

# LGBT affirming environments in hospice care settings

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# LGBT AFFIRMING ENVIRONMENTS IN HOSPICE CARE SETTINGS

by Maria Gore

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  
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## Abstract

The documented experiences and perceptions of lesbian, gay, bisexual, and transgender (LGBT) patients receiving hospice or palliative care gives merit to the need for the implementation of LGBT affirming environments in hospice care settings. The guidelines for creating these affirming environments are described in this paper. Applying the Donabedian (1988) model of structure, process, and outcome this thesis project analyzes identified interventions relevant to the implementation of LGBT affirming environments in hospice care settings. Utilizing a formal PICO questioning method, a search strategy was devised and studies were identified based on established criteria. The results suggest that there is a paucity of data in relation to the implementation of LGBT affirming environments in hospice care settings. In an effort to assist in identifying existing interventions that have not been studied this project also includes a recommended survey tool to measure the active efforts of hospice organizations to implement LGBT affirming environments.

## Dedication

For Sharon, I carry your heart with me.

For Mom & Dad, thank you for everything you do and for giving me the foundation of compassion and empathy that guides my life and my work.

## Acknowledgments

I would like to express my sincerest gratitude to my committee members, Mary Mann and Dr. Diane Andrews for their knowledge, their feedback and their patience throughout this project. A special thank you to Mary Mann for her unfailing support and encouragement that enabled this project to reach completion. This thesis would not have been possible without the guidance and wisdom afforded to this novice researcher by my thesis chair, Dr. Denise Gammonley. Thank you Dr. Gammonley for guiding me around all the obstacles involved in research.

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## Introduction

Development of culturally competent practice in the end of life care field has been a growing trend over the last several years. Proposed models, standards and recommendations on culturally competent practice have emerged for this field over the last decade. Yet there is a paucity of data examining the extent to which these models of practice are being employed to the lesbian, gay, bisexual and transgender (LGBT) population. General assumptions of heterosexuality and gender normativity are common in the health care system, which places the burden of disclosure on the patient or the partner (Glackin & Higgins, 2008). This socially constructed norm overwhelmingly leads to assumptions being made in the healthcare system that an individual is heterosexual unless he or she expresses otherwise (Morrow & Messinger, 2006). Non-disclosure of sexual orientation and gender identity is significant in regards to a patient's health needs (Rawlings, 2012).

The literature is in agreement that LGBT individuals may choose not to disclose their sexual orientation or gender identity to health care providers due to a myriad of reasons, including fear of negative biases, internalized homophobia and feelings of vulnerability (Mayer et al., 2008; Knochel, Croghan & Quam, 2010; Rawlings, 2012; Wilkerson, et al., 2011). Furthermore, a lack of knowledge among providers can create access barriers to appropriate and quality end of life care services for both the individual and their families. The existing literature suggests that creating an affirming or welcoming environment for the LGBT patient and family is a key instrument in being able to allow for self-disclosure and consequently impact the quality of the services and care that will be provided (Mayer, et al, 2008; Rawlings, 2012; Wilkerson et al.,

2011). This is particularly relevant in regards to hospice care where patient centered care and holistic approaches are applied to meet the physical, psychological social and spiritual needs of the patient (Harding, Epiphaniou, & Chidgey-Clark, 2012). Acknowledgement and acceptance of sexual orientation and gender identity is essential to meeting these needs (Harding, Epiphaniou, & Chidgey-Clark 2012; Rawlings, 2012).

## Objective

This thesis reports on the results of a critical review of the empirical evidence of active efforts to implement LGBT affirming environments in hospice care settings. Additionally, recommendations for surveying hospice organizations about their LGBT affirming implementation practices, including a model survey tool are presented. The critical review presented here used evidence-based review procedures developed by Sackett, Rosenberg, Muir Gray, Haynes & Richardson (1996) to answer the following question: If LGBT patients receive hospice care from a hospice organization implementing a LGBT affirming environment will it improve quality of care?

The literature suggests that cultural competence models in health and social services are trending to be more inclusive of sexual orientation, gender identity and expression but neglect standards of how to apply it (Van Den Bergh & Crisp, 2004). Examining how hospice organizations are implementing LGBT affirming environments as part of their cultural competence frameworks will allow for the opportunity to distinguish best practice models. If consistent methods in practice models can be identified this data may prove useful to organizations aspiring to increase the quality of care provided to their clients. Additionally, understanding what specific efforts are being made in response to the existing guidelines will assist service providers and policy makers to better support the LGBT population.

Applying the Diffusion of Innovations Theory (Rogers, 1995) allows an understanding that active efforts are equivalent to the area of implementation. Given that the guidelines exist and continue to evolve it is assumed that hospice providers are aware of the existing guidelines but will differ in their levels and methods of implementation. Applying the Donabedian (1988)

model the review will assess the intervention to either be a structural implementation practice or a process implementation practice.

## Theoretical Framework

The diffusion of innovations theory (Rogers, 1995) has been applied to health service provider organizations as a “novel set of behaviors, routines and ways of working that are directed at improving health outcomes, administrative efficiency, cost effectiveness, or user’s experience and that are implemented by planned and coordinated actions” (Greenhalgh et al., 2004). It can further be broken down into areas of diffusion, dissemination, implementation, and sustainability. For the intention of the thesis, the data collected for the evidence-based review focused on the areas of implementation, which can be further defined as the active efforts to mainstream an innovation within the organization or agency. For the purpose of this thesis LGBT affirming environment is defined as the innovation.

The Donabedian (1988) approach has been conventionally applied to health care quality assessments worldwide (Jackson, et al. 2004; Richie, 1987). This approach typically focuses on the areas of structure, process and outcomes. Structure components can be examined in terms of physical facilities, staffing patterns, foundation support and agency affiliations, range of services provided and geographical locations (Richie, 1987). Process components can be identified as the dominant indicators of the quality of care provided. These components can be measured in areas of agency policies, mission statements, inclusion efforts, community encounters and the delivery of services provided (Jackson, et al., 2004; Richie, 1987).

## Background

The National Hospice and Palliative Care Association (NHPCO) defines hospice care as:

the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well. At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so (p. 3356).

In order to provide this standard of care to sexual and gender minority patients and their families an affirming environment must be present (Mayer, et al. 2008). An affirming environment sets the stage for patients to self disclose and feel safe in discussing matters relevant to their sexual orientation or gender identity (Makadon, 2006). Additionally, research suggests that the lack of such affirming environments demonstrates the power of systemic heterosexism and potentially compromises the quality of care (Jackson, et al, 2004).

The Gay and Lesbian Medical Association (GLMA) drawing from the existing research have proposed the following guidelines for creating an affirming LGBT environment in health care settings (Gay and Lesbian, 2006). The guidelines can be broken down into the following themes for implementation practices:

- Update physical environment
- Add or change intake and healthy history form questions
- Improve provider-patient discussions

- Increase staff knowledge and sensitivity to LGBT patients

These guidelines and the existing literature also indicate examples of how these guidelines can be adopted in healthcare environments. Physical environments can be updated with simple additions such as LGBT-friendly symbols or stickers, brochure displays with relevant LGBT information, visible non-discrimination statements, and displays of LGBT-specific media (Gay and Lesbian, 2006; Wilkerson, et al., 2011). Larger changes to the physical environment that specifically target the transgender populations can be in the form of providing a gender-neutral bathroom (Gay and Lesbian, 2006). Although this may not be relevant to the patient in an inpatient setting it may provide guidance for family waiting areas in a hospice setting. Intake and health history forms can be changed to include more inclusive choices for answers, such as the use of partner in replace of spouse and providing transgender as a choice for gender or leaving a blank space to allow for patient to fill in (Gay and Lesbian, 2006; Mayer, et al, 2008). In the domain of provider-patient discussions some suggestions are to use gender-neutral language when talking about relationships, to avoid heterosexist and gender normative assumptions, and to take cues from the patient or client's terminology when identifying relationships or behaviors (Gay and Lesbian, 2006; Platzer & James, 2000; Wilkerson et. al, 2011). Increasing staff knowledge and sensitivity to LGBT individual's suggestions include areas of recruiting diverse staff members, providing periodic training for all staff members, and designating a LGBT resource person (Gay and Lesbian, 2006).

LGBT patients may seek gay and transgender friendly health care providers, yet in the situation of hospice care the choices are often limited (Rawlings, 2012). In order to provide the quality model of care advocated by the NHPCO to the LGBT population, affirming

environments must be implemented in order to foster a safe and welcoming space for LGBT clients.

The literature indicates that when assessing the delivery of culturally competent practice with minority populations, attention must also be paid to the impact of contributing factors of a heterocentric and gender-normative culture in the healthcare environment (Committee, 2011; Daley & MacDonnell, 2011; Jackson, et al., 2004; Mayer, et al., 2008, Wilkerson et al., 2011). To understand the necessity of affirming environments for the LGBT population it is suggested to employ the minority stress model originally developed by Brooks (1981) for lesbians and later expanded by Meyer (1995, 2003) to include gay men, even later bisexuals and is suggested to be relevant for transgender persons (Committee, 2011). Particular relevance should be paid to impacts of enacted stigma and perceived stigma. Perceived stigma is conceptualized to be the expectation of rejection and discrimination that leads to the concealment of an individual's sexual orientation or transgender identity. Enacted stigma refers to the veritable experiences of discrimination.

The majority of the existing literature on LGBT services in hospice care organizations and other health care settings have examined the disparities and marginalization this population experiences in health care. Much of the existing data focuses on the experiences and perceptions of care received. The studies that describe data on the perceptions of care received in health care settings concentrate on communication and disclosure (Harding, Epiphaniou, & Chidgey-Clark, 2012).

Boehmer and Case (n.d) reported data in a study ( $N=39$ ) that described patient's experiences with disclosure of their sexual identity with their provider. The participants



identified as lesbians and were recipients of treatment for breast cancer. The data indicated that the majority of women chose to disclose their sexual identity to their providers but providers did not ask. Those participants that chose not to disclose their sexual identity indicated anticipated homophobia as their top reasons for nondisclosure.

Platzer and James (2000) found that nurses often questioned a patient about marriage or a boyfriend, leaving a lesbian patient with a choice to either contradict the assumption or stay silent. The qualitative study was conducted in the United Kingdom (UK) in an effort to develop guidance for nursing students. The data was collected via focus groups and individual interviews. The aim of the study was to collect data on the healthcare experiences of lesbian patients. The experiences were not limited to interactions with nurses; they also included those experiences with doctors. One issue that was revealed in their data was that some nurses often reference their own heterosexuality. The authors note that this response, when given after a patient discloses their sexual orientation may possibly cause the patient to interpret this as a homophobic statement. Respondents also indicated in this study ( $N=35$ ) that feelings of vulnerability often led to keeping silent about their sexual orientation, particularly if they were experiencing physical pain. The authors speculate that this is due to a fear of negative biases and discrimination if sexual orientation is revealed. Reports of biased behavior were found in this study and reported in the form of descriptive narratives. They included descriptions of rough treatment during physical exams, inappropriate questioning about sexual practices, and unsolicited advice to seek the help of a psychosocial counselor. The small sample size and the setting of the UK may limit the relevance to hospice staffing in the United States. However, the

findings are noteworthy in understanding the potential stigma and discrimination to which the LGBT population may experience.

In contrast, Hash and Cramer (2003) found respondents in their study ( $N=19$ ) reported no overt homophobic behaviors by professionals, only what they perceived as minor disparages, such as slighting remarks and rude behavior. This qualitative study utilized a purposive sample that targeted gay and lesbian caregivers that had experience caring for their same-sex partners.

A study conducted in Sweden by Rondahl, Innala and Carlsson (2006) outlined findings in regards to social isolation. The researchers conducted qualitative interviews ( $N=27$ ) of patients and partners. The study aimed to examine heterosexual assumptions in nursing. Particularly noted by the authors was the respondent's desire to articulate the experiences of single, elderly lesbian and gay patients. The respondents expressed concern that older lesbian and gays were more likely to not be open about their sexual orientation and more isolated socially. Interestingly this study collected data on what the respondent's advice was to nursing staff. This data included the recommendation that gay and lesbian literature be openly displayed in waiting rooms of agencies.

A consistent theme in the literature was the experiences of the partners of lesbian women and gay men. Several of the studies emphasized the disenfranchisement of partners during care and the unique experiences of bereavement of a same-sex partner. Glackin and Higgins (2008) collected narratives of surviving partners. The findings spoke of exclusion from medical decisions and communications, funeral services and bereavement groups. One participant communicated that the bereavement support groups offered by hospice served to further isolate

their grief. The authors found that the majority of the participants experienced subtle rather than overt behaviors of homophobia. Studies have noted that LGBT individuals who experience disenfranchised grief with their existing support systems may be at a greater need for support from professionals (Bevan & Thompson, 2003).

There is a dearth of research in the context of understanding transgender individual's health care experiences. Many of the articles available for hospice care with sexual minorities focus only on the lesbian, gay and bisexual population. Although there are certainly parallels to the quality care issues affecting transgender individuals this group may often be at an even greater risk for discrimination and increased stigma (Finlon, 2002; Mayer, et al., 2008). The studies are scarce but it is reported that transgender patients consistently anticipate negative reactions from providers and often delay self-disclosure (Finlon, 2008, Knochel, 2011; Wilkerson et al., 2011).

## Methods

### **Search Strategy**

The search was restricted to the published literature available from the following five databases: PsycInfo, CINAHL Plus, Medline, Social Work Abstracts and Sociological Abstracts. The date range searched for all databases was 1997-present. These databases provide an interdisciplinary range of professions that hold articles of relevance to the topic. The search terms were piloted and established in an effort to encompass a broad collection of studies. The final search terms appear in Table 1, along with the number of studies found under each word grouping.

All abstracts were screened for relevancy to the following Patient, Intervention, Comparison, Outcome (PICO) question: If LGBT patients receive hospice care from a hospice organization implementing a LGBT affirming environment will it improve quality of care? LGBT affirming environments is the implementation and is determined to be an environment that aims to allow for settings of care where an LGBT individual can expect to find support, acceptance and affirmation of their sexual orientation and gender identity. Outcome is the improved upon quality of care that is expected or delivered as a result of the implementation of the innovation.

### **Inclusion and exclusion criteria**

A total of 729 articles were identified in the initial search. From this initial set of articles only three empirical studies were identified that examined interventions related to the PICO question of this review. Additionally, a hand search of the reference lists for the three matching articles were reviewed but no additional articles were discovered that met inclusion criteria for

this review. Although search terms were expansive enough to identify studies that described an intervention related to cultural competence, the studies that were not inclusive of either lesbians, gays, bisexuals or transgender individuals in their framework of cultural competence, were excluded. Papers that were not written in the English language were excluded. Non-peer reviewed studies were excluded as well as any gray literature. Full papers were reviewed after meeting the inclusion criteria.

## Data Synthesis

The characteristics of the studies are profiled in Table 3, using a format established in another review of empirical studies (Abel, 2000). Slight modifications have been made to the table format in an effort to outline the attributes relevant to the Donabedian model (1988) and the Diffusion of Innovations Theory (Rogers, 1995). The table identifies the implementation on practice as either Process or Structure. Implementation is defined as the planned and coordinated actions of an innovation (Greenhalgh, et al., 2004). Process is described as components of care delivered, such as patient/staff interactions, inclusion efforts, and attention to needs (Forbes-Thompson & Gessert, 2005; Jackson, et al., 2004; Richie, 1987). Structure includes components such as the care environment, physical surroundings, locale, and range of services provided (Jackson, et al., 2004; Richie, 1987). Population sample size is outlined for each study as well as the theoretical framework of the study if specified.

The design of the study is stated on the table, in addition to the methodology, measures, findings and limitations of each study reviewed. The evidence ratings of the studies can be found in Table 2, located in Appendix A.

## Results

All three studies tested interventions in a hospice or palliative care setting. Two of the interventions took place in the U.S. and one in Ireland. The Ireland study described an intervention with a specific focus on the lesbian, gay and bisexual (LGB) patient population. The two U.S. studies described interventions with improving cultural competence of hospice staff and are inclusive of either gay men, gays and lesbians or sexual orientation in their framework of cultural competency. Notably, the two U.S. studies were not inclusive of bisexual or transgender identities. The Ireland study did include bisexual patients in their framework but were not inclusive of transgender patients.

All three studies evaluated the intervention outcome by collecting data from the participants following the training. The Ireland study also utilized external evaluators that collected qualitative narrative interview data.

All of the interventions examined for this review can be described as being an implementation practice given that they are active efforts aimed at mainstreaming an innovation within an organization. Additionally, all of the interventions share the characteristic of being targeted to the process component of the Donabedian (1988) model. The Ireland study did include a structure component in the intervention. The shared process characteristic is due to the fact that all of the interventions were aimed at educating or improving the knowledge of cultural competence of staff members or their communication with a potential LGBT recipient of hospice care. Although, the outcome of the studies are reported only from the perception of the participants who were receiving the training or educational intervention, and not the LGBT

recipients of care, the interventions were delivered with the intention that increased knowledge and skill on the part of the provider will produce a quality improvement in care.

### **Cultural Competence Interventions**

Schim, Doorenbos, and Borse (2006) conducted an intervention for the purpose of enhancing cultural competence levels among staff members at eight hospice organizations. The sample ( $N=130$ ) represented a broad range of disciplines, including nurses, nursing assistants, social workers and administrators. The sample was randomly divided into two groups and baseline measures of cultural competence levels were completed with both groups. The instrument utilized was the Culture Competence Assessment (CCA), a 25-item tool with a 5-point Likert-like response set. Group A, the intervention group, participated in the cultural competence education session first, which consisted of a 1 hour cultural competence education session followed by a post-test CCA. Approximately 3 months later the intervention group participated in the control session, an ethics session, containing content on ethical issues and devoid of any cultural or diversity issues. A post-test CCA was performed again after the control session. Group B participated in the same sessions, measurements and time frames but in reverse order, receiving the control session first, followed several months later by the cultural competence session.

The aim of the research was to analyze changes in cultural competence levels in response to the educational intervention. The findings indicated that the intervention session produced higher scores on the CCA in both groups. The use of the control group was significant in that it provided data that suggested that the educational intervention in comparison with the control



session focused on ethics produced significantly higher scores on the CCA. The findings indicate that even a modest intervention resulted in an increase of cultural competence.

The researchers noted that a total of 23 people opted out of the study after the baseline measurement was performed. The demographic variables of those who dropped out did not differ significantly to those individuals who completed the study. It was noted that 60% of the participants reported previous cultural diversity training. It could be proposed that individuals with prior exposure to cultural competence training may display more readiness to further educational opportunities.

In relation to LGBT affirming environments, this study appears to be inclusive of gays and lesbians under the umbrella of cultural competence as evidenced by their introduction to the topic of the study. Furthermore, the researchers reported that the educational intervention module included content on populations that the hospice organizations reported serving and sexual orientation was listed as a diverse group. It is unknown what component of LGBT affirming environments or LGBT issues were discussed in the session. The content of the educational intervention is stated to be adapted from the End-of-Life Nursing Education Consortium Training Program Manual, which is inclusive of lesbian, gay, and transgender individuals (Matzo, et al., 2002).

Flavin (1997) constructed an intervention aimed at home health care providers that provided end-of-life care. The implementation was a training program that would enable nurses to elevate qualities of care by increasing their knowledge and understanding of identified local cultures. The sample ( $N=11$ ) was representative of multiple disciplines, including nurses ( $n=8$ ), an occupational therapist ( $n=1$ ), physical therapist ( $n=1$ ) and one social worker. The

intervention was defined as a cross cultural training program with the aim to increase the quality of care being provided to patients served in a particular geographic location in the state of Hawaii. The intervention included both a knowledge component and a behavioral skills component. The training protocol was inclusive of four population groups: Hawaiian, Japanese, Filipino, and Caucasians males who identified as gay. The target population groups were identified as the cultural groups currently being served by the sample. The training protocol was multi-component, consisting of a panel presentation from each population group, an interactive exercise that included role-playing, and a cultural assimilator technique.

Pretest measurements were taken one day prior to the intervention in the form of a 12-item instrument, and a written essay component intended to collect a description of a cross-cultural encounter between the participant and a patient. The intervention consisted of three sessions with posttest measurements taken at the last session. The posttest measurements consisted of the identical 12-item instrument used at pretest and collection of a written essay in which participants were asked to describe a patient encounter that was enhanced due to receiving the training intervention. The essays were evaluated with criteria that included identifying levels of empathy, verbal and non-verbal responses, and acknowledgement of appreciation by the patient or client.

There were no significant differences in the pretest and posttest measures in either the knowledge or behavioral component. However, participants self-reported increased or enhanced cultural knowledge and competency skills.

The small sample size of this study minimizes the external validity in presenting the results as representative of hospice or palliative care providers. There are two factors that may

have produced a ceiling effect. First, the sample consisted of at least 3 or (27.3%) of individuals who identified as members of the targeted culture groups. Second, the intervention was requested by members of the organization represented by the sample, which may indicate that their readiness levels would predispose the sample to obtaining close to their maximum score at pretest.

This study met the criteria for inclusion in this review owing to the hospice setting and the inclusion of the gay population in their cultural competency framework. However, the training protocol was inclusive only of Caucasian gay-males. This is indicative of the time period of the late 1990's when hospice was serving a large population of acquired immune deficiency syndrome (AIDS) patients. The implications of this intervention in reference to the implementation of LGBT affirming environments is limited to the components of improving patient/provider communication and increasing staff knowledge and sensitivity as it relates to a subpopulation of the LGBT community.

### **Targeted LGB intervention**

Reygan and Dalton (2012) conducted a large-scale intervention ( $N=201$ ) across two hospitals and two hospices. The intervention intended to enable the staff delivery of affirmative care to LGB patient and their families and enhance staff knowledge of LGB issues relevant to hospice and hospital settings. Multiple disciplines were represented in the sample including, nurses, healthcare assistants, social workers, occupational therapists, doctors, therapists, chaplains and physiotherapists.

Training modules were 50 minutes in length and were offered over the course of 8 months. The training protocol was inclusive of LGB terminology; presented research on LGB

health and had a specific focus on the care needs of the LGB recipient of oncology or palliative care. The training module also presented existing guidelines for practice that are very similar to the GLMA guideline and include a component of updating physical environments.

Individuals participated in one module only and post-test measurements were collected after completing the module. The instrument utilized was a self-reported questionnaire that appeared to include self-reported pre-intervention assessments of knowledge, comfort and confidence levels related to LGB patients. Additionally, external evaluators conducted post intervention interviews ( $n=4$ ) with one participant from each training site. Data from these interviews was reported in narrative form.

Evaluated results of this intervention report significant self-reported increases in awareness of LGB health related issues, comfort with LBG terminology, and increased confidence levels in relation to delivery of care to the LGB patient. The narrative data reported indicated effects that corresponded with the self-reported assessments. One participant reported a new awareness in regards to asking open-ended questions at intake and avoiding assumption of heterosexuality. Another participant noted the relevant LGB material now available on the wards.

The absence of baseline measurements minimizes this intervention's internal validity. Self-reported changes collected only as a post-test following the training do not accurately support that the intervention was the cause of any improvements. The study lacks any details on the instruments or evaluative criteria utilized in the post-test assessments. The researchers indicate that assessment was made in the areas of comfort with LGB terminology, confidence with providing care, and knowledge of relevant LGB issues. An explanation on the variables

employed to assess these areas would be helpful in interpreting the implications of this type of intervention.

In relation to the PICO question this study identified the aim of the intervention was to enhance the delivery of LGB affirmative care. Out of the three studies reviewed, this intervention most closely met the criteria for inclusion due to the hospice care settings, the distinct focus on LGB recipients of care, and the intention of improving quality of care provided.

## Discussion

The purpose of this review was to evaluate the empirical evidence on the implementations of LGBT affirming environments in hospice care settings. Selection of the studies to be evaluated were formed around the PICO question: If LGBT patients receive hospice care from a hospice organization implementing a LGBT affirming environment will it result in higher quality of care?

The findings of the review demonstrate that there is a paucity of research that describes interventions related to LGBT affirming environments in hospice care settings. Out of the 729 articles identified and evaluated in the search, only three met the PICO based criteria for inclusion. Only one of studies reviewed contained an intervention specific to the LGB population. The other two studies examined interventions that were aimed at increasing levels of cultural competence within hospice settings. These studies were inclusive of either the lesbian, gay, or bisexual population or specified sexual orientation as part of their cultural competence framework. Notably, none of the studies examined were inclusive of the transgender population and only one study included bisexuals.

The time span of the studies examined suggests a positive trend towards inclusiveness of the LGBT population in these types of interventions. The Flavin (1997) study included only gay-males in their target cultures, whereas the Schimm, Doorenbos and Borse (2006) study encompassed sexual orientation as part of their cultural framework. Most recently the Reygan and D'Alton (2012) intervention was specific to the LGB population. This timeline correlates with the qualitative research outlined in the background section of this thesis that supports the need for LGBT affirming practices in hospice care settings.

For the purpose of this thesis LGBT affirming environments were defined using the guidelines specified by the GLMA (Gay & Lesbian, 2006). These guidelines included the following themes for implementation practices:

- Update physical environment
- Add or change intake and healthy history form questions
- Improve provider-patient discussions
- Increase staff knowledge and sensitivity to LGBT patients

Furthermore, drawing on the theoretical framework of the Donabedian model (1988), these guidelines can be categorized as either structure or process practices. Physical environments are categorized as structure practice whereas the other three guidelines are categorized as process practices.

All three of the articles reviewed addressed two components of these guidelines and both were categorized as process practices: improve provider-patient discussions and increase staff knowledge and sensitivity to LGBT patients. Only the Ireland study described an intervention that included the structure practice of updating physical environments.

The interventions that encompassed a general cultural competence implementation could be replicated to be more inclusive or even specific to the LGBT population. Likewise the protocol or modules of the interventions could be adapted to include all of the components of the recommended guidelines for creating LGBT affirming environments.

## Limitations

It may be necessary to expand a search methodology that would identify interventions at hospice care settings that focus on other marginalized populations. These types of interventions may not be inclusive of LGBT individuals but the interventions could potentially be replicated to include or target the LGBT population. Additionally, it may be necessary to look past hospice care settings and expand the search to include the implementation of LGBT affirming environments across other disciplines, such as mental health care settings. One abstract was reviewed during the search process that described an intervention of LGBT affirming environments in a mental health care setting. Interestingly, the intervention was inclusive of the structure practice guideline of updating physical environments (Hellman & Klein, 2004). An attempt at expanding the search across disciplines may include the addition of other databases.



## Indications & Recommended Survey Strategy

The findings of this review suggest that further interventions are necessary to identify best-practice models at implementing the innovation of LGBT affirming environments. It would be valuable to know what active efforts hospice organizations are implementing in regards to serving the LGBT population. Data in this realm could potentially identify innovations that could be evaluated and replicated if appropriate.

Applying the Donabedian model (1988) in the collection of data related to physical characteristics of the facilities, staffing patterns, foundation support, agency affiliations, and geographical correlations will allow for distinctions to be made between the areas of structure and process and the agency levels of implementation. Additionally, data collected in this manner would allow identification of important correlations of structure that may indicate barriers to the innovation of LGBT affirming environments. For example a recent study surveyed elder care agencies ( $N=320$ ) regarding their LGBT services, training and beliefs and identified significantly higher degrees of willingness to provide LGBT specific training among urban-based agencies versus rural agencies (Knochel, 2012).

Appendix B describes a recommended strategy for surveying hospice organizations about their LGBT affirming implementation practices. The variables are built around the recommended GLMA guidelines for creating an LGBT affirming environment (Gay & Lesbian, 2006). Additionally the variables are categorized as either structure or process components in keeping with the application of the Donabedian model (1988). Appendix C contains a model survey tool created by applying the variables described in Appendix B.

## Recommendations for Practice and Further Research

The review findings indicate a significant gap in the inclusion of transgender individuals in the interventions evaluated. There is a propensity to umbrella transgender individuals with the LGB population. Given the underrepresentation of transgender issues revealed in this review further research is needed specific to transgender needs and perceptions of care at the end-of-life.

Further verification of the efficacy of the types of interventions evaluated is necessary in order to provide evidence-based models for improving the quality care outcomes of LGBT hospice care recipients. The evaluations of the interventions examined in this review were only collected from the staff participant perspective. They lack evidence of the innovation in practice as applicable to the LGBT patient and family perceptions.

Despite the minimal amount of research revealed in this review one common theme the interventions revealed was the representation of multiple professions in their samples. Hospice care does encompass a broad range of professional services delivered. It is worthwhile to note that the creation of culturally competent educational curriculums inclusive of LGBT experiences is recommended in both the nursing and social work professions at the graduate and undergraduate level (Abrums & Leppa, 2001; Newman, Dannenfelser & Benishek, 2002). This suggests that longitudinal studies following student recipients of these curriculums and their applications to practice would be beneficial in establishing the efficacy of educational interventions related to this topic.

## Conclusion

The aim of this thesis was to research the empirical evidence that was relevant to the innovation of LGBT affirming environments and evaluate the efforts of hospice organizations to implement LGBT affirming environments with the intention of providing a higher quality of care. Although there were few interventions identified to evaluate, the results were beneficial in identifying the gaps in the research and establishing the implications on future research. Additionally, the background information gathered to support the development of the PICO question allowed for the development of a model survey tool to collect data on the active efforts of LGBT affirming environment implementations in hospice care settings.

## Appendix A: Search Terms, Evidence Rating Criteria & Evaluation of Findings

Table 1

*Summary of Search Terms and Findings*

Search terms	Number of Articles Found	Number of Articles used in review
Lesbian/gay/bisexual/transgender/homosexual Combined with hospice/hospice care/palliative/palliative care/end-of-life/end-of-life care	117	1
Lesbian/gay/bisexual/transgender/homosexual Combined with hospice/hospice care/palliative/palliative care/end-of-life/end-of-life care Combined with diffusion/diffusion of innovation/innovation/implementation/Donabedian/Donabedian theory	1	0
Cultural competence/cultural competency/cultural diversity Combined with Hospice/hospice care/palliative/palliative care/end-of-life/end-of-life care Combined with diffusion/diffusion of innovation/innovation/implementation/Donabedian/Donabedian theory/training/development	127	2
Lesbian/gay/bisexual/transgender/homosexual Combined with hospice/hospice care/palliative/palliative care/end-of-life/end-of-life care Combined with affirm*/welcoming environment/safe environment/affirming environment	4	0
Lesbian/gay/bisexual/transgender/homosexual Combined with hospice/hospice care/palliative/palliative care/end-of-life/end-of-life care/health services/healthcare Combined with affirm*/welcoming environment/safe environment/affirming environment	235	0
Lesbian/gay/bisexual/transgender/homosexual Combined with hospice/hospice care/palliative/palliative care/end-of-life/end-of-life care Combined with quality of care/quality outcomes/quality improvement/QI/patient satisfaction/patient perception/caregiver satisfaction/caregiver perception/quality performance/outcome/outcome measures	12	0

*Summary of Search Terms and Findings*

Search terms	Number of Articles Found	Number of Articles used in review
Lesbian/gay/bisexual/transgender/homosexual Combined with hospice/hospice care/palliative/palliative care/end-of-life/end-of-life care/health services/healthcare Combined with quality of care/quality outcomes/quality improvement/QI/patient satisfaction/patient perception/caregiver satisfaction/caregiver perception/quality performance/outcome/outcome measures	233	0
	729	3

Table 2

*Evidence Rating Criteria*

Citation	Level of Evidence per criteria (Rate 1-5)
Flavin, C. (1997)	4
Reygan, F., & D'Alton, P. (2012)	4
Schim, S., Doorenbos, A., & Borse, N. (2006)	2
Average rating across all studies	3.33

*Note.* In this scale a lower number indicates better quality evidence.  
 Level 1: Systematic Reviews of Several Controlled Studies  
 Level 2: Individual Experimental Studies, RCT or multiple RCT's  
 Level 3: Comparison group(s) but not randomized  
 Level 4: Nonexperimental designs, descriptive, qualitative studies, post-intervention reports, correlational studies. Cannot test cause-effect relationships.  
 Level 5: Literature reviews, quality improvement projects, case examples or reports, utilizations, reports from agencies

Table 3

*Evaluation of Identified Interventions Related to PICO Question*

Citation	Type of implementation Practice	Was the implementation Practice Evaluated?	Population/ Sample size	Theory	Design	Methods	Measures	Findings	Limitations
Flavin, C. (1997)	Process: Staff education	Yes	Multiple disciplines of palliative home health care organization  11	Harrison's model of combined methods of behavior modeling & cultural assimilator	Quasi-experimental  One group  Pretest-posttest	Pre and post intervention tests after 3 educational sessions	Pre intervention knowledge levels: 12 item questionnaire (also given post)  Behavioral measures: evaluated in narrative form  Reaction measures: 5 point Likert scale	No significant difference in pre and post test measure on knowledge measures  Participants indicated knowledge increase of targeted cultures	Small sample size  Non-random  No control group  Cultural groups targeted in training modules very limiting  Potential ceiling effect
Reygan, F., & D'Alton, P. (2012)	Process & Structure Practice:  Staff training Update physical environment	Yes	Multiple disciplines in 2 hospitals and 2 hospices 201	Not stated	Pre-experimental  One Group Post Test Only	One 50min training component inclusive of LGB relevant health issues and terminology  Post intervention questionnaire  Qualitative evaluative interviews (n=4)	Self-reported questionnaire  Narratives taken post intervention In person or telephone interview with one person from each location used in sample	Self-reported increases in comfort levels with LGB terminology, comfort & confidence levels in providing care to LGB patients and increased knowledge of LGB health-related issues	Lack of pre test.  Lack of description of evaluation criteria and instruments utilized



Table 3.  
*Evaluation of Identified Interventions Related to PICO Question*

Citation	Type of implementation Practice	Was the implementation Practice Evaluated?	Population/ Sample	Theory	Design	Method-ology	Measures	Findings	Limitations
Schim, S., Doorenbos, A., & Borse, N. (2006)	Staff education	Yes	130 Multi-disciplinary; racially and ethnically diverse	Not specified	Cluster randomized trial; Longitudinal Crossover	<p><b>Random assignment into 2 groups.</b></p> <p>Baseline measurement</p> <p>Group A: cultural competence education session/post test measurement</p> <p>Group B: ethics session (control)/ post test measurement</p> <p>3-4 months later</p> <p>Group A: ethics session (control)/ post test measurement</p> <p>Group B: cultural competence session/post test measurement</p>	<p>Baseline: Cultural Competence Assessment (CCA) tool (5 point Likert scale)</p> <p>Post control or intervention session: CCA</p> <p>CCA measurement x3</p>	<p>Higher rate of increase from pretest to post test in intervention group vs. control group</p> <p>Significant overall increases in both groups after all sessions</p>	<p>Agencies were affiliated and therefore limit the generalization of the results.</p> <p>Significant amount of participant dropout</p>

*Note.* Adapted from Abel, E.M. (2000). Psychosocial Treatments for battered women: A review of the empirical literature, *Research on Social Work Practice*, 10 (1), 55-77

Appendix B: Recommended Domains of Assessment to Evaluate Staff Perceptions  
of LGBT Affirming Environments Implementation Practices in Hospice  
Organizations

Recommended Domains of Assessment to Evaluate Staff Perceptions of LGBT Affirming  
Environments Implementation Practices in Hospice Organizations

Key Concepts and Variables	Definition	Structure or Process Component
LGBT Symbols Displayed in Patient/Family Areas	Common visual symbols include the rainbow flag, pink triangle, double female and double male sex symbols and the lambda (lower case Greek letter)	Structure
LGBT Symbols on Homepage	Same as above	Structure
LGBT materials	LGBT information included in educational materials or organizational brochures	Structure
Intake forms	Patient intake/history forms	Process
LGBT Staff training	Has LGBT specific training has been offered	Process
LGBT Topics covered in training	Specific topics covered in training	Process
Percentages of staff/volunteer attendees	Percentage of staff/volunteers that attended LGBT specific training	Process
Outreach efforts	Number of community outreach efforts to the LGBT population	Process
Description of efforts	Description of community outreach	Process

Key Concepts and Variables	Definition	Structure or Process Component
	Effort to the LGBT population	
Urban vs. Rural	Primary population served by the hospice organization	Structure
Service settings	Settings in which care is provided (home based services, nursing home, hospital-based, hospice inpatient facility).	Structure
Ownership status	Non-profit ownership vs. For profit ownership	Structure
Religious Affiliation or support	Support or affiliation of organization with a religious institution	Structure
Staff Identity	Number of staff members that openly identify as LGBT persons	Structure
Volunteers	The most frequent service provided by a volunteer	Structure
Job Satisfaction	The ranking of importance of LGBT affirming environment implementation to overall job satisfaction of respondent	Structure

## Appendix C: Recommended Survey Tool

## Recommended Survey Tool

### Lesbian, Gay, Bisexual and Transgender (LGBT) Care in Hospice Organizations

This survey is designed to assess hospice agency efforts at providing LGBT affirming environments to their patients and their respective families. Your participation will assist in identifying any predictors at the agency level of innovation in implementing the existing models of LGBT affirming environments. The data will evaluate the level of implementation in Hospice agencies and identify gaps where further research is indicated at how to best succeed at serving the LGBT population in end of life care. Please answer the following questions:

Gender:

- Female
- Male
- Transgender
- Other

Race/Ethnicity:

- African-American
- American Indian
- Haitian American
- Latina or Hispanic (non-white)
- European-American (white, not Hispanic)
- Asian American
- Multi Racial
- Bi-racial
- Other

Agency position:

- Direct patient contact     Administrative only
- Both direct patient contact and administrative duties

1. Does your agency serve an area that is primarily

\_\_\_\_\_ Urban \_\_\_\_\_ Rural \_\_\_\_\_ Both Urban and Rural

2. What percentages of your total annual hospice services are delivered in the following settings?

- a. \_\_\_\_\_ % in the homes of patients
- b. \_\_\_\_\_ % in nursing homes or assisted living facilities
- c. \_\_\_\_\_ % in our own inpatient hospice facility
- d. \_\_\_\_\_ % in hospitals
- e. \_\_\_\_\_ % in other settings

3. Is your hospice organization Medicare certified?

\_\_\_\_\_ Yes \_\_\_\_\_ No

4. Is your hospice organization Medicaid certified?

\_\_\_\_\_ Yes \_\_\_\_\_ No

5. Our hospice organization ownership can be classified as:

\_\_\_\_\_ for profit \_\_\_\_\_ nonprofit \_\_\_\_\_ other

6. Is your hospice organization, affiliated with or receive support from a religious institution?

\_\_\_\_\_ Yes \_\_\_\_\_ No

7. Please estimate the total number of staff currently employed in your hospice organization.

\_\_\_\_\_ Full time \_\_\_\_\_ Part time

8. Please estimate the total number of current staff members that are openly identified as either a lesbian, gay, bisexual or transgender individual? If the answer is zero, please enter “0” in the space provided.

\_\_\_\_\_

9. Which of the following best describes how your hospice most often utilizes volunteers (Please select one)?

- a. Fundraising
- b. Bereavement services
- c. In-home or facility patient support
- d. In-home or in facility family support
- e. Other: (please describe)
- f. My hospice organization does not utilize volunteers

10. Does your agency display any LGBT-friendly symbols in areas accessed by patients and their families?

\_\_\_\_\_ Yes      \_\_\_\_\_ No

11. If your agency has a website, are LGBT-friendly symbols displayed on the home page?

\_\_\_\_\_ Yes      \_\_\_\_\_ No      \_\_\_\_\_ No website

12. Does your agency include relevant information for LGBT patients and families in any brochures or educational materials?

\_\_\_\_\_ Yes      \_\_\_\_\_ No



13. Does your hospice organization's intake forms include more inclusive choices for answers (for example using the term "partner" in place of spouse and including "transgender" as a gender choice or provide blank spaces for the patient to fill out their choice)?
- \_\_\_\_\_ Yes      \_\_\_\_\_ No
14. Has your organization offered or funded any staff training regarding:
- a) gay, lesbian and bisexual people? \_\_\_\_\_ No      \_\_\_\_\_ Yes
- b) transgender people? \_\_\_\_\_ No      \_\_\_\_\_ Yes
15. If yes, which of the following topics were covered (Please answer all that apply)?
- a. Using inclusive language in patient/provider discussion
  - b. Transgender terminology
  - c. Utilizing open-ended questions
  - d. Heteronormative Assumptions
  - e. None of the above
16. If yes, what percentages of the staff and volunteers have attended training?
- \_\_\_\_\_ % staff      \_\_\_\_\_ % volunteers
17. Does your agency target or fund any outreach efforts to the LGBT community?
- \_\_\_\_\_ Yes      \_\_\_\_\_ No
18. If yes, please describe:

19. How important is providing LGBT affirming services in regards to your overall job satisfaction?

1. Not at all important
2. Somewhat important
3. Neither important or unimportant
4. Somewhat unimportant
5. Unimportant

Thank you for your participation in this survey

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