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# The Lived Experiences of Intended Parents During Surrogate Pregnancy and Transition to Parenthood in Relation to the United States Healthcare System.

Kim L. Armour

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THE LIVED EXPERIENCE OF INTENDED PARENTS DURING SURROGATE  
PREGNANCY AND TRANSITION TO PARENTHOOD IN RELATION TO THE  
UNITED STATES HEALTHCARE SYSTEM

by

KIM L. ARMOUR

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
Department of Nursing

Susan Yarbrough, Ph.D., Committee Chair

College of Nursing and Health Sciences

The University of Texas at Tyler  
May 2012

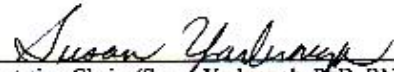
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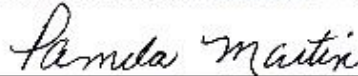
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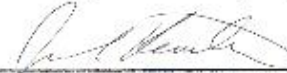
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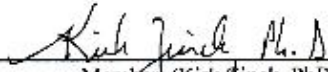
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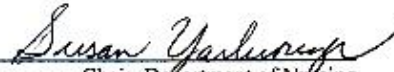
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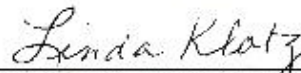
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## **Abstract**

# THE LIVED EXPERIENCE OF INTENDED PARENTS DURING SURROGATE PREGNANCY AND TRANSITION TO PARENTHOOD IN RELATION TO THE U.S. HEALTHCARE SYSTEM

Kim L. Armour

The University of Texas at Tyler  
May 2012

**Problem:** A state of the science surrogate pregnancy manuscript revealed a dearth of research regarding intended parents of surrogate pregnancy. Not one U.S. study could be located. Intended parents are overlooked by the healthcare system during pregnancy due to the fact that that their surrogate is receiving obstetric care. Research was proposed and completed.

**Purpose:** The aim of the research was to fill a gap by improving our understanding of intended parents lived experience during surrogate pregnancy and transition to parenthood with relation to the United States healthcare system

**Design:** A study of phenomenology using van Manen's methodology

**Participants:** Eleven intended parents of surrogate pregnancy

**Setting:** All interviews were conducted by telephone, with the exception of one that was done utilizing SKYPE video conferencing.

Analysis: van Manen's three prong approach to analysis was completed across all transcripts, identifying common or repetitive themes. Themes were coded and hermeneutic expressions were attached for the final phase of analysis, the narrative writing.

Findings: Five overarching themes were identified including Knowledge Acquisition and Preparedness; Access to the U.S. Healthcare System; Financial Risk and Exposure; Legal Complexities and Trust in Relationships.

Conclusion: Findings support the development of evidence based practice guidelines for the following periods: preconception, pregnancy including labor, delivery, birth and transition to parenthood. Recommendations are for future studies related to ART and third party reproduction, as well as enhancing models of care for the intended parent during surrogate pregnancy and transition to parenthood.

Key Words: Intended parents; surrogacy; surrogate pregnancy; surrogate woman or mother; assisted artificial reproduction; U.S. healthcare system



## **Chapter 1-Overview of the Research Study**

### **Overall Purpose**

A review of the scientific and healthcare literature, including research studies and articles revealed that the topic of intended parenthood was surfacing in public media, such as television series, movies and magazines such as Newsweek and Glamour (Ali & Kelley, 2008; Nosheen & Schellman, 2010). An extensive review of the literature over twelve databases including the disciplines of nursing, medicine, psychology, sociology, philosophy and law was completed. Literature of interest was determined after conducting a search of the following databases; Cinahl, PubMed, Medline, Ovid, JSTOR, Psychinfo, Academic Search Complete, the Web of Knowledge, the Web of Science and Academic Lexis Nexis. The majority of published literature has focused on surrogates, psychosocial issues and has been completed in the United Kingdom (UK), (van den Akker, O., 2007a, 2007b; 2005; 2003; 2000). The UK prohibits commercial surrogacy and healthcare is considered a socialized system; thereby creating an inability to generalize their findings in relation to the US. Not one U.S. study regarding this population, during pregnancy and transition to parenthood in relation to the U.S. healthcare system could be identified.

The purpose of the study was to understand the lived experience of intended parents during surrogate pregnancy and their transition to parenthood in relation to the U.S. healthcare system. Intended parents may be overlooked by the healthcare system during pregnancy due to the fact that they are not carrying the pregnancy and the surrogate woman is the identified patient who receives obstetric and prenatal services (ACOG, 2008). During this time the surrogate woman is considered the patient and is interacting with obstetric healthcare professionals. Conversely, this unique population of

intended parents is not carrying the unborn infant, nor are they visibly expecting an infant, leaving them at risk to be unidentified as expectant parents without access to traditional health services, including provider communication, access to the healthcare status of their unborn infant and pregnancy and parenting education. Understanding the experience of intended parents is important to promote the achievement of positive outcomes for intended parents and infant. The information gleaned from this study will bring attention to this growing population and their healthcare needs as well as assist in the development of guidelines for nursing and other health professionals to provide optimal and evidence based care.

### **Introduction of articles**

During the fall of 2010 and spring of 2011, with continued coursework and immersion in the literature, I completed my first manuscript towards dissertation requirements, *Surrogate Pregnancy: A State of the Science Report*. The development of this manuscript provided clarity that research regarding intended parents of surrogate pregnancy was indicated and would address a gap in science and healthcare literature. At that time, not one research study in nursing or medicine regarding intended parents in the US or in relation to the U.S. healthcare system could be identified. This state of the science manuscript set the foundation for my research proposal and study to follow. A proposal for a phenomenology study was developed and subsequently defended. After IRB approval from the UT Tyler, study enrollment began in late July, 2011 and when data saturation was determined and in late December, 2011 enrollment was closed.

As I continued to work on my research study this fall, I was approached by a guest editor of the journal, *Nursing for Women's Health*, to write a manuscript regarding the International perspectives of surrogacy for a new international feature in the journal,

“Beyond Borders”. I present that manuscript as my second of manuscripts, as it underwent peer review and I just received notification of acceptance for publication.

Study analysis was completed and a written narrative was completed regarding the interpreted lived experience of intended parents during surrogate pregnancy and transition to parenthood in relation to the U.S. healthcare system. This manuscript is presented as my third manuscript in partial fulfillment of requirements for my doctoral degree. This study has provided rich data creating an improved perspective of the lived experience of intended parents during this period of time. Five thematic areas (Figure 2) emerged from the data: (a) knowledge acquisition and preparedness, (b) financial risk and exposure, (c) legal complexities, (d) access to the U.S. healthcare system and (e) trust in relationships. These research findings provide an opportunity for healthcare professionals to better understand intended parents and their needs during pregnancy and transition to parenthood and will assist in creating new models of care and evidence based practice guidelines.

### **Modification to study inclusion criteria**

During the first eight weeks of the study, sampling enrollment was slow. Multiple contact attempts through email, U.S. mail and visits with office staff were made to enhance enrollment without results. With several participants offering to refer additional intended parents with a child older than age one, through snowball sampling, a request to revise inclusion criteria was presented to my committee chair. Upon her approval and appropriate filings, a revision to inclusion criteria was presented to the IRB at the University of Texas at Tyler and an approval to revise was obtained on September 21, 2011. The inclusion criteria for enrollment of an intended parent with a child no older than one year of age, born of a surrogate woman, was revised to a child no older

than five years of age, born of a surrogate woman. This change in inclusion criteria did assist in enrollment and eventual saturation of data and the study enrollment being closed.

## **Chapter 2: Surrogacy: A State of the Science Report<sup>1</sup>**

Abstract and manuscript prepared for the *Journal of Obstetric, Gynecologic and Neonatal Nursing*

### **Abstract**

**Objective:** To review the literature to create a more informed understanding of the state of the science regarding the reproductive methodology of surrogacy.

**Data Sources:** Cinahl, PubMed, Medline, Ovid, JSTOR, Psychinfo, Academic Search Complete, the Web of Knowledge, the Web of Science and Academic LexisNexis.

**Study Selection:** English only literature with the publication years left open to enhance the study selection.

**Data Extraction:** Single terms and multiple word combinations were employed, as well as cross referencing of authors based on the number of times their work had been cited in other publications. Inclusion and exclusion criteria were instituted to narrow the literature to human surrogacy with relationship to the healthcare system, individuals involved, and psychosocial, ethical, religious and legal perspectives. Review of all abstracts by author with predefined quality criteria was engaged to limit the review to further quality.

**Data Synthesis:** A narrative review synthesizing studies, scientific reports and clinical articles, in context of surrogacy and the individuals involved was completed.

**Conclusion:** There is a paucity of nursing and healthcare research regarding surrogacy, those involved and the significant issues that surround it both here in the United States

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<sup>1</sup> Second author, Susan Yarbrough, PhD, RN

and abroad. These findings clearly support research in the area of surrogacy and those involved, as well as the dilemmas they encounter.

Keywords: Pregnancy, Surrogacy, Surrogates, Intended Parents, Intended Mother, Commissioning Parents, and Assisted Reproductive Technology (ART).

#### Call Outs

- 1.) As we've entered the twenty first century the definition of family has constructed an entirely new look.
- 2.) The lack of federal laws and regulations as well as the inconsistencies between states and countries leads to anxiety and uncertainty for those engaged in the process of surrogacy.
- 3.) It is critical that we remind ourselves of the serious psychosocial, ethical, legal, societal and policy concerns at hand for all parties involved in surrogacy.

## Surrogate Pregnancy: A State of the Science

### **Background**

In the past four years consumer media sources have started publishing information about surrogacy; good, bad or indifferent. Both a *Womb for Rent* in Newsweek (Ali & Kelley, 2008) and the more recent article *The Most Wanted Surrogates in the World* in Glamour (Nosheen & Schellmann, 2010) reviewed perspectives of military wives as surrogate mothers. Several television shows including *Army Wives* (2007) and *Private Practice* (2010) have aired episodes with surrogacy as a focus of interest. In 2008, a major motion picture *Baby Mama* was released. This movie looked at many variables of surrogacy including single parenting, infertility and the relationship between the surrogate and intended mother (Baby Mama, 2010). Similar to real life, a single woman desiring motherhood and parenthood employed a surrogate to have her baby. A question to ponder is whether healthcare professionals have really addressed surrogacy; those involved and their specific needs as a population.

Psycho-social investigators have published the largest volume of research to date, with most of it conducted outside the United States (US). Researchers have looked at surrogacy, the complex issues of intended parents, the surrogate family and the future child, as well as the changing definitions of motherhood and parenthood (Shenfield et al., 2005). They have also questioned whether surrogacy is an acceptable modality for accessing motherhood and parenthood as known by definition and throughout society (Shuster, 1992; van den Akker, 2007a, 2007b).

It is estimated that approximately 1000 surrogates give birth in the U.S. annually with as many as 19% being military wives (Nosheen & Schellmann, 2010). In light of changing pathways to motherhood, fatherhood and parenthood, society must reconsider

how family is defined today. The USA Today (Jayson, 2010) reported that the American family certainly isn't what it used to be, Mom, Dad and kids. A recent Pew study based on 2,691 responding adults, reported that 86% of those surveyed recognize a single parent and a child as a family, 80% believe that an unmarried couple with a child is a family and 63% said a gay or lesbian couple living together with a child is a family (Jayson, 2010). (call out #1)

This state of the science paper will provide a review of the current literature with regard to surrogacy. The intention is to lay a foundation for nursing to identify gaps and initiate research regarding surrogate pregnancy and those involved in this third party reproductive methodology.

### **Definitions**

The term intended parents is referenced in a number of studies, as well as the term commissioning parents. As the word commissioning can provide a sense of payment (<http://dictionary.com>, 2010) and many surrogate arrangements are based on altruism versus commercial surrogacy for financial payment, the term intended parents will be utilized. To provide further clarity, the American Society of Reproductive Medicine (ASRM, 2006) defines intended parents as a couple or individual intending to raise a child born of a surrogacy arrangement, also referred to as third (3<sup>rd</sup>) party reproduction. The intended parents may or may not be genetically related to the child (Erickson, 2010). In the past, many assumed that surrogate intended parents were heterosexual couples; this is far from the present reality in reproductive healthcare. Specific to this paper and future work, intended parents may be a single woman, single man, same sex couples or heterosexual couples.



A surrogate mother will be defined as the woman carrying the pregnancy. A surrogate may be a genetic surrogate or a gestational surrogate carrier (Rosenberg, 2010; Zodrow, 2008). There are nine reported combinations for resulting offspring in surrogacy arrangements reported by van den Akker (2007a). A genetic or traditional surrogate offers her own DNA or ova and the gestational carrier surrogate is a woman who offers no genetic linkage. The gestational surrogate may carry a fetus that is genetically linked to both intended parents as with a heterosexual couple, through embryo transfer or there may not be any genetic linkage (van den Akker, 2007a, 2007b, 2005). As noted earlier, clearly there are a variety of ways that parents and children can make up a family (Jayson, 2010).

In a recent study of family and communication Edwards and Graham (2009) revealed three classes of definition for family. The first is based on family structure looking conceptually at extended family or those related by DNA or biology, marriage, adoption or those residing inside the same residence. This definition tends to focus on membership criteria and gender and age to create hierarchal entitlement. The second of three definitions of families focuses on transactional processes whereby images, rites and rituals help to create a sense of belonging, loyalty, identity, as well as a shared past and future. This definition lends itself to shared systems and fluidity of the family today by self-defining based on beliefs and views of family history and multiple forms. For the purpose of this study the third definition, that of the psychosocial family as published by Fitzpatrick and Wamboldt (1990, p. 425) “a psychosocial group constituted by at least one adult member and one or more others who work as a group toward mutual need fulfillment, nurturance, and development” will be utilized. Psychosocial models typically deem the family as a social unit accepting responsibility for both socializing and

nurturing children. Noller and Fitzpatrick (1993) noted that the framework of the family may include one or two adult parents taking responsibility for the children, no relationship to marriage and possibly no genetic link between children and or parents. For sexual minorities, such as transgender persons, bisexuals, lesbians and gay men, the road to family often becomes their conductor of love and relationships in a society that does not recognize them. These family relationships may offer the validation needed by individuals of sexual minorities to find their place of well-being (Weber, 2008).

## **Methods**

Literature of interest was determined after conducting a search of the following databases; Cinahl, PubMed, Medline, Ovid, JSTOR, Psychinfo, Academic Search Complete, the Web of Knowledge, the Web of Science and Academic LexisNexis. The key terms employed to guide and limit the search were: surrogate; traditional and gestational carrier, surrogacy, intended parents, commissioning parents, surrogate parents, artificial reproductive technology, pregnancy and 3<sup>rd</sup> party reproduction. The terms were utilized in single word searches, as well as in multiple combinations. The initial search identified 1188 articles that were narrowed by review of titles resulting in 285 abstracts being read for relevance. A process of cross referencing authors to determine the number of times the references were cited in additional publications was also employed to enhance the literature search, and an examination of reference lists identifying citations that had not been disclosed through the initial terminology search was undertaken.

An initial search from 2000 to 2010 was completed and a gap was identified with no citations identified regarding clinical practice issues in the care of traditional or gestational surrogates or intended parents. The search was then reopened with no

limitation by years in an attempt to assure that all relevant literature was being identified. This search from 1991-2010 was then strategically evaluated using inclusion and exclusion criteria. Abstracts were read and selected based on one of the following inclusion criteria: research, literature review or scientific focus on the topic area of surrogacy that included at least one of the following foci, pregnancy, genetic or non-genetic linkage in offspring, DNA donor, and ethical, legal, psycho-social, religious and healthcare system concerns. Only two exclusion criteria were engaged for elimination during the review. The first criterion specifically eliminated any literature regarding the use of surrogacy outside of human reproduction, such as animal and plant reproduction. The second exclusion criterion was invoked when more current articles supplanted the information previously reported. Literature from around the world including both the United States and a number of additional countries was accepted for evaluation. The search was not limited to English, although all citations identified were written in English and duplicate articles were eliminated.

## **Review of the Literature**

### **Healthcare System**

#### **Gynecology, obstetric and reproductive endocrinology and infertility.**

A Reproductive Endocrinology Infertility (REI) office is one of the first healthcare locations intended parents will seek assistance to become pregnant. It is often after much frustration and heartache in an attempt to have a child that sub-infertility or in the case of lesbian, gay or transgendered individuals, the inability to reproduce is addressed (van den Akker, 2000, 2003, 2005, 2007a, 2007b). Alternative options such as adoption and surrogacy are considered by intended parents. REI practices along with surrogacy agencies and specialized attorneys can be of great help to facilitate such

arrangements. Often these resources assist in linking intended parents to a traditional or gestational surrogate carrier and facilitate initial conversations towards pregnancy acquisition (American College of Obstetrician and Gynecologists, Committee Opinion, 2008; Erickson, 2010).

### **Surrogacy Agency.**

Surrogacy agencies are described by many as privately owned brokerages that often include private practice psychologists, physicians and nurses working collaboratively between their practice and the agency assisting in the orchestration of surrogacy arrangements. They could be representing surrogates, both traditional and gestational carriers, or they could be representing the intended parents seeking to find a surrogate. Some agencies may assist both parties at one point, however it is recommended that they have legal representation as individual parties interests will be different (Erickson, 2010). Surrogacy agencies are not clearly defined as a healthcare system practice, nor are they regulated by government regarding their services or the data they may have regarding this reproductive practice. Referral patterns often exist between agencies and healthcare offices. Counseling and follow up procedures should be consistent and available for those involved in surrogacy, however it is difficult to know if these services are consistently provided at the agency level when currently the regulation of such practices is absent or variable across the United States and the International reproductive world (Brazier, Campbell, & Golombok, 1998; Pashmi, Tabatabaie, & Ahmadi, 2010; van den Akker, 2007a, 2007b). Jones (2004) reported the importance of sharing appropriate information with potential reproductive endocrinology infertility patients and that timely referral for preconception counseling was extremely valuable.

Also reported was the importance for all nursing specialties to have knowledge regarding the growing number of assisted reproductive technology (ART) options (Kirk, 1998).

Surrogacy agencies are often involved in assisting intended parents to find a surrogate and serve as advocates throughout the process (Kleinpeter, Boyer, & Kinney, 2006). Although the literature reports that intended parents have higher education and report higher incomes, agency services can be costly and not all intended parents can or will afford an agency (Rosenberg, 2010; van den Akker, 2007a, 2007b).

### **Healthcare in labor & delivery and mother baby.**

The surrogate mother has been studied from a psychological and social perspective. The majority of publications (van den Akker 2007a, 2007b, 2005, 2003, 2000) have reported concerns or issues including knowledge and informed consent, motivation to serve as a surrogate, the type of surrogacy arrangement they are willing to be involved in, genetic or non genetic, emotional well-being, relinquishment of the baby, relationship with the intended parents, ethical and societal concerns, as well as financial and economic concerns. Of these studies only the 2005 study by van den Akker was longitudinal in nature; the remaining studies were retrospective in nature (van den Akker, 2000, 2003, 2005, 2007a, 2007b). This longitudinal study was comprised of 23 surrogate mothers and 11 intended mothers. Analysis revealed significant difference in socioeconomic and education levels. Self-confidence was also measured and clearly increased over time, yet both groups reported experiencing doubt and anxiety. Intended mothers reported higher anxiety levels than their counterparts. It was suggested that further regulation of this reproductive methodology could benefit all involved and continuation of this longitudinal study could assist in evaluation of family dynamics,

relationships between intended parents and surrogate parents, as well as the children born of this reproductive method (Edelmann, 2004; van den Akker, 2005).

A study in Iran (Pashmi et al., 2010) analyzed a comparison of intended mothers, surrogate mothers and mothers who conceived naturally on their own. Results revealed differences in individual characteristics and overall happiness related to their surrogate experience. This report is similar to that of van den Akker (2005) and Jadva, Murray, Lycett, MacCallum and Golombok (2003). The majority of surrogate mothers reported happiness with regard to involvement of intended parents during their pregnancy period and primary relationships were typically established with the intended mothers rather than the intended fathers (Jadva et al., 2003; Pashmi et al., 2010).

Interviews conducted with surrogate mothers married to U.S. military personnel shared many perspectives regarding surrogacy, including financial gain, altruism in their decision making towards surrogacy, psychosocial and emotional risks, overall costs of surrogacy, and ethical concerns such as the decision to use or not use their military healthcare insurance, Tricare (Ali & Kelley, 2008; Nosheen & Schellman, 2010). MacCallum, Lycett, Jadva and Golombok (2003) studied commissioning couples in the United Kingdom (UK) regarding their surrogacy experience. The study began retrospectively one year after surrogacy arrangements were completed. Intended parents described their experiences regarding motivation for surrogacy, decision making processes, relationships and feelings about the surrogate, how often they saw the surrogate, their experience after birth and transition of the child to their guardianship, openness towards use of surrogacy, openness and advising the child of their parentage, and economic concerns. Findings of this specific study indicated that intended parents felt their surrogacy arrangement was a positive one and would recommend the option to

others (MacCallum et al., 2003). Two studies documented intended parents being present at the delivery of the surrogate child, yet no further involvement with the healthcare system was reported (Pashmi et al., 2010; Sharan, Yahav, Peleg, Ben-Rafael, & Merlob, 2001).

### **Healthcare in neonatology/pediatrics.**

Sharan et al. (2001) evaluated the effect of hospitalizing the genetically linked intended parents immediate to delivery to enhance early bonding with their newborn. Parents also received three months of social work counseling prior to the estimated due date and results were reported favorable. Although only the intended mothers were hospitalized, both parents displayed affective physical and verbal interactions with their newborn and reported a reduction in fear related to caring for their newborn upon discharge.

Researchers also documented improvement regarding the intended parents' confidence to interact with their infant and build parenting skills. This extremely small study consisted of two intended mothers and their surrogate mothers. With positive findings in this small trial, larger randomized trials including prolonged periods of observation were recommended for future research especially with a focus on intended parents and their interactions with nursing and the healthcare system.

### **The Law and Legal System**

The process of surrogacy can be affected by the residence of the intended parents, that of the surrogate who is carrying the pregnancy, and where the birth of the child will take place. The laws that support or prohibit a surrogate agreement or contract vary from state to state here in the US as well as internationally between countries (Drabiak, Wegner, Fredland, & Helft, 2007; Erickson, 2010). Clearly surrogacy success is

dependent on the location of all involved parties throughout the process (Erickson, 2010; Soderstrom-Anttila et al., 2002). Advocacy and adequate representation of each party are recommended from the beginning of the surrogacy process. Ideally this should continue throughout the pregnancy, delivery and transfer of the child. A well orchestrated team of professionals including legal representation are considered necessary to ensure a successful outcome in surrogacy (Erickson, 2010; Rosenberg, 2010). Many areas of law are represented throughout the process of surrogacy. Without experts this process would be extremely anxiety provoking and have a much higher risk of failure. In addition, the use of biotechnology in human reproduction has been rapidly changing over the past three to five decades, yet the laws regarding it have not kept pace. This gap has created many difficult circumstances for those engaging in surrogacy and other medical technologies utilized in human reproduction (Erickson, 2010). A review of specific areas of law related to reproductive health is noted in Table 1.

### **Variation in Family Law**

#### **State to state.**

Variations in the state laws in the US are clearly problematic. Although laws have been considered from a federal perspective, nothing has been enacted in the past ten years at the federal level (Erickson, 2010). A summary of state laws is available for review in Table 2.

An example of state surrogacy litigation risk was cited in a recent investigative report (Nosheen & Schellmann, 2010) where a surrogate and her military husband were moving to Michigan prior to delivery. It was recognized that legal dilemmas would ensue as Michigan criminalized commercial surrogacy; in turn the couple chose to move



to Ohio, locating just over the state line to avoid litigation difficulties for themselves and the intended parents. (call out #2)

Erickson (2010) recommends selection of legal representatives who have a strong background in the many facets of law that are involved with surrogacy. Strategic planning by all parties starting from the initial desire of intended parents to engage a surrogate is optimal. The option of surrogacy should be explored with exceptional counseling, full disclosure of risks and benefits with informed consent, and all parties involved should have individual legal representation. Issues such as selection of a surrogate, health care coverage and agreements about the pregnancy, must also be established to ensure the birth and transition of the newborn will be successful for all parties involved (Erickson, 2010; Soderstrom-Anttila et al., 2002).

### **International.**

A large majority of the surrogacy studies have occurred outside the US, primarily in the UK. The UK has a regulation that does not allow for financial payment or commercial surrogacy, leaving altruistic surrogacy as the only option (Erickson, 2010). Some postulate that this type of regulation leaves many individuals and couples without options regarding their intention to become parents and have a family, causing them to look elsewhere. This may be one reason why many women provide surrogacy for intended parents outside of their home state or country borders (Ali & Kelley, 2008; Nosheen & Schellmann, 2010). Research indicates this may also lead to some misunderstanding regarding the intentions of surrogates, albeit altruistic efforts or financial gain. There are those not in favor of surrogacy who believe surrogacy is a form of prostitution (Broham, 1995; van Niekerk & van Zyl, 1995).

In addition to commercial surrogacy being banned in a number of countries (Table 3), additional legal stipulations with regard to egg/ova and sperm donation have been identified. Recently Israel lifted their ban of surrogacy in support of altruistic or nonprofit surrogacy (Erickson, 2010). Additionally, as recent as 2010, Mexico City, Mexico legalized altruistic or noncommercial surrogacy. This is the first law regarding surrogacy for any region inside the borders of Mexico (O'Kane, 2010).

Surrogacy brings with it a number of complicated legal issues including, but not limited to, disposition of unused embryos, egg and sperm donation, disclosure or openness to the children regarding their parentage, rights of children, use of surrogate agencies, location, maintenance and access to medical records for the future, federal and state requirements, use of trust or escrow accounts, politics and societal concerns regarding the use of such reproductive techniques that include payment as well as ethical dilemmas (Erickson, 2010).

### **Ethics and Surrogacy**

Many ethical issues surrounding surrogacy have been identified. The evaluation of ethics related to a situation is often influenced by the culture and societal norms of the community or population involved. Disparity of ethical concerns has been documented regarding altruistic and commercial surrogacy, both here in the US and in other countries. The biggest dilemma seems to begin with a woman's right to reproduce for someone else. The question would be, "Is gestating a child for someone else, ethical?" Then add the multiple factors or variables debated in the literature such as: Is reproduction a woman's choice? Is financial gain versus altruism an ethical issue? Does a genetic link to the surrogate mother, surrogate father or intended parents create conflict? If a child is created from donated DNA, should a donor be assured anonymity? Does lack of a genetic

medical history create ethical issues later in life for the child born of surrogacy, such as mating with a half sibling without knowing? Does a surrogate child have a right to know their genetic donor? All of these variables and many more illustrate the ethical issues and the importance of psychological screening and counseling for all parties involved. The American College of Obstetricians and Gynecologists (ACOG) released a committee opinion on Surrogate Motherhood that focuses on ethical concerns for obstetrician/gynecologists participating in surrogacy arrangements (American College of Obstetricians and Gynecologists, 2008). Significant areas of concern that were addressed included public policy, types of surrogacy, arguments for and against surrogacy, payment to the surrogate mother, responsibilities of the obstetrician/gynecologist, responsibilities of physicians to couples considering surrogacy, responsibilities of physicians to potential surrogate mothers, and pregnant women participating in surrogacy and responsibilities of REI physicians to both intended parents and surrogate mothers. Kirk (1998) reported that the growing number of ART procedures and combinations to contribute genetic material or not, were creating ethical concern for all health professionals to be aware of. According to Ber (2000), all four principles of ethics, autonomy, beneficence, non-maleficence and justice must be addressed with all parties involved and remain at the forefront of decision making with this significant population.

The American College of Obstetricians and Gynecologists (1991) also published a position paper to identify and share issues of ethical interest in relationship to surrogacy. One major contention in comparing adoption to surrogacy is that options of surrogacy can create a DNA link between intended parents and the expectant child. The intention of an intended parent is clearly to have and raise the child, and possibly go through adoption of the child, if legally necessary (Erickson, 2010). Although there are

individuals who may choose to enter into surrogacy for convenience issues, ACOG and others do not support or recommend that approach (American College of Obstetricians and Gynecologists, Committee Opinion, 2008; Edelmann, 2004; Shenfield et al., 2005). Additional concerns reported by ACOG (1991) include the financial and economic dilemmas that may ensue, as well as potential risk or harm to an unborn infant/child. Children are indeed a vulnerable population and in circumstances such as these, an unborn fetus or newborn has no say in the matter. Existing children of surrogate families may also be negatively impacted regarding concerns that the child resulting from their mother's pregnancy will be relinquished to someone else. In consideration for the surrogate fetus or infant, surrogate mother and intended parents, ACOG (1991) recommended eight standards for public policy on surrogate parenting arrangements in a committee opinion "Ethical Issues in Surrogate Motherhood".

The European Society of Human Reproduction and Embryology (ESHRE) published a report on ethics and law related to surrogacy (Shenfield et al., 2005). This report identified many issues including altruism being the only acceptable approach to surrogacy, when and if the surrogate fully comprehends the risks and benefits of carrying a gestation for another. The dilemmas identified that might present when one is being paid for surrogacy include issues such as insult to human dignity, instrumentalization of the human body, exploitation of vulnerable women, and the possibility of coercion or inducement of women. These ethical concerns highlight the importance of autonomy of women and informed consent and safety for all involved. Issues that may impact outcomes such as preconception and prenatal care, antenatal testing, potential need for termination of a pregnancy or gestation, mode of delivery and transfer of the infant newborn to the intended parents ideally will all be addressed and clearly agreed upon by

contract right from the beginning (Erickson, 2010). However, the ability to enforce the contract related to a surrogate's behavior is not possible until after the baby is born regardless of outcome. The intended parents must understand and address such serious concerns prior to this time through identification and counseling in the hope of avoiding all hazards possible (Shenfield et al., 2005).

Boundaries of ethics regarding reproduction and genetics are being pushed like never before with the rapid development of biotechnologies (Zodrow, 2008). Ber (2000) suggests that the advent of contraception put into motion the separation of sex and procreation and the use of ART and other reproductive methodologies have identified the need to redefine motherhood and family. Some critics of surrogacy have made rash statements such as that women are offering themselves as prostitutes in surrogacy. The comparison is built upon its relationship to money as a motivation to serve as a surrogate and the selling of the commodity, a baby (Ber, 2000). American feminist Andrea Dworkin responded with a new twist stating that old time prostitutes sold sexual capacity of the vagina for penile intrusion, yet women of surrogacy are selling reproductive capacity by use of their womb, thereby not having to deal with the connotation of whoring themselves (van Niekerk & van Zyl, 1995).

Zodrow (2008) reviewed issues of intent of parentage in relationship to contemporary issues such as multiple reproductive contributors, disclosure of genetic origins and donor anonymity, different needs of surrogate mothers and intended mothers, multiple births, selective reduction, embryo selection and disposition, disposal of unused embryos, and post divorce and post mortem parenthood. All of the aforementioned have the capacity to be significant ethical dilemmas. In addition, Ber (2000) reports two cases where women in a persistent vegetative state became pregnant, one delivering at term,

one losing the preivable pregnancy. Ber questions if a woman has recorded permission in writing, much like an organ donation registry, could she offer her uterus as a place of gestation and surrogacy?

### **Finance & Economics**

Many studies have reviewed the benefits and risks of surrogacy including the decision to utilize commercial surrogacy with payment versus that of non-commercial or altruistic surrogacy. A recent study by Connolly, Hoorens, and Chambers (2010) reviewed economic implications of ART in an attempt to better understand the financing of ART as well as potential opportunities to inform policy. Direct costs of ART treatment vary widely between countries with the U.S. reporting the highest in expenses and generally reflecting the costliness of the underlying healthcare system. In the US, costs for ART vary from state to state and from one insurance policy to another. Clearly multiple pregnancies, which often result from ART, were of higher morbidity and constituted higher costs to the system. Economic concerns are quite applicable to surrogacy as ART is utilized when artificial insemination is not feasible or is the choice selected.

Costs to intended parents may vary based on their access to healthcare coverage for reproductive care, pregnancy care through delivery, and newborn pediatric care. Reflective of individual state laws, ART may or may not be covered (Connolly et al., 2010). When a surrogate is employed, she may request additional compensation beyond healthcare coverage and this is known as commercial surrogacy. Costs for a single fresh ART cycle in the US was reported as high as 50% of an individual's reported annual disposable income, where Japan reported only 12% and the UK, Scandinavian countries, and Australia reported 20% (Connolly et al., 2010). When government subsidies were

imposed, the costs in the US did not change, nor did they change in Japan due to negligible public funding. However these subsidies did lower the costs in the UK and Scandinavian countries to 12% and Australia was able to cite a reduction from 19% to 6% (Connolly et al., 2010).

As noted previously, intended parents cross state and country borders to engage in ART in the attempt to have a child and family based on legal constraints placed upon the users of ART. Financial implications may also influence intended parent's decision making where there are lack of mandates in insurance coverage and or no government subsidies (Connolly et al., 2010). Estimates of costs in surrogacy for intended parents are quite variable based on the presence of mandated coverage of health insurance and contract agreements. However, a review of costs for ART in the US implied a willingness of intended parents to pay an estimated \$177,730 for a baby (Connolly et al., 2010).

A recent investigative report (Nosheen & Schellman, 2010) of commercial surrogacy reported varying costs from \$100,000.00 to \$125,000.00. This included ART associated fees as well as the surrogate fee. Additional costs of up to \$25,000 may be required for healthcare insurance coverage. Ber (2000) suggests fees to be paid from a perspective of services rendered, fee per 24 hour/day, 270 days of gestation, preparation for and stages of labor and delivery, as well as a hazard fee related to potential of risk to life and family.

### **Psycho-Social Implications**

Over the past twenty years, surrogate mothers and intended mothers have been studied related to surrogacy arrangements and for issues of psycho-social nature (van den Akker, 2007a, 2007b, 2005, 2003, 2000). The majority of van den Akker's studies

(2007a, 2007b, 2006, 2005, 2003, 2000) completed an evaluation of the surrogate mother's motivation, anxiety state and trait, prepregnancy and post pregnancy, genetic linkage, social support and attitudes toward the pregnancy, relinquishing the baby soon after delivery, anonymity and contact, self-efficacy, confidence and relationship with intended mothers. Several studies have included evaluation of intended mothers in addition to the primary focus of the surrogate mothers (Ciccarelli & Beckman, 2005; Pashmi et al., 2010; Soderstrom-Anttila et al., 2002; van den Akker, 2007a, 2007b). The majority of studies regarding surrogacy have been conducted in the UK and few studies of psychological nature have been carried out with intended mothers and even less regarding intended fathers and intended parents as a whole.

A study of Iranian women (Pashmi et al., 2010) had similar findings as van den Akker (2007a, 2007b, 2005, 2003, 2000) with significant differences in socio-cultural status of intended mothers and surrogate mothers being appreciated, as well as psychological trait differences, although these differences were considerably less.

Golombok's et al. (2004) study of intended parents, reported little to any concern relative to legal, emotional or social problems, or issues related to genetic linkage. A study by Sharan et al. (2001) recommended early hospitalization of the genetic mother in establishing early mother-infant bonding. Although this was a small study of two intended mothers with a short observation, a reduction in anxiety related to parenting and increased confidence was found.

An additional area of significance reported in Pashmi et al. (2010) was the belief that surrogacy was perceived negatively by society. The surrogate mothers interviewed felt that knowledge, via media options, could change societal perception of surrogacy and



intended parenthood. In addition a concern for declining lack of social support was reported by van den Akker (2000).

The value of relationships between surrogate mothers and intended mothers or intended parents was evaluated in several studies (Pashmi et al., 2010; Soderstrom-Anttila et al., 2002; Teman, 2009, 2008, 2006; van den Akker, 2000, 2003, 2005, 2007a, 2007b). The majority of surrogates acknowledged the importance of having a relationship with the intended parents and its value to assure success in the outcome of the arrangement (Soderstrom-Anttila et al., 2002; Teman, 2009, 2008, 2006). However, intended parents report that once the baby has been received it is less likely for them to have a desire to continue their contact with the surrogate, hence issues of potential risk for the surrogate may ensue, including long-term psycho-social issues related to relinquishing the child as well as risk of grief and post partum depression (van den Akker, 2007a).

## **Religion**

Many consider issues surrounding surrogacy related to fundamental values and morals with great concern. Surrogacy has been addressed by a number of religions including the Catholic Church. In 1987 the Vatican issued statements against both in vitro fertilization (IVF) and surrogate motherhood. To date the Vatican has not changed its perspective on contemporary morality or the sanctity of human reproduction. Many believe that the Catholic Church may have some significant points at hand when in the future it may take a very wise child to know whom their biologic mother or father actually is (Bulfin, 1991; Paulson, 1995).

Israel recently legalized only gestational carrier surrogacy. Much of their past concerns were related to religious and biologic confusion related to the 3<sup>rd</sup> party

reproductive process (Schenker, 1997). A small pilot study by Murphy et al. (2002) of fertile individuals found that if they had religious practices, they were less apt to support surrogacy for the childless, especially if they hypothesized surrogacy for themselves. Poote and van den Akker (2009) reported significance with 60% of women practicing religion unwilling to participate in surrogacy.

### **Gaps Identified**

A number of gaps have been identified related to the use of surrogacy in the United States and abroad. Research related to the provision of clinical care involving the intended parents as well as their interaction with the U.S. healthcare system represent significant gaps in the literature. Nursing and other healthcare providers require information and an understanding of a specific population's needs to assure evidence based practice, standardized care and desirable outcomes are achieved. Individuals involved in reproductive surrogacy are likely to present different needs and this information is clearly missing from the literature. Ironically, some of the strongest commercial surrogacy programs in the world are found in the US, yet they are operating with little standardization or regulation between states resulting in a lack of objective data reporting and lack of policy (Erickson, 2010).

Although case reports in the literature describe surrogacy as an option for lesbian, gay, and transgendered individuals, these intended parents have been studied from only a perspective of motivation and desire to have a child (Bos, H., van Balen, F. & van den Boom, D.C., 2003). Intended parents, whether a man, woman, same sex or heterosexual couple, play a significant role in 3<sup>rd</sup> party reproduction, yet little is known about them or how to assist them through this vulnerable time. Studies specific to evaluating surrogate fathers and families, as well as intended fathers and sexual minority intended parents,

were completely absent in the literature of surrogacy. As the use of surrogacy continues to grow and become more apparent in our global society, it is our responsibility to study these subsets of the surrogate population for an understanding of their experience of surrogacy, as well as provision of care and implications for policy and society.

Education for those involved in the transition to parenthood and family is also identified as a gap in the literature. The uncertainty and disappointment regarding an inability to reproduce is a tremendous burden. There may also be a burden of carrying a pregnancy and giving that child to someone else with the grief that may ensue. To navigate the experience of surrogacy without appropriate mechanisms in support of the experience, such as counseling, healthcare, education, social support and policy, seems incredibly wrong and adds to the risk of failure for both the surrogate family and the intended parent family.

### **Discussion**

The majority of intended parents who choose surrogacy as a method for becoming parents have experienced infertility or an inability to reproduce. The majority of professionals involved in this methodology agree that it should be used as a last effort toward reproducing (American College of Obstetrician and Gynecologists, Committee Opinion, 2008; Erickson, 2010; Shenfield et al., 2005). However, surrogacy is gaining popularity and is increasing in numbers, yet we have questionable data to evaluate and little in the literature to understand the populations utilizing surrogacy (Nosheen & Schellman, 2010). It is critical that we remind ourselves of the serious psychosocial, ethical, legal, societal and policy concerns at hand for all parties involved in surrogacy. (call out #3) This includes the surrogate mother, surrogate father, intended mother,

intended father and the unborn fetus, as well as the children of both the surrogate family and intended parent family, all of whom are considered vulnerable and at risk.

Those against surrogacy will often comment on the number of children waiting to be adopted and the similarities towards surrogacy. However, as van den Akker (2007a) clarifies, treatment for infertility is acquisition of pregnancy or a baby, where adoption is acquisition of a parent or family; both lend themselves to two completely different pathways of becoming a family.

### **Recommendations**

A recommendation for further studies regarding surrogacy and its co-associated concepts such as intended parents is clearly indicated. The fact that no research was identified in the literature regarding the interactions of those involved and the U.S. healthcare system supports this recommendation. Further opportunities to study subsets of this population including intended parents as a defined population, as well as single intended parents, heterosexual and same sex couples, and transgendered intended parents, would also present additional information in the care of this population. The paucity of literature surrounding this topic clearly offers great opportunities for additional studies here in the US. The fact that commercial surrogacy, economic implications, and healthcare reform are of significance and in great flux in the US, provides further foundation for future research. Investigative reports (Ali & Kelley, 2008; Nosheen & Schellman, 2010) acknowledged that military wives currently represent a large percentage of surrogates in the US; a formal study of military wife surrogates could produce very valuable information. The lack of education and cognition research represents an opportunity for measurable interventional studies with both surrogate and intended parent families.

As we move further into the twenty first century we must seize the opportunity to rewrite definitions of parenthood, fatherhood, motherhood and family. With the many variables that surrogates and intended parents encounter in surrogacy, it is crucial that the healthcare system understand this vulnerable, and at times, marginalized population. Nursing is the discipline to address and orchestrate the care of such a population and should seize the opportunity. The future holds great promise in defining and exploring this population and their needs in healthcare in support of evidence based practice, as well as standardization in the delivery of care to all involved in surrogacy. Without fully comprehending this population's experiences we do not have the knowledge to assess their needs or provide sensitive and culturally appropriate care.

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Table 1 Types of Law Practiced in Surrogacy and 3<sup>rd</sup> Party Reproduction

Type of Law	Relationship to Reproductive Health
Contract or Constitutional	Abortion/travel/privacy
Tort	Injuries/malpractice
Tax	Parentage & financial issues related to surrogate
Property	Embryos
Insurance	Coverage as indicated or required
Additional areas of law may be indicated case to case	Example: DNA linkage with traditional surrogacy may require legal interventions for resolution

Table 2 State Law Regarding Surrogacy

State	Legal Consideration of the Law
California, Florida, Illinois, Texas and Utah	Defined use of egg/ova, sperm or embryo donation in 3 <sup>rd</sup> party reproduction to recognize the offspring child. Surrogacy in these states will recognize a contract or agreement and it will be upheld in court if needed. The laws do vary, between each state, so it is extremely important to have an expert in this field assist both the intended parent/s and surrogate.
Arizona, Michigan, New York and Washington	Commercial surrogacy is considered a criminal action.
Arizona, Kentucky, Michigan and New York	Will not enforce surrogacy agreements
California, Florida, Illinois, Texas and Utah	Recognize surrogacy through legislation and case Law
Montana and Wyoming	Will not address surrogacy, so if there are agreements or contracts between parties, it is uncertain what their actual rights are from a legal perspective

Table 3 International Country Laws of Surrogacy

Country	Laws of Country
Germany and France	Commercial surrogacy is banned. Germany has banned the use of egg (ova) donation as well.
Canada, Greece, Israel, Italy, Norway, Spain, Sweden and Switzerland	All of these countries have legalized noncommercial or altruistic surrogacy. Sweden also bans the use of donated eggs/ova and sperm.
United Kingdom	Commercial surrogacy is banned and all donors of egg/ova and sperm lose their anonymity when the offspring turn 18 years old. Children of surrogacy may request to have the identify of their biologic DNA donor.

### **Chapter 3: Beyond Borders: International Surrogacy<sup>2</sup>**

Abstract and manuscript prepared for *Nursing for Women's Health*

#### **Abstract**

The road to building a family can be extremely unpredictable. When faced with medical complications, including infertility or the inability to reproduce, many individuals and couples, look at options such as foster parenting, adoption and surrogacy. Today surrogacy is becoming a more visible option to become a parent and build a family. Surrogacy is not a new phenomena, as traditional surrogacy was recorded far back in time through historical documentation, as described in the Christian bible. However, today surrogacy is not only available by insemination, it is actually available through in-vitro fertilization and use of a surrogate carrier, thereby removing the act of sex from reproduction. With variances between states and countries regarding the laws of reproduction, as well as professional, societal, ethical and morale concerns, this article provides insight regarding International surrogacy and its current state.

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<sup>2</sup> Manuscript 2 has been accepted for publication in *Nursing for Women's Health* and is in press for the June/July 2012 issue.



## **Beyond Borders: International Surrogacy**

### **Background**

In the past four years, consumer media sources have published more and more information about surrogacy: good, bad or indifferent. An article entitled, “Womb for Rent” in *Newsweek* (Ali & Kelley, 2008) and a more recent article “The Most Wanted Surrogates in the World” in *Glamour* (Nosheen & Schellmann, 2010) reviewed perspectives of military wives as surrogate mothers. *Wall Street Journal* (2010), published “Assembling the Global Baby” (Audi & Chang) describing international surrogacy as an option for individuals to avoid restrictive laws and financial constraints. In addition to print media, several television shows including *Army Wives* (Younger & Fugate, 2007) and *Private Practice* (Blackman & Verica, 2010; McCormick & Kindberg, 2010) have aired episodes with surrogacy as a focus of interest. In 2008, a major motion picture *Baby Mama* (Goldwyn & Michaels, 2010) was released. This movie looked at many variables of surrogacy including single parenting, infertility and the relationship between the surrogate and intended mother. Today, individuals around the globe, regardless of marriage or sexual orientation, are looking at surrogacy as an option to reproduce and have a family. Although the birth of a child is typically considered a very happy time for parents, surrogacy, whether traditional or gestational, can bring uncharted territory that becomes very stressful for all parties involved.

### **Definitions**

A number of definitions can be located in scientific literature regarding the process of surrogacy and those involved. The American Society for Reproductive Medicine (2006), the American College of Obstetricians and Gynecologists (2008) and the Council for Responsible Genetics (Gugucheva, 2010), have published definitions for

many of the terms associated with the process of reproductive surrogacy. Definitions provide clarity about this increasingly visible pathway to reproduction and are available for enhanced understanding in Table 1.

## **Literature**

### **International**

The majority of surrogacy studies have occurred outside the United States (US) and primarily in the United Kingdom (UK), evaluating psychosocial implications to the surrogate mother. The UK has regulation on surrogacy that does not allow for financial payment or commercial surrogacy; thereby leaving altruistic surrogacy as the only option (Erickson, 2010). Some postulate that this type of regulation leaves many individuals and couples without options with regard to their intention to become parents and have a family, causing them to look elsewhere. Situations such as this may create the foundation for women to offer and provide surrogacy for those intended parents seeking a surrogate outside their home state or their own country borders (Ali & Kelley, 2008; Nosheen & Schellmann, 2010). Research indicates individuals will move around restrictive laws to acquire a baby through the surrogacy process which adds to the confusion of this poorly understood and regulated process (Broman, 1995).

In addition to commercial surrogacy being banned in a number of countries including the UK, (Table 2) further legal stipulations in the UK have barred the anonymous donation of egg/ova and sperm donation (Erickson, 2010). The UK's policy is considered to be in the middle of the road with countries such as Italy and Germany banning surrogacy completely and countries such as the Ukraine, India and some of the US states having few restrictions as well as accepting the practice of commercial surrogacy (Gamble, 2009). Recently Israel lifted their ban of surrogacy in support of

altruistic or nonprofit surrogacy (Erickson, 2010) and as recent as 2010, Mexico City, Mexico legalized altruistic or noncommercial surrogacy making it the first law regarding surrogacy for any region inside the borders of Mexico (O'Kane, 2010). With regard to surrogacy and reproductive technology, legal stipulations vary within countries and around the world. While some countries and states report favorable laws toward these reproductive technologies, others are highly restrictive or even unclear (Gugucheva, 2010; Nakash & Herdman, 2007).

## **Statistical Data**

### **U.S. Statistics**

Although inconsistently reported due to a lack of regulation, surrogacy for human reproduction appears to be on the increase in the US. It has been estimated that approximately 1000 surrogates give birth in the US annually, with as many as 19% being military wives, although statistical data do not specifically denote whether the births are gestational or traditional surrogate births. (Nosheen & Schellmann, 2010). A recent report from the Council on Responsible Genetics (2010) evaluated statistics from both the Center for Disease Control (CDC) and the Society for Assisted Reproductive Technology (SART). Findings indicated a doubling in the total number of gestational surrogate births. This subset of surrogacy rates increased from 738 babies born in 2004 to 1400 in 2008, which is 400 greater than reported by Newsweek. The disparity of statistical data highlights the inconsistency of report standardization and possibly utilization of definition criteria. It is estimated that these statistics are just skimming the surface of what has been electively reported in the US, since neither professional organizations, or the United States government currently mandate reporting.

## **International Statistics**

Much like the United States, there is very little regulation internationally regarding surrogacy. Reviews of several online websites including the United Kingdom's Human Fertilisation and Embryology Authority (HFEA) concur with the lack of regulation and data reporting not only within the UK but around the world. The 2008 HFEA reports an 8.2% increase of in-vitro fertilization cycles and patients, a 10.2% increase in surrogacy births and a 10.3% in surrogacy babies. We could postulate there is a relationship between increased reproductive techniques and the use of surrogacy; however without a reporting mechanism we really don't know.

Stanford University reported on *Surrogate Motherhood in India* (2008) with a perspective on poverty and women's rights. This report cites the lack of statistics is directly related to the lack of completed and published research. The Stanford report also notes 25% of the total population in India exists below the poverty line with many women included in that subset, looking for ways to survive. Although far from traditional employment, being a surrogate may prove to be a source of income generation that thousands of women will turn to in efforts to help their family and community. That being said, we must continue to research the multiple effects of work as a surrogate and the risks attached, not only for the surrogate woman but for women in general (Stanford University, 2008).

## **Ethics & Surrogacy**

Many ethical issues surrounding surrogacy have been identified. The evaluation of ethics related to a situation is often influenced by the culture and societal norms of the community or population involved. Disparity of ethical concerns has been documented regarding altruistic and commercial surrogacy, both here in the US and in other countries.

The biggest dilemma seems to begin with a woman's right to reproduce for someone else. The question would be, "Is gestating a child for someone else, ethical?" Then add the multiple factors or variables debated in the literature such as: Is reproduction a woman's choice? Is financial gain versus altruism an ethical issue? Does a genetic link to the surrogate mother, surrogate father or intended parents create conflict? If a child is created from donated DNA, should a donor be assured anonymity? Does lack of a genetic medical history create ethical issues later in life for the child born of surrogacy, such as mating with a half sibling unknowingly? Does a surrogate child have a right to know their genetic donor? The UK addresses this by providing anonymity to the DNA donor until the offspring turns 18. At that time the offspring has the right to access their DNA donor information. Additional ethical dilemmas such as the imperfect fetus or newborn, higher order multiple pregnancies that may require reduction, medical complications, such as diabetes or hypertension, are all possibilities that may occur and present great strife for all parties involved. Clearly these variables and more illustrate the ethical issues and importance of psychological screening and counseling for all parties involved. The American College of Obstetricians and Gynecologists (ACOG) released a committee opinion on Surrogate Motherhood that focuses on ethical concerns for obstetrician/gynecologists participating in surrogacy arrangements (American College of Obstetricians and Gynecologists, 2008). European Society for Human Reproduction (ESHRE) has also published a report on ethics and law related to surrogacy (Shenfield et al., 2005) acknowledging many risks and benefits of surrogacy to all parties involved. According to Ber (2000), all four principles of ethics, autonomy, beneficence, non-maleficence and justice must be addressed with all parties involved and it must remain at the forefront of decision making.

## **Professional Perspective**

### **Nursing**

To date, there have not been any reports or published opinions by professional nursing associations regarding this reproductive methodology or the subset population engaging in its use. Nursing is currently positioned to address many of the issues intended parents, surrogate women and their families face today. Issues of practice, education, care coordination, legal, ethical and societal concerns, all require the attention of a multidisciplinary healthcare team. In the field of medicine, several professional associations around the globe have taken the time to evaluate and document a perspective regarding this burgeoning reproductive methodology.

### **Medicine**

#### **Canada.**

In 2007, the Canadian Medical Association published a guide titled *Surrogate Pregnancy: a guide for Canadian prenatal health care providers* to assist in standardization of care for a growing number of surrogate pregnancies being seen in Canada. This document addresses ethics and surrogacy, the law and surrogacy, the law and care of surrogates, prenatal care of the surrogate and how the commissioning or intended parents fit into the scenario (Reilly, 2007).

#### **Europe.**

The International Federation of Gynecology and Obstetrics (FIGO) published a committee report on surrogacy titled *Ethical aspects of human reproduction and women's health* (2008). This report focuses on the background and implications of surrogacy for human reproduction, as well as making recommendations for the population engaging in surrogacy and those providing healthcare. FIGO's report addresses issues of concern

related to the process of surrogacy including that only those with a medical indication, such as unmanageable hypertension or diabetes, should engage in surrogacy and that both surrogate and intended or commissioning parents, should have psychological evaluation. Most of Europe legally prohibits commercial surrogacy and FIGO recommends all participants of surrogacy obtain legal advice for all situations, regardless of the actual country laws. Further recommendations include research in the areas of coercion and harm to all individuals involved in and or exposed to reproductive surrogacy, such as the surrogate's previous children.

### **United States.**

The American College of Obstetricians and Gynecologists (ACOG) has published three committee reports. Two address the ethical issues of surrogacy (1988, 1991) and the third is a committee opinion statement regarding Surrogate Motherhood (2008). In the US, each state has jurisdiction to prohibit or legalize different aspects of surrogacy. Legal variance amongst states creates difficulty for providers with intended parents and surrogates often residing in different states. ACOG recognizes the need for providers to have up to date knowledge regarding their state mandates, with regard to surrogacy, while prioritizing the importance of fair and equitable care for the surrogate woman and the unborn child.

### **Conclusion**

The birth of a child through surrogacy can bring great joy as well as complicated issues, much of which is considered uncharted territory, maybe even a minefield. Global concerns may include but not be limited to psychosocial, physical, economic and legal situations (Erickson, 2010). Issues include societal and legal concerns of a woman carrying a baby for remuneration, often termed a "womb to rent", to obtaining a birth

certificate that documents legal parentage for the intended versus birth parents. Clearly when international surrogacy arrangements produce children born in one country, who will reside with intended parents in another country, greater challenges and constraints surrounding citizenship and acquiring a passport for the newborn will arise. These concerns are just starting to surface in the world of international surrogacy. The paucity of research and understanding, make it difficult to navigate such territories for would-be parents, as well as health care and legal systems.

With lack of consistent data reporting and what appears to be an increase in the use of in-vitro fertilization and surrogacy, global standardized definitions, evidence based guidelines of care and reporting processes need to be developed and implemented to facilitate future research and education regarding this very interesting, yet challenging area of reproduction.



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(Executive Director), *Army Wives* [Television series episode]. Charleston, South Carolina: ABC Studios, The Mark Gordon Company.

Table 1: Surrogacy Terms

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Biologic Mother/Genetic Donor	A woman who contributes her egg to reproduce the resulting child.
Biologic Father/Genetic Donor	A man who contribute his sperm to reproduce the resulting child.
Intended Parent/Commissioning Parent	The individuals who intend to become the legal parents of the child born of a surrogacy arrangement. They may or may not contribute DNA and be biologically linked to the expectant child.
Traditional Surrogate Mother	The woman who donates her DNA (egg/ova) and gestates (carrying the fetus) the pregnancy for someone else.
Gestational Surrogate Mother/Carrier	The woman who gestates (carrying the fetus) until it is born.
Traditional Surrogacy	Traditional surrogacy is an agreement by a woman to donate her egg, along with sperm of the intended father, or possible sperm donation. Most often this can be accomplished through artificial insemination, thereby avoiding the greater costs of in-vitro fertilization. This woman is considered the biologic, genetic and gestational mother and will carry the pregnancy till delivery, whereby she relinquishes all parental rights of the child to the intended parents.

Table 1 Continued

Gestational Surrogacy

This surrogacy arrangement is whereby a woman undergoes in-vitro fertilization to carry a fetus that has no genetic or biologic link to her, “a womb to rent”. She relinquishes all parental rights as the gestational mother, upon birth of the child. The fetus/child could be genetically linked to one, both or neither intended parents if donor DNA was utilized

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(Gugucheva, 2010)

Table 2: International Laws related to Surrogacy  
(Gamble, 2009; Nakash & Herdiman, 2007)

Country's Legal Perspective	Legal	Illegal
Anonymous donation of DNA	US UK (In UK the child has access at 18y/o)	Germany France
Use of donor DNA, identified & anonymous	US	France Sweden Japan
Commercial Surrogacy	US (variable by state) India Ukraine Russia	UK Australia is variable by state Canada China France Germany Greece Israel Italy Japan Netherlands Norway Spain Sweden Switzerland
Altruistic Surrogacy	US (variable by state) UK Canada Australia (variable by state) Denmark Greece India Israel Mexico (Mexico City, variable by district) Norway Spain Sweden Switzerland Ukraine	China Germany Italy Japan

## **Chapter 4: The Lived Experience of Intended Parents During Surrogate Pregnancy and Transition to Parenthood in Relation to the U.S. Healthcare System**

### **Abstract**

**Problem:** Intended parents of surrogate pregnancy may be overlooked in the U.S. healthcare system during pregnancy due to the fact that they are not carrying the pregnancy, and the pregnant surrogate woman is the identified patient receiving care.

**Purpose:** To understand the lived experience of intended parents during surrogate pregnancy and transition to parenthood in relation to the U.S. healthcare system.

**Design:** A phenomenological design was used to explore the lived experiences of intended parents in relation to the U.S. healthcare system. van Manen's philosophy and approach to phenomenology was utilized for thematic analysis, and semi-structured conversational interviews were completed by participants

**Sample and Setting:** The sample consisted of eleven intended parents of surrogate pregnancies. All interviews were conducted by telephone, with the exception of one that was done utilizing SKYPE video conferencing.

**Analysis:** All data sources were transcribed and coded for analysis utilizing van Manen's thematic approach.

**Conclusion:** Five overarching themes were identified including Knowledge Acquisition and Preparedness; Access to the U.S. Healthcare System; Financial Risk and Exposure; Legal Complexities and Trust in Relationships.

**Keywords:** Intended parents; surrogacy; surrogate pregnancy; surrogate woman or mother; assisted artificial reproduction; U.S. healthcare system

## The Lived Experience of Intended Parents During Surrogate Pregnancy and Transition to Parenthood in Relation to the U.S. Healthcare System

Becoming a parent is not always an easy process. Many couples and individuals struggle with infertility and experience years of frustration when reproductive treatments such as in-vitro fertilization and other techniques are unsuccessful and pregnancy is not achieved. In addition to heterosexual couples, single women and men and gay and lesbian individuals and couples may seek pregnancy through less conventional paths. Surrogacy is one such option. Before deciding on surrogacy, and while actively receiving treatment for infertility or seeking pregnancy, these “want to be parents” are well identified as patients and have a clear role and distinct interaction with the healthcare system. Once a decision is made to use surrogacy as an option, procedures are employed to create a pregnancy. This results in the surrogate being identified as a patient in the healthcare system; the intended parents are no longer perceived as patients during the pregnancy and transition to parenthood period.

Although intended parents of surrogate pregnancy are faced with multiple psychosocial, ethical, financial, legal and societal concerns, little is known about their experience or needs during this period. No research to date has focused on the experience of intended parents of surrogate pregnancy and their transition to parenthood in relation to the U.S. healthcare system. Consequently nurses and other healthcare providers lack important information on which to base the provision of care for these “non-patients.”

The dearth of research regarding intended parents and the acceleration of this reproductive method that crosses state lines and international borders, clearly support the call to research (Audi & Chang, 2010). In addition, The National Institute for Nursing



Research (NINR) has called for the integration of biological and behavioral science, both of which are threaded throughout this process and methodology (NINR, 2006). The aim of the study was to use a phenomenology approach to understand the experiences of intended parents during surrogate pregnancy and transition to parenthood in relation to the U.S. healthcare system.

### **Background and significance**

In terms of human reproduction, surrogacy is the practice of one woman carrying a pregnancy for another individual. There are two types of surrogacy arrangements (Figure 1). In the traditional arrangement, the surrogate contributes her egg with DNA genetic material and sperm from the intended father or a sperm donor requiring insemination. In a gestational carrier arrangement, the surrogate carries a pregnancy but does not contribute a genetic link. This method requires artificial reproduction, in-vitro fertilization with an embryo transfer of either the intended parents' DNA, donor DNA or a combination of both (American Society for Reproductive Medicine [ASRM], 2006).

A number of individuals may choose surrogacy as a method to become parents. These may be infertile couples who have unsuccessfully been treated for infertility or those with medical conditions that make acquiring or carrying a pregnancy impossible. Currently, many single and same sex couples also turn to surrogacy as an option for parenthood. Regardless of the parties involved, the ASRM (2006) maintains that surrogacy is a process that requires a watchful team of healthcare and legal professionals to ensure positive outcomes for the surrogate woman, intended parents, and infant.

In today's global world of health care, the use of surrogacy in human reproduction has extended across international borders and is becoming more and more visible through

reports in the media (Ali & Kelley, 2008; Baby Mama, 2010; Nosheen & Schellmann, 2010). Both a “Womb for Rent” (Ali & Kelley, 2008) and the more recent article “The Most Wanted Surrogates in the World” (Nosheen & Schellmann, 2010) reviewed perspectives of military wives as surrogate mothers, their positive experiences, and their financial gains. Audi & Chang (2010) published an investigative report in the *Wall Street Journal* on medical tourism, explaining how individuals looking to parent can procure an international surrogate as well as egg and sperm donors by working around restrictive laws and international borders. Television series such as *Army Wives* (2007) and *Private Practice* (2011) have also aired episodes with surrogacy as the focus. In 2008, a major motion picture, *Baby Mama*, called attention to many issues surrounding surrogacy including single parenting, infertility, and the relationship between the surrogate and intended mother (*Baby Mama*, 2010). In recent months, several celebrities have announced their participation in surrogacy arrangements bringing further attention to this option of reproduction and parenting.

Even though the process of surrogacy is thought to provide an increasingly popular pathway to parenthood, a clear picture of its frequency is unknown. The process is complicated by variations in state and international laws, insurance regulations and costs, and long-term consequences related to genetic and medical history of infants born of surrogate pregnancies. All of these factors have a significant impact on intended parents and the successful outcome of the surrogacy experience.

The lack of regulations regarding surrogacy and assisted reproductive technologies (ART) results in great variability in reporting of data in the United States. The Society for Reproductive Technology (SART) is the only known U.S. organization that attempts to track surrogate pregnancies, yet with approximately 15% of clinics not

reporting data, it is difficult to compute an accurate number. The SART only captured 260 surrogate pregnancies in 2006, which was considered a 30% increase over the preceding three years (Ali & Kelley, 2008). However, Ali and Kelley also reported that industry experts cited approximately 1000 surrogate births in the United States in 2007. In another recent investigative report, researchers estimated an annual rate of approximately 1,000 surrogate births in the United States, with as many as 19% believed to be carried by military wives whose pregnancy care is covered by TriCare military insurance, which is paid for by U.S. taxes (Nosheen & Schellmann, 2010). The Organization of Parents through Surrogacy (OPTS) (2011) estimated that more than 10,000 surrogates have given birth since the mid-seventies.

Just as there is lack of uniform regulation related to ART in the United States, there is also great variation between state laws including the type of surrogacy arrangements that are considered legal, i.e., altruistic or commercial. Other inconsistencies evoke questions of who is recognized as the legal parent or guardian during pregnancy and after birth, whether there is a need to adopt a biologic child after the birth, procedures for acquiring a legal birth certificate, and in some instances, extra legal procedures to acquire the right to use a deceased individual's banked sperm or ova donation for conception by surrogacy (Erickson, 2010; Rosenberg, 2010). Many of these same variations also exist between international borders (Audi & Chang, 2010; Nakash & Herdman, 2007).

Healthcare insurance coverage varies widely, although some states mandate that insurance coverage be provided for ART. Certainly financial issues are an additional concern for intended surrogate parents (Erickson, 2010; Resolve, n.d.). Ali and Kelley (2008) reported the cost to intended parents, including medical and legal fees, can run

from \$40,000 to \$120,000 and the demand for qualified surrogates is beyond the current supply. Connolly, Hoorens, Chambers and ESHRE Reproduction and Society Task Force (2010) reported that the United States had the highest costs associated with ART in the world. The International Committee for Monitoring Assisted Reproductive Technology (ICMART) estimated that approximately one million ART cycles (such as in vitro fertilization attempts) were performed worldwide in 2002, which accounted for a 12% increase from 2000. As many as 3.5 million children in the world have been born following ART treatment (Connolly et al, 2010). Of the countries reporting data, the United States had the most of ART cycles at an average cost of \$10,812 per treatment cycle and a cost effectiveness ratio that is extremely high at \$35,000 per live birth. The United States has the highest costs compared to the Netherlands (\$2452.00), Japan (\$3149.00) and the United Kingdom (\$4016.00). Connolly et al. (2010) purport that the cost of the treatment reported is directly related to the costs of the underlying country's healthcare system.

Concerns have also been expressed about short and long term consequences to the offspring born of surrogacy arrangements. Since sperm and ova are readily available in the United States with donor anonymity established through banking procedures, children born by surrogacy may have limited access to genetic or medical history. As an unintended consequence, there is an inherent risk of mating unknowingly with a half sibling that potentially could lead to genetic dilemmas in future offspring (Zodrow, 2008).

### **Purpose of the Research Study**

The purpose of this study was to understand the lived experience of intended parents during surrogate pregnancy and their transition to parenthood in relation to the

U.S. healthcare system. Intended parents may be overlooked by the healthcare system during pregnancy due to the fact that they are not carrying the pregnancy and the surrogate woman is the identified patient who receives obstetric and prenatal services (ACOG, 2008). In a traditional pregnancy, transitioning to parenthood is often assisted by pregnancy milestones (or events), such as feeling the fetus move and other physiological body changes. During this time the surrogate woman is considered the patient and is interacting with and receiving knowledge from nursing and other healthcare professionals. Conversely, this unique population of intended parents is not carrying the unborn infant, nor are they visibly expecting an infant, leaving them at risk to be unidentified as expectant parents without access to traditional health services, including provider communication and education. Understanding the experience of intended parents is important to promote the achievement of positive outcomes for the intended parents and infant. The information gleaned from this study will bring attention to this growing population and their healthcare needs as well as assist in the development of guidelines for nursing and other health professionals to provide optimal and evidence based care.

### **Literature Review**

A comprehensive literature search of twelve databases across the disciplines of nursing, medicine, psychology, sociology, philosophy and law was completed. Literature of interest was determined after conducting a search of the following databases; Cinahl, PubMed, Medline, Ovid, JSTOR, Psychinfo, Academic Search Complete, the Web of Knowledge, the Web of Science and Academic LexisNexis. The following key terms were employed to guide and limit the search; surrogate, gestational carrier, surrogacy, intended parent/s, commissioning parent/s, surrogate parent/s, artificial reproductive

technology, pregnancy and third (3<sup>rd</sup>) party reproduction. The terms were utilized in single word searches, as well as in multiple combinations. The initial search was conducted with the years 2000-2010. Not one clinical study from the U.S. was identified. The search was then opened without time limitation and did not result in changes. Not one study completed in the US with relation to intended parents in the U.S. healthcare system during surrogate pregnancy and transition to parenthood was identified. The majority of research conducted has been directed at surrogates involved in surrogate pregnancies and has been conducted internationally.

A limited number of international studies were identified. MacCallum and colleagues (2003) examined the experiences of intended parents in the United Kingdom, including their motivations for choosing surrogacy and their relationships with the surrogate mother. The researchers found that couples perceived surrogacy arrangements as a positive experience, sought out surrogacy only after a prolonged period of infertility, and considered it their last available option. They perceived anxiety levels as low, and for the most part their relationships with the surrogate were positive. A large majority of couples did maintain some contact with the surrogate mother following the birth of their children. All couples advised their families and friends about the surrogacy arrangement and voiced their intentions to tell the child in the future (MacCallum Lycett, Murray, Jadva and Golombok). In another study, Golombok, Murray, Jadva, MacCallum and Lycett (2004) evaluated psychological wellbeing, adaptation to parenthood, and infant temperament in families created through surrogacy. A total of 42 surrogate families, 51 through egg donation and 80 through natural conception, were evaluated by a standardized interview and questionnaire. Differences were noted with surrogate families

rating higher than other family types in the area of psychological wellbeing and adaptation to parenthood as compared to parents who conceived naturally.

In an Iranian study, the experiences of 15 surrogate mothers, 15 intended mothers and 30 normally reproducing mothers were examined. The findings indicated that the mothers' psychological characteristics were similar. The researchers found differences between intended mothers and surrogates with regard to their education levels, ages, and education level of their spouses. Intended mothers were older with an average age of 34.86 years compared to surrogate women with an average age of 25.86 years. Education levels were greater for both the intended mother and her partner in comparison to the surrogate, which demonstrates the difference in life style and social status of intended parents. Although this study documented a positive relationship between surrogates and intended mothers during the pregnancy and consent process, and satisfaction was documented by both parties, the intended mothers did not want to maintain the relationship with the surrogates after the children were born. The researchers reported that most surrogate and intended mothers did not consider surrogacy a problematic process, yet a number of surrogate mothers indicated they did not receive adequate counseling prior to the initiation of the surrogacy arrangement (Pashmi, Tabatabaie and Ahmadi, 2010).

In an Israeli study, researchers evaluated the effectiveness of hospitalizing the genetic intended mother prior to delivery by the surrogate woman and during the immediate postpartum period so that early maternal-infant bonding could be promoted. The reported findings were positive; however, the study was limited by the participation of only two intended mothers (Sharan, Yahav, Peleg, Ben-Rafael and Merlob, 2001).

In three studies (2000, 2005, 2007a) van den Akker investigated surrogate and intended mothers. In two of these, (2000, 2005) the researcher examined differences in intended and surrogate mothers regarding having a genetically related child. In the 2005 study of 61 surrogate mothers and 20 intended mothers, no differences were found between the two groups regarding a belief that a genetically linked infant was of more importance or that it was important to the surrogacy arrangement. However, in the same study, there were significant differences in confidence about the arrangement, about the health and wellbeing of the surrogate infant, and belief that it is easier to accept an infant if it is genetically one's own. In the 2000 study of 29 sub fertile women, van den Akker reported that 75% of participants believed that a genetic link was of importance, and their partners also reported a strong desire for a genetic link. Women who were unable to provide genetic contributions, however, were less likely to make such a statement, although it was still important to their partners.

Later, van Den Akker (2007b) compared the psychological trait and state characteristics of 20 intended mothers and 61 surrogate mothers. The longitudinal study evaluated personal inventory, state and trait anxiety and post natal risk of depression prior to arrangements of surrogacy and during the first, second, and third trimesters of pregnancy. Those who had positive results were assessed again at six weeks and six months after the surrogate infant was born. There were no differences in personality characteristics; however social support, marital harmony and anxiety differed significantly at different stages of the surrogate arrangement. Regarding social support, intended mothers had significant support from their parents during the first trimester compared to their surrogate counterparts; however in the second trimester, although the surrogate support remained lower, it was not significantly different and no difference was



reported for the third trimester. The surrogate mothers reported less support across all sources of support. Surrogates also reported that the support of their partner or husband support was significantly less than that of intended mothers. Significant differences between groups were also noted with attitudes toward the pregnancy and the infant. Surrogate mothers reported less concern for the fetus than intended mothers. These responses may be related to the intended mothers' desire to bond with the fetuses yet not become attached for fear of something untoward occurring. The surrogates' responses could be construed as a form of disassociation to assist in not attaching to the pregnancies or the infants that would be relinquished. No evidence of post natal depression was reported among the groups.

Psychosocial researchers in the United Kingdom have published the largest volume of surrogacy literature to date. In the United Kingdom, altruistic agreements are the only legal form of surrogacy. Because commercial surrogacy contracts are legal in some states, it is difficult to establish generalizability from the U.K. studies reviewed. These and other international studies have primarily focused on surrogate mothers and the complexity of psychosocial concerns with which they are faced, such as giving the infants up to the intended parent(s) and even postpartum depression (Poote & van den Akker, 2010; van den Akker, 2007a, 2007b, 2005, 2003, 2000; Shenfield et al., 2005). Researchers have questioned society's acceptance of surrogacy as a suitable method for reproduction (van den Akker, 2007a, 2007b; Teman, 2009; Shuster, 1992).

In light of changing pathways to parenthood, traditional definitions of family continue to evolve (van den Akker, 2000). A recent Pew study based on 2,691 responding adults reported that 86% of those surveyed recognized a single parent and a

child as a family, 80% believe that an unmarried couple with a child is a family, and 63% said a gay or lesbian couple living together with a child is a family (Jayson, 2010).

## **Philosophical Underpinnings**

### **Phenomenology**

Research in the area of psychology and philosophy is commonly grounded in phenomenologic or hermeneutic methodology. In phenomenology, the focus is placed on the lived experience of the individual, whereby we can deepen our understanding of phenomenon as revealed by the individual and his or her life. Using a hermeneutic perspective, one has the ability to interpret and then create meaning of these lived experiences secondary to social and historical context. The writings of three first generation phenomenologists, Husserl, Heidegger and Merleau-Ponty provided a foundation for van Manen's philosophy and method of phenomenology. Husserl, who developed descriptive phenomenology, asked, "What do we know as a person?" Descriptive phenomenology is based on descriptions of ordinary conscious experiences of everyday life, a consciousness that is pure rather than empirical (Husserl, 1952). Heidegger, a student of Husserl, developed interpretive or hermeneutic phenomenology with a belief that not all phenomena were founded in the descriptive form of phenomenology. The interpretive or hermeneutic approach of phenomenology was founded on the question, "What is being?" The importance of interpreting and understanding goes beyond describing the human experience to an understanding of what the meaning of something is, as revealed through an individual's ability to share his or her lived experience (Heidegger, 1927/1962).

Merleau-Ponty (1962), considered an existential phenomenologist, focused on the importance of perception of the individual's *situatedness* in the world through personal

experiences. His influences in the area of phenomenology lead him to a belief that the body could approach the world and that our perceptions would allow access to both interior and exterior worlds that cannot be separated. Merleau-Ponty has been acknowledged for his contributions to the health sciences through his work on the role of the body in perception and society. These three phenomenologists developed phenomenology as a philosophy. History reveals that many researchers were in search of a methodology of phenomenology and this led to the emergence of the second generation of phenomenologists, including van Manen, Giorgi, Colaizzi and van Kaam (Munhall, 2012).

van Manen developed a new method of phenomenology based on the human sciences while maintaining the practice of philosophy as described by first generation phenomenologists. Through his work, a human science approach was developed in which phenomenology is viewed as a philosophy of being as much as it is a practice. van Manen's phenomenology suggests that along with lived experiences, reflective writing can teach us what the phenomena reveal (van Manen, 1990). Munhall (2012) noted that the approach or method of phenomenology is used in many areas of health science research today, including nursing. Nurse scientists such as Benner (1994), Watson (1985) and Parse (1987) have employed phenomenology in nursing research.

van Manen's method of phenomenology was influenced by the European movement and is housed in the Utrecht School of the Dutch, which uses the term description to include both interpretive or hermeneutic and descriptive. Hermeneutics in this sense refers to the process of explaining and interpreting the lived experience of the individual as well as the essences or meanings representative of that experience. It is through understanding ourselves and other individuals in the world as they know it in

relation to the contexts and contingencies they have experienced, that we become more human (van Manen, 1990).

Qualitative research can be instrumental in answering questions about the essence or meaning of life experiences and promoting evidence based practice (Grace & Powers, 2009). The lack of U.S. research regarding intended parents supports a phenomenologic study to investigate their experience during surrogate pregnancy and transition to parenthood in relation to the U.S. healthcare system.

### **Research Question**

What is the lived experience of intended parents during surrogate pregnancy and transition to parenthood in relation to the U.S. healthcare system?

### **Design**

The design selected for this study is that of phenomenology utilizing van Manen's research methodology engaging both descriptive and interpretive approaches.

Phenomenology can facilitate a better understanding of the individual's lived experience, or the essence of life, as perceptions and experiences are shared. These lived experiences will begin to reveal the phenomena for which an understanding is being sought (van Manen, 1990).

Semi-structured conversational interviews were conducted either in person or by telephone with intended parents of a surrogate pregnancy. A grand tour question initiated the interview, "I am interested in learning more about the experience of intended parents during surrogate pregnancy and transition to parenthood in relation to the healthcare system. Would you please tell me about your own personal experience?" If prompts or refocusing of the participant was required, an Interview Guide (Appendix A) comprised of probing questions was utilized in guiding the interview (Munhall, 2012).

## **Sample and Sampling**

Purposive sampling, in which the researcher selects intended parents who meet study criteria, was used. After Institutional Review Board (IRB) approval (Appendix C) was acquired from the University of Texas at Tyler, participants were recruited through the use of study brochures, flyers (Appendix B) and professional contact. Additional recruitment through snowball sampling was also engaged after a modification to inclusion criteria was requested and approved (Appendix D). Snowball sampling is whereby current participants recruited others who met inclusion criteria (Munhall, 2012). Maximum variation in sampling was sought to include representation of men and women, minorities, variation in age and marital status, and differing sexual orientation.

Inclusion criteria included male or female intended parents, irrespective of marital status or sexual orientation, who engaged a surrogate arrangement or who had a child through the use of a surrogate with the child less than five years of age. Intended parent dyads were included, and participants were at least 18 years of age. Intended parents with primary residence outside of the United States or who now have a confirmed natural pregnancy themselves were excluded.

## **Location of Accessible Sample**

Eight healthcare provider offices providing infertility, obstetrics, and maternal-fetal services in Chicago Illinois and Charlotte, North Carolina and their surrounding areas were provided with study information, flyers and brochures (Appendix B). In addition to the healthcare practices, one west coast and two east coast surrogate agencies agreed to receive informational flyers and brochures to share with potential participants. An online ad was placed on a surrogate internet site where intended parents often visit.

Verbal or email permission was obtained from each practice location and the internet site prior to distribution of study information. Recruitment materials provided detailed information regarding the study, a contact phone number, and an email address for the principal investigator. In addition, an introduction to the principal investigator and a personal invitation to join the study was available at a secure YouTube video link that was posted in the recruitment materials and could be accessed via the internet.

### **Instruments**

A demographic data form (Appendix E) was completed prior to start of the interview. Demographic data is included in Table 1.

The Interview Guide (Appendix A) provided guidance for phenomenological dialogue and collection of qualitative data (Munhall, 2007; Polit & Beck, 2008). Data collection through semi-structured conversational interviews, using an Interview Guide when required, is well supported in qualitative research as discussed by Polit and Beck (2008), Starks and Trinidad (2007) and Munhall (2007). The Interview Guide was only used to assist participants in sharing experiences if areas of interest had not been fully explored or there was a potential area to be expounded upon (Wimpenny & Glass, 2000). As the study was iterative, unfolding or evolving, participants shared experiences that could lead to unexpected or unknown areas. In response to such findings, revisions of the guide may be necessary to enhance ongoing interviews and the capturing of all themes of interest; however this did not occur in this study (Munhall, 2012).

### **Procedures**

Individuals who were interested in learning more about the study were invited to view a security protected informational video on YouTube and then contact the principal researcher either by telephone or email. Once eligibility was met through study inclusion

criteria and individuals agreed to participate, an appointment with a mutually agreed date and time was arranged for either a face to face or telephone interview. Eleven participants requested telephone interviews; one connected via Skype video conferencing call.

Participants were assured of confidentiality and anonymity upon agreeing to participate. They were only identified with code numbers on the audio file name. Transcribed files removed all identifying information with only the code number attached. The master list of names and identification codes was secured separately from the audio files and transcribed verbatim with the exception of identifying information being removed, as instructed by the principal investigator. Participation was strictly voluntary, and the participants were free to withdraw from the study at any time. They were assured that their participation in the study would not affect their relationship with their providers in any way. The study was fully explained, and participants were assured that their interview could be stopped at any time if they become fatigued, distressed, or unwilling to continue.

The participants were asked to read and sign a consent form (Appendix F). When they met inclusion criteria and completed participation in the study, a small token of appreciation, a \$10.00 gift card to a photo book internet site, was offered.

### **Reflexivity versus Bracketing**

As the researcher is the primary instrument in qualitative research it is important to practice reflexivity prior to the study's inception and throughout the study. Reflexivity is the process by which the researcher engages in self-awareness and critically reflects on personal experiences as well as their progress in the field. The researcher, as the instrument, is an integral part of the research and all parts of the whole must be addressed

(van Manen, 1990; Munhall, 2012). This was accomplished through written notes and journaling. Journaling took place before and after every interview and throughout the process of data collection, transcription and analysis.

Although bracketing is typical in a descriptive study of phenomenology, it was not engaged in this study. The van Manen (1990) methodology does not support the Husserl (1952) perspective that bracketing must occur, rather van Manen believes that you cannot separate your lived experiences from who you are today and to believe that one can compartmentalize throughout a research study is highly unlikely.

### **Data Collection**

Private semi-structured conversational interviews with intended parents were conducted by the principle investigator with an intention to gather and reflect the essential human experience (van Manen, 1990). Interviews were all audio recorded utilizing a digital recorder and ranged from 68 to 112 minutes. The location, date, and time of the interviews were mutually agreed upon to assure privacy and comfort. At the beginning of the interview session, a demographic data form (Appendix E) was reviewed or completed.

The interviews were expected to last approximately one hour, although they ranged from 68 minutes with a single participant to 112 minutes with a dyad. Interview duration was subject to participants' continued sharing of new information or their perception that they were finished. Sampling and interviews were continued until data saturation was reached and no further additional information or themes were discovered. At this time, the principal investigator closed study enrollment. This is a subjective process, yet it has been reported that when meanings or themes begin to repeat themselves, the likelihood is that subjectivity is moving towards objectivity (Creswell,



2009; Munhall, 2012). Following each interview the principal investigator documented her reflections related to the interview and participant interactions.

### **Data Analysis**

Audio recorded interviews were transcribed verbatim by a professional transcriptionist to support data analysis, which is an iterative process occurring simultaneously with data generation, interpretation, and writing of the narratives. The researcher, also known as the instrument in this study design, was interpreting and evaluating meanings and themes that had been shared by participants throughout the data collection process. It is the researcher who must reflect and assess if critical questions of meaning have been shared, lending themselves to a deeper understanding and thereby allowing experiences to be experienced by others (van Manen, 1990).

Data analysis began with the initial interview and was a fluid process that required a systematic series of actions. All participants agreed to complete a participant read back or member check to provide clarifications or additions to their previously shared experiences. The interviews were audio recorded, transcribed and emailed back to them after the principal investigator reviewed for revisions and removal of all identifying information. Munhall (2012) suggested that the emergence of new themes, as well as a deepened understanding of experiences can be an additional benefit of participant read backs. Final analysis was shared through a creative description and interpretive document only after all themes had been exhausted and an ontological silence of the truth was believed to have been met. van Manen (1990), described ontological silence as “the silence of Being or Life itself (p. 114).

van Manen’s (1990) schematic approach to data analysis was in data immersion, highlighting of themes, and writing of interpretive statements reflecting phenomenologic

meaning. The principal investigator began analysis by reading each individual transcript to become immersed in the data. Through the process of several readings, themes essential to the phenomena or experiences participants described were identified. As individual experiential themes began to repeat themselves across the data, they were color coded and recorded in the codebook.

The next step in analysis was the transformation of themes into meanings. This step is considered to be a creative and hermeneutic or interpretive process of linguistic writing. The process of phenomenology denotes that the research process is inseparable from the writing process. Accordingly, a thematically written narrative of the study's phenomena was completed as the final stage of this research. Since themes are not exhaustive of the phenomena of intended parents of surrogate pregnancy, this writing approach supports a written systematic investigative report of those experiences shared. Through immersion in the data and reflection of themes, the hermeneutic activity of writing and rewriting was engaged to provide a deeper understanding of the experiences of an intended parent during surrogate pregnancy (van Manen, 1990). After completion of the thematic analysis, a draft was sent to the participants for their review and verification.

### **Trustworthiness**

Trustworthiness of a qualitative study is defined by Lincoln & Guba (1985) as a framework that includes credibility, dependability, confirmability and transferability and is suggested to enhance the rigor of a study. To support credibility the principal investigator's background in the field and pertinent study information was shared with participants through a YouTube video. This clearly set forth expectations of participants and created an intention to build a trusting relationship between them and the researcher.

Credibility was enhanced through member read backs where participants had the opportunity to clarify or provide additional information. The researcher also practiced reflexivity by writing in a personal journal. Reflexivity facilitated the separation of thoughts, experiences or biases that could contaminate interpretation; as well as the descriptive writing of the meanings derived from the sharing of lived experiences. Peer debriefing was also utilized with the engagement of at least one doctoral prepared colleague with an interest in qualitative research and occurred monthly throughout the study period. The intention was to gain insight and remain focused on the lived experience and avoid the risk of bias or inaccurate assessment of meanings that could be attached to the data.

Dependability references the stability or reliability of the data over time in context and conditions, such that replication may occur (Guba & Lincoln, 1985). Dependability requires that the researcher account for the many changes that occurred during the research study. Only one change in this study occurred with a request to enhance inclusion criteria of intended parents with a child born of surrogate woman from no older than the age of one to no older than the age of five. This change assisted in further recruitment of participants through snowball sampling and the ability to reach saturation of data.

Confirmability is considered as the congruence of two or more individuals shared experience or meaning having been identified through analysis of the data and a phenomenologic meaning attached. Confirmability was addressed by receiving participant confirmation that personally verified their lived experiences. To further enhance confirmability, an expert in qualitative research was utilized to audit the research processes throughout the entirety of the study. Her review included all participant

transcripts and researcher notes that could have impact on the study data, interpretation and analysis. The expert also had access to the code book which was created as an audit trail.

According to Lincoln & Guba (1985) transferability is the degree to which the results of qualitative study can be generalized or transferred to other contexts or settings. Transferability was enhanced by detailed description of the research process and procedures. In addition, maximum variation of sampling of women, men, those of differing sexual orientation as well as single, married or partners, and the capturing of different perceptions of lived experiences to enhance the transferability of findings to other contexts.

### **Findings**

Five periods of time will be used to report findings: preconception, the three trimesters of pregnancy, and the period of the birth and transition to parenthood. For the purposes of the study, the preconception period is the time preceding pregnancy when individuals consider goals and relationships and acquire information and knowledge that will assist them in preparation for a child.

The three trimesters of surrogate pregnancy are referred to as the first, second, and third trimesters, and during each, intended parents have a different focus. During the first trimester, intended parents focus on establishing pregnancy with the surrogate woman and transition of care from the REI provider to the obstetric provider. It is during this trimester that intended parents will first hear a fetal heartbeat or possibly experience untoward events such as bleeding or miscarriage resulting in a loss of the pregnancy.

The second trimester is an exciting period of time when the pregnancy is well established, appointments are routine, and ultrasound of the fetus reveals what is starting

to look like an infant. Intended parents are beginning to establish a relationship with this expectant infant, although they are still cautious, as they are removed from the physical presence of the pregnancy. The third trimester is full of anticipation. During this time, intended parents prepare with baby showers, and birth plans for labor and delivery and transition of the newborn.

The final period of time, birth and transition to parenthood, is a time of joy and great change for all involved. It can be an unpredictable period, as labor evolves and management of the process can change abruptly. During this time parents anxiously await the surrogate birth and receiving their newborn. There is great potential for extreme emotions to be experienced by all parties. Transitioning to the role of parent and caring for the newborn is the primary focus once the birth has been completed.

It is through intended parents lived experiences that five overarching themes have emerged: (a) knowledge acquisition, (b) financial exposure and risk, (c) legal complexities, (d) access to healthcare and (e) trust in relationships. These themes create a landscape of lived experience and provide us with an enhanced understanding. The five thematic findings will be presented through the timeframes of surrogate pregnancy as experienced by intended parents. A schematic of the journey with the five themes is presented (Figure 2).

## **Knowledge Acquisition**

### **Preconception.**

Information seeking and knowledge acquisition start very early for individuals who wish to have a child. When an individual or couple is not able to support a pregnancy, they look into alternatives such as surrogacy or adoption. Participants searched for knowledge online and found surrogate agencies, support group sites, blogs,

and message boards where surrogate and intended parents shared experiences and beliefs regarding surrogate pregnancy. As one participant noted:

Our initial conversation had happened and then it was a couple of years before we started actually looking into it. And with that, you know you, you start off with, you know Dr. Google, and looking up what you can find on the internet.

Healthcare professionals may be involved in surrogacy arrangements early during the preconception timeframe, as often there is a medical history that precludes a woman from becoming pregnant. Female participants shared diagnoses of cancer, infertility, hypertension, renal disease, and reproductive complications that led to seeking alternative birthing options. The five female participants shared their experiences and described how they had moved through many critical intersections from infertility to medical compromise, or to the inability to offer their DNA. These women's experiences provided a catalyst for the conclusion that having a child was more important than providing a genetic link or carrying the pregnancy. One woman described her angst upon learning that her diagnosis of cancer would affect her fertility:

The big huge emotional drain was not that I had the cancer; it was that I had this definitive end to my fertility. That was a huge blow. So it didn't take me very long in the process of the whole thing to realize I wanted a baby, I didn't really care about the experience of being pregnant. I mean, I was really willing to give that up pretty fast to have the baby.

Another participant discussed issues with the age of her eggs and her inability to provide a genetic link to the infant as she described a situation with her husband:

I said if we are using a donor egg and skip the hullabaloo, why not just adopt and I learned that it could be really different for him. He could pass on his genetic history and so it was a little short sided on my part, as I was like let's just adopt a kid and be done with it but for him he could have the genetic connection.

The same participant later shared having the history of two donor egg embryos transferred to her uterus and having lost that twin pregnancy at eight weeks. She noted:

I never felt anything different, that they were mine or not, as I was pregnant with them, they were mine. It was really hard for me to move through that process. I had to really think about is it important for her to have mommy's eyes or is it important for me to offer to a child what I can as a parent and that is the place I had to get to. I had to get to a place to realize I had something to offer a child regardless of whether it was my genetics or not.

Women and their health histories are not the only indication for use of surrogacy; for single men or those in a same sex relationship, having a family can be extremely important. Through reproductive techniques such as surrogacy, men have the same opportunity to become parents and build a family. One male participant shared:

We figured out that what we wanted to do was have a child that had a biologic or genetic relationship to at least one of us. I was ambivalent about commercial system of surrogacy, it seemed not intimate enough to me and a little bit too much like shopping. We came up with a fantasy that we would have a more intimate version of surrogacy with a relative or friend or whatever. And we managed to put that into being.

Even after a decision is made to use surrogacy, some intended parents may be distrustful of online sources of information. One participant shared the following experience:

I was pretty frightened by the process, you know, I had been on Google all of the time, and I had found like a surrogate moms online which is like pandemonium. And I had done a lot of research into different stories and I had heard of some women keeping the baby and traditional surrogates who were giving their eggs, and it seemed like a real cowboy land, totally outlaws, nobody—lots of ethical concerns, like the stuff that's going on in India, with these really poor women, or military wives who don't have anything else, or women being pushed into being surrogates because of their husband or financial situations.

Once surrogacy is selected, intended parents must decide whether to use a traditional surrogate or a surrogate carrier. If a gestational surrogate carrier is selected, will the intended parents provide the ova and sperm, also referred to as gametes, or will they be obtained from donor banks? If a traditional surrogate is selected, will the intended father provide sperm for male gametes or will these be from a donor bank? All eleven

participants selected surrogacy because of the desire to have a genetic link to their children. All male participants clearly desired a genetic link to their children, so adoption was not the first option. One participant stated, “We only had one option, and that was to get a surrogate. We didn’t have any other ways. Adoption was something that never entered my mind ever, you know, ever.”

The selection process required knowledge, time, and navigation, and once intended parents chose surrogacy, they began to prepare. Regardless of who donated the gametes, insemination would occur for a traditional surrogacy arrangement; when all gametes were donated, as with gestational carrier surrogacy, in-vitro fertilization (IVF) was completed through a reproductive infertility practice, requiring hormonal regulation of the gestational surrogate carrier to receive the embryo transfer.

#### **First trimester.**

During the first trimester, intended parents transitioned to an established pregnancy. Participants described seeking information directly from the surrogate regarding her pregnancy status and from the obstetric office. They voiced a desire to understand more about screening and testing for fetal conditions and again accessed information via the internet and online sites. However, no authoritative or credible site such as the March of Dimes was recommended by the healthcare providers. Intended parents signed up for “text4baby” and list serves that might provide knowledge about pregnancy and fetal development.

Some intended parents were involved in the selection of an obstetric provider; others were not. Some participants were unclear about how to access information related to the surrogate carrier and expected infant, since the carrier was now designated as the patient and the intended parents were no longer identified in the healthcare system.



Most of the participants described having contact with their surrogate on a daily to weekly basis. Some surrogate carriers called or texted regularly with messages regarding their status or pregnancy signs and symptoms. For some intended parents this created trust and provided reassurance that the pregnancy was moving along well. One participant shared the following:

We texted every day. Because of our loss before, and she knew that, how do I even put it; the fear of losing again was very high for us. So, she would just, I mean she texted me crazy stuff like...just went to the bathroom, pants checked, all is clear, like just joking, it gave me a reassurance there was no bleeding and everything was still progressing as it should. Or she'd text back, "I'm throwing up," and I'd text back, "have fun with that!" To know that your surrogate is throwing up is such a beautiful thing because it means they are still pregnant!

Other participants shared the importance of knowledge acquisition regarding their decision-making processes in regards to fetal testing that was offered in the first trimester, such as a nuchal translucency measurement and the biochemical screening for chromosome abnormalities. However, the majority of participants did not reference the U.S. healthcare system or its providers addressing these needs, as they normally would in a typical self-conceived pregnancy or even those who transfer from the REI office but are carrying their own pregnancy, not using a surrogate. These intended parents, undefined by the U.S. healthcare system during pregnancy, did their own search, seek, and find mission to acquire the knowledge they thought they needed. They all shared a common thought, we don't know, what we don't know, and many of their concerns were not even identified or defined until after their infant arrived and the journey concluded.

### **Second trimester.**

The second trimester was marked by a continued desire to stay informed, understand the process, and participate in the experience of pregnancy. The amount of information needed varied depending on the participants' previous experiences. Several

participants had one or more children at home and felt that they had already acquired the necessary knowledge. One participant had experienced the birth of two previous children, and four participants (2 couples) had had one prior child born of a surrogate arrangement similar to their current situation.

The amount and frequency of contact with the surrogate varied from daily texts to no contact for a week or more. One participant in his second surrogate pregnancy indicated that this time, he had less anxiety:

With our second, we didn't go to as many appointments and I think because of our track record with her during our first arrangement and with the hospital and her OB/GYN we already had developed a relationship...we provided the same level of neglect for baby number two as every parent neglects baby number two. The first child is always like the one you sink all your anxiety and neuroses into!

At times the amount of information acquired by the intended parents was directly related to how much their surrogate carrier was willing to communicate. Some participants were anxious when they did not hear from their surrogates. One surrogate only felt compelled to be in contact if there was something unusual happening. One participant described this experience:

She did not feel like she needed to do tons of communication with us. She was very hard to reach. We had concerns and we weren't trying to micromanage the pregnancy but we just were....we had very little information. And then when we tried to get medical information it was blocked.

Other participants attempted to stay informed by attending physician visits and ultrasound appointments or having family members attend. If this was not possible due to distance or schedule conflicts, participants and surrogates participated in office visits by using speaker phones or videos if permitted by the provider's office.

Participants also started the process of sharing information with the healthcare system by making appointments with key individuals such as the manager in labor &

delivery and a social worker. This activity was an attempt to educate the hospital personnel of their desired plan of care for the delivery. One participant verbalized the importance of knowledge sharing:

My surrogate and I wanted the hospital staff to see us in a non-crisis situation, that we really had respect for one another and were a family in a new definition and we entered into this with all eyes open as much as possible and we wanted a great positive experience out of this.

This intended parent, also a pediatric registered nurse manager, shared her belief that “The best defense is a good offense.”

### **Third trimester.**

As intended parents continued through the process of pregnancy, many began preparing for the arrival of their newborns. They had baby showers and readied their homes. Due to geographic distance, some parents had accepted the possibility of not being present at the birth. One participant shared the following:

That was one of the things where we both had to accept at the beginning, that we both may miss the birth. And we both, you know, normally a mother is there for the birth of children. That’s sort of an inseparable moment, but we both had to accept going into this that both of us may miss it. And that’s just... we had to be ok with that.

Continued preparation for parenthood included reading books and other informational materials. Friends and family also provided information and advice. At the same time, preparations and decisions were communicated with the surrogate carrier, the provider, and the hospital. Participants wanted to be involved in the birth plan and to know who was attending and how the infant would be transitioned to them. They wanted the hospital to provide them with their own rooms to bond with and care for their newborns after birth.

Only one participant realized that education was available through the healthcare system after she spoke to the obstetrician:

I wasn't going to take a birthing class as we were expecting a cesarean section. So what I did was to call my OB and we found a child, not a childhood educator, but someone who'd skip the birth part and just did the child education. She came here to our apartment and that was really, really wonderful. And she was just lovely and supportive and yeah. So we were lucky.

Other participants did not believe that the hospital had any responsibility in preparing them for parenthood:

I don't know what the hospital normally does with the parents to help them become parents. You know to raise a child and change the diapers and stuff is never something I expected to get from the hospital.

### **Birth and transition to parenthood.**

As expectant parents often experience, no birth plan is ever set in stone, and many unknown variables can change the situation. Several participants described their expectation of a normal spontaneous vaginal birth that resulted into a cesarean birth. Much to their dismay, there were care issues that had not been well thought through ahead of time. Labor and delivery plans changed quickly leaving some participants feeling off balance. For most, a sense of uncertainty and vulnerability was exacerbated by what they believed was a lack of control.

While transitioning to parenthood is a sign that the infant has arrived and that the journey is complete, intended parents continued to gain knowledge, some from healthcare personnel. An intended father shared an example in which the hospital personnel prepared the intended parents for discharge and infant care:

They did kind of walk us through how much you are going to feed the baby, and stuff kind of like that. They did give us a "what to expect," however they kept calling the surrogate the mom, and that was very distracting for us.

## **Financial Exposure and Risks**

### **Preconception.**

Intended parents who are involved in surrogate pregnancy arrangements have worked diligently to acquire the knowledge to navigate this very involved process. Participants agreed that there is not one source for information and knowledge related to the financial exposure one may experience as a result of the process. The financial agreements intended parents enter into can be capped to some degree by the design of the contract, however, the road is arduous and unpredictable when infants are involved. Emotions often take priority and most intended parents are unwilling to set limits on monetary amounts they endure on behalf of their desired or expected infant.

Any surrogacy arrangement is expensive; however costs related to a gestational surrogate carrier are even greater due to the need for procedures. Procedures required to establish a gestational carrier pregnancy include harvesting of gametes from the intended parents or acquisition of banked DNA, the in-vitro fertilization and the embryo transfer to the gestational surrogate carrier. All eleven participants in this study were involved in a gestational carrier arrangement. Parents who select the journey of pregnancy with a gestational surrogate carrier are very clear about their desire to have a genetic link to their child and they have accepted the financial responsibilities that are attached. However, financial costs are not limited to the reproductive techniques employed. When initially seeking knowledge regarding this reproductive option one male participant stated:

We probably investigated informally, you know, for a year, before we actually started going, ok, let's talk to doctors. Any doctor you talk to, they have a fee to talk to them. The initial consultation fee was 250 bucks, so, you know, we did a lot of informal stuff before we decided to move forward.

Estimating and preparing for the costs to acquire a pregnancy through reproduction is a small piece of this entire journey. Commercial surrogacy includes financial payment to the surrogate for carrying the pregnancy. Moreover, if the intended parents use a traditional surrogate, the surrogate is offering her egg as well. The cost in U.S. dollars as reported by eight participants who did not have confidentiality clauses in place, and who used commercial gestational surrogacy arrangements was reported to range between \$70,000 and \$130,000 with a mean cost of \$104,000. However, not all participants clearly indicated whether these costs included all of the REI costs in gamete harvesting, IVF and the embryo transfer, and therefore this may represent an estimate on the low side of true costs incurred.

Of the eleven participants, only one reported an altruistic surrogacy arrangement. In this case her best friend served as her surrogate carrier. Although she did not pay her surrogate a fee for carrying, she did have a financial agreement that covered all the fees related to the embryo transfer, co-pays for the carrier's insurance, medications, clothing and other incidentals related to the pregnancy and cited those costs at approximately \$17,000. Often surrogacy agreements include the costs of carrying the pregnancy, medical insurance if required, unexpected medical costs, clothing, food and housing. Depending on the agreed upon contract, the surrogate may also receive payment for lost wages during the pregnancy if medical complications arise. Additional payment may occur following the birth of the infant while the surrogate is recuperating. Some contracts will include reimbursement fees for breast milk produced by the surrogate mother (birth mother) for the infant.

These financial agreements must be agreed upon prior to the initiation of the surrogacy process to ensure that there is a clear and set contract or guideline for all

parties to follow, and legal representation for each party involved is recommended (Rosenberg, 2010). Intended parents and surrogates must be willing to negotiate these financial parameters. One participant described ending a potential surrogate arrangement. Just before signing her contract with them, she asked for significant changes in the financial agreement and he shared “It didn’t seem like a good way to start a relationship. So, before we got the contract and got farther, we changed.” In a contrary experience, another participant shared a situation in which financial costs incurred in the preconception period were overshadowed by the relationship that was being built. He shared the following:

There was one issue where, um the clinic was doing a mock cycle; they could not regulate our surrogate’s hormones correctly, meaning they couldn’t get her estrogen levels, I believe to go down sufficiently, to go ahead with the treatment. And we had gone through, I think, maybe three months of different regimens to try to decrease her estrogen level. And they were almost at, you know, at the wall. At that point we had spent...ah, three or four months with her and it wasn’t just the money...it was not the money, that wasn’t the driving factor. The driving factor was we already loved her. We were locked and loaded on her and we had spent numerous late night phone calls with her just shooting the breeze about stuff. So yeah, she had already become a partner in crime in this process. She was blown away by our commitment to her.

All participants felt that financial responsibilities are not a limited or a contained amount. Associated costs were not only related to financial exposure, but the toll on mental and emotional well-being of all parties involved.

### **First trimester.**

The intention of signing legal contracts during the preconception period would be to protect all parties and to avert any additional costs or fees associated with this reproductive methodology. However, untoward issues can occur and be costly in a variety of ways. During the first trimester several surrogate women experienced potential complications that required increased surveillance of the pregnancy by healthcare

professionals. Fees related to additional healthcare needs or time off work, may or may not be paid for by the intended parents. This is typically managed by the contractual agreements that were signed in the preconception period.

### **Second trimester.**

Although financial issues are not necessarily an everyday concern, when additional risks occur, financial exposure can become a huge source of fear, creating a new vulnerability for intended parents. One participant describes his lived experience when the surrogate mother had a significant bleeding episode and a possible placental abruption:

We were very scared because we thought that she had an abruption. We had baby insurance, but the ...we'd bought insurance for her. She didn't have her own insurance. But we did not have catastrophic insurance and if she was having an abruption and needed to go to the Intensive Care Unit, we faced financial ruin. We would have been responsible for her, obviously. And it was very scary.

Moving towards the 3<sup>rd</sup> trimester brings the realization that the infant is at viability (24 weeks gestation) and if issues of prematurity occur, additional costs for both the surrogate carrier and the delivery of a preterm infant could occur. Intended parents also start to think about the future costs to get ready for when they bring this infant home.

### **Third trimester.**

Entering into the third trimester, intended parents began thinking about costs related to their infant's needs and care. Additional expenses included furniture, clothing, car seats, time off work and then of course eventual childcare to return to work, all of which is costly. Even with the stress of these expected financial commitments, participants were able to share their growing excitement awaiting their infant's arrival as shared by this participant:



She was out to visit and we had a baby shower. That's where we got a lot of, you know that became, well we've got to get some things for the nursery. And I painted the nursery and you know, we got a crib from a colleague of mine and we just got ready physically. And that helped.

### **Birth and transition to parenthood.**

Financial obligations shifted from payment of their surrogate carrier to caring for their newborn infant. Participants understood and accepted that their financial priorities had changed and would now focus on their new family. Three participants shared stories of additional costs after birth related to their infant being born premature or requiring additional medical evaluation. One parent shared:

And it turns out, you know, that our infant was, was a premature delivery. He came out five and a half weeks earlier than any of us expected. Not only did we have an L&D experience, but we had an NICU experience for almost a week. And as a consequence....

During this transition period some participants reported difficulties with hospital billing departments. These participants found themselves needing to make repetitive calls to correct billing errors and have corrected invoices sent to them and their insurance.

### **Legal Complexities**

#### **Preconception.**

Surrogacy is fraught with many legal complexities. Laws vary from state to state in relation to the legality of surrogacy or related reproductive methods. Intended parents sought legal assistance to clarify the applicable laws and what could or could not be enforced in relation to the state where conception and delivery would occur. Donation of gametes also requires interpretation of laws as the donor may be required to waive their biologic rights of parentage. These legal issues are addressed through a personal contract with their surrogate carrier, either commercial or altruistic.

Intended parents describe legalities from a perspective of protecting their rights as parents in relation to the surrogate woman who is carrying their child and who is the identified patient. The need for legal guidance throughout the surrogacy process was expressed by all participants. The relationship between intended parents and a surrogate woman begins well before a pregnancy is confirmed. Preconceptual contractual agreements are put into place with the intention of protecting all individuals, as well as the expected infant. During this preconception period when intended parents are selecting a surrogate woman and identifying the specific process to establish a pregnancy, geographic locations become very important. One couple shared details regarding their choice of a surrogate based on her state residence, “We chose somebody in Maryland because it’s very favorable for us both to be on the birth certificate.” This specific situation was reflective of a same sex couple declaring parentage. Their hope was to minimize any legal barriers and maintain compliance to their surrogacy agreement. If contracts are not on file or if uncertainties arise, the risk of contentious issues may be exacerbated.

**First trimester.**

Contracts can be bound by confidentiality clauses and highly guarded. During the first trimester there were not many legal issues of concern, as conception had occurred and the pregnancy was established. However legalities can develop if the surrogate or intended parents do not maintain their agreements as stated by the contract. Certainly each party, with their own representation, will need to access legal assistance if difficulties of any legal sort arise. One participant shared issues surrounding falsified medical information given by her surrogate carrier that was not identified until a pregnancy was confirmed. The situation was addressed by the intended parents after

additional incidents of changed appointment times, work related issues and difficulties in communication ensued. The intended parents requested the surrogate agency enforce compliance of weekly contact to keep the intended parents informed. The intended parent participant shared:

The agency was like, oh we don't do medical and I said well you have some responsibility for what you sold me. After one or two more stunts happened the agency advised her to call us weekly. Sometimes she could be like a petulant teenager.

### **Second trimester.**

No significant legal issues were expressed by participants during this trimester. Intended parents had the opportunity to acquire pre-birth orders if they felt they would be needed or recognized by the state where the delivery would occur. Pre-birth orders, as shared by several participants, are documents issued by a judge with a declaration of who is designated to be the living parent or parents of an expected infant at birth. All participants stated they had great need for guidance and legal assistance due to variation in state laws, compounded by the healthcare system's lack of knowledge and understanding regarding the process of surrogacy.

### **Third trimester.**

During the third trimester participants were trying to anticipate issues that might arise and prepare for the birth of their expected infant. Some participants attempted to share information with the hospitals and providers to avert difficulties at delivery or immediately following the birth of their infant. One participant disclosed an emotional story of an event that occurred when he attempted to share legal information with a physician provider:

I presented him with the legal documents that we were then, you know, the birth parents, the birth order and what he had to do legally. He was offended and said how dare I present all this stuff to him. You know, and I said because you didn't respond to

any of my telephone calls; I came prepared. And he didn't even shake my hand. We had it out and I was very strong. I left there with the surrogate and walking down the hall, I just started to cry my eyes out. It's like, oh my God, all I want is just to have this baby. I might appear to be strong, but I'm not. This just took everything out of me to deal with that ass ... oh, excuse me but .... OB/GYN obstinacy, or just ignorance?

### **Birth and transition to parenthood.**

Not all states will acknowledge pre-birth orders just as experienced by two participants of this study. The intended parents had received pre-birth orders from their state of residence and had everything needed to provide the hospital registrar and others requesting the legal records and evidence at the birth of their child. However, the state where the infant was delivered chose not to acknowledge the originating state's pre-birth order. The intended parents shared:

They don't recognize our marriage here, we have a birth order, and we ... the legal process and they never recognized our birth order, as it stood. We had to go back to the courts in our home state, where we lived, say that this birth order is the equivalent of an adoption, before that state lawyer would accept that as proof that we were the parents.

Needless to say great complications came of this when attempting to admit the newborn, acquire the birth certificate and travel back to their state of residence.

Another participant shared his story that involved several legal complexities including the delay of filing appropriate documents that were not available at the delivering hospital. Due to state laws, the pre-birth orders were not acknowledged, leaving the intended parents without any legal recourse over a weekend. He shared "They recognized us as parents as soon as that form was completed." This intended parent went on to share that if additional medical risks had become an issue and the surrogate carrier could not speak on her own behalf, her spouse would have had the right to make decisions on behalf of her life, as well as their expected infant, or newborn. Power of attorney prior to delivery of a live birth was not legally acceptable either.

Additional legal complexities include how the newborn is identified at delivery. At a routine birth, hospital policy would require the infant to be banded with identification bands with matching bands placed on two parents. However, with a surrogate birth, this identification process became a significant issue. The surrogate or birth mother received a band leaving only one band available to the birth parents. Without the proper identification, birth parents had limited access to their newborn infant.

One participant spoke about her experience, “My husband got the band, and we chose him to have a band. In retrospect, we wouldn’t have. We would have given me the band because they were challenging me more than him.”

Conversely there were no significant legal issues regarding visitation of the newborn by the surrogate carrier and her family during this period of time. Most participants shared that they had already discussed this with their carriers and had made agreements. Several participants shared that they had created relationships that would keep them all in touch in varying capacities now and in the future. However, one participant who experienced difficulties creating a trusting relationship with her surrogate carrier, shared:

Our nurse said “Should you want her to see the baby?” And I really didn’t want to start out on a bad foot and have bad karma for my baby. I thought I’ll let her see the baby. The nurse then said “I have an idea.” She explained that our rooms were placed at opposite ends of the unit with intention as they never know what type of relationship the individuals have had and it protects privacy for all. Well, it wasn’t a great relationship but I understand why she would want some closure, to see the baby, cause, you know, she’s never going to see this baby again.

The nurse then said “We will bring the baby, you and the baby and I will go to her so that you remain in control.” And that was great. We went over there. She held the baby. And then after about 5 minutes the nurse said, “It’s time to go.”

Overall not one participant in this study described any significant conflicts or legal challenges with the surrogate concerning receiving their newborn infant or establishing their rights as parents.

### **Access to the Healthcare System**

#### **Preconception.**

Intended parents describe a variety of situations in relation to surrogate pregnancy and access to the healthcare system. As stated earlier, knowledge acquisition is often accomplished through the internet versus acquiring information via the healthcare system. One participant shared:

It took us about two or three years to be to the point where we had the money, the nest egg to do it. And frankly we started Googling surrogate agencies and we were fortunate enough to come across what later proved to be, you know, one of the most reputable agencies around. We didn't do it by word of mouth. We just Googled it.

Some participants reported interaction with the U.S. healthcare system due to an established medical condition that did not support conception or carrying of a pregnancy. These issues were typically dealt with through gaining access into REI office in seeking solutions of reproduction, such as surrogacy. During this period of time, the intended parent population is well defined as the patient as they are the individuals seeking care and treatment and have a clear identity and role in selecting gametes, a surrogate and establishing a pregnancy. Many participants indicated that prior medical care and inquiries resulted in a well established relationship with their REI provider team. One participant shared: "Our experience in the first 12 weeks of pregnancy, we are dealing with an R.E. issue as the patient and she is there to help us..."

Although seven participants had previously established healthcare relationships and access, four participants had not. These participants were male and did not have a

medical indication outside of their gender and inability to carry a pregnancy but clearly verbalized the importance of establishing a positive relationship with the healthcare team immediately upon accessing the system. One of the male participants stated:

They were the fertility clinic and they're the ones who start to, you know, they, they help you take the plane off, you know, there's the take off of the plane. And then, they abandon ship at a certain period of time when it's in the able hands elsewhere and they go away. So at the fertility clinic, we are very much the client or the patient if you will. We had excellent interactions with them.

They shared comments about the importance of having the healthcare team on your side, with remarks such as:

When I was a practicing physician, I mean, you know, rule number one is befriend every nurse that you possibly can, because they will either make or break your life. We made a point of befriend every single person that was there. We weren't being like, grossly manipulative, but we knew that it wouldn't come back and hurt us if we were friendly.

#### **First trimester.**

Access to healthcare was also described from a perspective of legalities, insurance coverage and the change of providers once a pregnancy was established and the care was transferred from the REI office to an obstetric provider. This required a change in geographic location for many, as intended parents had selected access to an REI in their own community or another location. Once the pregnancy was established at 10-12 weeks of gestation, the REI office transferred the surrogate for obstetric care. The arrangements for an obstetric provider for the expectant surrogate woman, involved some intended parents, however not all had that opportunity for input.

This critical intersection was not just a change in providers or geographical location for the intended parents and expectant surrogate woman; rather it was a change in the identity and role of intended parents, as they were no longer an identified patient in the U.S. healthcare system. Now the surrogate took on the role of the patient. All

participants believed that their undefined identity or status in the healthcare system during pregnancy was specifically related in part to issues of the Health Insurance Portability and Privacy Act of 1996 (HIPAA). Their inability to access healthcare information about their surrogate and their unborn infant or infants created much anguish at different times throughout the pregnancy. This comment was clearly heartfelt from one participant experience:

So we get the news on everything first and then all of a sudden when it is turned over to the OB's office, we are at best second, if not told at all. So what happens then, the surrogate, who has no medical knowledge, is relaying information to us second hand.

Issues of access to healthcare information during pregnancy quickly became apparent during the first trimester. It was through knowledge acquisition and legal representation that they attempted to improve such situations. One participant never got an answer as to what happened to a filed HIPAA release that was initially confirmed as being on the obstetric surrogate record and shared:

So, anyway we have HIPAA in place, and then somewhere when the babies heartbeats were going down, and I called to get information, I was told HIPAA no longer, they didn't have a HIPAA on us. So I don't know if the doctors weren't comfortable talking to us at that time or if the surrogate had gone and released HIPAA, so they couldn't talk to us. That was never confirmed one way or the other.

Another participant shared that although she had a HIPAA release written into her surrogate carrier contract prior to the pregnancy being established, her attorney advised her to put the contract away. The participant had no idea that the HIPAA release form needed to be completed with signature and on file at the healthcare office to acquire the release of her surrogate carrier's health status. This participant shared the following:

I felt like our surrogate carrier was able to provide us information about the pregnancy. But her OB/GYN really drew the line and said the surrogate carrier is my patient. Your babies are not my patients; therefore, I cannot speak to you unless you are physically present in the room with the surrogate carrier. And that was hard because it's like, well those are my babies.



One intended father shared his experience with his second surrogate born child when a provider chose to deny that a HIPAA release was signed or on file. This intended parent stated:

HIPAA for the second child didn't matter. The doctor would never speak to me. I called his office three or four times. I'm a healthcare provider myself. I understand HIPAA. I understand that she signed things. I don't think he ever collected them from her, but they were signed and available to them and then we never knew a thing medically about the fetus.

As the pregnancy proceeded and no information was shared, the intended father stated "And it was horrible because we could not get any information."

Transition of care to the obstetric office created a number of additional difficulties as described by the intended parent population. The first and foremost was their lost identity as a patient, thereby requiring a HIPAA release to access any health information about their expectant surrogate and unborn infant. The next problem was that the providers and healthcare personnel were uninformed or uneducated regarding the process of surrogacy. Of particular concern was the lack of knowledge related to the differences of traditional and gestational surrogacy. Providers did not comprehend the significance that with the donation of gametes from the intended parents themselves, the unborn infant was indeed their natural biological child. As a result of these access and communication issues, intended parents frequently had to rely on their surrogate to relay important medical information. One participant shared this concern:

I mean, without having access to medical professional or anything. I had to go through what she was saying and she was in a whole different, sort of realm because it was her body. I mean she's bleeding. And regardless of whether it's her kids or my kids, she's, it's her body. And so she was struggling with that aspect. And so, I didn't really get a lot of information. She did not sign HIPAA release; I did not know that that was possible until after my babies were born.

Most participants described at least one significant medical issue related to the pregnancy or expected infant when the surrogate was unable to clearly explain the situation adequately. One intended father stated:

So we were nervous because we really didn't know what was going on with the pregnancy. The obstetric office was like, "it's a HIPPA violation to say anything". I said well you know, if anything is wrong with the baby then you'll find out about what violation you're committing by not telling me whether she showed up for her appointment or not.

All participants reported access to communication with the healthcare professionals was challenged, all the while the expectant surrogate carrier is carrying their infant, yet another undefined patient till birth occurs.

### **Second trimester.**

Participant's level of frustration increased during the second trimester regarding continued difficulties of accessing healthcare information. The overall perception of participants was that they needed to find a way to remove barriers and enhance the engagement of their expectant surrogate carrier and their healthcare providers. One intended parent and her expectant surrogate made an appointment at the obstetric office specifically to share information and educate the physician provider and staff as to how they chose gestational surrogacy as an option to reproduce. All participants described their need for assistance in navigation of the system with a team approach to handle the logistics and be prepared in advance. One intended parent shared his experience:

My role was more of logistics and talking to the IVF doctor and talking to medical, talking to the medical side of it. I had to take care of the framework as it is a team building process, as opposed to a pregnancy.

Even though surrogate carriers received appropriate care, participants verbalized concerns regarding their ability to access or participate in healthcare decision making during the pregnancy period. One participant shared:

They made us wait out in the hallway while they did the ultrasound. After they did the ultrasound they allowed us to come in to see. Now, it's my child, my children, actually and had I been carrying them myself, I obviously would have been in the room. You can't remove a mother from the room if she is carrying the child so why remove the mother from the room if she is not carrying the child. Her motherhood doesn't change.

This was not always the situation as some participants actively participated in care as noted by this participant comment:

For our son, our first child we went to quite a few of the ultrasound appointments and we spoke with her, you know, once a week, maybe twice or three times, just depending. Because they were in Maryland and we're in New Jersey, you know, we couldn't go to every single doctor appointment, but we went to a bunch.

### **Third trimester.**

The knowledge and preparedness of intended parents moved them swiftly into the third trimester as they prepared for their infant's birth. An unusual thing to consider is that this group of parents needed to make very specific arrangements since they were not the carrier of their expected infant. Many encountered healthcare professionals confusing surrogacy and open adoption. Different from an open adoption, these intended parents had genetic ties to the expected infant who they always considered their own child. Many participants voiced their exhaustion at clarifying the differences. One participant stated:

You know we were at the hospital, you have someone telling us that they adopted. They know what we are going through. You don't know what we are going through. You don't know what we are going through at all. You are going to adopt. This is our child. It's always been our child.

Several participants identified social workers in the healthcare system as being instrumental in assisting. One participant said the following:

We met a social worker who was, um, you know her goal was to introduce us to the facility we would be using. She was like the head or the Grand Poobah! Between our Dr. and her, everything that needed to be taken care of was done. The staff was prepped and knew we were coming, all four of us, and the hospital was just awesome.

### **Birth and transition to parenthood.**

Several participants described situations of dealing with hospital personnel and staff. Their concerns were primarily related to hospital staff not understanding the surrogacy process and who the intended parents were or how they should be addressed.

One intended mother shared:

The nurses would come into the room, and address the surrogate as “Mom”, they would ask the surrogate about infant care and she would in turn say “she’s the Mom” and point to me. At that point the nurses were like “oh, right, and turned.”

The intended mother recalled this emotionally difficult situation and shared the following as well:

They were creating obstacles and barriers that were taking a lot of energy out of both myself and the surrogate. As a new Mom, you’re sitting there and, you know, a nurse said, “Oh you adopted too.” And she knew I was in a surrogacy. I am not adopting. There is no shame in adopting, it’s simply I am not adopting. This is my genetic child. We fought very hard for this.

This same intended mother described what she believed was ignorance regarding personnel not understanding differences in adoption and surrogacy. She went on to describe how the same staff member brought the birth certificate in and refused to give it to her.

She was actually the nurse that was the worst. I just kind of curled up in a corner with my kid. You feel like your motherhood is being challenged, which feels like a threat to your child. I didn’t want to have any interaction with them. It just makes you want to go away. Because it feels like a slap in the face, like a stab in the heart, every time somebody comes up to the room and you have the glow of a new mom, invalidating it constantly. I am obviously not a patient. Telling my surrogate that she is the Mom over and over again, that’s just I mean if she wasn’t secure and she is giving the baby back and if she had any emotional attachment for her that would have exacerbated that over and over, a million times over. You know. They weren’t doing anybody good service by continuing to call her Mom. There is no reason they couldn’t have worked with me.

This mother expressed her positive relationship with the obstetric provider sharing that they had selected the provider and always felt comfortable with the management of the

pregnancy and the physician being respectful and addressing them as parents. She believed that her positive relationship helped tremendously when these issues of hospital personnel became uncomfortable for her.

A number of system and process issues were identified as problematic by the intended parents. Issues included banding of the infant and parents, limitation of individuals in the surgical area, admission and birth certification registration of the infant, and a provision of a room for the intended parents to enhance bonding and transition to parenthood.

Hospital personnel's completion and application of infant identification bands was described as another conundrum. Some participants shared their frustration and dissatisfaction of not being banded thereby not having immediate access to their infant, as the surrogate carrier was banded as the birth mother and according to hospital policy. Yet several participants did describe personnel adapting the system by opening two sets of numbered bands, so all parties involved were banded according to the legal status of the situation, as well as hospital policy.

Immediately following the birth of the infant, admission of the newborn into the healthcare system is required. This process was cumbersome for some as the laws needed to be followed precisely with regard to who had guardianship. For some individuals there were no bumps in the road and within a few hours, paperwork had been reviewed and in order. Their infant went into the system under the intended parent names with the birth certificate procedures immediately following. For others, there were delays with the infant being admitted under the surrogate carrier or birth mother's name, which created more confusion and revisions to follow.

Several parents experienced the inability to be present at the birth of their infant as healthcare professionals deemed a cesarean section was required. Access was limited to the surgical suite creating stress with decision making as to who would be the one support person in the surgical area and permitted to be present at the birth. One participant shared:

Our next snafu. The hospital staff was fine, the Dr. was fine that my husband and I could be in the room with the surrogate and they all left it up to the anesthesiologist for a final decision, who then said one and one only in the section. We got bumped from that because of the anesthesiologist, it's his rule, no one wanted to buck him, not a physician, not staff, not a manager, not the charge RN, no body.

Room assignments were provided to several intended parents on the mother baby unit upon arrival to the hospital. However not all participants received a room, which resulted in a lack of privacy and congestion in the surrogate mother's (birth mother) room. The situation proved to be untenable causing an earlier than anticipated discharge. One participant shared "We just wanted to get out of there."

For those that did receive a room, intended parents felt affirmed in knowing their intended parent role was validated. Providing them a room also assisted in the privacy of receiving their infant and having a space for bonding and educational assistance by the nursing staff. Several participants described having the opportunity to engage with staff who promoted their participation in skin to skin care with their newborn. One intended participant mom shared how important this was for her:

I actually went to ten shops until I found a t-shirt with snaps on the front, so I could just whip the front open so I could put the baby on the chest and I snuggled with him and then he latched and attached and everything. And he is and I am still using the supplemental nursing system and have been able to nurse, supplying him about 1% of his milk, but still have the closeness.

Some participants met with a lactation consultant to induce lactation and breastfeed for a period of time with varying degrees of success. Others shared no interest

in inducing lactation, yet some experienced what they felt were inappropriate breastfeeding lectures provided by staff. One participant described what he and his wife felt was a very condescending attitude by the hospital staff towards them as intended parents. For some participants, the option of having their surrogate carrier pump breast milk and ship the frozen milk to them worked out very well. One participant couple had a friend who pumped for twins and offered them her breast milk.

## **Trust in Relationships**

### **Preconception.**

In previous thematic sections, the importance of relationships has been presented through intended parent experiences. With relationships, the concept of trust has been embedded and continually threaded throughout these results, yet it is a thematic expression of its own. Clearly relationships were critical for intended parents as they built a foundation for this journey of surrogate pregnancy. Many participants discussed stories of both positive and negative encounters, yet all participants agreed to the importance of building a relationship with their surrogate and other parties that were involved in the process. For some participants managing fear and vulnerability was directly associated with their ability to create a relationship built on trust. Unfortunately this did not always occur, as one participant shared:

What happened to us is our carrier's medical records did not match the agency application which was presented to us, which we based our decision on. And there were implications that could have affected our baby. It's almost like she knew the answers. She lied about having I think it was two abortions, due to....and I'm not talking from a moral standpoint, but she was on the use of Accutane, a drug, the acne medicine. That was, to me, irresponsibility. And here I am paying thousands and thousands of dollars. But also, here is this woman who has lied to me, carrying my child. I was angry. But first, I was in shock, you know. I couldn't believe it. I will say that we were fortunate in the sense that we had a fabulous, fabulous doctor who called ....you know it can be quite maddening. The carrier had signed a HIPAA release. The doctor looked at me and said "you didn't

know any of that information, did you?” and I said no, then she said “this woman has no business being a surrogate, she’s completely manipulated the situation.”

This experience clearly resulted in the loss of trust and an ability to build a relationship.

Intended parents were often negatively affected by the misrepresentation of potential surrogate carriers and egg donor agencies which are involved in matching services for surrogacy needs. Intended parents shared their belief that some agencies marketed by trying to instill fear while others made claims and assurances that they could not keep. It is only with blind trust that intended parents engaged with these service providers: One participant summed it up quickly saying “Trust is critical. It’s blind trust!” Another participant who experienced difficulties shared “I really do, I feel from the agency standpoint, I feel preyed upon. I don’t blame the surrogate as much as I blame the agency and the doctors.” Another participant, who did not use an agency for their first surrogate born child, shared this statement about using an agency with their second child born of a surrogate:

As far as the surrogacy, the agency was concerned we were very naïve. They said things that sounded good with us and we, I think, behaved or acted a little bit irrationally and signed on with them before investigating enough. We had a horrible experience with that agency.

Although the experiences described above were not favorable, other participants reported exceptional experiences with their selected agency. In fact one participant stated “From beginning to end, we had a fantastic experience with the agency.”

Several participants stated that genetic history was very important to them when selecting donor gametes or providing their own DNA contribution. After evaluation of the proposed surrogate woman, healthcare professionals need to communicate with the intended parents, regarding concerns of genetic or medical history. One participant expressed:



I really did think, I mean I also blame the REI for not saying, Hey, just so you know, she's going to need a cesarean section, are you ok with that? Someone needed to look at those medical records.

Yet, another participant's perspective with her REI office was different and described a trusting relationship:

With the REI it is a different world, has a different vibe. At about 9-10 weeks the Dr. said we need to turn you over to the obstetric provider, the three of us said "what?" I had been with their office for ten years and had a very strong relationship with them, you know and I was really sad to go and there is quite a trust and relationship you have built over that amount of time with that intense of a situation.

Several intended parents cited their existing relationship with a potential surrogate woman as the principle reason they believe they had a successful pregnancy and birth outcome. One participant shared "She was actually a friend before she was a surrogate for us." Another participant had her best friend as her surrogate carrier and viewed her lived experience with her friend as surrogate by sharing:

She wasn't my property, I didn't own her you know, so granted, she was carrying the most precious gift I've ever had, but we tried really hard to respect boundaries but yet be enmeshed with one another, which was an interesting balance.

During this period of time relationships are often strained due to the stress of multiple procedures in an attempt to create a pregnancy. One intended parent couple described their experience of being advised by the REI to consider not doing the embryo transfer as there is a slim to no chance of pregnancy occurring. The couple explained how important the relationship with their egg donor and surrogate was when deciding whether to move forward with an embryo transfer. This participant shared:

We had just had a celebration the night before with a big party and we were singing "We are Family" with the surrogate and the egg donor and us. And we knew our chances were slim to none but we'd all decided, "Let's just go with what we've got."

Moving forward in the process, one participant described the importance of developing a relationship with her surrogate carrier by providing an opportunity for shared decision making for obstetric care. She shared:

It was really important to me that she was comfortable with who her obstetric person would be, she was the one moving through the pregnancy, it was her body and someone else's care and she said who do you want to use for an ob and I said it's totally up to you. My husband and I went to every appointment with her.

Participants stressed how relationships with their surrogate, healthcare professionals, staff and the overall healthcare system became very valuable to them during this journey. Their experiences illustrate how these relationships reduced vulnerability and fears.

After looking at all eleven participants it is clear that trusting relationships were crucial to the continued acquisition of knowledge and preparedness in regards to their journey.

### **First trimester.**

The value of a trusting relationship during their journey could not be understated by any of the intended parents. One participant described an experience that kept her from fully developing a relationship after she was informed that the agency's screening of her surrogate carrier, was not truthful and contained falsified information. This had not been revealed until pregnancy was confirmed and transition of care had moved to the obstetric provider office. She shares the following about her experience:

I said to the agency owner, who I had put a lot of trust in, who was kind of like hands off, "you know, not his problem", after he got his \$20,000. and his fee for finding her and presenting this application. I said to him "you know, if I had watched a documentary of surrogacy, I would have never done this, what you have put me through was worse than anything I've ever already gone through. And you should really be ashamed of yourself." "In fact the obstetrician was angry enough that she called...she was on a conference call with my husband and I and to the agency owner and she said

“You need to do something differently. The child’s health has been compromised.” His response was “What are you trying to do litigate this over the phone?”

### **Second trimester.**

Intended parents continued to express the importance of relationships in a variety of ways. For two participants and their surrogate carrier, vacation time was a planned agenda for relationship building. They brought their surrogate carrier and her entire family out west for a long weekend late in the second trimester. They shared the importance of trust and took the opportunity to get to know her and what to expect as the pregnancy proceeded. The participant stated that “Her family was lovely and they liked us and we had a good time, having a good relationship. It was way beyond a contract.”

One participant compared their two surrogate experiences. In their first surrogacy, their friend was the carrier and in the second, they had a carrier from an agency. They explained how this changed how they interacted, as well as their not being as involved in attending appointments, ultrasounds and day to day updates of the second pregnancy. That participant couple shared “It was not the same as the experience with the first surrogate. There was just, we only knew information which was right in front of you. That’s the only time you knew you knew what you were gonna get.”

Two other intended parents shared that their relationships grew and developed into friendships. They shared that the trust in their relationship with these women was so significant that they went back to them as gamete donor and surrogate carrier for their second child. Each partner was then able to genetically contribute to one of the two children. Providing genetics and having the same birth mother for their children was clearly important and created memories. One intended parent father said “What it ended up being was a really extraordinary relationship.”

Attending appointments and shopping for maternity clothes with their surrogate carriers were a few of the activities shared during this period of time. Of course baby showers were hosted and attended, some with the surrogate carrier present and some without. One intended parent father shared an experience, “There were so many events that we were sort of the center of attention. And our babies were the center of attention, even though they weren’t physically present.”

Distances created difficulties for some intended parents while others were appreciative of the distance and their ability to keep some balance of the situation at hand. One intended mother shared:

I don’t know how to explain it. She doesn’t expect to be invited to the birthdays. If things don’t go well with us, she is not in my neighborhood, and at the same time she was somebody I trusted enough to have distance from us. And we’re really busy, I don’t – if she was, you know, four hours from me, I would feel obligated to go to every appointment. I didn’t feel obligated to go to every appointment because of that.

Many intended parents admitted to being concerned while also explaining that they did not want to micromanage or create difficulties inside their relationship. Some participants described surrogate carriers experiencing complications such as bleeding, diabetes and even preeclampsia that would require changes in care and a potential change in the delivery mode. Despite these concerns, all participants stressed the importance of relying on their relationships to get through these untoward events of surrogate pregnancy.

Intended parent participants voiced their relentless efforts to forge relationships with the providers of healthcare, and while some gained trust and respect, others experienced disappointment. One intended father said that as time passed and potential concerns presented themselves they felt more pressure to be with the surrogate. He shared:

We flew out there. I talked to the sonographer the person that had read that ... she talked to me. But her OB/GYN doctor never talked to me. I didn't meet him till three weeks before she was to deliver and he didn't even shake my hand. It was horrible.

### **Third trimester.**

The third trimester proved to be a period of time where all parties involved became more invested in their relationships. Discussions about labor and delivery and setting plans into motion became a focus. Several participants experienced changes regarding their agreed upon location for delivery. One intended parent couple stated:

“The plan was to deliver in Massachusetts again, where we knew everybody. It turned out that she didn't want to do that, but she was open to it initially and then by the time it came around she really didn't want to travel.”

This took some adjustment and had a small toll on the relationship, but all parties were agreeable that she should deliver near her home.

Another couple verbalized angst when their expectant carrier went into premature labor and her hospital did not have the appropriate level of care for the preterm newborns. Although a violation of the contract, they worked with her to manage the situation and maintain the relationship. They described the confusion that occurred when hospital personnel were uncertain how to address them due to their lack of a previous relationship. The overall lack of processes can become very difficult to navigate. This intended mother shared:

I don't think it was well organized. I don't they had the vocabulary to understand our situation because most of the nurses and the anesthesiologist and the social worker and the registrar did not have first-hand knowledge of our situation. Except, our OB/GYN knew that we were because we had attended the prenatal visits.

### **Birth and transition to parenthood.**

Parents shared stories of plans changing from who would participate in the birth of their infants, to last minute changes in the mode of delivery. As described by intended

parents, difficulties were experienced in maintaining relationships with healthcare personnel due to shift changes and differing departments. One participant shared:

As soon as she came onto her shift, she became rules lady. So, “You’re not allowed to sleep on the floor, you need to get up”, or “you need to put your shoes, your sneakers on.....even during the epidural she kicked us out, it was very impersonal.

He went on to share his concern that this nurse might keep them from attending the delivery and called his attorney asking him to check into his concerns. In the end the intended parent said:

“She was like a great delivery nurse and she was certainly very friendly to us during the process of her pushing and all that crap, but, it just left us very nerve wracked at a time when we really shouldn’t have been.”

Situations in this timeframe were very unpredictable. Participants described events such as labor not progressing and then a cesarean section was required for delivery. They expressed how they felt frustration, guilt and concern for not only their surrogate carrier but their infant as well. They also voiced concerns regarding the one person visitation rule in the surgical area and who should be in attendance. Several intended parents verbalized having encouraged their surrogate carrier to select a support person. One participant shared this about their experience:

I felt it was really important that she have a support person with her, and I wasn’t going to be her support person, I mean I love her and adore her, but she is not going to compare to my kid I am seeing for the first time. I mean everything fades away—and I mean I knew that would happen. I didn’t want her to, you know, when the baby goes out of the room I am following my baby.

Three different hospitals upheld policies that limited one support person in the surgical suite for the birth and no exceptions were permitted..

Families and friends were often nearby in waiting rooms and provided much needed support. One participant spoke about how important her relationship with her

sister was when the surrogate carrier selected another friend to go into the surgical suite for a cesarean section and the birth of her infant and shared:

The surrogate is feeling more vulnerable, I don't know if there is even a word for it. She picked our mutual friend to go in with her, I didn't fault her in anyway, she needed to focus on her. I had to suck it up. I was kind of upset, I was like I am not needed here... I am going to get my purse and go home and let the dogs out quick and I'll be back, marching down the hall! My sister was like running down the hall saying 'Where are you going? You need to calm down, you are needed here and it's not going to be that long and you know it, you need to regroup!'

She said that brought her back to her senses. She then went on to describe the moment when their baby was brought to them by sharing:

We had our own room, the surrogate's husband was with us, my mother, brother, nephew, um the whole family was there. The labor nurse/mother baby nurse brought her to us all wrapped up, none of us could see her and my sister had the camera. It was a perfect scenario that the nurse brought her in....pause teary... to our whole family. It was beautiful.

Another participant shared her perspective on trusting relationships when she had concern for both her surrogate carrier and her carrier's husband while receiving their infant. She shared the following:

The surrogate's husband ended up handing the baby over to us and we met her [infant] in the hallway. It was disturbing for me that she [surrogate] didn't have a family member or support person in with her anymore. But it was important for him to, I think, to find a role in all of this. And we got to meet her [infant] in the hallway and they allowed him to hand her off to us.

## **Discussion**

Achieving parenthood utilizing a surrogate pregnancy is a complex process comprised of a series of key steps accompanied by the ever present potential for negative complications and stressful issues. Nurses and other health care providers in the U.S. healthcare system are obligated to provide optimal care to all parties involved including the intended parents, surrogate mothers, and the unborn infant. Intended parents were happy to share their lived experiences, sometimes described as a long and harrowing

journey, in the hope that future intended parents would benefit from the knowledge gained from this study.

The study sample of intended parents was not initially easily accessible. As reported by Ciccarelli & Beckham (2005) research in the area of surrogacy has primarily been focused on surrogate women. With concerns for privacy, legal and ethical issues, and the lack of a centralized data source, intended parents were not easily identified as potential participants. The lack of a data repository related to intended parents has been appreciated in the literature of reproductive healthcare research (van den Akker, 2007b). With the implementation of snowball sampling techniques (Wimpenny & Glass, 2000) and a change in inclusion criteria approved by the university IRB, additional participants were located and enrolled.

Diversity of the sample was limited in ethnicity with all participants reporting White/Caucasian with the exception of one participant who self-described himself as biracial or White/Caucasian and Black/African American. The majority of the group had completed college or graduate level education and reported incomes over \$100,000 annually. These demographic data and higher socioeconomic backgrounds are consistent with previously reported studies of surrogacy (Ciccarelli & Beckham, 2005; van den Akker, 2007a, 2007b, 2005, 2003, 2000). Concerns regarding the inaccessibility of this reproductive method by individuals of lesser socioeconomic backgrounds have been reported (Ciccarelli & Beckham, 2005). This concern is supported by this study's demographic profile. The majority of this sample was engaged in commercial surrogacy arrangements, ranging in costs from \$70,000 to \$130,000. Similar findings were recently reported in *Surrogacy in America*, a report developed for the Council for Responsible Genetics (Gugucheva, 2010). With commercial surrogacy legal in some states, illegal



and undefined in others, the US faces concerns of disparity, including issues of legality, access, and affordability. The perception of many today is that surrogate motherhood in the US is unregulated and in a state of constant confusion, with no one law taking precedence thus leaving participants involved in this reproductive method at risk for untoward events (Spivack, 2010).

Both the CDC and SART, who have evaluated surrogacy data, reported this method of reproduction is accelerating (Gugucheva, 2010). However, surrogacy as a reproductive method is small in numbers compared to overall reproductive rates in the US. Data collection for both gestational and traditional surrogacy is not mandated, therefore partial or questionable data is what is available for analysis. The lack of data reporting is not limited to reproductive infertility practices; it is also an issue in agencies that offer surrogacy and donor gamete matching services. These agencies fall outside the realm of healthcare practices, yet are involved in the practice of surrogacy. Such agencies were reported by several participants as not being reputable and unknowingly placing them at risk. This lack of regulation and mandatory reporting, creates issues of concern and increases the risk of safety and health for all parties involved (Gugucheva, 2010).

Research of intended parents' motivations to choose surrogacy has been associated with the parents' desire to have a genetic link to their child (Ciccarelli & Beckham, 2005; MacCallum et al., 2003; van den Akker, 2000, 2005). Similarly, this study's findings support that a desire to have a genetic link to the child was of utmost importance to the participants. All verbalized their desire to use surrogacy with a gestational carrier and a genetic link before they would consider adoption.

The journey of surrogacy reveals a similarity to the journey of adoption, yet the genetic link appears to be the biggest difference. Sandelowski, Harris, and Holditch-Davis (1991) documented the perceptions of adoptive parents with regard to time and the actual adoption occurring. Intended parents engaged in surrogacy also speak of time in relation to making the decision to use this method of reproduction. Intended parents referenced time during the course of the surrogate pregnancy, when they reconciled having little control over situations they were removed from, such as not carrying the fetus. Similar comparable findings have been reported in several studies of surrogate and intended mothers conducted in the UK (van den Akker, 2007a, 2007b, 2005, 2000).

In the same adoptive parent study, Sandelowski et al. (1991) described adoptive parents feeling cut loose or adrift in relation to their adoption process and agency. Although different circumstances are noted, intended parents reported perceptions of feeling abandoned or second best when care transitions occurred between healthcare practices or an agency did not follow through on their agreements.

Participants shared concerns about financial exposure and risk, legal complexities, and managing their relationships with all parties involved. Several participants shared concerns regarding the surrogate woman not caring appropriately for herself and their infant, yet all participants verbalized a positive overall experience after the birth of their child. These findings are all consistent with Kleinpeter's (2002) study of 26 participants (24 women) who participated in a California based surrogacy program. The MacCallum et al. (2003) study of intended parents also documented positive parental perceptions of the surrogate pregnancy experience.

During this journey intended parents described experiences of being treated as second best and expressed difficulties when attempting to communicate with the

healthcare team regarding their surrogate, their unborn infants and their own needs. Experiences of dissatisfaction escalated when healthcare personnel had little to no knowledge about the process of surrogacy. Intended parents cited numerous issues where healthcare personnel were unclear about how surrogacy differs from adoption; parental rights; inclusion of intended parents through provision of a room for bonding and newborn care; adaptation of newborn identification and banding procedures; and admission and birth certificate registration procedures. Although a small study, Sharan et al. (2001) reported positive results with the admission of intended parents into a hospital room to facilitate bonding and caring for the newborn. Sharan also recommended that both intended parents of surrogacy and adoption be provided this level of care.

According to intended parent participants, healthcare professionals lacked knowledge regarding surrogacy as a reproductive method, as well as the legalities surrounding it from preconception, pregnancy, birth and transition of the newborn to their care. Increased knowledge was needed by both the intended parents and healthcare personnel. Intended parents expressed a belief that being informed and knowledgeable in a trusting relationship with others, assisted them to manage even the most difficult of situations. Similar to reports by Cline and Haynes (2001) where increasing numbers of individuals are seeking information via the internet, the intended parents stated that internet sites and other electronic sources of information, such as message boards and surrogate and agency sites, were their first choice of access in seeking information. Of the eleven participants, only one thought the healthcare system was available to provide information and education. With the continued electronic explosion of information via the worldwide web and more individuals having access to the internet, issues of reliability and validity will become more evident in the public perception of healthcare.

Review of the literature revealed no accessible studies of intended parents in surrogacy in relation to knowledge acquisition and preparedness. These intended parents were left to their own devices to prepare and navigate the healthcare system to manage these uncharted territories in reproduction. In contrast, adoption is not managed solely by parents; rather they are assigned to a case manager in the field of social work. This case manager works closely with the the couple, answering questions, setting up appointments and guiding them through the process (Sandelowski et al, 1991).

Similarly in the field of oncology, breast health navigators have been employed to assist in patient navigation. Korber, Padula, Gray, and Powell (2011) looked at barriers, enhancers and nursing interventions in a breast navigator program. Patients reported valuing the education and information received from their nurse navigator and reported this as the essential essence of their role.

Nurse navigators were also reported helping patients with access to financial and community resources, providing overall support and advocating a team approach to meet patient needs. A role such as this would be advantageous to intended parents as they are often overlooked when their surrogate pregnancy is established and the surrogate mother becomes the identified patient in the U.S. healthcare system. The findings of the Korber et al (2011) study would be of great value if replicated in the area of reproduction, specifically surrogacy and the intended parent population.

The opportunity for the U.S. healthcare system to better understand this population and their journey continues with the results of this study. Not one published nursing or medical study regarding the intended parent population and surrogate pregnancy as a reproductive method could be located in the US was located when this study was initiated in July 2011. In addition, the ability to generalize studies conducted

in the UK is limited as that country prohibits commercial surrogacy and has a socialized healthcare system; neither of these characteristics translate to the US.

The findings of this study represent the meaning or essence of life as experienced by intended parents during surrogate pregnancy and transition to parenthood in relation to the U.S. healthcare system. The five themes that emerged using van Manen's analysis provide us with an improved understanding of what intended parents experience; thereby assisting us to develop standardized and evidence based care towards improved clinical outcomes for this overlooked population.

### **Limitations**

As with qualitative research, the study size was relatively small consisting of eleven participants and a total of 8 interviews as some couples were interviewed together. There was also no intended parent currently experiencing a surrogate pregnancy enrolled. All reported experiences were retrospective in nature. An additional limitation was that the study had no intended parents of a traditional surrogacy which may have provided a different perspective. All parent participants voiced traditional surrogacy as something of the past. They now have the ability to create their own genetic link through gestational surrogacy and minimize additional legal risk out of the situation. Ten interviews were completed by telephone, one by SKYPE, body language was not observed however, voice intonation and laughing were captured by telephone and on the transcribed files. The principal investigator does not believe this would have changed the results captured.

It is the belief of the principal investigator that this study is the first to lay a foundation of improved understanding of this overlooked population and their relation to the U.S. healthcare system. As this reproductive method appears to be on the rise in the US and abroad, the study findings will be important to assist in the development of future

studies of this population, as well as the others involved in this reproductive process. Rich data was mined from these lived experiences and abundance of information awaits further investigation.

### **Implications**

This study illustrates the importance of understanding the lived experiences of intended parents of surrogate pregnancy in relation to the U.S. healthcare system. Findings from this study identify distinct implications for healthcare professionals involved in reproductive and pediatric care, surrogate and donor gamete agencies, as well as the legal community, society and policy makers. This study's findings will ultimately guide the development of evidence based care guidelines resulting in the improvement in clinical care and outcomes. The profession of nursing is perfectly positioned to lead this endeavor. Nursing is also poised to assist this overlooked population by first identifying them and then creating a trusting relationship to assist in their navigation of the healthcare system.

The intended parent participants in this study provided rich data that will set the foundation for research in the future. This study's focus in relation to the U.S. healthcare system confirmed several beliefs beginning with the perception that this reproductive method is accelerating in growth. As reported by Gugucheva (2010), the CDC and SART have evaluated the limited reported data. However, the lack of both consistent reporting and regulation creates disparities in what can be considered reliable or valid. There is a belief that we are only skimming the surface of true data regarding those participating in this reproductive method. A recommendation is set forth that both professional organizations such as the ACOG and ASRM, along with government entities

such as the CDC and NIH develop improved reporting techniques to enhance gathering of accurate statistics with a minimum of specific data reported.

Improved data reporting will enhance opportunities to identify this patient population which is often overlooked in the healthcare system today. This identifiable gap appears to be related to both the lack of knowledge of healthcare professionals, as well as those involved in the process of surrogacy, such as intended parents. Therefore a recommendation is made for continuing education of healthcare professionals, including physicians, nurses, social workers, registrars, risk management and ancillary personnel that may be involved in the process of surrogacy within the U.S. healthcare system. These healthcare workers need to acquire an improved understanding of the entire process of surrogacy, differences within the methodology, as well as the legalities that are imposed upon the healthcare system caring for these individuals. Schools of medicine, nursing and other disciplines involved in the reproductive field, should also create curricula that is reflective of this growing reproductive method and the processes associated with it, such as legalities and ethical dilemmas. This information should be updated as procedural and legal changes are made.

In addition to healthcare professionals and personnel receiving education, intended parents are in dire need to receive reliable information directly from the healthcare professional and other reliable and valid sources. The recommendation is made that multidisciplinary experts practicing in the area of surrogacy, create patient materials and access points on the internet where reliable information gathering by this population can occur. Lists of reliable internet sites could be provided to agencies, provider practices and professionally related websites where patients may access information, such as March of Dimes (MOD), American Academy of Family Physicians

(AAFP), American Academy of Pediatrics (AAP), American College of Nurse Midwives (ACNM), American College of Obstetrics and Gynecology (ACOG), American Society of Reproductive Medicine (ASRM), Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN), and the National Association of Nurse Practitioners in Womens Health (NPWH). This will require identification of appropriate stakeholders and a commitment by all parties involved to enhance the accuracy and sources of knowledge this population has been seeking. Coordination of such an activity takes time and financial investment by professional associations, professional experts and society as a whole.

The next recommendation is regarding coordination of care. As noted, when adopting a child, a case manager provides assistance along the way and in some settings a nurse navigator is provided to a breast cancer patient. The journey of intended parents during surrogacy often includes unexpected events and at times, difficulties accessing information and participation with their surrogate and unborn child in the U.S. healthcare system. These difficulties must be addressed. Intended parents voiced managing logistics in a system where they are not well identified, often overlooked and underserved. A recommendation for a reproductive nurse navigator is made following the findings of this study. The role of such a nurse navigator could include education and provision of knowledge, coordinating the multidisciplinary team and supporting the population they care for in a variety of ways. This is not a new role to healthcare, as oncology and other areas have employed this role with great success. It is believed that there are nurses in practice already fulfilling this role; however as a healthcare system we have not offered reliable standardized care for this population as whole, and their lived experiences document fragmented care at best.



To enhance reliable care and improve outcomes, evidence based guidelines should be developed and implemented. The next recommendation is directed to meet this need. This will not be an easy task, yet rich data from these intended parents will provide the foundation for this work. The following items should be evaluated and considered for inclusion to begin the process in both outpatient and inpatient facilities: (a) preconceptual care, (b) obstetric care, (c) birth care and transition of the infant, (d) pediatric and family care.

The final recommendation is to request that legal and healthcare experts, as well as experts in policy be identified and participate in a summit or panel discussion regarding legal complexities of surrogacy related to state to state variances. These issues impact both inter-state and international surrogacy and require immediate attention. This forum could be supported by a professional organization such as AWHONN, ACOG or ASRM at a National meeting with discussions and recommendations published in a report following the meeting. As noted by Spivack (2010) and Drabiak, Wegner, Fredland, and Helft (2007), the issue of commercial surrogacy and receipt of payment for service, such as carrying a pregnancy for someone else, lends itself to interstate commerce law. These experts present possible models for the enactment of a federal law for surrogate motherhood. Organization of expert individuals who can assist in building the framework to manage legalities and social concern of this growing reproductive method is recommended.

Further research studies are recommended across all areas explored and identified from the findings including gamete donation; surrogate women; agencies representing both gamete donors and surrogates; the healthcare system including IVF clinics; obstetric providers and hospitals or birth centers providing care to those involved in surrogacy;

policy issues; societal concerns and psychosocial concerns. In addition, the complexities of law within the US regarding ART and third party reproduction, as well as overall financial risk and exposure require further investigation. With this reproductive technique being utilized by more individuals who are crossing state and international lines to accomplish their goal, continued research will assist in guiding a safe, equitable and favorable outcome for all involved.

### **Conclusions**

Findings from this study have provided a narrative of the meaning or the essences of life as an intended parent during surrogate pregnancy and transition to parenthood. As noted, all participants had the joy of receiving their infants at their end destination, albeit there were trials and tribulations along the way. This population has the right to be identified during pregnancy. Access issues related to healthcare information of their unborn infant and eventual newborn, via the care of the surrogate woman, must be addressed. With intended parents' identity restored, during pregnancy and transition to parenthood, we have the opportunity to assist with their needs including education and transitions in the healthcare system. Adaptations in our healthcare processes and systems will lead to improved satisfaction and outcomes for both intended parents and their healthcare team.

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Table 1 Demographic Data

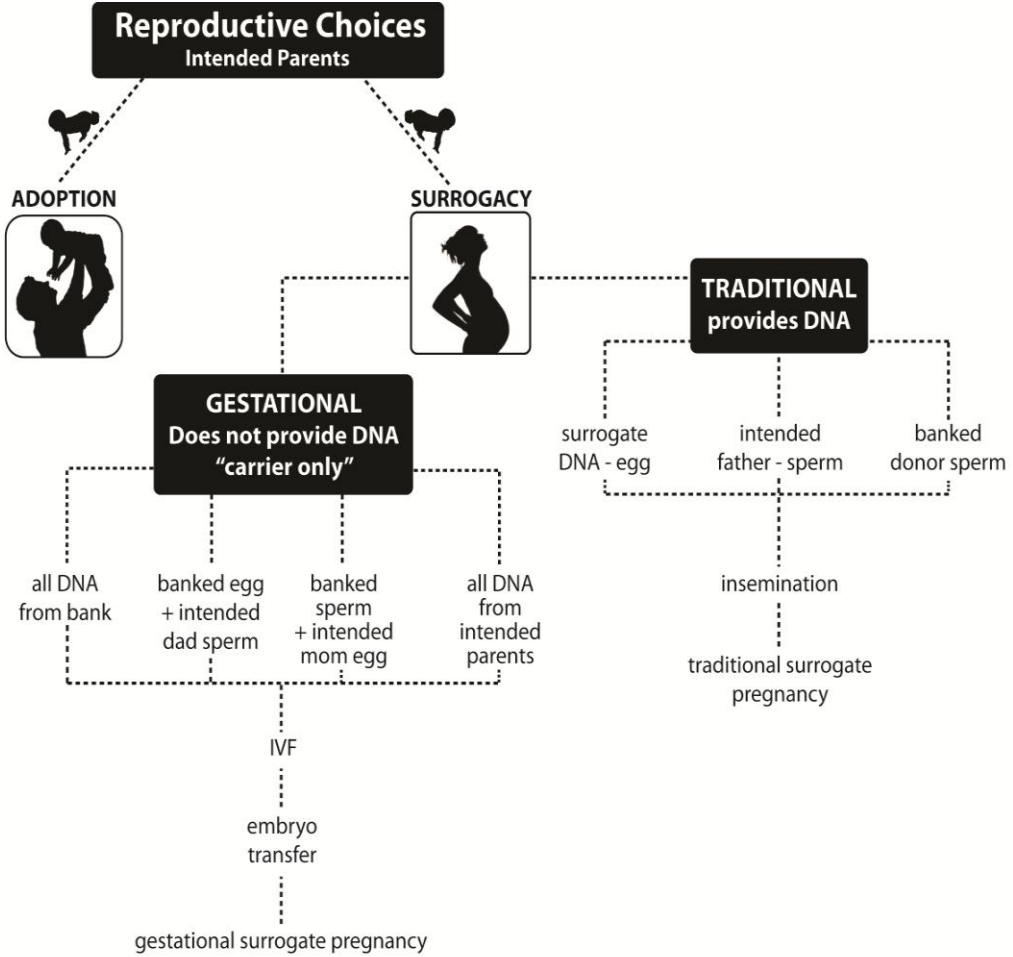
Characteristics	Number of respondents (11)
Gender	
Male	6
Female	5
Age in years	Range of 32-48
Relationship status	
Single	0
Married	8
Divorced	0
Widowed	0
Other	1
Long term relationship	2
Race/Ethnicity	
American Indian	0
Asian	0
Black/African American	1
White/Caucasian	11
Native Hawaiian or Other Pacific Islander	0
Other	0
Spanish or Hispanic origin or ancestry	
Yes	0
No	11
Education- highest level completed	
Grade School	0
High School	0
College	5
Graduate School	5
Post Graduate School	1

Table 1 Continued

Employment status	
Fulltime	8
Part-time	3
None	0
Salary range	
\$40,000-\$49,999	0
\$50,000-\$59,999	0
\$60,000-\$69,999	1
\$70,000-\$79,999	0
\$80,000-\$89,999	0
\$90,000-\$99,999	0
\$100,000 or more	10
Other	
Surrogacy arrangement	
Altruistic	1
Commercial	10
Type of surrogate	
Gestational	11
Traditional	0

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Figure 1: Surrogacy as a Reproductive Option





## **Chapter 5-Overall Summary**

### **Overall Summary**

#### **Evaluation of the project**

The aim of this research study was to have an improved understanding of what intended parents of surrogate pregnancy experienced as they moved through pregnancy and transition to parenthood, in relation to the U.S. healthcare system. The state of the science paper clearly identified a gap in the literature regarding this population. This reproductive method continues to accelerate in growth and without mandated reporting of statistics, regarding surrogacy and third party reproduction, this population is often overlooked. The findings of this research fill a major gap in the literature and provide an improved understanding of intended parent experiences. Opportunities exist with this improved understanding, to enhance healthcare processes and systems. It is expected that improvement in healthcare processes will be beneficial for future intended parents and all parties involved in the surrogacy process. Five overarching themes emerged from the data to represent intended parents' experiences: (a) knowledge acquisition and preparedness, (b) financial exposure and risk, (c) legal complexities, (d) access to healthcare and (e) trust in relationships.

#### **Recommendations**

Participants provided a vast amount of rich data that will provide a foundation for valuable research in the future. These findings are reflective of their quest to constantly acquire knowledge in preparation for a surrogate pregnancy, continued through birth and the infant's arrival. With knowledge acquisition and preparation, navigation of the healthcare system was managed with all participants agreeing, that it was difficult at best. Financial exposure was associated with risk, as commercial surrogacy agreements were

reported at a mean cost of \$104,000 and not reflective of incidental costs such as travel, complications of pregnancy, or additional infant care required after delivery. Throughout interviews, one common thread continued to reappear in all essences of life, that of trust in relationships. All eleven participants described the importance of their creating and maintaining healthy trusting relationships with everyone that was involved in their surrogate arrangement. During this time if relationships were strained, the intended parents described considerable mental and emotional stress, as the pregnancy didn't live in their home and they felt removed. As this population is not receiving healthcare during the pregnancy period, participants described unsettling situations with the belief that they are unidentified. These concerns varied from healthcare professionals not releasing information, when a HIPAA release was on file, to personnel having a complete lack of knowledge or comprehension, regarding the process of surrogacy. These lived experiences provide data to create improvement with processes and systems in regard to the care of intended parents. Providing clinicians with an enhanced understanding of intended parents' experiences will now provide insight to assist in the development of new models of care and evidence based practice guidelines. Improvements such as these will enhance outcomes for all parties involved in surrogacy. Nursing is positioned to address these patient family centered issues of care.

Evidence based guidelines should address both outpatient and inpatient practice and include identification, education and support of intended parents. Processes inside the healthcare system must be adapted to include safe and adequate care of both the surrogate woman and the intended parents. Identified issues of concern, yet not limited, include communication handoffs between practices and departments, parents request of a room assignment to bond and care for their newborn infant, admission and identification

banding of the newborn infant and parents, as well as appropriate filing of the birth certificate. Legal complexities of parentage along with differing state laws and residences, creates difficulties with regard to how standard processes have been set for the obstetrical patient. Healthcare providers along with their risk management and social service teams must be current in their knowledge to manage these situations.

This summary is by no means inclusive of all findings of this deep and broad study of intended parents during surrogate pregnancy and transition to parenthood. Yet, it provides great insight for healthcare professionals to begin understanding intended parent needs and create change for future improvement in outcomes.

### **Limitations**

As with qualitative research, the study size was relatively small consisting of eleven participants and a total of eight interviews as some couples were interviewed together. There were no intended parents currently experiencing a surrogate pregnancy enrolled, therefore all reported experiences were retrospective in nature. An additional limitation was that the study had no intended parents of a traditional surrogacy which may have provided a different perspective. All parent participants voiced traditional surrogacy as something of the past. They now have the ability to create their own genetic link through gestational surrogacy and minimize additional legal risk out of the situation. Ten interviews were completed by telephone, one by SKYPE, body language was not observed however, voice intonation and laughing were captured by telephone and on the transcribed files. The principal investigator does not believe that this would have changed results captured.

It is the belief of the principal investigator that this study is the first to lay a foundation of improved understanding of this overlooked population and their relation to



the U.S. healthcare system. As this reproductive method appears to be on the rise in the US and abroad, the study findings will be important to assist in the development of future studies of this population, as well as the others involved in this reproductive process. Rich data was mined from these lived experiences and abundance of information awaits further investigation.

### **Conclusion**

These findings have provided a narrative of the meaning or the essences of life as an intended parent during surrogate pregnancy and transition to parenthood. As noted, all participants had the joy of receiving their infants at their end destination, albeit there were trials and tribulations along the way. With intended parents' identity restored, during pregnancy and transition to parenthood, we have the opportunity to assist with their needs including education and transitions in the healthcare system. Adaptations in our healthcare processes and systems will lead to improved satisfaction and outcomes for both intended parents and their healthcare team. Further research studies are recommended across all areas explored and identified from the findings including gamete donation; surrogate women; agencies representing both gamete donors and surrogates; the healthcare system including IVF clinics; obstetric providers and hospitals or birth centers providing care to those involved in surrogacy; policy issues; societal concerns and psychosocial concerns.

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- van den Akker, O. B. (2005). A longitudinal pre-pregnancy to post-delivery comparison of genetic and gestational surrogate and intended mothers: Confidence and genealogy. *Journal of Psychosomatic Obstetrics & Gynecology*, 26(4), 277-284. doi:10.1080/016748/20500165745
- van den Akker, O. B. (2007a). Psychological trait and state characteristics, social support and attitudes to the surrogate pregnancy and baby. *Human Reproduction*, 22(8), 2287-2295. doi:10.1093/humrep/dem155
- van den Akker, O. B. (2007b). Psychosocial aspects of surrogate motherhood. *Human Reproduction Update*, 13(1), 53-62. doi:10.1093/humanupd/dm1039

## Appendix A: Interview Guide

### Grand Tour Question:

“I am interested in learning more about the experience of intended parents during surrogate pregnancy and transition to parenthood in relation to the healthcare system. Would you please tell me about your own personal experience?”

Planned probes to be used if needed:

1. Tell me more about your decision to engage a surrogate to carry a baby for you. Describe how the process of engaging a surrogate occurred. What were some of the issues that you encountered during this period?
2. Tell me about your relationship with your surrogate mother. How was the surrogate mother selected and what role did you play in that process? Describe your interactions with the surrogate mother and the frequency of those interactions.
3. Tell me about how you are learning to become a parent. What activities are you involved in that help you to become a parent? Describe your interactions with physicians, nurses, and other health professionals during this time.
4. What is your involvement in the healthcare decisions for your pregnant surrogate? Describe the types of healthcare decisions that you have participated in.
5. Is your surrogate mother an altruistic arrangement or commercial? Does that make a difference to you?
6. Is your surrogate baby related to you genetically? Does that matter to you?
7. Tell me about your communication with the surrogate mother? What changes, if any, would you like to see?
8. What would you want to be different regarding your interactions and relationships with healthcare providers? How confident are you in taking care of the infant?
9. Is there anything else that you would like to add to the discussion?

### Study Importance



Through intended parents sharing their experience of surrogate pregnancy in the U.S. health care system, healthcare professionals such as nursing and medicine, as well as other disciplines, will have an improved understanding of their needs which will enhance how we provide care as well as enhance their outcomes.



**Kim L. Armour, Principal Investigator**

The University of Texas at Tyler  
Graduate School of Nursing  
Institutional Review Board  
C/O Office of Sponsored Research  
3900 University Blvd.  
Tyler, Texas 75799  
  
Email: [karmour@patriots.uttyler.edu](mailto:karmour@patriots.uttyler.edu)  
Phone: 630.414.0772

### What is the Lived Experience of Intended Parents During Surrogate Pregnancy and Transition to Parenthood in Relation to the U.S. Health Care System?

The University of Texas at Tyler  
Graduate School of Nursing



**Kim L. Armour, PhD(c), NP-BC, RDMS  
Principal Investigator**



**About the Study**



You are invited to participate in a research study that seeks to understand the experiences of intended parents during surrogate pregnancy in relation to the U.S. health care system.

The study will provide information regarding the experiences faced by intended parents during surrogate pregnancy in the U.S. health care

**IF YOU CHOOSE TO PARTICIPATE AND ARE ELIGIBLE YOU WILL BE ASKED TO COMPLETE**

- **DEMOGRAPHIC FORM**
- **AN INTERVIEW THAT WILL LAST APPROXIMATELY 1 HOUR**

**Information**

View this YouTube at

<http://www.youtube.com/watch?v=ubjt0DacMM>



**Questions**

**If you are interested in participating please call the principal researcher at**

**630.414.0772**



**Thank YOU!**

Eligible study participants who complete the interview process will be provided a

**\$10.00 gift card**

towards an online photo site.



**This study has been approved by:**

The University of Texas at Tyler  
Institutional Review Board  
C/O Office of Sponsored Research  
3900 University Blvd  
Tyler, Texas 75799

## What is the Lived Experience of Intended Parents During Surrogate Pregnancy and Transition to Parenthood in Relation to the U.S. Health Care System?

You are invited to participate in a research study that seeks to understand the experiences of intended parents during surrogate pregnancy and transition to parenthood in relation to the U.S. health care system.

This study will provide information regarding the experiences faced by intended parents during surrogate pregnancy in the U.S. Health Care system.

Eligible study participants who complete the interview process will be provided a

**\$10.00 gift card**

towards at an online photo site



Through intended surrogate parents sharing their experience of pregnancy and transition to parenthood in relation to the U.S. health care system, healthcare professionals such as nursing and medicine, as well as other disciplines, will have an improved understanding of their needs which will enhance how we provide care and improve outcomes.

# THANK YOU!

**Kim L. Armour, PhD(c), NP-BC, RDMS**

**Principal Investigator**

The University of Texas at Tyler

Graduate School of Nursing

Institutional Review Board

Email: [karmour@patriots.uttyler.edu](mailto:karmour@patriots.uttyler.edu)

Phone: 630-414-0772

**This study has been approved by:**

C/O Office of Sponsored Research  
3900 University Blvd., Tyler, Texas  
75799



**INFORMATION**

View this YouTube at

<http://www.youtube.com/watch?v=ubjti0DacMM>

**To participate or  
if you have questions**

Call the principal researcher at

**630-414-0772**



## Appendix C-IRB Approval

The University of Texas at Tyler  
Institutional Review Board

July 15, 2011

Dear Ms. Armour:

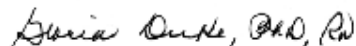
Your request to conduct the study *The Lived Experience of Intended Parents During Surrogate Pregnancy and Transition to Parenthood in Relation to the United States Healthcare System*, IRB #SUM2011-76 by The University of Texas at Tyler Institutional Review Board. This approval includes the written informed consent that is attached to this approval letter. Please use this consent for your participant signatures. If you have to use a recorded phone consent, please only do so as a last resort, and ensure that you are the only person accessing that recording. Also ensure that the consent recording is separate from the interview transcript. Please confirm that any research assistants or co-investigators have completed human protection training, and have forwarded their certificates to the IRB office (G. Duke).

**Please review the UT Tyler IRB Principal Investigator Responsibilities, and acknowledge your understanding of these responsibilities and the following through return of this email to the IRB Chair within one week after receipt of this approval letter:**

- This approval is for one year, as of the date of the approval letter
- Request for Continuing Review must be completed for projects extending past one year
- Prompt reporting to the UT Tyler IRB of any proposed changes to this research activity
- Prompt reporting to the UT Tyler IRB and academic department administration will be done of any unanticipated problems involving risks to subjects or others
- Suspension or termination of approval may be done if there is evidence of any serious or continuing noncompliance with Federal Regulations or any aberrations in original proposal.
- Any change in proposal procedures must be promptly reported to the IRB prior to implementing any changes except when necessary to eliminate apparent immediate hazards to the subject.

Best of luck in your research, and do not hesitate to contact me if you need any further assistance.

Sincerely,



Gloria Duke, PhD, RN

## Appendix D – Modification Request and IRB Approval

### THE UNIVERSITY OF TEXAS AT TYLER INSTITUTIONAL REVIEW BOARD

#### IRB MODIFICATION REQUEST

IRB: SUM2011-76

Approved by: G. Duke

Date: 9-21-2011

**Date:** September 20, 2011

**Principal Investigator:** Kim L. Armour

**Department:** Nursing

**IRB #:** SUM2011-76

**Project Title:** The Lived Experience of Intended Parents During Surrogate Pregnancy and Transition to Parenthood in Relation to the United States Healthcare System.

**Original Approval Date** July 15, 2011

**Please complete all sections as appropriate and submit to the UT Tyler IRB Chair.**

#### IDENTIFICATION OF CHANGE(S)

##### **A. GENERAL**

- Change in Title of Protocol
- Resubmission to Grant/Contract Agency
- Change in Extramural Sponsor
- Change in Cooperating Institution
- Change in Status of Protocol (e.g., from "active" to "hold")

Explain any related changes

Explain rationale for changes:

##### **B. DESIGN**

- Change in Study Design

UT Tyler IRB Modification Request  
Approved 3-10-05; Revised 0106; 0207; 0507; 0408; 0209; 0910



## Appendix D Continued

- Change in subject evaluation (e.g., number of visits, etc.)
- Change in administration or dosage of drug
- Change in drug formulation
- Change/Deletion of any test
- Change/deletion of device

Explain any related changes

Explain rationale for changes:

### G. STUDY POPULATION

- Change in sample size
- Change in eligibility criteria
- Change in exclusion criteria
- Alteration of study groups
- Other:

**Explain any related changes** The current inclusion criteria was detailed as those intended parents currently in a surrogate pregnancy arrangement awaiting the birth of their baby or those who have had a child no older than one year of age born of a surrogate woman. I would like to increase the inclusion of a child up to the age of five born of a surrogate woman.

**Explain rationale for changes:** I have only had 3 interviews since mid July and these participants have advised me that they have many friends with children between the ages of two and five who have voiced a willingness to participate. I have also heard from these intended parents as well as others, including faculty and my committee, that parents have exceptional recollection of their pregnancy and birth experience and that the data will not be harmed, rather enhanced by opening the inclusion criteria for further participation. Certainly opening the study inclusion criteria up to age five of the offspring of surrogate women will also allow further participation and study results to be ascertained for publication of findings.

### H. SUBJECT RECRUITMENT

- Change in recruitment procedures
- Change in ads, flyers, etc.

Explain any related changes

Explain rationale for changes:

UT Tyler IRB Modification Request  
Approved 3-10-05; Revised 0106; 0207; 0507; 0408; 0209; 0910

Appendix D Continued

September 21, 2011

The University of Texas at Tyler  
Institutional Review Board

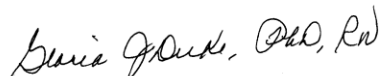
Dear Ms. Armour,

Your request to modify the approved research project: *The Lived Experience of Intended Parents During Surrogate Pregnancy and Transition to Parenthood in Relation to the United States Healthcare System* IRB #SUM2011-76, has been approved by The University of Texas at Tyler Institutional Review Board. This modification includes the change in eligibility criteria as indicated on your request form.

**Please acknowledge your understanding of the following through return of this email to the IRB Chair within one week after receipt of this approval letter:**

- This approval is for the duration of the original study that was approved November 4, 2010.
- Request for Continuing Review must be completed for projects extending past the year above
- Prompt reporting to the UT Tyler IRB of any proposed changes to this research activity
- Prompt reporting to the UT Tyler IRB and academic department administration will be done of any unanticipated problems involving risks to subjects or others
- Suspension or termination of approval may be done if there is evidence of any serious or continuing noncompliance with Federal Regulations or any aberrations in original proposal.
- Any change in proposal procedures must be promptly reported to the IRB prior to implementing any changes except when necessary to eliminate apparent immediate hazards to the subject.

Sincerely,



Gloria Duke, PhD, RN  
Chair, UT Tyler IRB

Appendix E: Demographic Data Form

Code #: \_\_\_\_\_ No. of total minutes: \_\_\_\_\_

Place of interview: \_\_\_\_\_

1. Birthdate: \_\_\_\_\_ (mm/dd/yyyy) Age: \_\_\_\_\_

2. Gender: Male \_\_\_\_\_ Female \_\_\_\_\_

3. Ethnicity: Which of the following best describes your race?

\_\_\_\_ American Indian or Alaskan Native

\_\_\_\_ Asian

\_\_\_\_ Black/African American

\_\_\_\_ White/Caucasian

\_\_\_\_ Native Hawaiian or Other Pacific Islander

\_\_\_\_ Other

4. Are you of **Spanish or Hispanic** origin or ancestry? Yes \_\_\_ No \_\_\_

5. Relationship Status: Single \_\_\_\_\_ Married: \_\_\_\_\_

Divorced \_\_\_\_\_ Widowed \_\_\_\_\_

Other \_\_\_\_\_

6. How many other children do you have, if any? \_\_\_\_\_

7. When is your baby due? \_\_\_\_\_ (month/date/year)

8. Expected baby is: Male \_\_\_\_\_ Female \_\_\_\_\_

9. If baby already born, what is birthdate: \_\_\_\_\_ (mm/dd/yyyy)

10. Education (highest level of schooling completed; indicate # of years completed):

\_\_\_\_ Grade School

\_\_\_\_ High School

\_\_\_\_ College

\_\_\_\_ Graduate School

11. Employment status (Are you currently working?)

Appendix E Continued

Full-time \_\_\_\_\_ Part-time \_\_\_\_\_ None \_\_\_\_\_

If so, what is your occupation?

\_\_\_\_\_

If you are NOT currently working, what was your previous occupation?

\_\_\_\_\_

12. Please indicate your annual salary:

- \_\_\_\_\_ 1) \$40,000 - \$49,999
- \_\_\_\_\_ 2) \$50,000 - \$59,999
- \_\_\_\_\_ 3) \$60,000 - \$69,999
- \_\_\_\_\_ 4) \$70,000 - \$79,999
- \_\_\_\_\_ 5) \$80,000 - \$89,000
- \_\_\_\_\_ 6) \$90,000 - \$99,999
- \_\_\_\_\_ 7) \$100,000 or more
- \_\_\_\_\_ 8) Other \_\_\_\_\_ (indicate amount)

13. Surrogacy Arrangement: Altruistic \_\_\_\_\_ Commercial \_\_\_\_\_

14. Type of Surrogacy: Genetic \_\_\_\_\_ Gestational \_\_\_\_\_

15. Cost of Surrogacy: \_\_\_\_\_

16. Preferred contact information for potential follow up:

a. Cell Number: \_\_\_\_\_

b. Email Address: \_\_\_\_\_

**THE UNIVERSITY OF TEXAS AT TYLER**

**Informed Consent to Participate in Research  
Institutional Review Board #Sum2011-76  
Approval Date: July 15, 2011**

1. **Project Title:** What is the lived experience of intended parents during surrogate pregnancy and transition to parenthood in relation to the U.S. healthcare system?
2. **Principal Investigator:** Kim L. Armour
3. **Participant's Name:**  
\_\_\_\_\_

**To the Participant:**

You are being asked to take part in this study at The University of Texas at Tyler (UT Tyler). This consent form explains why this research study is being performed and what your role will be if you choose to participate. This form also describes the possible risks connected with being in this study. After reviewing this information with me, you should be able to understand and make an informed decision on whether you want to take part in this study.

**4. Description of Project:**

The purpose of this study is to understand your experience as an intended parent in relation to the U.S. healthcare system. This will include the period during the surrogate pregnancy as well as the transition to parenthood when you receive your baby.

**5. Research Procedures**

If you agree to be in this study, we will ask you to do the following things:

- Talk with the researcher and receive a full understanding of the study.
- Read and sign a form (this consent form) agreeing to participate in the study.  
Meet with the researcher at an agreed upon location or by telephone
  - Complete a general information form with assistance of the researcher ;
  - Agree to talk with the researcher about your experience (interviewed) for approximately one hour and have the conversation audio recorded;

## Appendix F Continued

- The recording will only be listened to by me or a member of my research team who will type them;
  - The recording and typed interviews will not have your name on them;
  - A number will be used in place of your name to protect your identity and provide anonymity and confidentiality;
  - Only I will have access to the code numbers;
  - Signed consents and research papers will all be locked in a file in my home office;
  - The recording will be erased after the information is typed and listened to for accuracy.
- Have the opportunity to review your typed interview and give more information or provide corrections if needed.
  - Have the opportunity to review the full report of the lived experiences as described by all participants, once the study has been completed and prior to publication.

### **6. Side Effects/Risks**

Possible side effects may include increased anxiety related to sharing of your present or past experiences during your surrogate pregnancy in relation to the U.S. healthcare system. The questions may make you uncomfortable. You may choose not to answer a question or stop at any time. If you need a break or are not feeling well or become tired, or need to stop the interview or reschedule, please advise the interviewer. Your involvement in the study will not affect your relationship with your healthcare provider.

If you have any concerns please contact me, Kim L. Armour. Contact information by phone and email are listed at the end of this consent.

Identifiable risks have been listed, however unpredictable risks may exist.

### **7. Potential Benefits**

Your participating in this study will help researchers and healthcare workers to understand your experience as an intended parent in surrogate pregnancy and the transition to parenthood in relation to the U.S. healthcare system. It may also help in the development of practice guidelines for those who care for intended parents. Information from the study could also help with the development of laws and social

## Appendix F Continued

policy in the future. Your involvement in the study may not provide you a direct benefit; however it may benefit other intended parents in the future.

### **Understanding Of Participants**

8. I have been given an opportunity to ask any questions concerning this research study and the researcher has been willing to answer my questions.
9. If I sign this consent form I know it means that:
  - I am taking part in this study because I want to. I chose to take part in this study after having been told about the study and how it will affect me.
  - I know that I am free to not participate in this study and that if I choose to not participate, then nothing will happen to me as a consequence.
  - I know that I have been told that if I choose to participate, that I can stop being a part of this study at any time. I know that if I do stop being a part of the study, nothing will happen to me.
  - I will be told about any new information that may affect my willingness to continue participating in this study.
  - The study may be changed or stopped at any time by the researcher or by The University of Texas at Tyler.
  - The researcher will gain my written consent for any changes that may affect me.
10. I have been assured that that my name will not be revealed in any reports or publications resulting from this study without my expressed written consent.
11. I also understand that any information collected during this study, including any health-related information, may be shared with the following as long as no identifying information as to my name, address, or other contact information is provided:
  - Organization contributing money to be able to conduct this study
  - Other researchers interested in combining your information with information from other studies

Appendix F Continued

- Information shared through presentations or publications
12. I understand The UT Tyler Institutional Review Board (the group that ensures that research is done correctly and that measures are in place to protect the safety of research participants) may review documents that have my identifying information on them as part of their compliance and monitoring process. I also understand that any personal information revealed during this process will be kept strictly confidential.
  13. I have been told of and I understand any possible expected risks that are associated with my participation in this research project.
  14. I also understand that I will not be compensated for any patents or discoveries that may result from my participation in this research.
  15. If I have any questions concerning my participation in this project, I shall contact the principal researcher: Kim L. Armour, doctoral nursing student at the University of Texas at Tyler at 630-414-0772 or [karmour@patriots.uttyler.edu](mailto:karmour@patriots.uttyler.edu)  
  
You may also contact her Dissertation Committee Chair, Dr. Susan Yarbrough, at The University of Texas at Tyler at 903-566-7220 or [syarbrough@uttyler.edu](mailto:syarbrough@uttyler.edu)
  16. If I have any questions concerning my rights as a research subject, I shall contact Dr. Gloria Duke, Chair of the IRB, at 903-566-7023 or [gduke@uttyler.edu](mailto:gduke@uttyler.edu), or the University's Office of Sponsored Research:

The University of Texas at Tyler  
c/o Office of Sponsored Research  
3900 University Blvd  
Tyler, TX 75799

I understand that I may contact Dr. Duke with questions about research-related injuries.



Appendix F Continued

**17. CONSENT/PERMISSION FOR PARTICIPATION IN THIS RESEARCH STUDY**

Based upon the above, I consent to taking part in this study as it is described to me. I give the study researcher permission to enroll me in this study. I have received a signed copy of this consent form.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Person Responsible  
Relationship to Participant (e.g., legal guardian)

\_\_\_\_\_  
Witness to Signature

- 18.** I have discussed this project with the participant, using language that is understandable and appropriate. I believe that I have fully informed this participant of the nature of this study and its possible benefits and risks. I believe the participant understood this explanation.

\_\_\_\_\_  
Researcher/Principal Investigator  
Kim L. Armour, PhD(c), NP-BC, RDMS

\_\_\_\_\_  
Date

Appendix G: Letter of Release for In Press Manuscript #2



*Promoting the health  
of women and newborns.*

March 21, 2012

Dr. Wolf  
Office of Graduate Studies  
University of Texas at Tyler  
Tyler, TX

Dear Dr. Wolf,

I am writing on behalf of graduate student Kim Armour to confirm for your office the following:

1. Kim Armour has submitted and the clinical journal, *Nursing for Women's Health*, has accepted for publication (March 8, 2012) an article entitled "Beyond Borders: International Surrogacy," which is currently In Press
2. Kim Armour has the express permission of the Association of Women's Health, Obstetric & Neonatal Nurses to include the article in her Dissertation at the University of Texas at Tyler
3. As copyright holder of said article, AWHONN agrees that should the University want to provide said article for dissemination, permission would be granted and AWHONN requests that when published, as possible, the accepted version of the article is the one that is circulated within the Dissertation.

If I can be of any further assistance, please do not hesitate to contact me at the number or email provided herein.

Best to you today,

Carolyn Cockey

Carolyn Davis Cockey, MLS  
AWHONN Director of Publications

(877) 377-5326  
carolyndc@awhonn.org

2000 L Street, Suite 740 ~ Washington, DC 20036  
(202) 261-2400 ~ Fax (202) 728-0373 ~ www.awhonn.org

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## BIOGRAPHICAL SKETCH

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NAME Kim Lucille Armour PhD, NP-BC, RDMS	POSITION TITLE Director of Operations, Northwestern Memorial Physician Groups, Obstetrics & Gynecology		
INSTITUTION AND LOCATION	DEGREE <i>(if applicable)</i>	MM/YY	FIELD OF STUDY
College of DuPage, Glen Ellyn, IL	ADN	06-84	Nursing
Keuka College, Keuka Park, NY	BSN	01-96	Nursing
University of Pennsylvania, Philadelphia, PA	MSN	08-97	Nursing/Perinatal Nurse Practitioner Certificate
University of Texas at Tyler, Tyler, Texas	PhD(c)	05-12	Nursing/Global Healthcare/Communities

### A. Personal Statement

The purpose of this study was to understand the lived experience of intended parents during surrogate pregnancy and their transition to the parenthood in relation to the United States (U.S.) healthcare system. Intended parents are overlooked by the healthcare system during pregnancy due to the fact that they are not carrying the pregnancy and the surrogate woman is the identified patient who receives obstetric and prenatal services (ACOG, 2008). The results of this study will enhance healthcare professionals understanding of the lived experience of intended parents during surrogate pregnancy and transition to parenthood in relation to the U.S. healthcare system. Thematic analysis gleaned from this study will bring attention to this growing population, their healthcare needs and assist in the development of evidence based care guidelines for nursing and other health professionals. In addition, research findings will fill a large gap in the scientific literature and provide foundation for further studies of intended parents, the surrogate mother and her partner, the child born of the surrogate, the intended parents, their family including siblings of the surrogate child, the surrogate mother's children and will begin to address the NIH call for genetic-related studies (NINR, 2006).

### B. Positions and Honors

2012-Current, Director of Operations, Northwestern Memorial Physician Group, Ob/Gyn  
 2006-Current, Expert Faculty, Institute for Healthcare Improvement, Cambridge, MA  
 2010-2011, Faculty Instructor, School of Nursing, Queens University, Charlotte, NC

1999-2010, NP/Patient Care Manager, Central DuPage Hospital, Winfield, IL

**Professional Associations**

**American Nurses Association, Washington, D.C.**

**Association of Women's Health, Obstetric and Neonatal Nurses, Washington, D.C.**

Chair, National Nominations Review Committee, Appointed, January 2011-June 2011

Past President/Nominations Chair, Elected position, January 2010-December 2010

President, Board of Directors, elected position, January 2009-December 2009

National Board of Directors: President Elect, January 2008-December 2008

National Board of Directors: Director, January 2006-December 2007

National Board of Directors: Director, January 2004-December 2005

Illinois Nurses Association, Springfield, IL

National Association of Nurse Practitioners in Women's Health, Washington, D.C.

National League of Nursing, Washington, D.C.

Sigma Theta Tau, Indianapolis, IN

Society of Diagnostic Medical Sonographers, Dallas, TX

South Carolina Nurses Association, Columbia, SC

**Honors**

The following graduate honors were received at the University of Texas at Tyler, TX

Buie Presidential Scholarship, Recipient Fall, Spring, Summer 2010, 2011

Herbert & Mervina Buie Pr II Scholarship, Recipient, Spring, 2011

Virginia Smith Wilks Nursing Scholarship, Spring, 2011

Ruby Stubblefield Scholarship, Recipient Fall, Spring, Summer, 2010

Ruggles-Gate Fellowship, Recipient, Fall 2008, Spring, 2009

Competitive Waiver Scholarship, 2008, 2009, 2010, 2011, 2012

Various honors received

The Tom Williams, MD Nursing & Patient Care Services Recognition Award;

Volunteerism, Recipient December, 2006

March of Dimes, Eighth Annual Jonas Salk Health Leadership Award; Nursing

Chicago, IL, Recipient September, 2005

AWHONN's National Award of Excellence: Clinical Practice, Recipient, June, 2003

Sigma Theta Tau International-Induction, Honor Society of Nursing

**C. Selected Peer-reviewed Publications**

Armour, K. (In press, 2012). Beyond Borders: International surrogacy. *Nursing for Women's Health*.

Armour, K. (2009). Maternal mortality here and abroad: Awareness, advocacy and action. *Nursing for Women's Health*. June-July, 13(3): 187-190.

Armour KL, Callister LC. (2005). Prevention of triplets and higher order multiples: trends in reproductive medicine. *The Journal Of Perinatal & Neonatal Nursing*. Apr-Jun; Vol. 19 (2), pp. 103-11.

Armour K. (2004). Antepartum maternal-fetal assessment: using surveillance to improve maternal-fetal outcomes. *AWHONN Lifelines*, Jun-Jul; 8 (3): 232-240