborations, mothers’ strengths, and progress made. Encouraging and hopeful words for each of the mothers’ future successes accompanied each summary letter. See Appendix for sample summary letter.

In addition to the strategies to maintain the mothers’ focus, attention, and engagement when determining appropriate interventions, non-traditional strategies, like humor and hands on help were used to foster an interpersonal relationship between the nurses and mothers.

***Humor (nurse generated).*** Humor was employed to “diffuse tensions” in a non-threatening manner often confirming a shared sentiment between nurse and mother. Nurses described infusing wit or sarcasm into situations when there was developing tension, or when needing to amplify a message. The mothers often responded with humor as well. For example, after one nurse brought a small gift to her child, the mother questioned, “What gift do I get?” In response, the nurse answered “you get much more; you get me week after week after week”. In response to the nurse’s wit, the mother injected her own wit stating, “ [I would] rather have a gift. We both laughed.”

In another example, when working with a mother who had shared her difficulty in controlling her temper, one nurse suggested a staying calm strategy of counting to 10, and jokingly added, “You may have to count to 20 or 30! She laughed and agreed”.

***Hands on Help (nurse generated).*** Nurses offered hands on help to actively help the mothers out in a practical or reasonable way. The intimate home setting and repetitive nature of the nurses’ visits afforded multiple opportunities for offering and accepting hands on help. It was not uncommon for nurses to offer help like: holding the baby, folding laundry, driving mother to EHS, sweeping the floor, tutoring, or washing the dog, repairing drywall, or mailing letters.

Mother said I don’t know where to start (at this point I am thinking that she is just too energy depleted to make a start) so I said, ‘OK, I’m going to start in the kitchen and you talk while we work. I moved to kitchen and began sweeping the floor.’

Offers to help out were mostly accepted by mothers, however some mothers refused: “I came into the bedroom and asked if I could help out – she was folding clothes. She said no and thanked me for asking and invited me to sit down in a chair across from the bed.”

In sum, the key process of determining appropriate interventions captured the collaborative work of the intervention using skills sheets, problem solving, and cognitive reframing. Strategies to maintain engagement, crucial to the success of the invention included: refocusing/redirecting, suggesting, and summarizing. Finally, non-traditional strategies like using humor and offering/providing hands on help facilitated their collaborative work.

**Evaluate Regularly (ICM).** Evaluation involves tracking and monitoring the mothers’ capacity to engage and their progress in the intervention, to assess which strategies and engagement efforts were most effective (Carman et al., 2013; Drenkard et al., 2015). Nurses evaluated the mothers’ level of engagement, their depressive symptoms and parenting skills and

adjusted and adapted engagement strategies and interventions accordingly. Specifically, after every meeting, the nurses assigned adherence ratings, indicating how well the mothers were executing the co-created plans for the week and completing the assigned skill sheets and “homework” (0= not at all, 1= Very little, 2= Somewhat, 3= Well, 4= Very Well). The mothers’ adherence rating, a nurse- assigned proxy for engagement, indicated how well the nurses perceived that mothers were using the interpersonal skills and strategies in her everyday life and relationships. For example, one nurse recounted a mother had a fight with her husband, and during the fight, “ she used the ‘Staying Calm’ skill sheet, and then stated clearly she needed help with the children.” In response, both her husband and in-laws pitched in to help out with the children, and the mother reported back to the nurse, her realization that the work with her nurse “was working!”

Additionally, the nurses evaluated the mothers in terms of their parenting skills and behaviors. For example, one nurse took note when one mother’s young children were watching an age appropriate Disney movie; different from the inappropriate horror film they watched during the initial visit. The mothers’ self-report also gauged their progress, as in this case when one mother shared: “[I] have not yelled at all in a couple of days and no one got whooped this week. Have not smoked in 2 days.”

Assessment circles from previous weeks and formal evaluation tools (e.g. Depression Symptom Inventory) helped nurses to evaluate and track the mothers’ depressive symptoms and progress in the intervention. Less formal evaluative methods like simple observations were also used to evaluate the mothers’ progress: “I commented that she had finished the focus-finish task completely.”

At times, nurses kept their detailed descriptions of evaluation and engagement complexity solely to her narrative note:

This is a tough mom and I have to be very careful to not appear overly excited by something, as she often looks for ways to squash what she perceives as false reassurances. But I did see a glimmer several times of a slight movement to become invested, though I could see that the effort was a risk to her.

At times, evaluation involved the acknowledgment that progress was not being made, prompting the nurses to adjust engagement skills and strategies accordingly:

As I began to talk about the skill sheet I could sense her anger. She identified as losses: the death of her mom, the abortion in August and her childhood. I attempted to move her in the direction of exploring growth potential, but she could not go there.

Weekly evaluations were essential in determining the mother's level of engagement, her depressive symptoms, and the effectiveness of engagement skills and strategies used in the mental health and parenting intervention. Additionally, evaluations were essential in planning and navigating future meetings.

Elements of the five key phase of the Interactive Care Model were represented in the nursing narrative notes. The nurse generated engagement strategies added specific and detailed actions to the key phases and offers a rich and robust picture of engaging a traditionally underserved population.

### **ICM Partnership Roles and Nurse Generated Engagement Practices**

The Interactive Care Model's seven clinician and person/family partnership roles will now be examined. Again, specific nurse generated engagement skills and strategies are under the

ICM headings and offer specific examples as to how the ICM is operationalized in nursing practice. The seven ICM partnership roles, nurse generated engagement practices, and data extraneous to the ICM are displayed in Table 4.4.

Table 4.4 Summary of Key Findings ICM Partnership Roles, Nurse Generated Engagement Practices, and Data Extraneous to the ICM Processes

<u>ICM Partnership Roles</u>	<u>Nurse-Narrative Data</u>	<u>Data Not Fitting the ICM categories</u>
Whole person	<ul style="list-style-type: none"> <li>• Aromatherapy</li> <li>• Spirituality</li> <li>• Faith</li> </ul>	
Exchange Information/ Communicate Choices	<ul style="list-style-type: none"> <li>• Silence</li> <li>• Permission</li> <li>• Gesture</li> <li>• Control of intensity</li> <li>• Facilitation of catharsis</li> <li>• Physical touch</li> <li>• Facial expression</li> <li>• Gratitude</li> </ul>	
Caring and trusting	<ul style="list-style-type: none"> <li>• Cultural specification</li> <li>• Self-disclosure</li> <li>• Empathy</li> <li>• Facilitation of Grieving</li> <li>• Gift giving</li> </ul>	<ul style="list-style-type: none"> <li>• Hands on help</li> <li>• Humor</li> <li>• Boundary maintenance</li> <li>• Anticipatory warnings</li> <li>• Role clarification</li> </ul>
Knowledge Exchange	<ul style="list-style-type: none"> <li>• Knowledge Exchange</li> </ul>	
Collaboration	<ul style="list-style-type: none"> <li>• Role play</li> <li>• Reflection</li> <li>• Problem solving</li> <li>• Review</li> <li>• Questioning</li> </ul>	
Coaching	<ul style="list-style-type: none"> <li>• Letter writing</li> <li>• Praise</li> <li>• Self-reflection</li> <li>• Encouragement</li> </ul>	
Navigating	<ul style="list-style-type: none"> <li>• Referrals</li> </ul>	

**Whole person (ICM).** The partnership role of whole person involves addressing matters of the body, mind, and soul (Lyttle, 2002; Wolever, 2011). To promote the mothers' holistic health and healing, nurses used historically alternative therapies like aromatherapy, mindfulness, nutrition, yoga, meditation, relaxation techniques, and focused on faith. One nurse often introduced aromatherapy to the mothers as a way to enhance their psychological and physical well-being by reducing stress levels, improving concentration, and enhancing mood and memory (Herz, 2009). Aromatherapy and other holistic approaches to care offered a complementary approach to the interpersonal psychotherapy in addressing the mothers' depressive symptoms. Additionally, holistic styles presented opportunity for the nurses to actively practice mindfulness with the mothers as described below:

Since we had had an intense yet productive session, I felt the need to calm her as well as strengthen her own energy. Therefore, we sat in the front seat of my convertible under a huge oak tree, listening to the birds, watching a squirrel and making occasional comments about the creatures and her mother's garden . . . She did not move from the car once we set the time for next week. It was a restful, restorative time for both of us and I concentrated on sending her peaceful, healing energy. It was such a great way to end the session and 'smooth the ruffles.'

Notably, the nurses supported and encouraged the mothers' spiritual practices in terms of reminding mothers to use dream books and journals, or by acknowledging the power of faith, prayer, and spirituality. Specifically, a few nurses frequently wrote down the Serenity Prayer for mother's referral, self-disclosing how the prayer helped them in times of struggle and may help mother "work through her anger, grief and loss." In discussing complex life issues, conversations often became spiritual in nature. For example, when asked by one mother, how she found her

peace, the nurse responded: “Peace comes with doing what you know you are supposed to be doing in this life, from gratitude for what you have and are, and for asking for what you want and believing it will come to you.”

**Intentional presence (ICM).** Nurses practiced intentionality by being fully aware and present with mothers in an effort to heal and build genuine, trusting relationships (Beeber et al., 2007). Intentional presence was described when the nurses described “looking intently” at the mothers, “listening,” “nodding,” non-verbally communicating her “attention to and investment in the mother.” Simple alterations and exaggerations in body language, volume, and pace of speech used by the nurses intentionally expressed via intonation and subtle behavior that “what she (mother) was telling me (nurse) was important to me (nurse).”

Although silence, the absence of intentional sound can be construed as the antithesis of active engagement (Jaworski, 1992; Voegelin, 2010) silence was highly represented in the nursing narratives as an effective engagement strategy. Silence was frequently employed by the nurse allowing time and space for “cognitive reframing to settle into mothers thoughts” or “to allow mother time to engage”. Silence, often used to “honor the heaviness of the topics” recognized the “significance of mother’s (sic) insight and expressions”. Silence provided mental space for the mothers’ to work through their innermost thoughts, feelings, and life perspectives.

She stated since her childhood was so bad, she felt like she deserved better. I encouraged her to explore further that line of thinking. Mother was quiet for a few seconds (I remained silent). Mother then stated, ‘I do have great kids, a home and a husband who loves me.’ I smiled and nodded.

**Permission (nurse generated).** Permission, defined as the act of giving consent or authorization (American Heritage Dictionary, 2011) was used when the nurses asked the

mothers: “Can I come upstairs?” “Can I give him a cookie?” “Can I sit here?” As guests in the mothers’ home, the nurses described asking permission to underscore both acknowledgement and respect for the mothers as host. Nurses were deliberate in asking for permission as described, “She asked me to get the folded sheet of paper out of the diaper bag. I complied, asking her if she wanted me to open it (I did not want to assume).”

In another example, a nurse asked for parents’ permission to share educational information about using time outs with their children. Asking permission shifted power to both parents as decision makers, to allow or deny the nurse’s request. Notably, nurses asked permission to hug goodbye, especially when they were “unsure if a goodbye hug would be welcomed or not.” Asking permission facilitated a transfer of power to the mothers to actively decide what happens or doesn’t happen next.

***Gesture (nurse generated).*** A gesture is any action, courtesy, and communication, intended for effect (e.g. thumbs up) or as a formality (e.g. handshake) (Dictionary.com, n.d.). Nurses used gestures like “taking off her coat, taking out paperwork, and sitting down next to mother to signal to the mother her intent to start.” Gestures such as “making eye contact,” “nodding in agreement,” “giving high fives,” or “thumbs up,” demonstrated the nurse’s intentional presence with the mothers. At times, gestures were subtle expressions of intentionality demonstrated by nurses putting paperwork aside, leaning back on the couch, and attempting to communicate recognition of the “heaviness of the subject” being discussed. Nurses were mindful “to listen” and “try and be fully present as possible.” One nurse purposefully cupped her ear to express she could not hear over the blaring TV, or used her hands to visually demonstrate the ups and downs when referring to relationships, exemplifying how some nurses used gestures to punctuate their expressions, and amplify intended messages.



Mothers often reciprocated with gestures of social convention, like walking nurse to the door, clearing a place for the nurse to sit, or cleaning crumbs off the table before the work got started. Nurses speculated gestures in this context were non-verbal messages expressing both intentional presence and readiness to engage and connect via an unspoken language.

***Facial expression (nurse generated).*** Nurses described a myriad of facial expressions to non-verbally express: “amazement,” “appreciation,” “surprise,” “puzzlement,” “sympathy,” and “concern.” Expressions were described as using “quizzical” and “questioning expressions” or expressions of “confusion” to punctuate the nurse’s level of understanding. Simple smiles, often contagious and reciprocated by the mother, were effective in “relieving some of the developing tension” between mother and nurse.

Nurses indicated giving “big smiles” often accompanying praise, delivering both a verbal and non-verbal expression of enthusiastic commendations. Moreover, the nurses were deliberate and mindful to abstain from using facial expression at certain times. For example, one nurse noted purposefully keeping a neutral expression as the mother vented about her husband with the intention to deliberately “not buy into her hostility towards him .” Facial expressions convey emotions; the nurses noted their awareness of their non-verbal facial expressions and body posturing to draw in mother’s engagement while maintaining professional boundaries and standards of care.

***Control of Intensity (nurse generated).*** Nurses controlled the intensity in the exchanges with the mothers by purposefully increasing or decreasing pressure when addressing heavy, as in highly intense or difficult, or anxiety-laden issues in the mother’s life (Beeber et al., 2007). Nurses described “pressing” some mothers who were quick to dismiss their feelings, by encouraging them to reflect about her specific issues, reactions, and feelings. However, instances

of “decreasing intensity” were more heavily reported throughout the narratives as many of the interactions with nurses and mothers dealt with highly sensitive and serious topics. Nurses purposefully “backed off” or “did not push” the mothers, giving them the time and mental space to gradually begin to address difficult past and present life issues. Nurses commented on the fragile psychological state of many of the mothers and purposefully adjusted interpersonal intensity to prevent mothers “shutting down her (mother’s) willingness to talk completely”. For example, one nurses acknowledged when her conversation with the mother was open and animated and controlled the intensity of the exchange by dropping the topic of her husband’s relationship with her son “when she did not seem to want to discuss it” to sustain the mother’s engagement and progress in the intervention. In contrast, the nurses noted the seriousness of previous discussions (e.g. visits discussing sexual abuse, rape, abortions), and were purposeful in refraining from challenging or delving into anything “heavy” prematurely.

***Facilitation of catharsis (nurse generated).*** Catharsis is the "the process of reducing or eliminating a complex issue by recalling it to conscious awareness and allowing it to be expressed" (Schultz & Schultz, 2004, p.506). Nurses facilitated catharsis by listening and encouraging mothers to verbalize and vent their frustrations and anger regarding her past and/or present challenges and feelings. Mothers recounted day to day sadness as well as numerous difficult and tragic histories including: “witnessing a fire take the lives of three children in the trailer park,” feeling “humiliated” in receiving Medicaid services, or “feeling terrified by the violence” (e.g. stabbings, break-ins, shootings) that constantly surrounded her and her children, or feeling violated by injustices of “the system.” By facilitating catharsis, the nurses supported the key ICM process of information exchange, and gathered information to inform future health and health care choices. Nurses listened to the mothers’ accounts, acknowledged how upset they

were, refrained from offering immediate solutions to the multi-layered issues, and allowed time and space (i.e. silence, listening, intentional presence) for the mothers' emotional release.

***Facilitation of grieving (nurse generated).*** Facilitation of grieving was marked with nurses promoting mother's affective expression and facilitating catharsis around issues of her loss (Beeber et al., 2007). Nurses encouraged the mothers to talk about their experiences with loss due to a family members passing, loss of childhood secondary to physical and sexual abuse, loss of mothering opportunity secondary to miscarrying, or other traumatic events in her past. By asking about her sadness and loneliness, and by providing time, opportunity, and validation to cry, and experience pain, the mothers could grieve and begin their own personal healing process.

***Physical touch (nurse generated).*** Physical touch was an approach used by nurses to accentuate concern, support, or encouragement by softly patting mother's hand, knee, or back, Physical touch punctuated the nurse's presence and concern for the mothers and was also used to facilitate gaining and keeping the mothers' focus and attention. At times, physical touch was used for assessment, either assessing a child's ankle injury or helping the mother remove a foreign object from her eye. Notably, the nurses asked for permission before touching a mother and her child. Nurses were mindful when to modify a hug to a handshake, or refrain from physical touch altogether, working from mothers' cues before using physical touch: "Normally, I would never have touched Mom at this point in our relationship, as she seems not to want that. But, because she had touched me first, I touched her shoulder, and said, 'thank you.'"

We talked about how the children had been saved by the mother breast-feeding them. I shared how awesome women were and thank God for mothers. My voice cracked a little with emotion as I said that. She definitely noticed this as I saw it in her face. We were a

few feet apart and I moved toward her with my arms open. We shared a hug. It felt like we had bonded with the acute awareness of the human condition that we all share.

***Gratitude (nurse generated).*** Gratitude, or the quality of being thankful; showing appreciation for and to return kindness was frequently reciprocated between mothers and nurses. Mothers often expressed gratitude for the nurse's emotional support and words of encouragement and small gifts like cards or pictures. Nurses in turn, expressed feeling it was "an honor" to have "worked with" the mothers and "travelled with them (mothers) on your beautiful journey," underscoring the caring, trusting, respectful nature of their collaborative partnership. Nurses expressed gratitude to the mothers for their sacrifice of time, honesty, hard work, and effort in meeting with and discussing sensitive and sometimes painful memories, thoughts, and feelings.

I thanked her for telling me how she really felt. I said that I know that I can never really get what it is like for her but that it is very important for me to try to understand what she is going through because that will be the only thing that helps us change.

Nurses repeatedly thanked the mothers for participating in the HILDA project and for allowing the nurse to enter her home and acknowledged mothers' small gestures of thoughtfulness. For example, one nurse who was recovering from knee surgery expressed gratitude when a mother set up a special chair for her. Another mother encouraged the nurse to park her car in the driveway, and watched the nurse until she got to her car. The nurse speculated these actions were to ensure both the car and nurse stayed safe and free from harm. The expression of gratitude facilitated recognition and appreciation for both the nurse's and the mothers' kind and considerate gestures.

***Caring and trusting relationship (ICM).*** An undeniable connection exists between caring and trust as caring and concern often engender credibility and trust (Covey & Link, 2012).

Upon reflecting how to effectively communicate with and engage with the mothers one nurse noted, “Timing and trust are everything.” In their narrative notes, nurses appeared to be intentionally transparent, using their words and actions to demonstrate their caring, concern, and investment in helping improve the mothers’ depressive symptoms. Beginning with the pre-engagement phone call and sustained throughout the entire intervention, the nurses were upfront about issues of confidentiality and disclosure of being mandated reporters. Caring was demonstrated throughout the intervention as the nurses expressed concern to the mothers when the mothers missed appointments, did not return phone calls, or seemed distraught during challenging circumstances. Caring was also expressed when celebrating the mothers’ successes, one nurse describing, “I jumped for joy” in response to “mother’s newfound enthusiasm and confidence.” Nurses were invested in the mothers and their children, expressing care and concern for them and their well being week after week, evidenced by their reflective commentary and tailored approach with each mother. For example, the nurses inquired about specific events like getting the orange juice out of the fish tank or inquired about the boy’s football tryouts, conveying genuine care and concern for the mothers and their children.

***Cultural Specification (nurse generated).*** Cultural specification is any behavior done to acknowledge or support dimension of or within, cultural, religious, or group affiliation (Beeber et al., 2007). Throughout the intervention, opportunities were presented for nurses to learn about the mothers’ cultural and religious traditions. Accordingly, before entering a Muslim mother’s living space, one nurse removed her shoes in a demonstration of respect for the mother’s culture and tradition. Similarly, when discussing one mother’s limited options with her difficult and demanding father, a nurse purposefully substituted the word “darn” when conveying the

sentiment “Damned if you do, damned if you don’t” out of reverence for the mother’s religious traditions.

Through cultural specification differences as well as similarities between the nurse and the mother were highlighted.

Mom finally wrapped her up in this beautiful blanket to calm her. It reminded me of the ‘swaddling’ the bible talks about. I said this to Mom and we both watched as her daughter finally calmed down and went off to sleep. I think we both appreciated the age-old mothering intervention, no matter what the cultural origins.

In addition to the nurses learning about certain implements of culture, like Iranian natural toothbrushes, the Muslim faith, and African headdresses, nurses also gained new perspectives as to what it was like “being black in a Caucasian world.” Although non-equivalent, the horrors of racism and slavery emerged as the mothers shared challenges faced by being a “black woman working with all white teachers in an inner-city school with mostly black children.” One nurse “found it appalling” when she accompanied a mother to court, and saw firsthand how the black mother was treated by “rude” and “insensitive white attorney and clerical staff”, while the mother seemed to be used to their behavior and treatment. As such, nurses reflected upon how different their life perspectives as Caucasian middle class woman were from a low-income African American mother in terms of the criminal justice and legal system, racism, cultural differences in “gaining respect” or being labeled “too white.”

***Self-Disclosure (nurse generated).*** Nurses deliberately shared personal information or experiences for the purpose of normalizing the mother’s experience, engaging the mother, reducing a perceived barrier, or other strategic reason (Beeber et al., 2007). Information shared included the nurse’s thoughts, feelings, aspirations, goals, failures, successes, fears, and dreams,

or their likes, dislikes, and favorites. Specifically, several nurses self-disclosed: shared difficulty in cutting her own infants nails, using the television as a babysitter when necessary, the comfort found in the Serenity prayer, experiences as mothers and public school teacher, and the sustained nervousness felt months after a car accident. When one mother apologized for a messy house the nurse buffered the situation, reminding the mother that she had young children or would say: “You should see my house and I don’t even have a child!”

Perhaps the most striking example of self-disclosure was one nurse who readily discussed her prosthetic arm, using it as an opportunity to talk about having only one choice in life: and that was “to be a survivor.” The nurse noted that the mother (with physical scars of her own) “nodded and seemed to really understand & appreciate where I was coming from.” In sharing her personal experience, this nurse revealed vulnerable and sensitive aspects of her private life, initially admitting to feeling self-conscious of her original hook type prosthetic arm, but then getting more comfortable with letting it all show. The nurse and the mother agreed on the sentiment: as they got older, they cared less about what others thought and became more focused on doing what was right for them.

***Role Clarification (nurse generated).*** Role clarity is a crucial facet of effective interpersonal communication and collaboration, as poorly defined roles can breed false expectations, confusion, and conflict (Leebov, & Ersoz 2003). Transparent communication about the expectations and responsibilities of the mothers as active collaborators in care were delivered often, especially with the mothers who missed scheduled appointments. Nurses reminded mothers of their responsibility and commitment for following through with the work of the intervention and meeting for scheduled appointments. Similarly, when providing emotional support, nurses clarified what she was willing and not willing to do for the mothers. For

example, the nurses were not able to see the mothers privately outside of or after the intervention completion for counseling or vouch for the mothers on matters they were not qualified to do so.

***Empathy (nurse generated).*** Nurses expressed empathy throughout the narratives, noted by feeling a heightened sense of understanding of the mother's issues but not losing her sense of separateness between herself and the mother (Beeber et al., 2007). Highly represented in the nursing narratives, empathy was operationalized as the nurses purposefully listened and "tried to put herself in the mother's shoes" when the mothers spoke about pressing and difficult situations. For example, when one mother shared challenges she was having with "her husband in jail and trying to keep her son off the streets", the nurse was sympathetic and tried to genuinely understand what it means to be a minority and deal with those circumstances and challenges. Nurses recognized and shared in the mothers' feelings of "exhaustion," "frustration," "anger," "anxiety," and "discouragement". In one case, the nurse's sympathy was misconstrued as "pity," potentially stifling the mother's engagement and prompting her to shut down. However, the nurse was quick to explain she did not feel pity towards mother, but rather was trying to show compassion in wishing her circumstances would improve.

***Boundary maintenance (nurse generated).*** Professional boundaries are the spaces between the nurse's power and the mothers' vulnerability (National Council of Boards of Nursing, (NCBON), 2014). Nurses employed verbal and behavioral tactics to clarify and emphasize existing professional boundaries. Nurses clearly used multiple expressions of various engagement strategies throughout the intervention, however, protected the professional relationship by setting clear limits and boundaries in terms of the nurse's legal responsibilities and the time, attention, and assistance they had available. For example, when a mother asked to borrow the nurses cell phone, the nurse clarified that because the call was about the child she



allowed it, but would not let her use the phone for social calls. Nurses had to remind several mothers post-termination relationships were neither possible nor appropriate and were firm in refusing to engage in a business relationship with one mother (e.g. Avon). Nurses used boundary maintenance to protect the mothers' privacy when family members were present and loitering within an earshot of their confidential conversation.

***Gift giving (nurse generated).*** Gift giving was employed as a physical symbol of the developing personal relationship and expression of the social ties being built between the nurses and the mothers. Small spring bouquets, a family picture, outfits for her newborn, healing oils, or Christmas cookie decorating supplies were often given to the mothers by the nurses to acknowledge an exchange from the previous visit. Therapeutic in nature, gifts included a sports water bottle belt to encourage walking, or over the counter Benadryl to help mother sleep, or soothing sound CDs to help a mother relax. Other gifts included food, like a mug of hot chocolate, a pizza, a salad, or dark chocolate, fueling not only the mother's body, but the nurse-mother social connection as well.

**Knowledge Exchange (ICM).** While the nurses held valuable expertise and knowledge about health and health care, the mothers held expertise and knowledge as to her health conditions and symptoms, their care goals, their children's behaviors, and their responses to her current circumstances (Drenkard, 2015). Nurses took the lead and helped mothers navigate through the knowledge exchange process and described the risks and benefits of her potential care choices. As such, the nursing narrative data were rife with detailed accounts of the mothers' current health status and circumstances, past history, current thoughts and feelings, and care goals.

For example, nurses helped mothers focus and weigh the risks and benefits of her past decisions to engage in physical violence, return to school, or learning the paternity of her unborn child. Nurses provided education for mother's physical ailments, parenting strategies, and communication strategies often writing down the pros and cons for different approaches (e.g. moving in with parents, confronting EHS director about parenting, calling Child Protective Services to file a complaint about child's father) and then together, the nurse and mother decide which approach to take and work on.

Below is an example that demonstrates how the mother exchanged her knowledge with the nurse:

Mom has severe insomnia. She denies getting more than 3 hours of sleep a night. She falls asleep, but cannot stay asleep. Through a series of questions, I learned that this began after the birth of her 7 year-old son, and became worse, after her daughter fell out of an upstairs window in January. I (nurse) also learned of her mother's heart by-pass surgery this spring, and her father's pneumonia, and that even though she has siblings, she is the one in the family that everyone goes to for help.

Next is an example of how the nurse shared her knowledge with mother to help her guide the behavior of the children. Although similar to the mothers' exchange of knowledge, nurses exchanged knowledge from a position where they were able to help navigate, advise, and lead the mothers through the parenting enhancement activities.

I drew a diagram of how to set up a chart for each boy using the neon tag board & markers. I brought play money, stars, 2 types of stickers, and 2 Nerf balls; emphasized using different stickers or money for each boy. We practiced: bad behavior, she looks but does not speak, waits to see if behavior stops, then if not, shrugs and says, "too bad, H.

just missed getting a star.” Then walks away (uses “Staying Calm”) or sends child to time-out if behavior does not stop (no attention reward for the behavior. We practiced delivering the “hairy eyeball” and saying the comment that the boy had lost the prize in a matter-of-fact way and when to give the rewards. Left her with the materials to create the charts and try it out this week.

Knowledge exchange exemplified the ICM’s partnership role in that the nurses and the mothers took turns as being both the teacher and the student in order to advance their relationship and work of the intervention. Although often lead by the nurses the exchanges became bi-directional with the nurses and mothers practicing strategies together, thus facilitating mothers’ engagement.

**Collaborating (ICM).** Collaboration has been defined as a “true partnership, valuing expertise, power, respect on all sides and recognizing and accepting separate and combined spheres of activity and responsibility”(Drenkard et al., 2015, p.507). Nurses did not “do for” the mothers but rather “partnered with” them to improve her depressive symptoms and self-care and parenting strategies. Drenkard et al. (2015) describe a collaborative approach as one that requires a shift in thinking to one where the nurse and the mother are equals on the care journey. However, throughout the narratives, although at times equal, there was more of a constant waxing and waning of power differentials between the nurses and mothers. Throughout most of the intervention, the nurses were clearly in charge, seeking out contact and interpersonal relationships with the mothers, presenting contracts, setting and maintaining professional boundaries, assessing the mothers’ capacity for engagement, establishing flow of conversations, and giving the mothers’ time and space to reflect, grieve, and engage. By leading in this way, nurses set up opportunities for the mothers’ to engage and collaborate.

Although the intervention was nurse-directed and nurse-driven, nurses used an interpersonal collaborative approach, as the success of the intervention was predicated upon the mothers' engagement. Collaboration was clearly represented in one narrative note, recounting how one mother and one nurse worked together to create a safer home environment for the mother's boys.

She then brought up her parenting in the past- the incidents that got reported to Child Protective Services. This was the first time she had ever volunteered it or taken responsibility for it (it had always been 'they say that I do this or that'). We discussed each incident and looked at the places where the 'holes' were that created danger for the boys.

Collaboration was demonstrated when the nurse and the mother worked on actionable change. For example, when preparing one mother to confront the Early Head Start director, the nurse did not tell mother what to say, but rather, actively participated in practicing the words and tones mothers would use.

I got "Resolving Disputes" out and walked her through the process of initiating discussion with the director. I had her practice using 'I need . . .' statements to me as [I role played] the center director. After 3 tries, she was able to state 'I need you to have confidence in me as a parent'- and I congratulated her on it.

***Role-play (nurse generated).*** Role-playing was used to prepare mothers for upcoming, potentially anxiety producing, interpersonal meetings and communications with teachers, service directors, peers, and potential employers. Nurses would play the part of the teacher and mothers would rehearse their dialogue and practice responding to comments initially feared, like "you don't have enough experience" or "we are not hiring." Collaboratively practicing for these

encounters was intended to ease the mothers' apprehension and help them gain confidence. In addition, collaborations, when successful, were opportunities for the nurse to deliver constructive praise.

***Reflection (nurse generated).*** Nurses would often reflect a mother's words back to her to allow for the mother to hear for herself, and evaluate the reasoning or logic behind her words and statements. Nurses used reflection in a non-threatening manner by "wondering out loud," about reasons for, logic behind, and potential consequences of certain situations. Reflection was used by the nurse to verbalize the rational of her thinking and openly invited mother to join her in problem solving:

As we discussed this I acknowledged that the boys may be picking up on the tension in the home, or may be hot, or may be bored with school out, or? And wondered if there was a stress reduction activity she and the kids could do together.

In using reflection, the nurses provided opportunity for the mothers and family members to engage in a shared discussion, without any direct pressure to answer or contribute.

***Problem Solving (nurse generated).*** Nurses purposefully targeted the mothers' most pressing life problems, to help mothers "feel immediate gains from the therapy" (Beeber, 2007, p.10), and keep her engaged and retain her in the intervention. Problem solving involved simple activities the mothers and the nurses worked on right then and there, like "how to confront her sons teacher", how to "ask for help and take some time for herself", ways mother could "make ends meet until she gets another job", or "how to release her anger in a more healthy way" with the goal to improve her immediate situation.

***Review (nurse-generated).*** Frequently reviewing assessment circles and the areas the mothers and the nurses concentrated on helped to reinforce the work the pairs have done,

including lessons learned, and directions for the future. Review was a strategy nurses used to ensure the mothers and the nurses “were on the same page,” with a shared mental model and understanding as to where they have been and the direction they are headed. Nurses frequently reviewed the assessment circle, verbalized how many sessions they had left, and reviewed key points from the previous visits, giving structure, rhythm, and predictability to each encounter.

Review also allowed opportunity to reflect and highlight and underscore important revelations and lessons learned. During the final visit, the nurses gave the mothers written letters, tangible records of their collaborative partnerships summarizing their time together, work performed, and progress made.

I shifted to M. herself and reviewed her progress. I read the final letter to her. She was obviously moved by it. I gave her a small box that had inside several of the affirmations, interpersonal ‘lessons’, and her own resolutions cut into small card sizes, laminated and attached to a key ring. I went through each one of them, reviewed in the letter, and linked them to our overall work. I encouraged her to use the key ring to review her strategies when the symptoms returned.

***Questioning (nurse-generated).*** Open-ended questions were used to generate discussion and begin dialogue between the nurses and the mothers. Nurses again led the exchange by assuming the role of student and through questioning, learned about mother’s circumstances and innermost thoughts.

Mom became more thoughtful then and talked about how much her son reminds her of her husband. Through a series of questions, I learned that Mom knew at the age of 15 that her husband was going to get into trouble, and that she sees some of those same personality traits in her son.

At times, questioning was delivered via tone and reflection, intending to obtain important and relevant information from the mother, without being intrusive.

She stated that she wanted to get out of the angry-hate-cycle concerning her abusive step dad. She added ‘it’s not his fault.’ I was quite puzzled by that comment and I reiterated what she said with a questioning inflection in my voice and facial expression.

Thus, questioning was a strategy used to foster engagement and was used in a way to let the mothers drive interactions.

**Navigating (ICM).** Nurses acted as navigators, leading and partnering with the mothers to ensure they understood what health care and support resources were available to assist them, when they should seek these services and how to access them. For example, it was common for nurses to reference WIC programs, food stamps and Medicaid programs for prescription refill assistance.

We discussed her financial situation and resources available, which might help to ease the burden, (i.e. food stamps, Medicaid), discussed the need for time for her to be able to go to gym, which she identifies as a social time as well as a stress relief.

One nurse expressed sensitivity and recognition of a mother’s ambivalent feelings towards receiving assistance and responded by providing encouragement and support.

She wants to look at getting some help with the financial situation by applying for food stamps. She says she is reluctant because she wants to do this ‘on her own.’ I praised her for her courage to try this on her own but also encouraged her to look at help as a temporary situation and how this might free up some funds and take off some of the pressure she feels financially.

Nurses helped mothers navigate through the Family Services program, Social Service Program, provided resources to help one mother move out of the projects to a safer home, and offered the availability of a 24-hour crisis contact line if she should ever need help in the middle of the night. Navigating was a collaborative effort as nurses and mothers both took the lead in discussing feasibility of using services. Importantly, nurses emphasized mother would be in control of whom she wanted or did not want to help.

I emphasized that there are allies for her – Early Head Start, Child Protective Services, mental health services, her in-laws – and that she could be in control of who she wanted to help her. She acknowledged that. I gave her a list of resources – mental health, crisis hotlines, child help, etc.

***Referrals (nurse generated).*** Referrals for additional therapy or services were mentioned when appropriate. Not always well received, nurses still mentioned referrals and advocated for the mothers' using appropriate support services.

Her lack of resources and mistrust of others plus her anger and frustration seemed a volatile combination to me. When I suggested she talk to her family worker at Peace [social support agency], she proceeded to refuse because of more complaints that seemed unrealistic to me, and also talked of taking her kids out of EHS. I encouraged her not to take that action yet.

***Coaching (ICM).*** The partnership role of coaching was evident throughout in the nursing narratives, as nurses regularly gave positive feedback and direction to mothers when they actively engaged in the intervention, their health and health care. The nurses, as coaches, through direction, encouragement, and praise facilitated mother's mental and behavioral life enhancements.



Mom showed some of her visitors her folder on Sunday and called me “her little therapist”—first time she has referred to me as such! Anyway, she was proud of the fact and one of the women visiting wanted a copy of the assessment circle because she thought it could help her. She said, “Oh I couldn’t give you a copy”. I said, “Sure you can and show her how the circle works!” She got a smile and I could tell she was pleased.

Coaching celebrated mother’s efforts to improve her circumstances and offered support when struggles were encountered. As coach, one nurse wrote: “I let her know I didn’t think mothers hear thank you’s often enough and especially when she was working hard to make changes.”

***Letter writing (nurse generated).*** Nurses wrote letters and notes as a means to initially establish and maintain contact, but also regularly sent notes of encouragement, and customized reminders of affirmations and strategy sheets for the mothers. In addition, nurses also wrote mothers final letters, summarizing the events and progress made each week together. See Appendix for summary letter exemplar.

Letters served to concretize the mothers’ work and progress and would be accessible for the mothers’ reference long after the HILDA project was completed.

***Praise (nurse generated).*** Praise was used as an expression of warm regard, approval, or appreciation of the mothers’ efforts and engagement in the intervention (Blase, & Kirby, 1992). Nurses recognized and praised the mothers’ engagement and effort, encouraging the mothers’ to keep working towards her behavioral and interpersonal goals.

I don’t think that she quite gets this yet, but she just beamed at my praise at how she handled the entire nightmare with Child Protective Services. She became tearful and said,

‘you know, I really do try and it really will help.’ I smiled and gave her a hug. ‘Yes you do, and you are a good mother and a good woman.’

Praise was a powerful motivating strategy as it allowed the nurses opportunity to selectively encourage specific aspects of the mothers’ behaviors and lines of thinking. One nurse noting, “We did the circle and she wanted to start with her strengths which floored me and I said, ‘You go girl!’

***Self-reflection (nurse generated).*** Nurses used the narrative notes to comment on what they themselves did or did not do and why, or how they reacted or did not react to certain circumstances.

I was genuinely glad to see her and said warmly, ‘So how have you been, honey?’ As soon as the ‘honey’ was out of my mouth, I was sorry that I let it slip as I wondered if it would offend this very proud woman.

Nurses’ self-reflective practices often underscored the notion that although leading the intervention, the nurses were constantly learning, evaluating, and adjusting their own engagement practices in terms of what was most effective with each mother. During one exchange a nurse asked the mother to identify her ultimate goal:

She immediately said, ‘getting my children back.’ I said, ‘other than your children,’ in a firm but gentle way. Then I thought that was a bit controlling on my part, and said, ‘well, you know what, let’s first trace that thought on the circle so we can see how all of this fits together.’

To summarize, the seven clinician and person/family partnership roles of the Interactive Care model were highly represented in the nursing narrative notes. Nurse generated strategies added specific detail to the partnership roles and the process of engaging a traditionally

underserved population. Engagement strategies extraneous to the ICM (e.g. hands on help, humor, boundary maintenance, anticipatory warnings, role clarification) were also explored. The remaining research questions will now be addressed.

### **Variation of Engagement Skills by Phases of the Nurse-Client Relationship**

*Research Question 2: How do nurse's description of the engagement skills and strategies that they employed vary across phases of the nurse-patient relationship?*

The second research question used quantitative data from the HILDA study to test if the nurse's descriptions of the engagement skills and strategies varied across the three phases of the nurse-patient relationship (i.e. orientation, working, and terminations phases). Nurses indicated what stage of the interpersonal relationship nurse and mother were in, in each weekly narrative note. Statistically significant differences were found between the Interactive Care Model codes (n=12) used by nurses and the three different phases of the nurse mother relationship- as determined by one-way ANOVA ( $F(2,33) = 15.6, p = .00002$ ).

A Tukey post-hoc test revealed the mean number of Interactive Care Model key processes and partnership roles assigned in the nursing narratives were statistically significant between the orientation phase (phase 1;  $120.5 + 67.7$  min) and the working phase (phase 2;  $311.5 \pm 138.2$  min,  $p < .001$ ). However, there were no statistically significant differences between the phase 1(orientation) and phase 3(termination) ( $p = .997$ ). Additionally, there were statistically significant differences between the working phase (phase 2;  $311.5 + 138.2$  min,  $p < .001$ ) and the terminations phase (phase 3;  $123.5 + 69.5$  min,  $p < .001$ ). Figure 4.2 and 4.3 show the variation in the Interactive Care Model's five key processes and seven partnership roles by phase of the interpersonal relationship.

Fig. 4.2. ICM Key Processes and IPR phase

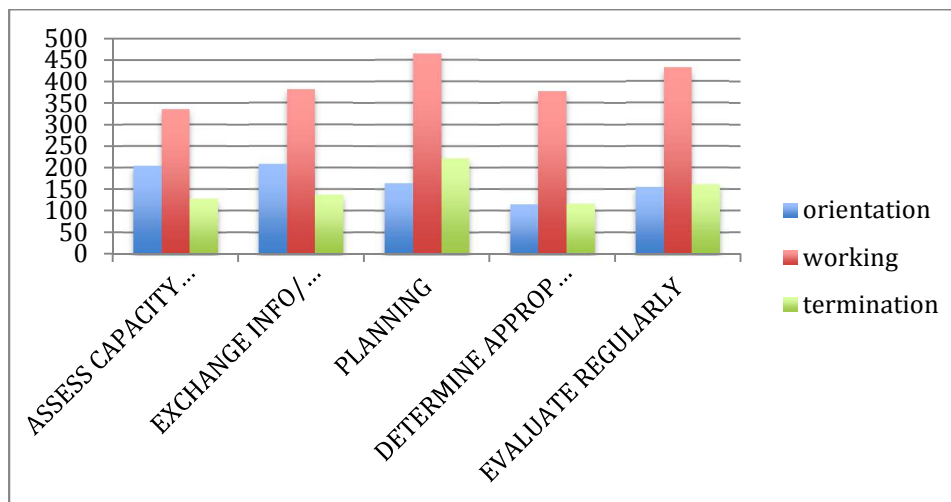
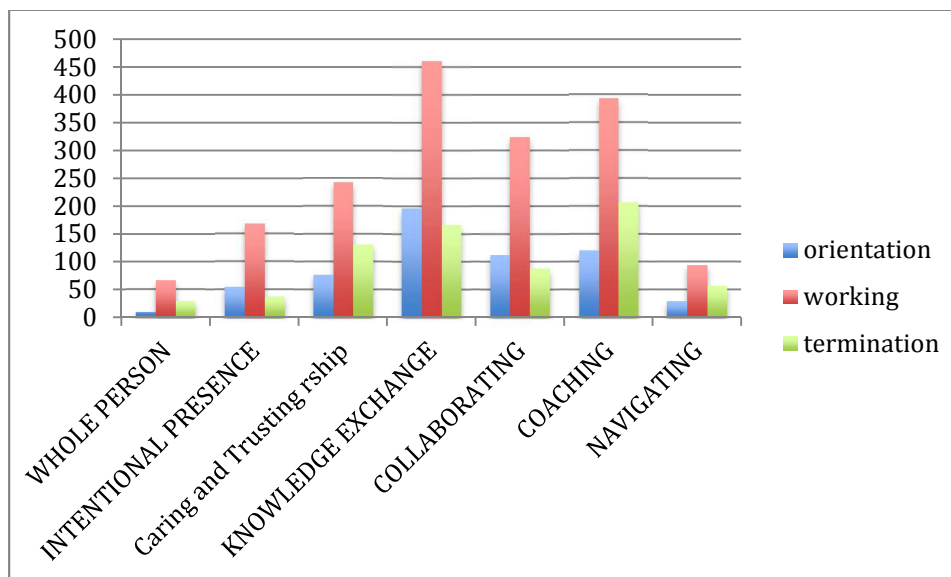


Figure 4.3. ICM Partnership Roles and IPR Phase



The five key process components and seven partnership roles central to the ICM were represented throughout the nursing narratives describing how nurses engaged low-income depressed mothers of infants and toddlers in a mental health and parenting intervention. Notably, each of the five key process components and seven partnership roles of the ICM significantly spiked during the working phase of the mother-nurse interpersonal relationship.

In the orientation phase, assessing mother's capacity for engagement and exchanging information and communication choices were highly represented, as was the partnership role of knowledge exchange. During this phase, mothers and nurses exchanged information, got acquainted with one another, attempted to build trust and rapport, thus setting the stage for the working phase of the intervention. In the working phase, all of the Interactive Care Model's key process components and partnership roles of the orientation phase were represented and increased during this particular phase. Nurses increase their use of collaboration, coaching, and promotion of a caring and trusting relationship, to keep mothers engaged and retained in the intervention by actively partnering with them to explore and problem solve underlying issues contributing to mother's depressive symptoms.

In the termination phase, engagement skills and strategies decreased as the intervention and therapeutic relationship neared completion. Linkages between mother and nurse began to decrease as the collaboration ended, and they prepared to go their separate ways.

### **Variables of Engagement Skills by Nurse-perceived Adherence Levels**

*Research Question 3: How do nurse's description of their engagement skills and strategies differ between mothers with varying adherence levels (highly engaged, fluctuating engagement, minimally engaged)?*

The third research question tested whether nurses used different engagement skills and strategies when they perceived variations adherence levels (i.e. highly engaged, fluctuating engagement, and minimally engaged). Based upon their summative adherence ratings, I grouped the mothers into one of 3 possible groups (minimally engaged, fluctuating engagement, highly engaged). The minimally engaged group scored primarily 0's (adherence level- not at all) and 1's (adherence level=very little) throughout the intervention. Scores in the fluctuating

engagement group varied, ranging from 0-4 with no distinct pattern throughout the intervention. Finally, the highly engaged group included mothers who scored 3's and 4's throughout the entire intervention. Interestingly, no statistically significant differences were detected between the 12 Interactive Care Model codes and levels of mother's engagement (minimal, fluctuating, high) as determined by one-way ANOVA ( $F(2,33) = 1.99, p = .153$ ).

However, when the ICM was broken down into the five key processes and seven partnership roles, statistical differences were found when analysis was run separately. Although there were no statistical differences found between the seven partnership roles and mother's level of engagement as determined by one way ANOVA ( $F(2,18) = 851, p = .444$ ), there were statistical differences found between the five key processes of the Interactive Care Model and level of mother's engagement as determined by one way ANOVA ( $F(2,12) = 6.78, p = .011$ ). A post-hoc Tukey test showed significant differences between the five key processes of the ICM in mothers in the minimally engaged group ( $201.2 + 30.1, p = .008$ ) when compared to mothers with in the fluctuating engagement group ( $289 + 40.6, p = .008$ ). Nurses' engagement strategies were significantly limited with the minimally engaged group when compared to the group with fluctuating engagement. Although nurses tried to engage all the mothers in the intervention, nurses perceived mothers with minimal engagement as non-responsive to the nurse's engagement efforts and appeared to thwart nurses' additional efforts.

### **Variations in Client Engagement and Duration of the Orientation Phase of the Nurse-Client Relationship**

*Research Questions 4: What is the relationship between the level of mother's engagement and the length of time spent in the beginning (orientation) phase of nurse-patient relationship prior to problem-specific (working) phase?*

The fourth research questions addressed if a relationship existed between the level of mother's engagement and length of time spent in the orientation phase of the nurse-mother relationship. Examining correlations between the adherence levels and the relationship phase produced evidence of linkages between mothers' level of engagement and the length of time spent in the orientation phase prior to the problem-specific working phase of the interpersonal relationship. Mothers who were not at all engaged (scoring 0 on weekly adherence level) spent more than twice the time in the orientation phase (37%) when compared to mothers with higher levels of engagement (3.7-14.8%).

#### **Nurse Generated engagement strategies and mother's level of engagement**

*Research Question 5: What is the relationship between nurse generated engagement skills and strategies employed and mothers level of engagement (adherence ratings)?*

The final research question examined if there was a relationship between nurse generated engagement strategies and mothers level of engagement. In addition to the five ICM key processes and seven-partnership roles, the nurses (n=16) assigned their own specific relationship based strategies used to engage mothers (n=30) in the sample. The top 12 nurse generated codes were: (1) questioning, (2) contact, (3) assessment, (4) encouragement, (5) reflection, (6) exploration, (7) control of intensity, (8) empathy, (9) social conversation, (10) praise, (11) suggestion and (12) social rituals.

Statistically significant differences were found between the top 12 nurse generated strategies and mother's level of engagement as measured by weekly adherence ratings using a one-way ANOVA ( $F(4,55) = 16.1, p < .001$ ). A Tukey post hoc test revealed that the top 12 nurse generated engagement strategies assigned in the nursing narratives were statistically significant

between engagement level 0 and levels 2, level 0 and level 3, and level 0 and level 4.

Additionally, statistically significant differences were detected between level 4 and all other levels (0,1,2, and 3). A post hoc Tukey test showed that the “not at all” engaged group (adherence level=0) differed significantly from somewhat engaged (adherence level =2) and engaged well (adherence level =3). The highly engaged group (engaged very well) (adherence level=4) was significantly different from the other three less engaged groups ( $p < .001$ ).

Correlational analysis was used to examine the relationship between mothers’ level of engagement (ranging from 0-4) and nurse generated engagement skills and strategies. Results indicated a strong relationship between mothers’ level of engagement and nurse generated engagement skills and strategies used,  $r(60) = +0.66$ ,  $p < .05$ .

Similar to the ICM results, statistically significant differences were found between the top nurse generated engagement codes ( $n=12$ ) and phases of the nurse mother relationship (phase 1-orientation phase, phase 2- working phase, and phase 3-termination phase) as determined by one-way ANOVA ( $F(2,33) = 29.6$ ,  $p < .001$ ). A Tukey post hoc test revealed that the mean number of nurse generated engagement codes assigned in the nursing narratives were statistically significant between the orientation phase (phase 1;  $75.3 + 26.4$  min,  $p < .001$ ) and the working phase ( $223.8 + 82.2$  min,  $p < .001$ ). Similarly, there were statistical differences between the working phase and termination phase ( $89.1 + 26.8$  min,  $p < .001$ ). There were no statistically significant differences between orientation and termination phases ( $p = .796$ ).

To summarize, the Interactive Care model was validated by the nursing narrative data. The five key processes and seven clinician- person/family partnership roles were all represented in the nursing narrative notes. Moreover, specific nurse-generated engagement strategies provided a view of how the process of engagement was operationalized in the nurse-mother



interpersonal relationship. The key components and partnership roles of the ICM are fluid, dynamic, with different components operating at different intensity and frequency depending upon the phase of the mother-nurse relationship (RQ2 and RQ4) and level of mother's engagement (rq3). Engagement skills and strategies were significantly limited when mothers were not engaged- underscoring the importance of the work and time spent in the orientation phase (rq5).

The Interactive Care Model was evident in the HILDA data examined, therefore captured the process of patient engagement with a traditionally underserved population. However, patient engagement, as a highly dynamic and fluid concept, was not fully captured in the one-dimensional model. In addition to the positive findings discovered in the data in relation to the ICM, demographic differences between the nurses and the mothers, built in power inequalities and dynamics, and timing and intensity of patient engagement were not addressed in the ICM and will be discussed in the following chapter.

## **CHAPTER 5**

### **DISCUSSION AND CONCLUSION**

Patient engagement has been identified as strategy to facilitate the transformation of health care by shifting the traditional patient and provider roles to a more collaborative partnership (Groves, Kayyali, Knott, & Kuiken, 2016; Hibbard & Greene, 2013; Hook, 2007; Shaller, 2007). Projected to improve health care outcomes while decreasing health care costs, patient engagement has been touted “the blockbuster drug of the 21<sup>st</sup> century” (Kisch, 2012; Koh et al., 2013). However, a lack of clarity and consensus exists as to the conceptual underpinnings of patient engagement, and more important, how patient engagement is operationalized in clinical practice. Therefore, an urgent need exists to understand the components of effective patient engagement to inform both patients and providers as to the expectations and responsibilities of their new relationship and roles as active collaborators in care. The purpose of this study was to illuminate the process underlying patient engagement and to determine how the components of patient engagement were operationalized in the nurse-patient interpersonal relationship. This study was an examination of engagement extremes, as the advanced practice mental health nurses were experts in non-verbal and verbal communication, and the mothers were representative of a traditionally underserved population. Understanding what nurses needed to do in order to engage a difficult to engage population can illuminate core tenets of patient engagement that may be applicable to all client-nurse relationships.

The chapters in this dissertation demonstrated that the process of engaging a traditionally underserved population was a complex and multifaceted endeavor that could not be explicated

completely by any one nursing skill, strategy, or action. As such, multiple components and nuances of patient engagement emerged upon analysis of advanced practice mental health nurses' written narratives of their engagement practices with low-income depressed mothers of infants and toddlers.

This final chapter begins with a discussion of how the nursing narratives validated the key processes and clinician and person/family partnership roles of the ICM. In addition, supplemental engagement practices will be discussed that added rich detail to the current structure of the ICM. Topics and themes not reflected in the ICM, (e.g. demographic differences, reflective practice, power dynamics, phases/timing of interpersonal relationships) but were reflected in the nursing narrative empirical data will also be explored. A new concept, liminality, will be introduced and discussed within the context of this analysis and health care transformation at large. Finally, limitations and implications for future practice and research will be examined.

The Interactive Care Model (Drenkard et al., 2015), a relatively new patient engagement framework, demonstrated great utility in capturing the process of patient engagement of low-income depressed mothers in a mental health and parenting intervention. The ICM was sufficiently comprehensive in capturing the fundamental nature of patient engagement and provided a sound organizational structure for capturing specific nurse generated engagement skills and strategies used to engage a traditionally underserved population. However, data emerged that did not fit the ICM categories. Table 4.2 and 4.4 summarize the ICM processes and partnership roles supported by the nursing narrative data and data that were extraneous to the model.

## **Interactive Care Model as a Patient Engagement Process Model**

**Validation of the ICM.** Each of the five key processes of the ICM (i.e. assessing a person's capacity for engagement, exchanging information and communicating choices, planning, determining appropriate interventions, and evaluating regularly) and seven clinician-person/family partnership roles (i.e. whole person, intentional presence, caring and trusting relationship, knowledge exchange, collaborating, coaching, navigating) of the Interactive Care Model (ICM) were validated by the nursing narratives describing the process of engaging mothers in a home-based mental health and parenting intervention. As a patient engagement framework, the ICM was expansive, encompassing and capturing nurses' perceptions of the engagement process. Moreover, specific nurse generated engagement practices (e.g. questioning, exploring, controlling intensity, facilitation of catharsis) provided multiple expressions of the five key process and seven partnership roles providing both validation of the ICM concepts, while simultaneously adding robust, supplemental detail to the structure of the framework.

***Assessing mothers' capacity for engagement.*** An assumption of the ICM is that provider and client are both willing and able to actively participate in the engagement process. Assessing the mothers' capacity for engagement included noting the mothers' responsiveness to the nurse's active and persistent pursuit in establishing and maintaining interpersonal contact. Initially, some nurses described some of the mothers as being hard to reach or evasive. In fact, after waiting in front of a mother's house and leaving a hand written note, one nurse later found out, the mother was across the street warily watching the nurse through a window, cautiously contemplating whether to meet with her or not. Nurses responded to the mothers' evasiveness by departing from traditional health care provider posturing, and shifted into creative, flexible, and active pursuit of making contact with the mothers.

Non-conventional proactive approaches, diligent and persistent pursuit, encouraging verbal and written words, and making accommodations by frequently rescheduling demonstrated the nurse's asymmetrical dedication and investment in establishing an interpersonal connection with the mothers. Thus, when using the ICM to guide the engagement of a traditionally underserved population, modifications such as active and recurrent pursuit of clients, demonstrations of providers' dedication and investment, and scheduling flexibility should be considered.

***Exchanging information and Communicating Choices.*** A person's values, beliefs, and subsequent preferences are greatly influenced and shaped by history, as history often shapes the way we view the present. A mother's past behaviors and experiences were important determinants as to how she addressed her present health and health care (Sallis, Owen, & Fisher, E 2008). As such, exchanging information was instrumental in planning mother's mental health care interventions to match and synchronize with her value system and health care goals.

Importantly, the mothers' expertise on her competing demands and circumstances were recognized and valued as essential contributions to her health and health care. Specifically, by listening, questioning, exploring, and using silence, the nurses facilitated bi-directional information exchange, prerequisites to collaboration and engagement. Moreover, the nurse's engagement skills and strategies involved critical elements of skilled judgment as to when to explore more deeply, when to assume the role of student and learn from the mother, or when to refrain from questioning and give the mother time and mental space to gather and share her thoughts.

***Planning.*** Contracts, both verbal and written, added a degree of transparency and accountability to the nurse-mother exchanges, helping to underscore the important tenets of

mutual respect, honesty, trust, and safety in the nurse-mother interpersonal collaborative relationship. Planning was collaborative, as input from the mothers was both encouraged and valued. Nurses did not assume what was the most preferable plan for the mothers, but did enlist the mother's help in defining what was the most preferable plan for her.

***Determining appropriate interventions.*** Once armed with knowledge of the mother's capacity to engage, important and relevant historical information, and mutually agreed upon goals and outcomes, the nurse used specific educational resources (e.g. assessment circles, skills sheets) that fostered the collaborative work of the intervention. Engineered to ensure fidelity of the evidence based intervention, the topics on the skills sheets addressed pressing life issues common to most mothers, but were also personalized to address the mothers' unique needs and issues. The tangible and visual nature of the assessment circles and skills sheets served as a springboard to facilitate the problem solving work of the intervention. Moreover, specific engagement strategies like refocusing, suggestion, cognitive reframing, and summarizing fostered active dialogue and collaboration with the mothers.

***Evaluate regularly.*** The repetitive nature of the nurse-mother visits provided the opportunity to evaluate the mothers' level of engagement and the intensity of the depressive symptoms. In addition, the home setting was a prime backdrop to evaluate the mothers' progress. As such, nurses supplemented the mothers' verbal account with direct observation, and personally evaluated mothers' parenting style, interactions with family members and neighbors, and the ways in which she was meeting the demands of daily life.

To summarize, the nursing narrative data validated the five key process of the Interactive Care Model. While each of the 30 nurse narratives about their interpersonal relationships and interactions with the mother were different, the ICM captured the common threads of patient

engagement.

**Seven clinician-person/family partnership roles.** In addition to the five key processes, the seven person-clinician-family partnership roles of the ICM, employed to enhance the mothers' engagement in the intervention, were also validated by the nursing narrative data. While the partnership roles of knowledge exchange, collaboration, and coaching were represented more than the others in the data, data to support each role was found.

***Whole person.*** Holistic approaches like aromatherapy, meditation, or incorporating faith into the weekly discourse presented opportunities for the nurses and the mothers to focus on aspects of the mother outside the scope of the intervention such as her positivity and hope. Discussing the benefits of aromatherapy and the Serenity prayer, and practicing deep breathing exercises together broke up the heavy concentration on the mothers' problems and depressive symptoms. These aspects appeared to allow the nurses and the mothers to nurture their bodies and souls together, strengthening their interpersonal bond.

***Intentional presence.*** Intentional presence was operationalized using seemingly simplistic, yet highly skillful and impactful strategies such as silence, permission, and gratitude. Nurses intentionally created silent spaces within conversations between the nurses and the mothers to provide time and opportunity for the mothers to connect with the topics being discussed and reflect upon their feelings and thoughts. In asking for the mothers' permission to enter certain rooms or to sit in certain places, the nurses were demonstrative in exercising caution from overstepping interpersonal boundaries, and respecting the dynamic power equity between the mothers and the nurses. Similarly, nurses infused cultural sensitivity into their practice, e.g. removing shoes, censoring language that conveyed an unspoken understanding and respect for

the mothers' culture and traditions. Cultural differences between the nurses and the mothers often provided unique learning opportunities for both women, and at times, highlighted shared underlying values and sentiments. Gratitude was customary when leaving the mothers' home, and conveyed the powerful sentiments of acknowledgement and appreciation for the mothers' time and attention. These strategies were evidence of the important tenets of power reciprocity within interpersonal relationships and collaborative work.

***Caring and trusting relationship.*** Through their words and consistent, persistent actions, the nurses demonstrated care and concern about the well being of the mothers and their children. Nurses' self-disclosure of personal information about themselves, created opportunities to reduce perceived interpersonal barriers and build trust (Beeber et al., 2007). Glimpses of the nurses' personal experiences, challenges, and vulnerabilities appeared to create an opportunity to validate and normalize the mothers' shared feeling and struggles, and strengthen the interpersonal connection. Examples of intentionality in the data included the nurses' admissions of messy home and no children to blame for the mess, having used the television as babysitter at times, choosing to be a survivor when faced with medical challenges, and admitting to not knowing about certain topics.

The narrative data appeared to support that self-disclosure helped to build rapport, shifting the context from a mental health nurse and depressed mother having a health related discussion to that of two women, discussing the rewards and challenges of motherhood and womanhood. In addition, I suggest that the nurses' self-disclosure indirectly fostered the mothers' engagement, by humanizing the nurses, exposing limitations in the nurses' power and authority as expert professionals. The strategy of self-disclosure appeared to equalize the unspoken power imbalance that existed between nurse (provider, professional) and mother



(participant, non-professional). Provider self-disclosure can be catalogued under the ICM's key process of information exchange or the partnership roles of caring and trusting relationship and knowledge exchange. Although professional discretion of appropriate timing and use is essential, self-disclosure is one approach that may facilitate trust building, allowing for a deeper interpersonal connection.

***Knowledge Exchange.*** Knowledge exchange was woven throughout the intervention and underscored recognition of the nurses' and the mothers' respective expertise and collaborative partnership. Nurses were purposeful in recognizing and respecting, mothers' expertise, often fueling the collaborative effort. A hallmark of active engagement was when the nurses and mothers seamlessly transitioned and exchanged roles of teacher and student, and together, advanced both their interpersonal relationship and the work of the intervention.

***Collaborating.*** Nurses used hands on strategies like role-play and problem solving to create and facilitate experiential learning and collaborative opportunities with the mothers (e.g. practicing job interview conversations or confrontations with significant others, peers, supervisors, support agencies). Often beginning with the nurse's initial phone call, the back and forth nature of scheduling, exchanging information, choosing topics to discuss and work on, and planning, all required conscious collaboration between the nurses and the mothers. When the mothers actively collaborated with the nurses, the nurses were able to pull from a cadre of engagement strategies, to keep the mothers engaged and retained, and make collaborative progress. However, when some mothers did not to collaborate, the nurse's strategies were significantly limited and the work of the intervention stalled.

***Coaching.*** As coaches, nurses helped the mothers set reasonable goals (e.g. a walk around the block once this week, list-cutting, quiet time to settle their mind) and encouraged the

mothers' plans and efforts to reach them. Nurses repeatedly celebrated the mothers' successes and provided praise and encouragement for the mothers' positive health behaviors. As a coach, authority was implicit, requiring the nurses to engage and inspire within professional boundaries and standards of care while helping the mothers advance towards their health care goals.

***Navigating.*** As navigators, the nurses often helped the mothers discover and access available support services and health care resources. Navigating was a supportive role that involved providing contact and service information as well as emotional support to the mothers. The latter was accomplished by nurses through exploration of the mother's thoughts and feelings about accessing and using services. As such, navigating as a partnership role, required assessment of and sensitivity to the mothers' psychological and emotional response to using support services and resources.

To summarize, the seven clinical-person/family partnership roles were validated by the nursing narrative data. The partnership roles captured specific actions that nurses took to enhance and maintain the mother's engagement. In addition to the five key processes and seven partnership roles, supplemental details like hands on help, humor, role clarification, boundary maintenance, and anticipatory warnings also emerged from the nursing narrative data.

***Hands on help and humor.*** Hands on help (e.g. holding children, folding clothes, cleaning the kitchen) and appropriate humor were often employed by the nurses to augment personal connections with the mothers. However, using hands on help and humor came with associated risk. In offering hands on help to the mothers, or when infusing humor into the discourse, the nurses took risk, making themselves vulnerable to the mothers' rejection or misinterpretation of the offer or humor. Perhaps by exposing such vulnerability, the traditional

hard lines and boundaries between providers and clients softened, allowing for more active collaboration.

***Role clarification, boundary maintenance, anticipatory warnings.*** Nurses were diligent and persistent in their efforts to engage and retain the mothers using specialized relationship based engagement strategies. However, nurses were also vigilant in clearly establishing and maintaining professional boundaries and limits. Role clarification, boundary maintenance, and anticipatory warnings balanced the active pursuit of the nurse's engagement strategies by clearly delineating expectations of nurse's professional and ethical responsibilities. Role clarification, boundary maintenance, and anticipatory warnings outlined and protected the professional context in which the multiple expressions of relationship-based interpersonal engagement skills and strategies were used. Although the narrative data supported all aspects of the ICM and supplemental nurse-generated engagement skills and strategies, there were aspects not consistent with the ICM that emerged from the empirical data.

### **Factors Affecting Engagement Not Addressed by ICM**

The ICM, based upon a rethinking of the relationship between person and clinician (Drenkard et al., 2015), paired with the at home nature of the intervention offered a very unique opportunity to view how patient engagement and patient centered care were operationalized. Although not directly addressed in the ICM, aspects of patient engagement including demographic differences, reflective practice, and power dynamics were represented in the nursing narrative data.

**Demographic differences.** In the United States, racial, ethnic, and social disparities in health care have been well documented in the literature (Bakullari et al., 2014; Chen, Vargas-Bustamante, Mortensen, & Ortega, 2016). Sources of these disparities include geographical

differences, limited access to providers and health care, communication challenges between providers and clients, and cultural barriers (Crowley, 2010; Nelson, Stith, & Smedley, 2002). In this study, demographic disparities (e.g. socio-economic status, cultural practices, age, and education) between the low-income, depressed mothers and the advanced practice mental health nurses raised the potential for substantial patient engagement and health care delivery challenges to be encountered. However, with challenges came great opportunity to examine the core tenets of patient engagement.

***Socio-economic status.*** Stark socio-economic differences between the nurses and the mothers presented opportunities for nurses to learn and understand the mothers' reality and moreover, encourage and empower the mothers to undertake the role of educator and life expert. Nurses often suspended their role as health care expert, and encouraged mothers to lead and share their expertise on their lived experiences, values, preferences, and health care goals. Despite differences in their socio-economic status, the nurses and the mothers often shared similar life experiences as nurturing women and loving mothers transcendent of their demographics.

***Cultural differences.*** While the ICM does recognize the importance of the clients' cultural values in exchanging information, it does not directly address provider-client cultural differences. Nurses employed active engagement strategies of cultural specification to acknowledge and direct their attention to the cultural differences that existed between the nurse and the mother. By recognizing and verbalizing existent cultural differences, the nurses prompted the mothers to respond and lead the way in terms of educating the nurses about their cultural influences. Conversely, in one particular case, when the nurse failed to address the cultural differences between she and the mother, the nurse-mother interactions remained

superficial and the relationship failed to develop. As such, demographic mismatches in this research challenge studies that promote peer-to-peer counseling programs, promotoras, and culturally matched patient- providers as the primary pathways to enhance patient engagement of underserved populations (Field & Caetano, 2010; Fisher, Burnet, Huang, Chin, & Cagney, 2007. Kahler, 2014; U.S. Department of Health and Human Services (USHHS), 2006, 2013). Possible alternatives to provider-client matching is that the providers, regardless of their demographics, become skilled in using demographic differences with clients to accelerate patient engagement and personalized healthcare.

***Age and Education.*** Although age and education were not formally addressed within the narratives, differences surfaced peripherally when nurses talked about their grown children or when the nurse fondly, or not so fondly, shared her memories of raising young toddlers and infants with the mothers. The age differences between the older nurses and younger mothers may have introduced a maternal-like dynamic, potentially fostering or blocking mothers' engagement.

In a 2003 Institute of Medicine (US) report on *Understanding and Eliminating Racial and Ethnic Disparities in Health Care*, age, ethnic minority status, poor health status and lower educational achievement were associated with lower participation in health and health care visits (Smedlley, Stith, & Nelson, 2003). By addressing and openly navigating socio-economic and cultural differences between the nurses and the mothers, the nurses opened a gateway for learning and engagement. Information about the clients' socio-economic, ethnic, and lifestyle information could be added to the ICM as a consideration to the assessment or added to the key process of Exchanging Information/Communicating Choices and partnership role of knowledge exchange. The model could be expanded to consider the demographic differences between the

clients' and the providers' as 1) influential factors to their engagement in their health and healthcare and 2) topics addressed to enhance engagement.

**Reflective Practice.** Another concept highly represented in the nursing narratives but not captured by the ICM model was nurse's self-reflective practice. Reflection is defined as the "throwing back of thoughts and memories in cognitive acts such as thinking, contemplation, meditation, and any other forms of attentive consideration, in order to make sense of them and to make contextually appropriate changes if they are required"(Taylor, 2000, p.3). As such, the very act of writing narrative notes after each interaction with the mothers was an exercise fostering the nurse's reflective practice.

Data revealed nurse reflections about their actions, reactions, thoughts and feelings when engaging with the mothers in the study. The practice of reflection helped nurses gain a deeper understanding and insights into their nursing practice, sorted out complexities in their responses, and informed changes in their practice accordingly (Beeber, 2007; Freshwater, Horton-Deutsch, Sherwood& Taylor, B. 2005). Sherwood and Horton-Deutsch (2012) recognize reflective practice as a transformative change process, having the power to improve nursing focus, practice, satisfaction and retention. As such, recommendations have been made for reflective practice to be incorporated in nursing education, research and clinical practice (Freshwater et al., 2005).

Reflective practice can potentially be woven into each key process of the ICM to remind providers to consciously focus, analyze and learn from their engagement practices that were effective or ineffective in engaging clients more fully in their health and health care. The key process of Evaluate Regularly focuses on the clients' engagement and clinical outcomes but could be expanded to include the clinicians' practice through self-reflection practices.

**Partnerships and Power.** To advance health care delivery, Drenkard et al. (2015) suggests more equal care partnerships between clinicians and clients. However, the very nature of the provider-patient relationship is asymmetrical, characterized by providers holding legitimized, referent and expert knowledge and power (Beisecker, 1990; Bourdieu, 1991), and patients needing and relying on treatment and care services (Bending, 2015). Present in all interpersonal relationships, power and power dynamics were constant thematic backdrops to nurses' perceptions of patient engagement, but were not directly addressed in the ICM.

***Shifting power dynamics.*** Drenkard et al. (2015) call for a required shift in the mindset of clinicians in entering an “equal partnership” with the person in control of his/her health decisions. Although an equal partnership between nurse and mother was demonstrated when sharing in the decision making process and during the planning and determining appropriate interventions, data about the partnership between the nurses and mothers supported a waxing and waning of the power differentials. For example, in the orientation phase, the nurse actively and persistently pursued the mother with the intention of establishing initial contact. Mothers held the power in the burgeoning relationship as mothers were in positions to refuse, not call back, not show up, or not let the nurse through the door. However, upon commencement of the intervention, nurses were in a position of power as they used clinical judgment, to assess mother's capacity and level of engagement. Power dynamics equalized during the in the exchanges of information and communication of choices component/processes as the nurse often assumed the role of student as the mother expressed and shared her expertise on the intricacies of her daily circumstances and reality. The processes of planning and determining appropriate interventions often exemplified the shared balance of power and shared decision making in the nurse-mother therapeutic partnership. However, power shifted back to the nurse when

establishing and maintaining professional boundaries and during frequent assessments and evaluations. Thus, entering into a therapeutic partnership with mothers required nurses to facilitate dynamic shifts in power with the mothers to enhance engagement.

**Intensity and timing of engagement.** Although the ICM was validated by the nursing narrative data, the model did not address phases of the engagement relationship, and the differing intensities and frequencies of the key processes and partnership roles and the influence of repeated, intensive contact between the nurses and mothers.

**Phase of relationship.** Consistent with the rhythm and flow of Peplau's Theory of Interpersonal Relations (1952), the findings of this analysis suggest the ICM concepts and engagement strategies employed by nurses differed between the phases of the interpersonal relationship and as a function of the mothers' various levels of engagement. For example, assessing the mother's capacity for engagement and exchanging information was present throughout the intervention but was highly concentrated in the orientation phase of the nurse-mother interpersonal relationship. In addition, all the concepts of the ICM and all of the nurse generated strategies increased during the working phase. This suggested that engagement strategies intensified, possibly retaining the mothers in the intervention. Finally, the decline of engagement strategies in the termination phase parallels the intervention strategy of gradual disengagement that nurses did to prepare the mothers for the end of the relationship and the intervention.

**Level of engagement.** Engagement skills and strategies used by nurses were significantly limited with mothers who were minimally engaged and were significantly higher with the highly engaged mothers. Thus, time spent in the orientation phase- demonstrated the reciprocal effect



that engagement may have on the skills and strategies used. Mothers who were less engaged spent more time in the orientation phase than mothers who were more engaged, underscoring the importance of giving mothers time and space to engage, and the need to adjust timelines for patient engagement and other key tasks that need to be accomplished.

Notably, the key processes of Planning and Determining Interventions were used less with mothers in the minimally engaged group when compared with the group with fluctuating engagement. However, no differences were found between the ICM's seven partnership roles and mothers' level of engagement, suggesting that data supporting the seven partnership roles of the Interactive Care Model spanned across all levels of the mothers' engagement. These findings provide a beginning understanding of the core components of patient engagement practices in which to build upon and tailor.

Therefore, the results of this analysis suggest that engagement is a fluid and dynamic concept, requiring different engagement skills and strategies, operating at different intensities and frequencies dependent upon contextual factors, phase of interpersonal relationship, and client's level of engagement.

***Repeated, intensive contact.*** Mothers and nurses partnered week after week for a prescribed 10 weeks, creating the time and space to potentially establish a relationship, build trust and rapport. The repetitive nature of the nurse's visits and active pursuit and persistence of scheduling and rescheduling demonstrated client centered care. These actions were in stark contrast with the traditional provider-centric paradigm, often characterized by episodic care delivered in multiple care settings that disengage clients from their natural world, and that place patients in the role of pursuing providers, accommodating provider's schedule and preferences,

and having significant lag times in between visits. Thus, actively pursuing clients and having recurring contact with them may have great utility as effective modifications in health care delivery for difficult to engage clients.

To summarize, this analysis has demonstrated how demographic differences and power dynamics between the nurses and mothers, nurses' reflective practice, intensity and timing of engagement strategies and a care model of repeated, intensive contact were factors that affected the mothers' engagement but were not addressed by ICM. Empirical evidence generated from this study may suggest directions for further development of the ICM to more fully capture the multi-dimensional nature and complexity of patient engagement.

### **Defining Liminality in Relation to the Nurse's Role in Patient Engagement**

Directed content analysis of the nursing narrative data accomplished the goal of validating components of the ICM. In addition, during the analysis, the concept of liminality emerged that was related to the specific context of the health care home visits. Liminality will now be discussed and may be a valuable in the future as healthcare moves into a greater variety of settings.

**Liminality.** From a sociocultural perspective, liminality is described as the margin or threshold when a person loses one identity and proceeds to reconstruct a new meaningful identity (Gibbons, Ross, & Bevans, 2014; Turner, 1994; van Gennep, Vizedon, & Caffee, 1961). Used in anthropology to describe the experience of tribal members during initiation rites, liminality is a time of transition separating from a previous position, entering into a liminal state of unspecified duration, and concluding with the emergence of a new state of being (Gibbons et al., 2014; van

Gennep 1961). My interpretation of the data is that the nurses left the professional comfort and context of the clinic setting and crossed over the literal threshold to the mothers' homes, entering a liminal state, in a new role as a guest and pursuer of collaboration in care. As guests, the nurses' practiced interpersonal rituals like asking for permission, expressing gratitude, engaging in social conversations, and socially engaging others in the home. As guests, the nurses were flexible and accommodating to the mothers' schedules and competing demands, often offering hands on help and making accommodations. As guests, nurses practiced mother-centered care by actively seeking the mothers' participation, listening to them, hearing their stories, being open and honest with them and taking action with them (Leape et al., 2009). As guest, nurses facilitated the mothers' engagement, which was crucial to the success of the intervention. In departing from the traditional health care provider posturing and entering the mothers home as guest and active collaborator in care, nurses navigated their new role as providers practicing within a truly patient centered paradigm.

The idea of health care providers presenting themselves as guests is not a new one (Berwick, 2009; Leape et al., 2009). In his 2010 Yale Medical School address, Dr. Don Berwick reminded new doctors they are the guests in the hospital, intruding in on the private and sacred moments shared between families and loved ones, and should conduct themselves as such to deliver care that is respectful and responsive to patient preferences, needs, and values (Richardson et al., 2001). This secondary analysis of the nursing narratives provides an intimate glimpse of how Berwick's advice plays out in actual clinical practice.

***Home setting/Gateway to engagement.*** A noticeable marker of this liminal state was reflected and referenced by the concept/perception of the front door. The front door, a physical

barrier initially separating nurse from mother, was frequently referenced throughout the narrative data. A lexical search revealed the word “door” (referenced 436 times in 216 of the documents) described as “open” “closed” “having missing and broken window panes” “heavy” “broken” and “having multiple locks”. Nurses, on one side of the door, crossed over the threshold and entered into the mother’s intimate spaces. Entering the mothers’ home as guests, the nurses were *in need of* mother’s time attention and participation. As such, the door represented control, in that the mothers had the power to answer or not answer the door, open the door, and close the door. Doors were referenced when nurses expressed silver linings and glimmers of hope, as one nurse recalled when reflecting on interactions with a minimally engaged mother “*Well, at least she let me in the door.*”

Doors are structurally bidirectional, providing both an entrance and exit to a home or building. As an entrance, the mothers’ doors represented a gateway for nurses to enter into the mothers’ sacred space and witness her life circumstances. When nurses crossed the threshold into the mothers’ homes, a collision of the horizons between the nurses and the mothers occurred, causing an unsettling of the traditional clinician-client relationship and roles. Nurses capitalized on this collision using relationship based strategies to facilitate engagement and active collaboration in care.

As an exit, the door signified a peripheral reference to the demographic differences between the nurse and the mothers as the nurses had a means to escape the mothers’ reality. Doors were pathways for the nurses to exit the home, and drive away, physically leaving the mothers and her difficult circumstances behind.

Having the ability and access to exit the mothers’ reality underscores the implicit illusion of equality in the ICM. The nurses and the mothers did not have a true working partnership. The

intervention was clearly nurse-led and nurse- driven, with nurses creating and offering opportunities for the mothers to engage and collaborate in their health and health care. Nurses used their position of power to initiate, control, and direct interactions with the mothers to elicit the mothers' participation and involvement in the intervention.

The ICM would benefit from recognizing implicit power differentials in the clinician-person/family partnership roles and guide clinicians as to how to effectively navigate existing power imbalances to maximize patient engagement.

### **Conclusions**

Findings from this study add to the knowledge base of patient engagement by providing empirical data as to how patient engagement was operationalized with a traditionally underserved population. The ICM's five key processes and seven clinician-person/family partnership roles were validated by the nursing narrative data. The data additionally supported concepts not reflected in the model including demographic differences between providers and clients, reflective practice, shifting power dynamics, and differing intensities and timing of engagement strategies. This study helped to illuminate the rhythm and flow of patient engagement, as multiple expressions of specific engagement strategies were used at different times, in different intensities and frequencies based upon the phase of the interpersonal relationship, mothers level of engagement and several contextual and influential factors. Thus, findings from this study provide valuable guidance as to how the ICM can be expanded upon and enriched to more fully capture the process of patient engagement to better guide providers as to how to engage their patients more fully in their health and health care.

## **Limitations**

The use of secondary data has become increasingly popular method of improving the efficiency and effectiveness of nursing research (Cheng & Phillips, 2014; Thorne, 1994). Secondary analysis provides a mechanism for high impact questions to be asked while avoiding prohibitive cost and time issues (Smith et al., 2011). The research questions in this dissertation were compatible with the existing data as engagement skills and strategies were the vehicles in which nurses gained entre with the mothers, allowing them to deliver the mental health and parenting intervention. However, several methodological issues related to the use of secondary data may have impacted study findings.

First, the use of secondary data prohibits any control over the design of the original parent study. As such, in designing the secondary analysis, the primary research should be understood thoroughly in order to anticipate any conceptual problems (Kothari, 2004). For instance, lack of operational definitions of the points on the adherence rating scale make it difficult to distinguish among mothers with varying levels of engagement.

Secondly, data on engaging mothers in the intervention were limited to the perspectives of the nurse, giving only a one-sided and limited account of engagement skills and strategies employed. Moreover, the nurses were delivering an evidence-based treatment for depression, and were limited even further by the goals and strategies of the interpersonal psychotherapy. No data were available regarding the perceptions of engagement practices from the mother's perspective. Furthermore, the parent study was a time-limited intervention. Nurses were encouraged to transition to the working phase by the second or third meeting with mothers, regardless of mother's level of engagement. As such, placing limits on the time spent in orientation phase potentially limited variability of the findings.

Finally, using a directed content analysis approach did present some inherent limitations. First, possible bias may have been introduced by using the ICM as the pre-determined guiding framework, as the data were purposely explored for evidence supporting and not supporting the model. However, a pilot study, using a conventional content analysis approach was performed prior to this study using narrative notes from one case, and found many of the same ICM concepts emerged without having the ICM concepts to draw from. Secondly, at times, the descriptive narrative notes were lacking in specific contextual details that may have influenced the mothers' engagement.

### **Directions for future research**

This study provides direction for future research. First, the empirically validated engagement strategies employed within the context of the nurse-mother therapeutic relationship and differences found expand the ICM definitions as well as our knowledge base about patient engagement. How the ICM operates with other populations in other contexts is important to guide further refinement, extension, and enrichment of the process model.

In addition, the analysis revealed additional dimensions not addressed by the ICM, like demographic differences, reflective practice, shifting power differentials between providers and clients, and fluctuating intensity and timing, which could expand the ICM, and nursing practice at large. Future research should address how clinical practice can mimic the neutralization and reversal of power imbalances, extend and maximize the duration of the orientation phase during health care delivery when needed, and the implementation of recurrent contacts with clients.

The home setting of the parent study was significant in receiving mothers in their unique life context, and not out of context like the traditional clinic or office setting. Thus, implications for technology to alter traditional health care delivery contexts should be explored. Specifically,

empirical results from this analysis can help inform digital interfaces (Skype, face time, e-health platforms, tele-health, instant messaging) between providers and clients to establish and maintain patient engagement in a patient centered context. However, although such technologies can help connect traditionally underserved populations with providers and access to health care, an unintended consequence of digital interfaces is the real patient is even further removed from their naturalistic life. In this study, nurses made an impact by using their time, energies, and physical presence to overcome engagement barriers and establish interpersonal relationships with the mothers. The nurses' dedication and investment to establishing an interpersonal connection with the mothers and to delivering the intervention was accomplished by meeting face to face, literally entering the mothers' sacred home space, and navigating the home setting as both guest and provider. Thus prompting the question: could the nurses' dedication and investment, and engagement style (marked with strategies like assessing a person's capacity for engagement, intentional presence, caring and trusting relationship, evaluate regularly) be transmitted and received as well through a computer screen or text message?

Future research should examine patient perceptions of engagement and examine where those perceptions match with provider perceptions and where important elements of engagement, from the patient perspective, are still missing. Finally, future research should address engagement skills and strategies used to engage non-depressed low-income mothers to tease out differences if any, between depression and level of engagement.

### **Implications for nursing practice**

For the delivery of health care to truly transform, both sides of the patient –provider relationship must be open and willing to change. Nurses used traditional and non-traditional skills and strategies to facilitate mother's communication, collaboration, and engagement in her



health and health care. Regardless of demographics, nurses used written contracts, humor, letter writing, gift giving, hands on help, the expression of gratitude and asking for permission, to secure mothers much needed participation, energy and attention. Thus, confirming the notion -in order to truly transform health care and engage people in their health and health care will require a departure from the traditional health care paradigm.

Paternalistic presentations are qualities characteristic of the traditional health care paradigm where providers hold implicit power and expertise, often acting as the sole decision-maker in a person's health and health care. The traditional health care paradigm delivered provider centric care, that is, care that revolved around the preferences and needs of the provider. However, a new health care paradigm has been emerging, one that places the patient at the center of health care delivery and considers the person's expertise and input in the decision making process. This study begins to illuminate how patient engagement required a shift from the practicing behaviors of the traditional health care delivery paradigm, to a new health care delivery model with a primary focus on patient centered care and engaging clients more fully in their health and health care.

Reflective practice enabled advanced practice nurses to make meaning of the interactions with the mothers and mothers' varying levels of engagement prompting them to adapt their practice accordingly. Built into the design of the original study, time for reflective practice was afforded to examine the engagement practice as part of the research endeavor, and is not normally afforded in day-to-day healthcare practice. Health care productivity standards (i.e. outcomes, cost, quality of care) do not include standard reflective practice but are certainly impacted by reflective practice. A call for action is necessary to weave reflective practice into clinical practice and nursing education based upon the powerful impact reflective practice had in

engaging and retaining a traditionally underserved population in a mental health and parenting intervention. Based upon this analysis, recommendations are for current and future health care providers to be trained in patient engagement strategies including: how to recognize and manage implicit power differentials and dynamics between providers and patients, how to effectively employ silence, coaching, and summary as engagement strategies, and how to resurrect interpersonal, relationship based engagement strategies in this day and age of advanced and advancing technology.

The business case for reflective practice stems from the potential impact of retaining competent, professional nurses in clinical practice, improving their practice in terms of safety and quality of care delivered, and facilitating providers' proficiency in engaging and retaining patients in their health and health care. As the U. S. healthcare payment system landscape shifts from volume-based care to value based care, providers are and will be incentivized to improve quality, outcomes, and costs. This dissertation provided a refined view of the complexity in skills required to engage difficult to engage populations. Nurses were able to capture and articulate the strategies and skills required to engage a traditionally underserved population more fully in their health and health care. These skills and strategies can be applied to all patients in varying degrees and settings. Findings from this dissertation can expand the knowledge base and understanding of patient engagement, a crucial element in transforming the current inefficient health care delivery into a coherent, effective, and more inclusive system.

## Appendix A

### Final Summary Letter

#### FINAL LETTER

Dear B.,

Here is a summary of our 10 visits together.

**Visit 1:** You were worried about moving in with your boyfriend as the two of you had been arguing and fighting a lot. You talked a lot about issues related to your family. We also talked about the importance of stress management techniques given all the stress you feel. **We listed your strengths as using support systems very well and your loving bond with your baby girl.**

**Visit 2:** You were feeling better because you had moved into your new apartment with Anthony and things were going well. You had also enrolled in the GED program, moved, gotten your SSI sent to your new address and were also beginning to look for a job. **We listed your strength as the ability to somehow get things done even in the face of many obstacles!**

**Visit 3:** You were very concerned about all the fighting going on between you and Anthony. We talked about the power of one person to break the cycle of an argumentative relationship by changing their reaction to the other person. However, the other person has to also take responsibility for their behavior. You expressed concern that your daughter was like you in temperament, and that you felt guilty about that. **We listed your strength as your willingness to fight your negative self-esteem and change some of your negative views of yourself into more positive views.**

**Visit 4:** You were feeling better because you and A. were not fighting as much. You said this was because the two of you had been able to sit down and talk the issues out. We talked about the conflict in your family of origin and how important it was to see you, Anthony and Carissa as your new family and set limits with your mother and brother. **We listed your strength as your desire to set a boundary around your new family, while still allowing some time with your mother and brother. Another strength identified was your ability to challenge your negative thinking by breaking some bad thoughts about Anthony cheating on you.**

**Visit 5:** You were feeling a lot of frustration with your mother this visit, as you felt that she did not want you to be happy with your boyfriend. You said that when you are with your Mom you start to believe what she is saying. Then when you are with A. you start to believe him. It is hard for you to form your own thoughts and hang on to them. **We listed your strengths as your insight into your problems and your openness to other's thoughts and ideas.**

**Visit 6:** You were upset again over conflicts with your mother and Anthony. As we talked you said that conflict is very common in your life and that you have so much trouble with it as you

emotions take over and “flood” you. You said that a previous therapist had encouraged you to use essential oils to help with your emotional control. I said that I would bring you some next time. **We listed your strengths as your ability to reach out for help and the fact that you persevered and passed your driving test!!!!**

**Visit 7:** On this visit your boyfriend was home so the three of us talked about some of your family concerns, especially how to handle the upcoming Christmas holiday, given that Thanksgiving had been so stressful. We talked about how very important it is for both you and Anthony to support each other during the next few weeks. **We listed your strengths as your compassion and intelligence, and your willingness to see another person’s viewpoint.**

**Visit 8:** You were very stressed and hassled by the holiday pressures and talking did not seem to help at all. I brought out the essential oils I had brought and just smelling the lavender helped you to feel more relaxed. You talked about wanting to be a better mother and that you should know how to meet all of your daughter’s needs right now. I suggested that might be an unrealistic expectation. **We listed your strengths as your insight, your motivation to learn and the goals you have set for your life.**

**Visit 9:** You were very happy with how well your daughter’s first birthday party had gone, and that you had prepared for it all by yourself. We talked about the fact that sometimes just venting your feelings does not help when you are very upset. We worked on the idea that you really needed to sit down and figure out what you wanted your life to be, not just try to do what other people wanted you to do. **We listed your strength as your awareness that you need to stand up for yourself and what you want which will give you more confidence.**

**Visit 10:** You said that you were really pretty happy. You said that the holidays had gone well and that you were very glad they were over!! You said that you had realized that you needed to take “one day at a time”. You also said that you realized that you could not stress about everything that was “coming down the road”, but that you had to “appreciate my life as it currently is”. **We listed your strengths as your wisdom, perseverance, and motivation to change and improve your life.**

B.,

I have really enjoyed knowing you. I admire your commitment to family, your motivation to learn, your ability to reach out for help, and your desire to achieve your dreams. You have great wisdom for one so young. Don’t give up on those dreams, B. Learn to love and respect yourself as much as you love and respect others, and I know that you will have the life you want.

All the best to you.

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