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Review of Factors Affecting the LGBT Population When Choosing a Surrogate Decision-maker

Christina Stewart Browning
University of Central Florida, NOELLE.BROWNING@uca.edu



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**REVIEW OF FACTORS AFFECTING THE LGBT POPULATION
WHEN CHOOSING A SURROGATE DECISION-MAKER**

by

CHRISTINA STEWART BROWNING

**A Thesis submitted in partial fulfillment of the requirements
for the Honors in the Major Program in Social Work
in the College of Health and Public Affairs
and in the Burnett Honors College
at the University of Central Florida
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Thesis Chair: Dr. Julia Buckey

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ABSTRACT

Choosing a surrogate to make medical decisions for a patient is an emotionally challenging task. In hospital settings, it is estimated over 86% of life saving medical decisions have been made by a surrogate (Swigart, Lidz, Butterworth, & Arnold, 1996). For the marginalized populations of lesbian, gay men, bisexual, and transgender persons (LGBT), decisions are especially difficult, compounded by issues of discrimination, lack of legal support, level of relationship commitment, and complicated disclosure to family and medical professionals (Riggle, Rostosky, Prather, & Hamrin, 2005). Limited research has been presented regarding environmental and social factors that impact the choice of a surrogate decision-maker for a LGBT individual. This in-depth literature review will examine factors influencing individual surrogate choice, identify obstacles and gaps in the literature findings, and explore services required by the LGBT population.

DEDICATIONS

For my loving sister and family, who have always believed in me. Especially for my husband and daughter, who are my best friends and fill the role of mothers of the house when I am not there.

For all the teachers that have pushed me with the expectation that I will succeed, without you none of this would be possible.

And for all my friends, who charge my batteries by being great listeners and providing their loving support.

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INTRODUCTION

The National Hospice Foundation Survey (1999) determined that “one out of every two Americans overwhelmingly state that they will rely on family and friends to make decisions about care at the end of life” (p.1). Approximately 86% of life sustaining medical decisions are made by someone other than the patient in hospital settings: yet, only 15% have completed some type of medical directive outlining their wishes for guiding medical decisions (Swigart, Lidz, Butterworth, & Arnold, 1996).

When a person chooses a medical surrogate, the personal psychology, life experiences, culture, religion, and length of relationship between the patient and his or her prospective surrogate must be contemplated (Kagawa-Singer & Blackhall, 2001). When a lesbian, gay men, bisexual, or transgender (LGBT) person is planning for end of life, these concerns are magnified. This marginalized population must adapt to laws and statutes written primarily for a heterosexual population, as well as societal values and religious views that the LGBT community may view as non-supportive (Bonvicini & Perlin, 2003).

To identify as a member of the LGBT community, a person may experience *internalized homophobia*, or the dislike of a person’s self for identifying with the LGBT orientation (Bonvicini & Perlin, 2003), discrimination in all areas of his or her public life, and a fear of disclosing their sexual orientation (Riggle & Rostosky, 2005). The LGBT individual is challenged to choose a surrogate that can navigate these concerns while protecting the care giving

recipient's wishes concerning end of life medical care (Stein & Bonuck, 2001).

This paper will explore the social and legal environment that influences the choice of surrogate decision maker for the LGBT population. However, it is helpful to review the brief history of surrogacy in the United States and how that history impacts the needs of the LGBT surrogate populations.

Surrogates

As technology increases, so does the human lifespan as well (Cruzan v. Director, Missouri Department of Health, 1990). The evolving and continuing advancement of life sustaining treatment has created a need for the patient to have a substitute decision-maker. In the United States, it is estimated that over 75% of decisions regarding life-threatening illnesses are made by surrogates (Vig, Starks, Taylor, Hopley, & Fryer-Edwards, 2007).

The decisions surrogates must make for their loved ones are grounded in the *substituted judgment principle*. This guides surrogate decisions based on the patient's choice of which medical treatments they would want if they were able to make decisions when they were not incapacitated (Bailey, 2002). When *incapacitated*, a patient exhibits a lack of competence in making decisions and, therefore, the individual requires a substitute to make decisions for them (Ditto, 2006).

In 1990, the Patient Self-Determination Act's (PSDA) initial purpose was to ensure that federally funded individuals had a choice in their own end-of-life care (PSDA, 1990). The PSDA allowed people the ability to document, by using

advance directives, their preferences in life sustaining treatment, such as artificial hydration and nutrition, the use of a ventilator, and a Do Not Resuscitate order. In addition, individuals were given the right to document their choice of a surrogate in the event of incapacity through a document commonly called a *Power of Attorney for Health Care* (Douglas & Brown, 2002).

The effectiveness of health care surrogacy and advance directives can be limited by a number of complications. Patients may not have communicated to their surrogates their wishes regarding end of life decisions (Bailey, 2002).

Advance directives can be too general and fail to list enough specific treatment details. For example, a choice preferring artificial nutrition would be made, but there would be no reference to a choice preferring the use of artificial hydration. Consequently, a doctor or nurse may not administer a treatment consistent with patient preferences. In addition, wishes expressed when patients were healthy may not match wishes made during the progression of a critical illness (Bailey, 2002). When trying to make a timely medical decision, a surrogate may struggle with the influences from their own value systems, have difficulties in communicating with medical professionals, and face acceptance or rejection of their medical decisions by other family members (Vig et al., 2007).

If a patient does not choose and document a choice of surrogate, legislative systems provide a safety net to protect the incapacitated patient. In Florida, for example, hierarchical order of responsibility for becoming the surrogate falls to the spouse and then, to the adult children, parents, grandparents, aunts and uncles, and cousins (Absence of Advance Directive,

Fla. Stat. Ann.765.401, 2009). A *surrogate*, also called a proxy in some states, is the individual that is chosen to act on behalf of the patient as the substitute decision-maker (Buckey, 2007). If a surrogate cannot be found, then the courts must make a judgment for treatment on behalf of the patient (Riggle et al., 2005).

Judicial History of Surrogacy

In 1976, Karen Ann Quinlan, suffering in a *persistent vegetative state* (PVS), drew media attention after the hospital and doctor refused her father's request to remove his daughter's ventilator (Quinlan v. New Jersey, 1976). PVS is a condition in which the patient is not cognitively aware of their environment nor can he/she consciously control their bodily functions (Hahn, 1996). In such a situation the individual is not capable of articulating their treatment preferences. This case went to the New Jersey Supreme Court which ruled that individuals have the "right to die" under the Constitution's protection of a right to privacy. This ruling became a model for other states (Quinlan v. New Jersey, 1976).

Later in 1983, the American public's attention was again drawn to the dilemmas of end-of-life care when the *In re Guardianship of Sharon Kowalski*, *Ward* 478 N.W.2d 790 (as cited in Smolinski & Colon, 2006) surfaced as a landmark court battle for a homosexual's right to choose their partner as a surrogate decision-maker. Sharon Kowalski, struck by a drunk driver in 1983, suffered severe injuries that placed her in a comatose state. When her partner of 4 years, Karen Thompson, identified herself to Kowalski's parents, the parents reacted unfavorably. An 8-year court battle ensued; Kowalski's father was

appointed legal guardian and barred Thompson from seeing her partner. After many years of rehabilitation, Sharon Kowalski taught herself to type messages on a computer; she immediately began to ask to live with Thompson. All requests were denied by the courts and by Kowalski's father until, in 1988, the courts found Kowalski competent. At that time, she was awarded occasional visits with her partner. Eight years later, in 1991, Sharon Kowalski finally won the right to live with her partner, Karen Thompson (Smolinski & Colon, 2006). While not directly a surrogacy issue, this case illustrates the difficulty that Lesbian couples can have in having their partnership recognized legally.

In 1990, the removal of Nancy Cruzan's feeding tube, followed by the public battle to maintain Terri Shiavo's feeding tube in 2005, provided the American public exposure to the strengths and weaknesses of advance directives (Smolinski & Colon, 2006). In each situation, surrogates made end-of-life medical decisions for an incapacitated individual. Surrounding the media attention, in 1990, the federal government passed the Patient Self Determination Act that required service providers that file Medicaid or Medicare claims to ask patients if they have advance directives. To further protect the patients, the patient providers are required to document if the patient has an advance directive in the medical charts (Douglas & Brown, 2002).

Surrogacy in LGBT Population

In 2005, there were 763,000 householders living in a same-sex partnered home (United States Census Bureau, 2008). Lesbian, gay men, bisexuals, and

transgender (LGBT) individuals represent every economic, age, religious, and geographic group, not to mention every diverse culture and ethnic group, in our society (Bonvicini & Perlin, 2003). The Metlife Mature Market Institute Study (2006/2010) found a total of 18% of gay men and lesbian baby boomers are caring for their partners. Stein and Bonuck (2001) found that 43% of the LGBT participants preferred their partner to be the surrogate, yet only 21% had documented their wishes.

In a heterosexual marriage, the spouse has the primary responsibility for making medical decisions even if no advance directives are signed. Although an automatic right is given to heterosexual married couples to make health decisions, there is no guarantee of mutual support for LGBT partners that have been together for many years (Smolinski & Colon, 2006). Absent a legal marriage contract and the non-familial connection, LGBT couples must complete advance directives if they choose to become the surrogate decision-makers for each other. Many in the LGBT community must face these concerns without the support of offspring or the legal protection of marriage (Bonvicini & Perlin, 2003).

After passage of the Defense of Marriage Act (1996), in which the federal government only recognized a union between a man and a woman (Smolinski & Colon, 2006), the United States eradicated pro-LGBT legislation and no longer legally acknowledged same-sex couples. To date, only five states (Massachusetts, Connecticut, Iowa, New Hampshire, and Vermont) recognize a marriage between two persons of the same gender (Knochel, 2010). The District of Columbia and eight states (California, Maine, Maryland, Nevada, Oregon,

Washington, and Wisconsin) do recognize civil unions, also known as domestic partnerships, as another means to bypass federal law (Fredriksen-Goldsen & Hooyman, 2007; Knochel, 2010). Consequently, although surrogacy laws were written to apply to all American citizens, the utilization of the surrogacy laws by the LGBT community possesses difficulty for the LGBT patients they represent. This fragmentation provides little in the way of support or guidance for professionals working with this marginalized population (Knochel, 2010).

Summary

In an effort to shed light on concerns of the LGBT community, this review of existing literature will examine the information on the LGBT population in order to identify the social and environmental factors that influence the choice of surrogate. Its purpose is to (a) elucidate current circumstances for LGBT individuals, (b) educate the research community on the needs of the LGBT population, and (c) examine current literature to recommend future evidence based practice to increase social work and related human services available to the LGBT population. This literature review will concentrate on the empirical literature on surrogacy, interdependence, and interactions within the social environments that influence the choice of surrogate for the LGBT community.

Throughout this review, various acronyms are used referring to the lesbian, gay men, bisexual, and transgender population. This researcher will endeavor to identify this population as LGBT, unless this population is referred to under a different acronym by the author being reviewed. In which case, this

researcher will give the acronym used by that author when discussing the work.

Implications for social work practice must ethically address both the diversity and scope of the LGBT population, inclusive of age groups, geographical locations, ethnicities, religions, educational levels, and income levels. Not only is extensive research needed surrounding the selection and appointment of a surrogate representative for members of this population, but new research techniques and methods to reach this population should be addressed.

METHOD

Databases utilized in searching the literature for health care surrogacy for LGBT persons included Academic Search Premier, LexisNexis Academic, PsychInfo, and Social Work Abstracts. Keywords used were *LGBT, gay, lesbian, same-sex, end of life, medical surrogates, health care proxy, and advance directives*. Although numerous articles were found addressing decision making in the surrogate population, studies addressing the challenges faced by the LGBT community when choosing a surrogate decision-maker were limited to 14 articles.

Utilizing the literature categories and framework by Klein and Bloom (1994) and as applied by Buckey (2007), the first category to be reviewed will be the commentary, or position papers, followed by valuation literature, indicating ethical positions. Empirical work, divided into subcategories of qualitative and quantitative literature, will follow. Of the articles located, seven were commentary or valuation literature; the remaining articles were identified as qualitative or quantitative empirical studies. The theoretical framework of Klein and Bloom will support this researcher's efforts to uncover the dynamic environment that surrounds this issue within the framework of the culturally prescribed norms of current society.

Contributions to this review of literature have been gathered from the fields and journals of psychology, psychiatry, political science, and social work, and span the years from 2001 to 2010. The majority of the literature found was

published between the years 2004 to 2006 ($n = 7$) with an upsurge of literature recently in the latter year, 2010 ($n = 3$). The articles reviewed here were found in *Journal of Gay & Lesbian Social Services* ($n = 2$), *Journal of GLBT Family Studies* ($n = 2$), *Journal of Feminist Family Therapy* ($n = 1$), *Patient Education and Counseling* ($n = 1$), *The Journal of Social Work in End of Life & Palliative Care* ($n = 1$), *The Journal of Gerontological Social Work* ($n = 1$), *Family Process* ($n = 1$), *The Journal of Psychological Oncology* ($n = 1$), *Professional Psychology, Research, and Practice* ($n = 1$), *Psychology, Public Policy, & Law* ($n = 1$), *Journal of Palliative Medicine* ($n = 1$), and *The Journal of Family Issues* ($n = 1$).

An overview of the commentary and valuation literature is provided in Appendix A. Each of the eight qualitative and quantitative empirical articles were examined for the following criteria: (a) sample size, (b) age range, (c) design, (d) findings, and (e) limitations. A summary of the qualitative and quantitative empirical literature is provided in Appendices B and C.

REVIEW OF COMMENTARY AND VALUATION LITERATURE

Although this review spans literature from political science to psychiatry, social workers are especially equipped in working with and advocating for the LGBT population. In the National Association of Social Workers Code of Ethics Preamble (2009), social workers are expected to be "sensitive to...and strive to end discrimination, oppression, poverty, and other forms of social injustice" (para. 2). Many other helping professions uphold ethical standards in working with clients and patients, yet the role of the social worker expands to advocate for dignity and respect despite the obstacles of discrimination and bias (Smolinski & Colon, 2006).

Social workers begin the relationship with the client by starting where the client is in their current life situation (Hepworth, Rooney, & Larsen, 2002). When interacting with this marginalized population, a person-in-environment perspective is used to identify the environmental, social, physical, and psychological forces that influence the individual (Payne, 1997). The social worker must appreciate the obstacles and provide accurate resources to assist the client to rise above them (Smolinski & Colon, 2006).

In a study performed in New Hampshire among the critically ill, general population, 44% of participants had a completed Durable Power of Attorney for Health Care, or surrogacy form. Overall, patients responded that they feel ambivalence and anxiety when faced with making end of life decisions due to the ensuing responsibilities for their chosen surrogates (Hayslip, Hansson,

Starkweather, & Dolan, 2009).

Commentary Literature

As defined by Klein and Bloom (1994), commentary literature comments, describes, or critiques research by presenting complex analyses or simplistic descriptive summaries. Commentaries often define the contemporary problem, review the literature, and offer general opinions. This literature calls for exposure to evaluate professional practices and ground theory in research (Klein & Bloom, 1994).

Literature from all five commentary articles focused on the social environment and challenges facing the LGBT population in the United States. End of life concerns, aging within the LGBT community, and advance planning, were discussed and three articles identified a lack of social, legal, and medical support for this community (Riggle & Rostosky, 2005; Neustifter, 2008; Smolinski & Colon, 2006). Physician-LGBT patient communication patterns were discussed by Bonvicini and Perlin (2003) and an in depth review of the importance of relationship recognition was addressed by Killian (2010).

The authors contend that many LGBT individuals receive less support because of the lack of recognition and acceptance of their relationships (Bonvicini & Perlin, 2003; Neustifter, 2008; Riggle & Rostosky, 2005; Smolinski & Colon, 2006). Not only does the LGBT population face a lack of recognition of their romantic relationships by their families and society, they also encounter a lack of recognition of their *fictive kin* by society and by the government when

awarding benefits (Bonvicini & Perlin, 2003). Fictive kin refers to people that are not traditionally related to the LGBT person, yet still considered family (Neustifter, 2008). Especially important is this nontraditional family structure of close friends when relationships within LGBT families of origin are strained (Bonvicini & Perlin, 2003).

According to Riggle and Rostosky (2005), disclosure of sexual orientation to the family of origin creates a risk of discrimination and rejection, in conjunction with creating stress within the relationship when one member of the same sex couple discloses more about their same sex relationship than the other member of the couple. Disclosure levels vary even within a family, so that an extended family may be unaware of LGBT member's relationship (Riggle & Rostosky, 2005). A LGBT individual may not enjoy a supportive environment to discuss their relationships as a heterosexual person traditionally does with their friends, co-workers, religious community, or family (Bonvicini & Perlin, 2003). After death of a partner, the LGBT individual may also be excluded from funeral arrangements and, therefore, suffer due to lack of disclosure or acceptance (Smolinski & Colon, 2006).

Importantly, these environmental issues continue in the patient population, where physicians see an estimated 3-6% of patients who identify with the LGBT population (as cited in Bonvicini & Perlin, 2003). Bonvicini and Perlin noted that attitudes of clinicians reflect those of society and that physicians receive little training addressing the specific needs of the LGBT population. Additionally, clinicians are uncomfortable discussing sexuality with their patients and generally

make assumptions of heterosexuality (Bonvicini & Perlin, 2003).

To achieve appropriate treatment and an accurate diagnosis, communication between physician and patient is crucial (Bonvicini & Perlin, 2003). When a physician assumes that a LGBT is heterosexual, confidence in care can be endangered and, as a result, the patient may not seek care as often. Lesbians avoid treatment and disclose their sexual orientation to physicians less often because of a higher rate of negative experiences, which is a greater concern because of the potential for increased need for services as they age (Neustifter, 2008). Additionally, same sex couples fear substandard care if they disclose their sexual orientation to physicians due to discrimination (Riggle & Rostosky, 2005). As a result, LGBT patients are concerned that when bias is present advance directive documents may be ignored by medical staff or turned aside in favor of traditional family members' wishes (Killian, 2010).

Certainly, the legal and social environment for choosing a surrogate for the LGBT population is challenging. So, without a signed Durable Power of Attorney for Health Care (DPAHC), a partner cannot make medical decisions (Bonvicini & Perlin, 2003). Partners and fictive kin may also be denied entrance into critical care units or excluded from conversations with medical staff (Killian, 2010). Especially important in a time of crisis, advance directive documents may be employed and consequently, at which time the same-sex relationship becomes unveiled to the medical staff and the family, creating the potential for conflict regarding patient care and the fears of discrimination and bias from medical staff and family (Riggle & Rostosky, 2005).

Overall, the commentary literature expands the knowledge base about the challenges and barriers facing the LGBT population before choosing a medical surrogate decision maker. Universally throughout the literature, the issues of disclosure, patient-physician communication, and the legal environment in the United States appear as high priority concerns for this population.

Valuation Literature

The valuation literature, as defined by Klein and Bloom (1994), presents a value position purposefully and is the ends and means of action. This literature clearly presents a preferential choice of a value position, as the valuation literature can support ethics or morals or can simply make general suggestions of social work reform (Klein & Bloom, 1994).

Two articles focused directly on the transgender population within the surrogacy decision making literature for LGBT individuals (Knochel, 2010; Witten, 2009). As components of this literature category, these two articles examined the transgender population apart from lesbians, gay men, and bisexuals.

It is estimated there are approximately 1 million transgender individuals aged 65 or older in the United States (Witten, 2009). Historically, new or existing marriages face termination when a person changes sex from male to female (MTF) or from female to male (FTM), in part, due to the provisions within the Defense of Marriage Act. Also for these individuals, the cost of legally documenting in the court system the transition to the new sex by changing the birth name and legal sex at times creates a barrier to completion of advance

directives because for advance directives to be officially recognized the name on the legal documents must match government records (Knochel, 2010).

Therefore, both Knochel (2010) and Witten (2009) state transgender individuals fear that because their birth documents do not match their daily lives, the right to visit a partner, to make medical decisions, or make burial arrangements might be ignored. Knochel (2001) recommends the passing of laws to utilize Reciprocal Beneficiary Agreements, an agreement providing benefits to those that legally cannot marry, is recommended.

As transgender individuals are more at risk for a lack of social support and discrimination, families can become fragmented after a male to female (MTF) or female to male (FTM) transition. Therefore, parents, siblings, children, and friends may no longer communicate with the transgender individual. Social isolation can occur and the choices for an end of life surrogate are further diminished (Witten, 2009).

The valuation literature presents a view of the lives of transgender persons marked by legal constraints, discrimination, and the lack of social support, all greatly magnified through the context of social isolation. Extensive research into the needs of the transgender community, as a subgroup in the LGBT population, at the end of life is necessary. Research on effectiveness of Reciprocal Beneficiary Agreements should be conducted (Knochel, 2001).

REVIEW OF EMPIRICAL LITERATURE

Empirical literature records and observes social events that are planned so that measurement is possible. Two major categories of empirical literature are qualitative and quantitative literature (Klein & Bloom, 1994). A total of seven empirical articles were found on the environmental and social factors that influence the choice of a medical surrogate by a LGBT individual: three qualitative studies and four quantitative studies. A review of the empirical literature follows which provides an overview of familial and community support systems, long term planning by use of advance directives, and the needs of the aging in this population.

Qualitative Literature

A total of three articles were examined. Two studied the use of advance directives for aging LGBT individuals, in conjunction with examining their expressed attitudes, beliefs, and opinions of needs (Hash & Netting, 2007; Orel, 2004). The third article studied perceptions of family support by same sex couples (Rostosky et al., 2004). The overwhelming lack of research into LGBT concerns and the use of advance directives for medical surrogacy lead this researcher to extract from these studies the social and environmental context in which this population lives. An overview of the studies can be found in Appendix B.

Research design. The qualitative studies reviewed used grounded theory

that involves coding and analyzing of transcriptions from respondents in interviews and focus groups (Hash & Netting, 2007; Orel, 2004; Rostosky et al., 2004). Grounded theory is used in qualitative research to systematically develop a theory to explain a process or interaction on a given topic. In this type of research, transcripts are coded for repeated categories which then are developed into themes (Creswell, 2008).

Sampling. All three studies used purposive sampling to select LGBT participants (Hash & Netting, 2007; Orel, 2004; Rostosky et al., 2004).

Purposeful sampling techniques are used to intentionally chose sites and participants to examine the topic of interest (Creswell, 2008). Additionally, in all three articles, convenience sampling, which involves using groups of participants that are available and willing, was used. In particular, Orel (2004) used snowball sampling that involves asking groups or individuals to identify other groups to participate (Creswell, 2008) in conjunction with convenience sampling.

Study participants were recruited through advertisements, announcements, and listserv postings on the internet that serve lesbians and gay men (Hash & Netting, 2007; Rostosky et al., 2004). In addition, local and national lesbian and gay men advocacy groups, support groups, religious groups, and mental health counselors were contacted to recruit study participants (Orel, 2004). Studies by Hash and Netting (2007) and Orel (2004) gathered participants from locations across the United States, whereas Rotosky et al. (2004) studied participants in a single mid-sized southern geographical location.

Samples ranged in focus from being simply over 18 and in a same-sex

relationship for over six months (Rostosky et al., 2004) to over 50 years old who currently or previously cared for a chronically or terminally ill same-sex partner (Hash & Netting, 2007). In the Hash and Netting (2007) study, all but one participant could be identified as a post caregiver. For Orel's (2004) study, participants had to be an elder, defined as over age 50, and identify with the lesbian, gay men, or bisexual orientation. No transgender individuals or male bisexual individuals participated in any of the studies; three women identifying as bisexual participated in one study (Orel, 2004).

Studies sampled both couples and individuals. Sample sizes ranged from 14 couples (Rostosky et al., 2004) to 26 individuals (Orel, 2004). Two of the studies focused on aging LGBT with ages ranging from 50-84 (Hash & Netting, 2007; Orel, 2004). The average ages of these studies were 60 and 72.3 respectively. The age of the participants in the third study ranged from 18 to 50 with the average age at 34.5 years (Rostosky et al., 2004).

All samples were homogeneous regarding race/ethnicity, income level, and education level. In Hash and Netting's (2007) study, the majority of the participants ($n = 17$) were Caucasian, had a Bachelor's level education or better ($n = 14$), and were employed ($n = 10$) or retired ($n = 7$). In 2004, Orel conducted a study of 26 participants with a majority of participants identified as white ($n = 17$), middle income ($n = 15$), and having a high school diploma only ($n = 17$). Lastly, the study performed by Rostosky et al. (2004) included a total of 28 individuals, 25, white and 26, with some college or better.

Data collection. Data collection was performed through the use of face to

face, open-ended, and semi-structured interviews (Hash & Netting, 2007; Orel, 2004; Rostosky et al., 2004). Hash and Netting (2007) performed fourteen of their in-depth interviews over the telephone and recorded the conversations. Three groups of focus groups were interviewed for sessions of one and a half to two hours conducted over a period of six months in the study by Orel. All three studies either audio or video taped the sessions (Hash & Netting, 2007; Orel, 2004; Rostosky et al., 2004).

Data analysis. Study procedures were identical. Individual transcripts were transcribed, categorized, and coded to identify emerging themes (Hash & Netting, 2007; Orel, 2004; Rostosky et al., 2004). The coding process was completed using constant comparison for Hash and Netting's article, whereas triangulation was utilized in the other two articles (Orel, 2004; Rostosky et al., 2004). Further rigor was established by peer debriefing and member checking in Hash and Netting's (2007) study, while Rostosky et al. used Consensual Qualitative Research procedures, a process using two coders, one internal auditor, and one external auditor to come to a consensus on the emergent themes of the study (Hill, Thompson, & Williams, 1997). Uniquely, after transcribing all study materials ($n = 40$) and identifying themes, Rostosky et al. (2004) randomly chose seven female and seven male couple transcripts to analyze the data.

The importance of family support and social networks were identified as a major theme throughout all three articles in terms of disclosure of sexual orientation (Hash & Netting, 2007; Orel, 2004; Rostosky et al., 2004). Hash and

Netting found that one major reason advance directives were completed focused on the perceived fears by LGBT individuals of intrusion by family or friends attempting to make medical decisions for them instead of allowing their choice of surrogate to make decisions and to prepare for who would be the caregiver when illness struck.

Interactions with formal systems, such as legal, medical, and religious, were addressed in two of the articles (Hash & Netting, 2007; Orel, 2004). The lack of legal rights for same-sex couples, inherently granted to heterosexual couples, affected actual completion levels of advance directives (Hash & Netting, 2007). Discrimination and bias were identified as fears in medical settings that could affect the quality and quantity of medical service received (Orel, 2004).

Physical and mental health issues were explicitly addressed by Orel (2004). In this study, concerns over poor physical health yielded information that over half of the participants were not allowed to visit their partners when hospitalized at least on one occasion. Yet, those with a higher level of disclosure to the health care team and family experienced less frustration with the health care system, indicating perhaps a greater comfort communicating in that system. Over half of the participants in this study reported experiencing depression, substance abuse, and anxiety at some point in their lives (Orel, 2004).

All qualitative studies lacked diversity in sampling (Hash & Netting, 2007; Orel, 2004; Rostosky et al., 2004). Obtaining prospective samples in the LGBT community is difficult due to potential participants' lack of disclosure to their family or community. Therefore, researchers relied on primary recruitment from

LGBT organizations or literature. The lack of the researchers' ability to interview both members of a couple is a limitation of the studies (Hash & Netting, 2007).

Quantitative Literature

A total of four articles were examined. Two studies specifically examined the use of advance directives in the LGBT population (Riggle, Rostosky, & Prather, 2006; Riggle et al., 2005). Stein and Bonuck (2001) examined the preferences of the LGBT community for end of life care and included advance directives. Lastly, the MetLife Mature Market Institute (2006/2010) study has been included because it reviewed the demographics and preferences of this population nationally. An overview of the quantitative literature studies can be found in Appendix C.

Research design. All of the quantitative studies reviewed used survey designs (MetLife Mature Market Institute, 2006/2010; Stein & Bonuck, 2001; Riggle et al., 2006; Riggle et al., 2005). Survey questionnaires determined the characteristics, values, opinions, and behaviors of this population jointly with correlational statistical tests to measure the degree of association between several variables (Creswell, 2008).

Sampling. All of the studies employed convenience sampling through web-based announcements and invitations (MetLife Mature Market Institute, 2006/2010; Stein & Bonuck, 2001; Riggle et al., 2006; Riggle et al., 2005). Additionally, snowball sampling was utilized through the use of community-based organizations, word of mouth, and community newsletters (Stein & Bonuck,

2005) and email forwarding (Riggle et al., 2006; Riggle et al., 2005). Researcher approach to participant recruitment varied from New York City metropolitan area to nationwide (Stein & Bonuck, 2001; MetLife Mature Market Institute, 2006/2010; Riggle et al., 2006; Riggle et al., 2005).

Sample sizes ranged from 131 (Riggle et al., 2006) to 1000 participants (MetLife Mature Market Institute, 2006/2010). The focus of the studies were on LGBT individuals, aged 18 up to age 83 (Stein & Bonuck, 2001; Riggle et al., 2006; Riggle et al., 2005), while the MetLife Mature Market Institute (2006/2010) study examined the GLBT "baby boomer" population between the ages of 40 to 61. Furthermore, Riggle et al. (2006) surveyed couples individually that were in a same-sex relationship for over six months.

As in qualitative studies, demographics in the quantitative category portrayed a picture of a white, middle income, well-educated adults living with their partner in a committed relationship, from 44% (MetLife Mature Market Institute, 2006/2010), to 75% (Riggle et al., 2006) of participants choose to disclose to immediate family.

Data collection. Data collection was performed through the use of web-based questionnaires (MetLife Mature Market Institute, 2006/2010; Riggle et al., 2006; Riggle et al., 2005) and a face to face questionnaires (Stein & Bonuck, 2001). The MetLife Mature Market Institute (2006/2010) study, conducted by Zogby International, spanned seven days. Stein and Bonuck (2001) performed their survey, incorporating a Spanish translation of the questionnaire, from March to June of 1998. Stein and Bonuck's presentation of the survey was preceded

by 20 hours of personal outreach to all potential participants to explain the survey and allow time for completion.

Data analysis. Descriptive statistics were used to explain the distribution of variables, i.e. central tendency, variability, deviation from normality, and spread (Creswell, 2008). The data from all the quantitative studies used descriptive statistics that included demographics of age, ethnicity/race, sexual identity, education, income, and relationship status (Stein & Bonuck, 2001; MetLife Mature Market Institute, 2006/2010; Riggle et al., 2006; Riggle et al., 2005). Furthermore, inferential statistics were used in the correlational research studies (Riggle et al., 2006; Riggle et al., 2005). Inferential statistics are used to describe the relationship between variables (Creswell, 2008).

In the Riggle et al. (2006) study, positive correlations were found between higher rates of execution of advance directives and age, income, education, relationship commitment, and levels of relationship disclosure. The completion of health care surrogate documents was two times greater when a LGBT person was partnered (Riggle et al., 2005). Additionally, Riggle and colleagues (2005) found higher income and being female was positively correlated with advance directive completion rates, whereas internalized homophobia was negatively correlated (Riggle et al., 2005).

Throughout the four studies, family and social support networks, legal, medical, religious, and physical health were reviewed (MetLife Mature Market Institute, 2006/2010; Stein & Bonuck, 2001; Riggle et al., 2006; Riggle et al., 2005). The MetLife Mature Market Institute (2006/2010) found over 75% of baby

boomer GLBT participants had “families of choice” which included non relative members. Of this sample, 53% of participants wanted their partner to be the caregiver.

In the 2001 Stein and Bonuck study, 79% of individuals had not informed their health care provider of their wishes regarding emergency medical treatment, while 73% of participants wanted their providers to know. In the MetLife Mature Market Institute (2006/2010), 19% of participants stated they had little confidence in medical personnel’s ability to treat them with dignity and respect.

Religion was identified by Stein and Bonuck (2001) as a predictor of completion of advance directives. Catholic based religions were indicators of low levels of completion due to religious restrictions on treatment at end of life. Overall, 61% of participants in this study described themselves as “very” or “somewhat” spiritual, yet 58% stated they “rarely” or “never” attend church (Stein & Bonuck, 2001).

Participants’ physical health was identified as excellent (68%) by Stein and Bonuck (2001), with 14% having HIV/AIDS and 67% having a friend, partner, or relative that has died from HIV/AIDS. Riggle et al. (2005) found 35-40% of participants described chronic health problems.

Similar to the qualitative studies reviewed, the quantitative research lacked ethnic diversity in the sampling and consequently, even though the sample sizes were larger (MetLife Mature Market Institute, 2006/2010; Stein & Bonuck, 2001; Riggle et al., 2006; Riggle et al., 2005). A representative sample is difficult to obtain, given the lower levels of disclosure, therefore generalization from studies

will continue to be a difficult area in evaluating research on this population. (Stein & Bonuck, 2001).

Web-based sampling was used in three of the four studies. Self-selected participants were identified as those having the time, and ability to connect to the internet. This sampling approach may create samples favoring predominantly white participants with higher educations and incomes (Riggle et al., 2006). Furthermore, sampling from LGBT web sites, newspapers, or organizations may only address those individuals that frequent those sites or have a lower degree of internalized homophobia (Riggle et al., 2005).

Stein and Bonuck (2001) piloted the scale used in their study called the Health Care Attitudes in the Lesbian and Gay Community Scale. This scale, a rapid assessment instrument, or RAI, could be completed 20 minutes and consisted of 64 questions. Riggle et al. (2005) used the Internalized Homophobia Scale and Rosenberg's Self-Esteem Scale, whereas Riggle et al. (2006) later used the Commitment Subscale of the Triangular Love Scale. Descriptive statistics were provided in each study used to explain the distribution of variables, i.e., central tendency, variability, deviation from normality, and spread (Creswell, 2008). Descriptive statistics were provided in the sample demographics, name them here, , in all quantitative studies in this review

Riggle and colleagues (2006) found positive correlations between execution of advance directives and age, income, education, relationship commitment, and levels of disclosure. Interestingly, all four studies addressed the commitment level of participants with over half the participants being in a

committed relationship (MetLife Mature Market Institute, 2006/2010; Stein & Bonuck, 2001; Riggle et al., 2006; Riggle et al., 2005). Additionally, Riggle et al. (2005) found 30% of immediate family were not supportive of participants lifestyle "at all" or "very little".

Stein and Bonuck (2001) found that 42% of participants had completed health care POAs; yet of participants under age 30, only 40% knew what a health care proxy was and only 1% reported completing the document. In 2001, Stein and Bonuck found 43% of participants wanted their partner to be the medical decision maker, yet only 21% had completed the legal documents to do so. A health care POA was completed by nearly 65.6% of the participants in the 2005 survey by Riggle et al.

Importantly, in the 2001 Stein and Bonuck study, 79% of individuals had not informed their health care provider of their wishes regarding emergency medical treatment, while 73% of participants wanted their providers to be informed. In the MetLife Mature Market Institute (2006/2010), 19% of individuals participating stated they have little confidence in medical personnel to treat them with dignity and respect.

Similar to the qualitative studies reviewed, the quantitative research lacked sample diversity and consequently, even though the sample sizes were larger, the possibility of generalizing study results to this population is lower, as the ages, race/ethnicity, education, and incomes levels were predominantly older, white, higher educated, and higher income individuals that participated (MetLife Mature Market Institute, 2006/2010; Stein & Bonuck, 2001; Riggle et al., 2006;

Riggle et al., 2005). A representative sample has not been determined for this population due to the lower levels of disclosure; therefore, generalization is difficult (Stein & Bonuck, 2001).

LITERATURE SUMMARY

Each study in the literature review focused on different topics affecting the LGBT population to address aspects surrounding the issues facing a LGBT individual when choosing a surrogate decision maker. The social, familial, and environmental influences emerging from the LGBT empirical literature and the gaps remaining that should be addressed are discussed in the following summary.

The literature focused on challenges in the social environment concerning the use of advance planning and designation of DPAHCs (MetLife Mature Market Institute, 2006/2010; Neustifter, 2008; Riggle & Rostosky, 2005; Riggle et al., 2006; Riggle et al., 2005; Smolinski & Colon, 2006; Stein & Bonuck, 2001), patient-physician communication (Bonvicini & Perlin, 2003), and the importance of relationship recognition (Killian, 2010; Rostosky et al., 2004) for a LGBT individual and their loved ones.

Advance Directives

Advance directives were completed two times more often when a LGBT individual was in a committed or partnered relationship (Riggle et al., 2005). Riggle et al. (2006) also found positive correlations between a higher completion of advance directives and age, income, education, level of commitment, and level of disclosure to friends and family. This study also found an inverse relationship between higher levels of internalized homophobia and lower rates of completion

for advance directives.

The completion of advance directives, and specifically the DPAHC, requires a supportive person to be chosen as the surrogate that will uphold and advocate for the wishes of the LGBT individual (Bonvicini & Perlin, 2003). Without this document, a same-sex partner can legally be excluded from discussions with medical personnel regarding medical treatment wishes of the LGBT patient or even from visiting the patient in hospital critical care units (Killian, 2010; Orel, 2004), as Orel found over 50% of the participants were denied entry at least once when their partners were hospitalized.

Stein and Bonuck (2001) found health care power of attorneys were completed by 42% of participants overall; of that number, only 1% of participants under the age of 30 completed HCPAs. Only 40% of persons under 30 were familiar with what a DPAHC was (Stein & Bonuck, 2001). Unsurprisingly, Hash and Netting's (2007) participants, lesbians and gay men, cited advance directives were completed because when facing life threatening illnesses, they feared family would become intrusive.

Patient-Physician Communication

Equally important are the risks of discrimination or bias from medical personnel and service providers when a LGBT individual chooses to disclose their sexual orientation within the medical system (Orel, 2004; Riggle & Rostosky, 2005). Disclosure within the medical system is especially important to achieve an accurate diagnosis and treatment, because false assumptions about

a person's sexual orientation can reduce quality of care (Bonvicini & Perlin, 2003).

Yet, in Stein and Bonuck's 2001 study, 79% of participating LGBT individuals had not communicated their wishes for emergency medical treatment. Fear of discrimination and bias by medical personnel affecting the level of service was one explanation offered by Orel (2004), who recommended establishing stronger patient-physician communication through using language more sensitive to all sexual orientations.

Support System

The authors expressed that LGBT individuals have lacked a formal recognition in their romantic relationships by legal, medical, and familial systems (Bonvicini & Perlin, 2003; Hash & Netting, 2007; Killian, 2010; Neustifter, 2008; Orel, 2004; Riggle & Rostosky, 2005; Rostosky et al., 2004; Smolinski & Colon, 2006).

According to Riggle et al. (2005), 30% of the immediate family of LGBT study participants offered very little or no support to their family member as perceived by the LGBT participants. Therefore, the inclusion of fictive kin into a LGBT person's nontraditional family creates supportive relationships, especially when the LGBT person does not have support of either traditional family support systems or a partner (Bonvicini & Perlin, 2004). Transgender individuals were found more isolated from social and familial support (Knochel, 2010; Witten, 2009).

Gaps in Research and Service

The majority of the gaps in the research conducted on the LGBT population are due to homogeneous samples, i.e., participants' race/ethnicity, income, and education levels. Critical next steps in the research should broaden the LGBT samples to reflect more heterogeneous groups that will expand generalizability of findings. Additionally, the bisexual and transgender populations should be explored for more in-depth examination and assessment of their needs when choosing surrogate decision makers, to support and define their needs for service from social work and other health care professionals.

Specifically, research into the completion of DPAHC for LGBT individuals has not fully been addressed; the future research should include samples in which consequences of completing and lack of completing advance directives can be addressed to understand actual effects of advanced directives in health care settings for LGBT individuals. By furthering the knowledge base to understanding how advanced directives are used and implemented, findings would inform education and training programs for all stakeholders: LGBT individuals, service providers, medical professionals, and social workers. Additionally, an investigation into Reciprocal Beneficiary Agreements may determine effectiveness for use by members of LGBT population in a committed relationship.

As no longitudinal studies have been performed, it is important to examine the changing views and opinions of LGBT individuals concerning advanced directives to understand at what point within their lifetimes such documents

become necessary to complete.

As a limited number of articles were found on the topic of LGBT population and the choice of a surrogate, it should be noted that of these articles ($n = 14$), Riggle and Rostosky (2004-6) were collaborating authors for four different studies. Although their contribution to the body of knowledge has been extensive, broadening the researcher involvement would add further depth and diversity to the growing body of knowledge in this area.

Overall, the reoccurring themes in the literature reviewed represent a snapshot of a LGBT individual's perceptions of these primary concerns: disclosure of sexual orientation to family and governmental or community systems, fears over medical bias and discrimination, better patient-physician communication, and increased familial support systems. Although these studies represent an initial beginning to inquiry into the opinions and attitudes of the LGBT population, findings are beneficial for emerging educational programs for all stakeholders, such as the LGBT population, social workers, and medical professionals.

IMPLICATIONS FOR SOCIAL WORK PRACTICE

Social workers historically have been supportive to patients and their families in health care settings before and during the medical decision making periods (Christ & Somariti, 1999). Social workers receive the theoretical background and training specific to work with the complex issues surrounding families and patients (Rose & Shelton, 2006). When working within the LGBT population, social workers can be especially beneficial as they are more aware of and sensitive to the environmental factors which can help LGBT persons overcome their fears and give voice to this population (Smolinski & Colon, 2006).

LGBT individuals are often perceived as an invisible population in our society; therefore, as social workers we must assist with educating the public and advocating for the LGBT population to minimize damage from society's sexual orientation bias that favors heterosexual over other types of personal relationships, primarily in providing safer methods of disclosure and self-identification (Neustifter, 2008). This can be accomplished through a message of acceptance and inclusion directed toward the LGBT community characterized by professional techniques such as asking gender neutral questioning when asking about a partner, providing statements of equal treatment for all, and inclusion of partner in plans of treatment (Bonvicini & Perlin, 2003).

Social workers can be more proactive in raising awareness into the special ramifications for the LGBT population who do not complete advance directives (Metlife Mature Market Institute, 2006/2010). An increase in

awareness of institutional discrimination is necessary to provide culturally competent social work practice (Rostosky et al., 2004). Thus, in the absence of marriage rights, same sex couples need to be aware of their legal options of ensuring their committed relationships are protected (Riggle et al., 2005).

Community organizations that serve the LGBT population must work to educate the public and the organization's members to assess the benefits and costs of completing advance directives. Health care providers, religious leaders, and policy makers need to assume a larger role in assisting members of the LGBT community in filling out and completing proxies and advance directives by using focused education to their employees and the community (Stein & Bonuck, 2001).

Aging LGBT elders require services and programs that address their specific needs. Due to many individuals in medical and organizational positions assuming patient heterosexuality and LGBT patients internalizing homophobia, this cohort may be less likely to utilize available services geared toward the heterosexual community. Social workers must use their heightened sensitivity in developing and serving this population by designing programs to specifically address the aging LGBT community's needs (Orel, 2004).

Professional development for social workers must include initial and lifetime learning in specific areas pertaining to the LGBT population. Medical, nursing, and social work educational programs should include understanding and commitment to diversity courses that focus on LGBT concerns, aging, and needs. Specific emphasis should be on self-regulation of individual practitioners'

own biases and stereotypes, relationship recognition and acknowledgment, and the need for visibility to reduce discrimination in society (Killian, 2010).

**APPENDIX A: COMMENTARY AND VALUATION
LITERATURE**

Appendix A: Commentary and Valuation Literature

Author	Literature Type	Summary	Conclusions
1. Bonvicini and Perlin (2002)	Commentary	Gay and lesbian patients have a higher level of health care risks because of avoidance of health care and dissatisfaction with health care.	Clinician-patient communication should be enhanced by non-judgmental, gender neutral methods that include patients' families.
2. Killian (2010)	Commentary	Explains the impacts of U.S. policy on health care services, financial issues and adoption for LGBT individuals.	Recommends the use of continuing education for service providers regarding relationship recognition and continuing political advocacy when working with LGBT population.
3. Neustifter (2008)	Commentary	Acknowledgement of the day to day role age, gender, and sexuality plays in clinical application of family therapists to lesbian elders.	Service providers must resist stereotypes, advocate, and provide healthy interventions for lesbian elders.
4. Riggle and Rostosky (2005)	Commentary	Examined culturally competent psychological practice to understanding the legal implications when working with a same-sex couple.	Same-sex couples face unique challenges when faced with making end of life decision. Psychologists must become more culturally competent in understanding issues of minority stress and challenges in advance planning.
5. Smolinski and Colon (2009)	Commentary	Discussed issues of disclosure, discrimination, legal and financial barriers, and disenfranchised grief for lesbians and gay men in end of life and the role of oncology social workers.	Oncology social workers must be sensitive when creating interventions to surmount societal attitudes and barriers of lesbians and gay men.
6. Knochel (2010)	Valuation	Explanation of relationship recognition and transgender marriage policies and history.	Recommends the passing of laws to use Reciprocal beneficiary agreements (an agreement that benefits belong to one another) to offset much of the political and legal restrictions of same-sex couples and others that cannot marry.
7. Witten (2009)	Valuation	Aging for elder transgender individuals are often invisible in the family/community.	Identification of quality of life, impact of support system, and coping techniques need to be addressed in research and theory in regards to transgender individuals.

APPENDIX B: QUALITATIVE EMPIRICAL LITERATURE

Appendix B: Qualitative Empirical Literature

Author	Sample	Age Range	Design	Research Purpose	Results
1. Hash and Netting (2007)	N = 19	50-77	Survey	Examined issues of long-term planning and decision-making among midlife and older gay men and lesbian caregivers.	High percentage of completion of advance directives for partner, but not self. Informal family dynamics and interactions with formal systems were concerns.
2. Orel (2004)	N = 26	65-84	Focus groups	Examined the concerns facing LGB elders by the use of a focus group.	LGB elders concerns matched heterosexual concerns, but had less safeguards in place for legal, societal, and physical issues due to discrimination, bias, and level of disclosure.
3. Rostosky, Korfhage, Duhigg, Stern, Bennett, and Riggle (2004)	N = 14	18-50	Survey	Examined conversations about family support in same-sex couples.	Couples perceived levels of support affected the quality of a couple's relationship. Couples lacking family support offered no suggestions for norms or models to follow.

APPENDIX C: QUANTITATIVE EMPIRICAL LITERATURE

Appendix C: Quantitative Empirical Literature

Author	Sample	Age Range	Design	Measures	Predictor Variables	Outcome Variables	Research Question	Results
1. MetLife Mature Market Institute (2010)	N = 1000 lesbian and gay baby boomers	40-61	survey	None identified	None identified	None identified	Designed to identify demographics and preferences as a national snapshot of GLBT baby boomers.	High incidence of GLBT caregivers, high percentage of GLBT with important connection to families of choice, 27% fear of discrimination, and high percentage want to die in their homes.
2. Riggle, Rostosky, and Prather (2006)	N = 131 same sex couples	19-61	survey	None identified	(a) Demographics, (b) commitment, and (c) disclosure	Establishment of: (a) a will or living trust, (b) power of attorney for finances, (c) power of attorney for health care, and (d) a living will	Is advance directive execution more prevalent in couples that are older, have high levels of income, and higher levels of education?	Older couples and couples with higher level of education were more likely to complete advance directives. Higher disclosure rates indicate higher rate of completion.
3. Riggle, Rostosky, Prather, and Hamrin (2005)	N = 398 individuals in same sex relationships	18-73	survey	Internalized Homophobia Scale; Rosenberg's Self-Esteem Scale	(a) Relationship status, (b) disclosure, and (c) knowledge of legal documents	Establishment of: (a) a will or living trust, (b) power of attorney for finances, (c) power of attorney for health care, (d) a living will, and (e) hospital visitation authorization	For BGLT population, who completes advance directives? Do BGLT individuals have a lower level of completion if they have internalized homophobia and lower levels of disclosure?	BGLT individuals in a committed relationship, have higher levels of disclosure to immediate family, higher level of completion of advance directives, and a higher income.
4. Stein & Bonuck (2001)	N = 575 gay men and lesbians	19-83	survey	Health Care Attitudes in the Lesbian and Gay Community	None identified	None identified	What are the preferences of the lesbian and gay community for end of life care, physician-assisted suicide and euthanasia, and advance care planning?	Support existed for physician assisted suicide, palliative care approach to end of life care, and a higher level of completion of advance directives for gay and lesbian respondents.

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