



The Experiences of Gay, Lesbian, Bisexual and Transgender People around End-of-Life Care

Scoping Study Report

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About the Authors

Dr Tania Lienert, who was the principal researcher on the project, has a PhD by research in Women's Studies and has worked on a number of research and evaluation projects using surveys and interviews in health and community services. She has also worked in project coordination and management for several non-government organisations with a focus on aged care and disability services, including ACON with its focus on GLBT health and ageing. Consequently, she has a strong knowledge of the sector and a wide range of contacts in this area.

ASLaRC Director, **Professor Colleen Cartwright**, was a co-researcher on the project; she has more than 15 years of teaching and research experience in ageing, ethics and medical decisions at the end of life, at national and international levels. She regularly runs information and training sessions for community and health professional groups on ethical and legal issues relating to end-of-life care, including advance care planning, informed consent and capacity. Reports and articles from Professor Cartwright's work as well as templates that readers can download and use for their own end-of-life planning are available on ASLaRC's website (<http://aslarc.scu.edu.au/downloads>). Her commitment to social justice, and to the rights of all people to access to knowledge about end-of-life care, led to this project being initiated.

Katherine Beck was the research assistant on the project. Katherine has a Bachelor of Social Science, and a Bachelor of Psychology with Honours. Katherine is currently undertaking a Master of Psychology (Counselling) while teaching psychology at Southern Cross University, Lismore campus. Katherine's key research interests include developmental psychology, perinatal loss and infant mental health, and social psychology. In 2006 Katherine developed an Abuse of Older Adults Prevention Program for the Northern Rivers Social Development Council and published a training manual for service providers working with older adults. Her support to the researchers and her attention to detail was invaluable in bringing the project to fruition.

TABLE OF CONTENTS

Acknowledgements	i
Executive Summary	v
CHAPTER ONE – BACKGROUND AND LITERATURE REVIEW	1
Background	1
Literature review	3
CHAPTER TWO – METHODOLOGY	19
Study design.....	19
Development of data collection tools	19
Ethics approval.....	19
Sample selection	20
Data collection	21
Data management and analysis	22
CHAPTER THREE – RESULTS	23
Participant Profiles.....	23
Major Themes from the analysis.....	25
Failure to acknowledge appropriate decision-makers	25
Lack of knowledge about Person Responsible	28
The importance of communication	30
The importance of advocates	31
Dealing with complex needs.....	32
Benefits of good end-of-life care planning	34
Extent of awareness and use of advance care planning	34
Awareness of legal mechanisms for advance care planning.....	35
Use of legal mechanisms for advance care planning.....	35
Financial planning.....	37
Attitudes and barriers to doing advance care planning.....	38
Not wanting to think about end of life	38
Lack of interest in ageing and death among gay men.....	40
Lack of time/Low priority.....	41

Lack of knowledge of where to go for help.....	41
Not knowing who to appoint	41
Conclusion	42
CHAPTER FOUR – DISCUSSION AND RECOMMENDATIONS	43
Discussion and analysis	43
The legal need for advance care planning	43
Barriers to advance care planning.....	45
Barriers to appropriate end of life care: lack of knowledge by service providers	48
The need for advocacy	49
When advance care planning works	49
Issues for further research.....	50
Recommendations.....	51
Systemic change	51
Information resources targeting GLBT people.....	51
Interventions to prevent social isolation and encourage social connection	51
Education of service providers	52
Study limitations	52
REFERENCES	53
APPENDICES	
Appendix 1: Schedule of Questions for Community and Service Provider Consultations .	55
Appendix 2: Brief Survey for Service Provider Consultation	57
Appendix 3(a): Information Sheets for Community Member Consultations	59
Appendix 3(b): Information Sheets for Service Provider Consultations.....	61
Appendix 4: Consent Form for Community and Service Provider Consultations.....	63
Appendix 5: End-of-life Care Planning for GLBT People – Explanation of Terms	65
Appendix 6: Confidentiality Form for community and Service Provider Consultations	67

EXECUTIVE SUMMARY

INTRODUCTION

All States and Territories in Australia have implemented legislation relating to end-of-life decision-making and substitute judgment. However, reports to relevant legal and community services indicate that many gay, lesbian, bisexual and transgender (GLBT) people in NSW – estimated to be about four to five percent of the population – are being denied their legal rights in the end-of-life care of their partners and other important people in their lives.

The Aged Services Learning and Research Centre (ASLaRC), Southern Cross University, undertakes scholarship, research, education and training to improve the lives of older people.

ACON is a NSW community-based GLBT health promotion organisation with a Statewide brief and an interest in supporting healthy GLBT ageing.

In January 2009 the ACON Northern Rivers branch manager was seconded to ASLaRC for six months to investigate this locally-identified need.

OBJECTIVE

The project sought to identify the legal need for GLBT people to arrange wills, Enduring Power of Attorney, Advance Health Care Directives and Enduring Guardianship, and to be aware of their rights relating to Person Responsible. In this report, the terms ‘end-of-life care planning’ and ‘advance care planning’ both encompass all of these legal mechanisms, and are used interchangeably.

EXPECTED OUTCOMES

The project intended to:

- undertake an Australian and international literature review
- conduct consultations with GLBT community members and legal, health and community services staff
- write a report and a journal article discussing the findings
- submit a grant application for further research.

BACKGROUND AND LITERATURE REVIEW

It is well documented that GLBT people are socially and economically disadvantaged as a result of historical discrimination, social stigma and lack of legal recognition of relationships and gender identity (ACON, 2006). If advance care planning does not take place, GLBT people can be further disadvantaged at the end of their lives.

For the Literature Review, searches were conducted on relevant databases to find books and journal articles. In addition, a range of reports and strategic planning and policy documents were reviewed from Australian and international GLBT health research centres and GLBT community organisations.

Issues identified included:

- The stigma and discrimination faced by gay and lesbian people prevents end-of-life care planning for fear of being outed, leading to ‘disenfranchised grief’ and loss of entitlements for same-sex partners;
- GLBT people need to engage with advance care planning in order to protect their rights, counter discrimination and die with dignity;
- Barriers such as lack of knowledge and difficulties identifying alternative decision-makers mean there is a need for information resources on advance care planning;
- The actual discrimination and violence faced by GLBT people in health care settings and the fear of such discrimination leads to a failure to or delays in GLBT people accessing health services, resulting in problems in end-of-life care;

- Difficulties in end-of-life care mean there is a need for advocacy;
- Future challenges include systemic change to help end stigma and discrimination; training of and advocacy in mainstream services; establishing GLBT specialist and specific services; and informing GLBT people of their rights so they can act as agents of change.

METHODOLOGY

Study Design

The methods for this project included an international literature review, development of data collection tools and an ethical framework for the research, including submission of two applications to Ethics Committees for approval. Plans were made for a GLBT community consultation and a service provider consultation, both in the Northern Rivers region of NSW. While the service provider consultation went ahead, the community consultation had to be cancelled. As a result, anecdotal evidence from community members and service providers who spoke to the researcher about the proposed community consultation, and its cancellation, was noted.

Development of Data Collection Tools

A schedule of questions was developed, based on the literature review, to guide the format of both the community and service provider consultations. These questions were designed to gather information about experiences of end-of-life care of GLBT people. In addition, a brief survey was adapted from previous surveys used by one of the study investigators (Cartwright et al., 2005) to assess knowledge of advance care planning.

Ethics Approval

A framework for conducting ethical research at the community and service provider consultations was outlined in applications to the Southern Cross University Human Research Ethics Committee and the ACON Research Ethics Review Committee. These applications were approved.

Target Group / Sample Selection

The target group for the project was GLBT residents in North Coast NSW.

Community and service provider consultations planned for May and June 2009 in Lismore were advertised via a range of health and community service email lists and newsletters and by word of mouth. A media release was sent to mainstream media and the events were promoted on Northern Rivers radio. In addition, an *Explanation of Terms* resource, including where to go for more information on advance care planning, was published in the ACON newsletter *Rainbow News*.

The community meeting had to be cancelled due to rising floodwaters (a common occurrence in the Northern Rivers) and low response numbers. The service provider consultation went ahead.

Data Collection Process

The format for the planned community and actual service provider consultations included welcomes, with lunch and/or afternoon tea provided; review of the research information statement and consent and confidentiality forms, and gathering of signed forms; a brief survey of participant knowledge about the topic; a presentation about Advance Care Planning and other end-of-life issues with a take-home *Explanation of Terms* resource sheet; a scan of participant experiences in GLBT end-of-life care using a list of questions; and invitations to tell particular stories.

Service providers at the forum had provided direct end-of-life care to GLBT people and gave first-hand accounts of their experiences. With the permission of participants, the service provider consultation was recorded on audio cassette and transcribed. Following this event, transcripts were provided to participants for verification and/or clarification, and extra details and further stories were provided by some participants.

From the beginning of the research project, and as it progressed, a number of people volunteered their stories of GLBT end-of-life care. In addition, after the GLBT community consultation was cancelled, the researcher asked community members for their opinions on

why the numbers of RSVPs were so low and their thoughts about advance care planning in general. The results of an additional six conversations with GLBT community members were noted and are included in this report as anecdotal evidence. An additional seven service providers provided feedback and comments which are also included as anecdotal evidence.

RESULTS

Participant Profile

Twenty-five individual participants were recruited. Twelve service providers attended the service provider forum, and an additional seven provided comments to the researcher during the course of the project, a total of 19 service providers. Four were males and 15 were females. They worked across a range of fields including nursing, home and community care, residential aged care, palliative care, allied health, social work, voluntary community care and the funeral industry. Three had experiences of multiple episodes end-of-life care dating back to the early days of the HIV epidemic. Despite the GLBT community consultation being cancelled, six GLBT community members provided comments to the researcher during the course of the project. Four were males and two were females. Due to the high number of gay and lesbian people working in health and community services, it is likely that a significant proportion of service providers were also GLBT community members, although this information was not collected. There were no transgender participants, although two of the service providers spoke about their work with transgender clients.

MAIN FINDINGS

A major theme that emerged from the analysis was the lack of legitimacy of same-sex relationships, sexual and gender identity accorded by family, health care professionals, and society, and the subsequent failure by family and health care professionals to acknowledge the appropriate substitute decision-maker/Person Responsible in end-of-life care for GLBT people. Exclusion caused additional grief, loss of dignity and loss of property upon the death of their partner.

At the service provider consultation, several participants did not know about the rights of same-sex partners to claim status as Person Responsible, and therefore to make health care decisions should their partner lack capacity. Levels of awareness and use of the legal mechanisms that assist in advance care planning also varied considerably among clients of the service providers consulted. When service providers encouraged the use of legal mechanisms, awareness and use was higher.

Other participants stressed the importance of GLBT people communicating their end-of-life care wishes to family and health care professionals before they become incapacitated. If they did not, they risked their wishes and those of their close friends and partners being overridden by blood relatives and health care workers. Further, they described the important role of advocates in ensuring that the wishes of the dying person were met.

Some GLBT people can be isolated from family and friends, and/or experience mental illness or problematic alcohol or drug use at the end of life. Service providers agreed that clients not wanting to be institutionalised or treated, but who nevertheless might have very pressing health issues that need attention, including mental health issues, are a very difficult group to assist and to manage in service settings. A cooperative approach between agencies could support both the client and agency staff in these instances.

When same-sex relationships and other important relationships are communicated to and recognised by families and health care professionals, and advance care planning is well organised and communicated to significant people, it is possible for GLBT people to experience appropriate end-of-life care and to die with dignity.

Barriers to advance care planning identified by participants included:

- not wanting to think about the end of life
- for gay men only, a denial of the realities of ageing and death
- lack of time / low priority
- lack of knowledge
- not knowing who to appoint to significant decision-making roles

DISCUSSION

The literature and the data were consistent on the legal need for GLBT people to engage with advance care planning because of the actual discrimination and violence faced by GLBT people in health care settings. The failure by GLBT people to access health services, leading to problems in end-of-life care, was also found to be consistent across the literature and the data from this study, as was the range of barriers to carrying out advance care planning and the stated need for information resources to assist GLBT people and service providers in this area. An additional barrier was identified by this study: ageism in the gay male community possibly resulting in a lack of interest in ageing and consequently in advance care planning.

While the education of service providers to offer GLBT-friendly and appropriate care is a long-term goal, the legal mechanisms to assist people with end-of-life care planning are available now. GLBT people are well advised to know their rights and to use the mechanisms available to help prevent discrimination, loss of dignity and inappropriate care. Large scale, confident use of these mechanisms could well help educate health professionals and facilitate the kind of changes desired in health services so GLBT people are treated equally to the rest of the population when accessing services.

However it is still not known the extent to which GLBT people are aware of or using these mechanisms or their experiences in so doing.

RECOMMENDATIONS

The following recommendations address the barriers to advance care planning by GLBT people, and the subsequent implementation of that planning.

Systemic Change

As was found in the literature review, the first and most important change that could benefit GLBT end-of-life care would be legal and social recognition of same-sex relationships, and the diversity of sexual and gender identity. The lack of legitimacy of same-sex relationships, sexual and gender identity accorded by family and health care professionals led to a call by

participants for equal rights and recognition in society and an end to discrimination. This may then have a flow-on effect to service provision.

Information Resources Targeting GLBT People

The results of this study suggest that GLBT people do not know about and are not using the available legal mechanisms relating to end-of-life care, while at the same time there are compelling reasons for their use. While organisations such as ACON and the Gender Centre seek to educate health professionals and other health services staff to appropriately serve GLBT people, this is a long-term goal that requires participation from government and non-government health agencies and services. By contrast, the legal mechanisms to assist people with end-of-life care planning are available now. However, they are little known.

Consequently, information resources to inform GLBT people's rights in this area and how to advocate for them are an important part of advance care planning. Very specific information is required for closeted rural and regional GLBT people and those still married.

Interventions to Prevent Social Isolation and Encourage Social Connection

The study found that social isolation and a lack of significant connections was a barrier to advance care planning, particularly for gay men. Interventions by health and community services and activities by GLBT community groups that promote social interactions and connections may assist GLBT people to develop the kinds of close friendships and partnerships that might be relied upon at critical times, such as the end of life. Particular efforts may need to be made with gay men in the context of the impact of the HIV epidemic and the challenges of responding to ageism in the gay male community.

Education of Service Providers

Homophobia and transphobia among service providers can be addressed by education programs that raise awareness about issues facing GLBT people and stress the benefits of an inclusive workplace. Such programs could be provided by workplace consultants.

The lack of knowledge of service providers about end-of-life decision-making, in particular about changes to the Guardianship Act (1987), requires immediate action. Relevant agencies need to provide education on this topic. If service providers are aware of the hierarchy of

people who can be alternative decision-makers for GLBT people under Person Responsible, it is more likely the appropriate person will be able to step in should the patient lose capacity. At the same time, people who are not appropriate alternative decision-makers will be less likely to be able to make decisions on behalf of the patient. The rights of GLBT people are therefore more likely to be respected and their wishes met, leading to appropriate and dignified end-of-life care for the patient and the appropriate support being available for their loved ones.

STUDY LIMITATIONS

This study consisted of a literature review and consultations with 25 GLBT individuals and their service providers in the Northern Rivers region of NSW. A larger study, conducted over a wider geographic area, and involving more GLBT community members/service users, may produce different results.

ISSUES FOR FURTHER RESEARCH

While the education of service providers to offer GLBT-friendly and appropriate care is a long-term goal, the legal mechanisms to assist people with end-of-life care planning are available now. GLBT people are well advised to know their rights and to use the mechanisms available to help prevent discrimination, loss of dignity and inappropriate care. However it is still not known the extent to which GLBT people are aware of or using these mechanisms or their experiences in so doing. A future research project could investigate this, and use the research results to generate targeted resources.

Attitudes to advance care planning and end-of-life care were not canvassed in this study but they emerged in the literature. In a future study, attitudes to the range of end-of-life care options held by GLBT people and their service providers should be explored.

An additional issue which was not investigated in this study was the effect of whether patients hold private health insurance or are treated in the public health system. Future research should ask this question when enquiring about end-of-life care.

CHAPTER ONE – BACKGROUND AND LITERATURE REVIEW

BACKGROUND

All States and Territories in Australia have implemented legislation relating to end-of-life decision-making and substitute judgment. However, reports to relevant legal and community services indicate that many gay, lesbian, bisexual and transgender (GLBT) people in NSW – estimated to be about four to five percent of the population – are being denied their legal rights in the end-of-life care of their partners and other important people in their lives. To investigate this issue, the Aged Services Learning and Research Centre of Southern Cross University (ASLaRC) partnered with ACON, a NSW community-based GLBT health promotion organisation with a Statewide brief. The ACON Northern Rivers branch manager was seconded to ASLaRC to follow up on this locally-identified need by undertaking an Australian and international literature review, conducting consultations with GLBT community members and legal, health and community services staff, and writing a report, a journal article and grant applications for further research.

Organisational Context

ASLaRC is committed to improving the lives of older people through research, teaching and community engagement. ASLaRC's work on end-of-life care has, to date, been based on the general population only. The focus on GLBT people for this project, a group with limited access to information about legal mechanisms to support end of life care, and poor experiences of mainstream aged care, builds on and diversifies the Centre's existing work.

The project was of interest to achieve ACON as it helps to achieve ACON's aim to improve knowledge about end-of-life decision-making and to seek funding to produce resources aimed at advising ageing GLBT people of their legal rights in relation to end-of-life issues (ACON, 2006). It also meets the objective in ACON's *Strategic Plan 2009-2012* to "help people plan ahead for a healthy older age financially, physically, mentally and emotionally" (ACON, 2009 p. 32).

It is already well documented that GLBT people are socially and economically disadvantaged as a result of historical discrimination, social stigma and lack of legal recognition of relationships and gender identity (ACON, 2006). If end-of-life care planning does not take place, GLBT people can be further disadvantaged at the end of their lives.

More specifically, should a GLBT person unexpectedly become ill or incapacitated, without appropriate legal mechanisms in place, and if they do not know or are unable to stand up for their rights, medical practitioners and other health care professionals may provide care they would not want. It may be possible for others to make decisions not in line with theirs, and people who should have a say may be excluded from the decision-making process.

OBJECTIVE

The project sought to identify the legal need for GLBT people to arrange wills, Enduring Power of Attorney, Advance Health Care Directives and Enduring Guardianship, and to be aware of their rights relating to Person Responsible. In this report, the terms ‘end-of-life care planning’ and ‘advance care planning’ both encompass all of these legal mechanisms, and are used interchangeably. The target group for this first stage of the project was GLBT residents in North Coast NSW.

EXPECTED OUTCOMES

The project intended to:

- undertake an Australian and international literature review
- conduct consultations with GLBT community members and legal, health and community services staff
- write a report and a journal article discussing the findings
- submit a grant application for further research.

LITERATURE REVIEW

A literature review was conducted of both the published academic literature and the reports and policy documents of a range of GLBT research bodies and community organisations. Searches were conducted on relevant databases, including ProQuest 5000, the nursing and allied health database CINAHL, the MURA online catalogue of the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) and Libraries Australia. These databases contained both Australian and international references. A wide range of terms was entered to discover the most often used keywords for end-of-life care for GLBT people. The keywords searched included advance care planning, advance directives, capacity, death, decision-making, family, decision making, patient, dying, end-of-life, end life, gay men, informed consent, euthanasia, homosexuals, lesbians, palliative care, palliative treatment, terminal care and transsexuals.

This review summarises the key themes in the literature:

1. The stigma and discrimination faced by gay and lesbian people prevents end-of-life care planning for fear of being outed, leading to ‘disenfranchised grief’ and loss of entitlements for same-sex partners;
2. The legal need for GLBT people to engage with advance care planning in order to protect their rights and counter discrimination;
3. The actual discrimination and violence faced by GLBT people in health care settings leads to a failure to or delays in GLBT people accessing health services, resulting in problems in end-of-life care;
4. The fear of discrimination leads to a similar failure to access services;
5. Barriers such as lack of knowledge and difficulties identifying alternative decision-makers mean there is a need for information resources;
6. Difficulties in end-of-life care mean there is a need for advocacy;
7. Advance care planning can work to assist GLBT people to die with dignity;
8. Future challenges, including
 - 8.1 systemic change;
 - 8.2 training of and advocacy in mainstream services;
 - 8.3 GLBT specialist and specific services; and
 - 8.4 informed GLBT people as agents of change.

(Note: some of the literature consulted refers to gay and lesbian people only, some to GLBT people, and some also to intersex people, in which case the abbreviation GLBTI is used. Specific data relating only to intersex people are not included in this report).

The Legal Need for GLBT People to Engage with Advance Care Planning

A number of reports, resources and academic literature talked about the legal status of gay and lesbian and transgender people compared with heterosexual people, examples of heterosexism, homophobia and transphobia and overt discrimination in end-of-life care from service providers and blood relatives, and internalised homophobia or a desire to protect privacy on the part of gay men and lesbians themselves (Stein and Bonuck, 2001; Smolinski and Colon, 2006; Cahill et al., 2000; Hash, 2006; ACON, 2006; Auger, 2003; Pitts et al., 2006; Feldman and Parkinson, 2005; Casey, 2003). Consequently, it is argued that GLBT people need to engage in advance care planning to protect their rights.

Although the current generation of younger and mid-life GLBT people more openly disclose their sexual orientation or gender identity, this may not always be possible for older GLBTI people (Auger, 2003; Feldman and Parkinson, 2005). Many older GLBT people have been closeted and experienced violence, stigma and discrimination prior to gay liberation as well as subsequently (Auger, 2003; Feldman and Parkinson, 2005). The same issues confront both urban and non-urban dwellers (Auger, 2003; Feldman and Parkinson, 2005). Pitts et al (2006) and Feldman and Parkinson (2005) report that several studies note that almost three quarters of older GLBTI people report some form of sexual orientation victimisation, with men reporting higher rates than women. There is a link between physical attacks and lower self-esteem, loneliness and poorer mental health (Pitts et al., 2006; Feldman and Parkinson, 2005). These events can lead to increased risk of depression, suicide, addictions and substance abuse, which can contribute to difficulties in coming out when seeking health services (Chandler et al., 2005).

Older gay and lesbian couples often encounter legal problems when one partner becomes incapacitated or dies (Cahill et al., 2000). Cahill et al describe events that occurred when two older lesbians, who had been together for 42 years, both became ill: distant family members took over decision-making responsibilities and disregarded the women's desire to be together. Family members ignored their lifelong relationship, separating them into two different

nursing homes, selling their home (which legally belonged to only one of them) and selling off their belongings. Family members refused to let them visit each other, claiming that to do so would be "upsetting"(Cahill et al., 2000 p. 86).

Cahill et al (2000) also report that hospital staff may limit visits to "immediate family", which would include a sister-in-law but not one's own same-sex partner with whom one has shared one's life. Treating physicians may follow the instructions of a patient's parent or sibling rather than that person's life partner (2000 p. 86). In a highly-publicised case in the US, after Sharon Kowalski was nearly killed by a drunk driver, her partner Karen Thompson was not allowed to see or care for her, due to the homophobia of Kowalski's family of origin. Only after a legal battle of several years was Karen allowed to see Sharon, help in health-care decision-making and bring her home to care for her (Casey, 2003).

In an interview study of 19 mid-life and older gay men and lesbians in the US on their experiences of caring for chronically ill, same-sex partners, Hash (2006) found that although homophobic attitudes were not often overtly expressed by professionals, they were often apparent through slighting remarks or rude or hostile behaviour. Some services were insensitive to same-sex partners, insisting that a partner could not be considered "next of kin". Others experienced further discrimination based on race, age, mental health status, and HIV status. In this study unsupportive practices were also apparent outside of health services in community businesses. For example, the term "partner" was omitted from newspaper obituaries and in one case two male partners were not permitted to share a mausoleum drawer. In addition, caregivers had to face sometimes hostile family members, and were unable to gain support from co-workers due to fear of coming out and losing their jobs, which were important when they were sole breadwinners (Hash, 2006).

Religious organisations delivering aged care programs in NSW are currently permitted under law to discriminate against GLBT people because they are exempt from anti-discrimination laws (ACON, 2006). There are no Federal anti-discrimination laws for GLBT people so federally-funded organisations can also discriminate. This means ageing GLBTs will experience different levels of service and access depending on the funding source of particular agencies. Transgender people face the additional hurdle of accessing services due to contrasts between individual and services' definitions of identity, and therefore service eligibility (Wilson, 2009).

Solutions to this issue put forward by non-Government organisations include to lobby the Government and educate the general public about the need for equality, liaise with GLBT-friendly service providers and provide referrals only to selected organisations who will serve clients fairly, and join with other organisations in training and raising the awareness of service providers to better serve GLBT clients (Wilson, 2009; ACON, 2006).

While there have been some legal changes granting rights to same-sex couples in Australia in 2008 and 2009, partnerships do not have the same legal status as marriage and consequently, discrimination continues. Writing about the legal status of gay men and lesbians in Canada, Auger (2003 p.87) comments:

As long as lesbians and gay men continue to live with the fear of homophobia they will continue to be careful about making their relationships visible and public. Even though there is some acceptance of our relationships, there is still a very long way to go before we achieve the recognition that is accorded heterosexual couples.

In order to avoid such problems, GLBT people are encouraged to create valid legal documents for end-of-life care by consulting with a lawyer. In her 2003 book *Passing Through*, one of Auger's research participants spoke of the need for end-of-life education, information and resources aimed at same-sex partners. Another participant said that it is "crucial to make directions and complete such tasks because it helps the surviving partner cope with the loss and the process of grieving. It may be the last loving gift one can leave their partner" (p. 86).

Such documents need to be prepared well in advance of need. Smolinski and Colon (2006) reported on a situation where not addressing legal matters can result in exacerbated distress for health care professionals. An on-call page was made regarding a man in his late 30s, whose life partner was not embraced by his family, was very ill and expected to die within hours. The nurse was requesting a lawyer to come to the hospital to draw up a will because the partner explained "I will lose everything" upon the patient's death. Unfortunately the patient lacked decision-making capacity and could not execute a will. Smolinski and Colon (2006 p.61) report that "the nurse felt helpless as he realised the opportunity to assist this patient had passed". Stein and Bonuck (2001) argue that the legal importance for gay men and lesbians to execute advance health care directives should encourage health care providers and community organisations to assume a larger educational role in this area.

Auger (2003 p.96) recommends that gay men and lesbians give key documents to lawyers, doctors, family and friends, and that:

we use wills not only to say who we want to get assets and belongings, but also to say who we *don't* want to get assets and belongings, and use advance health care directives to tell health care providers not only whom we do want making decisions but also whom we do *not* want making decisions about our health.

However it is costly to engage lawyers to prepare some documents. In Canada, if not left to same-sex partners, biological next-of-kin automatically become the beneficiaries of wills and estates (Auger, 2003). One participant in Auger's study commented on the financial costs of making wills for gay men and lesbians, who have to take "extraordinary and expensive measures to *make* happen what is considered automatic for heterosexual couples"(p.88). In Australia, changes to the NSW *Guardianship Act* (1987) mean same-sex partners or an unpaid carer or another close friend has decision-making authority for health care decisions as the Person Responsible should the patient lose capacity (replacing next-of-kin). However clients and their health care professionals need to know about the laws in order for their rights to be enacted in an often stressful end-of-life situation, and the implementation of advance health care directives is more likely when an Enduring Guardian or other Person Responsible knows about and advocates for them (Fagerlin and Schneider, 2004). Auger (2003 p.29) cites ethicist Peter Singer:

Advance care planning is not about legislation, lawyers and doctors, but rather about relationships, communication and families. Governments and professional groups could do much to support the process of advance care planning.

Commenting on the need for gay men and lesbians to engage in advance care planning to avoid potential problems, Auger (2003 p. 32) also cites Doni Gerwirtzman:

One day our laws will embrace an expansive definition of family that will provide lesbians and gay men with the same automatic legal safety nets as our non-gay counterparts who can marry. Until then, there is no substitute for careful planning. Get your documents in order, and then take charge of this aspect of your life!

Stigma and Discrimination against Gay Men and Lesbians Prevents End-of-Life Care Planning

Auger's (2003) study with closeted and rural gay and lesbian participants showed they feared making wills and appointing proxy health decision-makers because of the prospect of these documents revealing the true nature of important relationships after the death of one partner. In many cases, partners had been together for between 10 and 30 years. Having been in the closet for so long, participants were reluctant to prepare documents or talk to their families about their wishes for fear of being judged about not having been more open about their partnerships previously. It was easier not to address the issue at all. This left bereaved same-sex partners with no acknowledgement of their relationship, loss of rights over funeral arrangements and loss of property, pets and personal possessions upon the passing of their loved ones. They then experienced what Doka has called "disenfranchised grief" due to the lack of recognition of their relationship (1989).

Discrimination and Violence Prevents Health Care Access and Disclosure

It is well documented that GLBT people are less likely than other people to seek routine health care because of their discomfort in coming out to providers and disclosing their sexual orientation or gender identity (Smolinski and Colon, 2006; ACON, 2006; Auger, 2003; Pitts et al., 2006; Chandler et al., 2005; Birch, 2004; Feldman and Parkinson, 2005; Ministerial Advisory Committee on Gay and Lesbian Health, Victoria, 2003). Pitts et al (2006) report that of the male and female participants in their study with a regular GP, only two thirds believed that their GP knew of their sexuality. However this rose to almost all of the transgender respondents, possibly because they have been more likely to need to discuss issues of medical intervention with their GP.

The pattern of modifying behaviour due to fear of discrimination or prejudice "would seem to be well grounded" given the evidence of actual experiences of discrimination and violence against GLBT people in many health and aged care settings, in particular in hospital settings (Pitts et al., 2006 p.48). Chandler et al suggest the residential aged care sector is unprepared to cater appropriately for GLBTI people and that staff are not trained to handle gender-variant residents (2005). Overseas studies demonstrate that fears of abuse and homophobic violence are prevalent and based on actual incidents such as staff refusing to bathe a lesbian and

physical maltreatment and threats to out a gay man if he complained about the service he was receiving (Chandler et al., 2005).

In Australia, Pitts et al (2006) found that there is an increase in modification of daily activities at home for those over 70, which may indicate a renewed need to "hide" when accommodation changes with age. The authors note that this is consistent with the work of Harrison, who found a high degree of invisibility in GLBTI people in the aged care sector in a 2001 study (cited in Pitts et al, 2006). While they might have come out of the closet in recent years, when requiring assistance from aged care and nursing facilities, they are "re-entering the closet" for fear of discrimination (Chandler et al., 2005).

Sexual orientation and gender identity are social determinants of health and discrimination on these grounds has been shown to be a threat to health and wellbeing (Marmot and Wilkinson, 2006; Ministerial Advisory Committee on Gay and Lesbian Health, Victoria, 2003). Gay and lesbian people have been shown to have poorer health than the general population on a range of indicators, use drugs and alcohol at rates much higher than the general population, and are at greater risk for a number of conditions including breast and ovarian cancer for women and anal cancer for men (ACON, 2009). Bisexual people self-identified extremely high levels of anxiety and stress related to their bisexuality (ACON, 2006), and transgender people have an increased rate of depression and suicidal planning and thoughts of suicide than the general population, and are more medically dependent because of ongoing hormone replacement therapy and surgery (Chandler et al., 2005).

Discrimination against GLBT people and subsequent failure to access health services can lead to isolation, late presentation, the need for crisis management and premature hospitalisation or institutionalisation. These issues have consequences for GLBT people's ability to seek appropriate end-of-life care, and are predictors for problems in end-of-life care, including elder abuse and neglect (ACON, 2006; Auger, 2003; Pitts et al., 2006).

There are particular issues for transgender people in ageing and accessing services due to their very specific health and psychosocial issues. Feldman (2005) suggests transgender people are at particularly high risk of reduced quality of health care and health service access, especially where personal care is provided. Physical appearance and assumed gender may not equate, and service providers who are not accepting and aware may respond in inappropriate or

discriminatory ways (Wilson, 2009). As a result of restrictions on Medicare rebates and service discrimination, transgender people may not be able to access the health care they need, for example cancer screening (Ministerial Advisory Committee on Gay and Lesbian Health, Victoria, 2003). Transgender older people may require referrals to supportive services and advocacy assistance (Wilson, 2009).

Fear of Discrimination in Health and Aged Care Settings

Along with actual experiences of discrimination in health and aged care settings comes the fear of future experiences for the current generation of younger and mid-life gay and lesbian people as they age. Gay and lesbian people who have put a lifetime's effort into nurturing friends, family and community and an authentic way of living have a strong desire to hold on to that sense of authenticity (Weeks et al., 2001). They are likely to be less tolerant of a system that does not accept them (Callan and Mitchell, 2007).

Callan and Mitchell (2007) report on a 2006 market research study in the US which found a wave of 'out and proud' lesbian and gay baby boomers heading towards a time when they may need aged care services, with more than a quarter experiencing great concern about discrimination as they aged. Less than half had confidence that health care professionals would treat them well.

“This is a new phenomenon which we can expect to have an impact on aged care services in Australia”, they argue. “We may, for the first time, be experiencing the visibility of gay and lesbian people within the ageing client group, which may, in turn, compel services to find a way of working with them” (Callan and Mitchell, 2007 p.31).

By contrast, GLBT people's fear of discrimination provided a rationale for Victorian investor Peter Dickson in his work to establish a GLBT “retirement haven” (Rolle, 2009).

Barriers to Advance Care Planning

Research in the general population sponsored by the Law and Justice Foundation of NSW, *The Legal Needs of Older People* (2004), reveals that many older people do not know what the legal tools that assist in advance care planning do, or how to access them. They also face barriers due to the lengthy time and complex procedures involved in completing them,

mistrust of the process, lawyers and the legal system, reluctance to think about end-of-life issues and difficulties predicting future health circumstances accurately (Ellison et al., 2004). A NSW Health project (in progress in 2009) has found that the genesis of many disputes in end-of-life care in the general population is the failure to identify a substitute decision-maker (J Letts 2009, pers. comm., 31 July). In the US, in relation to advance health care directives, Fagerlin and Schneider (2004) had similar results. In addition, they reported uncertainty among patients as to whether they needed advance health care directives, concern about whether they would be effective, hesitation in broaching the topic with their doctors and a preference to leave decision-making to trusted others (health care professionals and family members).

There is very little literature on Australian research into advance care planning by, or relating to, GLBT people. In NSW, ACON's research for its *Healthy GLBT Ageing Strategy* could not find any evidence of whether GLBT people are aware of or using the legal mechanisms that can assist in advance care planning (2006).

In the international literature, there were mixed results on the extent to which GLBT people took advantage of legal mechanisms to protect their rights at the end of their lives. Stein and Bonuck (2001), in a study of 575 GLBT people in a metropolitan setting, found a high level of awareness of the mechanisms for end-of-life care planning. While there was no direct evidence, the authors speculated that this was the result of experiences of many participants of the early years of the HIV epidemic in the late 1980s and early 1990s, when many gay men died of this illness. At the time, a diagnosis of HIV meant a sometimes swift progression to AIDS, and no effective treatments or cures existed. Family conflict at the bedside meant GLBT people were sensitised to the importance of advance care planning. The Kowalski case described earlier also promoted an awareness of the importance of advance care planning. However a Canadian study found rural and closeted GLBT people failed to use such mechanisms for fear of being outed (Auger, 2003).

In the Stein and Bonuck study (2001), participants overwhelmingly preferred palliative care rather than extending life (86% versus 14%), consistent with other attitudinal studies of US adults. However an overwhelming 92 percent supported the legalisation of physician-assisted suicide (PAS) under a wide variety of circumstances, compared with 65 percent of adults nationwide. This comparison was even stronger among those over 60 years of age, with 93

percent supporting the legalisation of PAS compared with rates between 35 percent of those over 70 and 56 percent of those over 65 in two other polls. This data is consistent with the high levels of euthanasia practice found in the early days of the HIV epidemic both in Australia and the US (Magnusson, 2003).

Despite high levels of knowledge about health care proxies (72%) and advance health care directives (90%), Stein and Bonuck (2001) found that only about half of these groups actually completed these documents - 42 percent and 38 percent respectively. Women were much more aware and likely to have done so than men. While the rate for advance health care directives (38%) is still higher than a comparable US poll (28%) of the general community, given the anecdotal reports and legal cases of biological family members making medical decisions that supersede those of gay partners, Stein and Bonuck (2001) strongly advocated their completion. In Hash and Netting's (2007) study of 19 gay and lesbian caregivers, all but four persons reported that their partners had advance directives, but the majority of caregivers did not have advance directives for themselves.

Stein and Bonuck (2001) explored potential barriers to undertaking advance care planning processes. Three quarters of the participants had thought about who should make medical decisions "very much" (41%) or "somewhat" (34%). Thinking about it did not translate into action. Partners were the most commonly chosen persons to make decisions (43%), but few (21%) had legally appointed their partner to do so. Others would like to assign the responsibility to a relative (31%), a friend (19%) or their doctor (2%), although these people were rarely formally designated in legal documents. Reasons for not completing advance care planning documents included: not necessary now (28%); unsure who to name (25%); hard to think about (20%); don't know where / how to do it (18%); and haven't found the time (18%).

Researchers who investigated this topic argued that it is important for health care providers, policy-makers and gay/lesbian community organisations to educate community members about and assist them to complete health care proxy appointments, and intervene across individual, organisational, and community levels in advocacy for the health and end-of-life care needs of older gay men and lesbian clients and those with serious or chronic medical conditions (Hash and Netting, 2007; Stein and Bonuck, 2001).

The 25 percent of participants in the Stein and Bonuck (2001) survey who were unsure of who to name as a health care proxy begs the question as to why this might be the case. The literature on gay and lesbian ageing and advance care planning that revealed the extent to which gay and lesbian people are connected to others, or alternatively, are socially isolated, may shed some light.

A number of studies demonstrate how gay men and lesbians construct 'families of choice' for themselves and a way of life that includes affirmations from and intimacy with same-sex partners, friends, children, blood relatives and community (Weeks et al., 2001; Weston, 1991; Lienert, 2003). Participants in the Weeks et al (2001 p.102) study illustrate how families of choice supported the earliest victims of AIDS, while also acknowledging that "ill health and ageing can test to the limits the strength of home and community connections".

Several people interviewed by Weeks et al (2001 p.103) talked about how issues of ageing, home and care require forethought and planning. Several women identified the need for an "old dykes' home", and another told of a roster of friends who supported her during her recovery from an operation. Planning for the future, they argued, involves making commitments to others and it also highlights the value attached to caring "for ourselves".

Despite these findings, between 64 and 77 percent of participants in the Private Lives study (Pitts et al., 2006) indicated they would turn to GLBTI friends for emotional support, but when asked who would care for them in times of sickness, blood relatives (biological family) or partners were rated higher than GLBTI friends. While friendship ranked more highly than blood relatives in a question about "the three best things" in life, this result indicates that family remains an important lifeline in a crisis (Pitts et al., 2006 p. 57). Several respondents in Hash's (2006) US study voiced concern over who would be available should they need care in the future. Very few felt they could rely on a circle of friends for assistance and many feared the type of treatment they would encounter, as a gay man or lesbian, should they need skilled nursing care. In a Victorian study on the needs of older GLBT people, Chamberlain and Robinson (2002) found that 20 percent of the sample, all gay men, were isolated and 'doing it tough'. These studies suggest the limits of friendship for some individuals, who may not have anyone close enough to them to appoint as an alternative decision-maker.

Difficulties in End-of-Life Care – The Need for Advocacy

Just because advance care planning documents are completed does not necessarily mean they will be followed. Fagerlin and Schneider (2004) describes how, even if someone has an advance health care directive, they also need an Enduring Guardian, a Person Responsible or at the very least, a supportive treating doctor to advocate for them in a health care setting, or the directive may not be implemented.

Hash and Netting (2007) found concerns about informal family dynamics, interactions with formal systems, financial issues and ownership issues. They argue that it is important for social workers to intervene across individual, organisational, and community levels in advocacy for the needs of older gay men and lesbian clients.

When End-of-Life Care Planning Works

In a Victorian study, in-depth interviews explored the experience of 19 GLBTI seniors receiving aged-care services (Barrett, 2008). By their choice, real names are used in a case study of one 67-year-old lesbian woman, Thelma. The case study was constructed from interviews with Thelma's partner Maureen and friend Jean. A community of lesbians including Maureen and Jean negotiated a partnership with district nursing and palliative care services to provide care for Thelma who died at home in 2003. The challenge in this situation was to educate the service providers and health care professionals involved so they were accepting and supportive of Thelma, Maureen and their lesbian friends. Thelma's story highlights the importance of GLBT seniors accessing services in their own home, rather than relocating to a hostel or nursing home where they are likely to receive inappropriate treatment (Barrett, 2008).

Future Challenges

In response to concerns about discrimination and invisibility in aged care, the literature discussed the need for change in four areas: systemic change; training and advocacy with existing aged care service providers to maximise access to better community, in-home and residential aged care services; establishing GLBT-specific and specialist services; and educating GLBT people to be more informed consumers and agents of change. Researchers also made recommendations for further investigations in some areas.

Systemic change

In order for GLBT people to enjoy optimum end-of-life care, researchers recommended same-sex relationship recognition in law and consequently a society more accepting of gay men and lesbians (Hash, 2006); and work to combat homophobia and transphobia and support diversity in society (Ministerial Advisory Committee on Gay and Lesbian Health, Victoria, 2003). There also needs to be consideration of many policy and legal issues which impact on same-sex partners (Feldman and Parkinson, 2005).

Training and advocacy

Organisations such as ACON and the Gender Centre in NSW and Gay and Lesbian Health Victoria and the ALSO Foundation in Victoria conduct workshops and information sessions with mainstream service providers to raise awareness of the needs of GLBT people who are ageing (ACON, 2006; Callan and Mitchell, 2007; Birch, 2004; Gender Centre, 2010). A new WA research project aims to investigate industry attitudes and practices around accommodating older GLBTI residents (GRAI, 2009). The literature reviewed concurred that more training and advocacy with existing aged care service providers is needed to maximise access to better community, in-home and residential aged care services for GLBT people.

Callan and Mitchell (2007) describe how the assumption that all people are heterosexual – what they call “heteronormativity” – takes many shapes in service provision: the assumption that older people are essentially asexual; the emphasis on privacy leading to the belief that it is not important for service providers to know sexual identity; and that treating everybody the same means treating everybody as heterosexual, thereby devaluing any other way of being. The initial processes of intake, assessment and filling in forms before accessing services or referrals can be stressful: "where the question 'married, single, divorced, de facto?' may create instantaneous panic as the client struggles to choose a safe option" (p. 32).

Callan and Mitchell (2007) suggest that services need to signal inclusivity in publicity material and resources, actively engage in inclusive practices, train staff to be inclusive and non-discriminatory and have the category of 'partner' on intake forms to encompass gay and lesbian relationships. Even if the client is not in a relationship, forms that are inclusive can facilitate disclosure for those who may wish to make their identity known.

Other suggestions made are that issues relating to GLBTI ageing should be included as a special needs group in all Aged Care Certificate III/IV courses (Birch, 2004); that staff training should position sexuality as a component of identity, rather than viewing it only within behavioural or biological frameworks (Feldman and Parkinson, 2005); that services' own gay and lesbian staff could be encouraged to be more visible e.g. by wearing a pink triangle pin (Hash, 2006); and that staff should initiate access to GLBTI services and communities (Chandler et al., 2005).

GLBT-specific and specialist services

As well as working towards acceptance of GLBT people in mainstream services, some researchers also argue that there is a need for GLBT-specific and specialist services. From an investigation of experiences of heterosexism or homophobia among older gay, lesbian and transgender people in Victoria, Chamberlain and Robinson (2002) found a widespread sense that gay men and lesbians and other non-heterosexuals do have special needs. They talked about it being 'more comfortable' to be with one's own kind, particularly in retirement villages.

A number of studies conclude that there is a need for outreach services specifically for GLBT people who wish to remain in their own homes; for more social activities, groups and spaces for older GLBT people, and for nursing homes and retirement villages specially catering for non-heterosexual people, staffed by GLBT-friendly workers, where they are able to be themselves without fear of discrimination (Chamberlain and Robinson, 2002; Birch, 2004).

In Victoria, the Ministerial Advisory Committee on Gay and Lesbian Health (2003) recommended that all local councils be encouraged to run support groups for ageing gay men and lesbians who may feel excluded from mainstream support groups and from GLBTI social networks and community groups. They also recommended government funding for groups providing support and counselling for the partners, children, parents and in-laws of transgender and transsexual people, with adequate resources to ensure their sustainability and the employment of trained staff.

In Australia and the US, a number of privately owned retirement facilities for GLBTI people have been established. Australia's first is in Victoria, where the Linton Estate retirement community was launched in July 2009 for gay, lesbian and transgender people with the motto that "ageing with dignity regardless of sexual preference is everyone's right" (Rolle, 2009, media release). On their website, the community is promoted for people:

that are able to be themselves ... this safe haven will be tolerant of everyone, so all people are welcome if they respect and accept other people's sexual choices, religion, race and colour (Linton Estate, 2009).

Linton Estate is a \$26 million project with 120 single story independent living units and a range of other facilities. Situated in the town of Ballan in Victoria, it is majority owned by a gay person, Peter Dickson, who after a dinner party conversation 16 years ago was "able to bring this dream into fruition" (Rolle, 2009, media release). Dickson's rationale is that:

there are major concerns that a growing number within the gay, lesbian and transgender community in particular are facing a discriminatory environment when it comes to current attitudes to ageing ... Post war baby boomers have started to retire ... the questions arise will they eventually be forced to submit to old institutions ... or will they continue to live the life they have enjoyed as a life choice [with] like-minded people to surround themselves with (Rolle, 2009, media release).

However, Chandler et al (2005) provide a contrasting discussion of issues around addressing homophobia and discrimination in mainstream services versus establishing private facilities especially for GLBTI people. The US has led the way in the latter, they report, providing residents with a comfortable environment and a sense of security. While older US citizens have responded positively, the provision of specific facilities for GLBTI aged care may "hinder the development of appropriate models to address GLBTI needs in the remainder of the sector" (Chandler et al., 2005 p. 20). Also concerning is that changes made in some facilities may infer that GLBTI people should be quasi-segregated from society, rather than be part of society and diverse aged care facilities, they argue.

Informed GLBT people as agents of change

In her PhD study of gay and lesbian caregivers, Hash (2006) recommended gay men and lesbians be open about their relationships to give professionals and others the opportunity to be accepting and supportive. Clients can also be more informed, inquisitive and assertive with professionals. Hash's respondents expected insensitive health professionals. They suggested

that to increase the likelihood of supportive treatment, other gay men and lesbians network with gay and lesbian individuals and services to find supportive professionals, be upfront with professionals about their partner relationship, and draft advance health care directives.

RESEARCH NEEDS

Chandler et al (2005) recommend that future research is needed, specific to GLBTI health needs and ambitions including differences in socio-cultural needs. The Private Lives study (Pitts et al., 2006) recommends further qualitative research on the need for, and experience of, aged care services, and better targeted research with transgender and intersex people to better reflect their diversity and specific needs.

CONCLUSION

This chapter has described the background to the study and the findings from an international literature review. It has established the legal need for GLBT people to engage in advance care planning in order to protect their rights and die with dignity, some of the challenges and barriers to this planning, and recommendations for action and future research. The next chapter, Chapter Two, describes the methodology for this study.

CHAPTER TWO – METHODOLOGY

STUDY DESIGN

The methods for this project included an international literature review (Chapter 1), development of data collection tools and an ethical framework for the research, including submission of two applications to Ethics Committees for approval. Plans were made for a GLBT community consultation and a service provider consultation, both in the Northern Rivers region of NSW. While the service provider consultation went ahead, the community consultation had to be cancelled. As a result, anecdotal evidence from community members and service providers who spoke to the researcher about the proposed community consultation, and its cancellation, was noted.

DEVELOPMENT OF DATA COLLECTION TOOLS

A schedule of questions was developed, based on the literature review, to guide the format of both the community and service provider consultations (Appendix 1). These questions were designed to gather information about experiences of end-of-life care of GLBT people and were included on the agenda for both consultations. In addition, a brief survey was developed for distribution at the consultations. This was adapted from previous surveys used by one of the study investigators (Cartwright et al., 2006) to assess knowledge of advance care planning among service providers (Appendix 2).

ETHICS APPROVAL

A framework for conducting ethical research at the community and service provider consultations was outlined in applications to the Southern Cross University Human Research Ethics Committee and the ACON Research Ethics Review Committee. These applications were approved.

The ethical framework included providing a detailed information sheet to community members (Appendix 3a) and service providers (Appendix 3b) about the aims, benefits and risks of the research; a consent form (Appendix 4) for participants to sign; and an Explanation of Terms resource for participants which included where to go for further information on Enduring Power of Attorney, Advance Health Care Directives, Enduring Guardianship, Person Responsible and Wills (Appendix 5). All data was de-identified so participants' contributions remained completely anonymous. A confidentiality form outlining the privacy laws in relation to HIV was also provided for participants to sign, in the event that any participant disclosed their HIV status in either forum (Appendix 6).

In addition, because the topic being discussed included stories about death and dying, professional social workers who were also members of the GLBT community were briefed and prepared to attend the GLBT community consultation to talk to anyone who might have become distressed, and to follow up afterwards if necessary. A plan was put in place to debrief and support the researcher, the social workers and the hosts from Tropical Fruits in the event that the community consultations caused distress to anyone.

SAMPLE SELECTION

Community and service provider consultations were planned to be held in Lismore in May and June 2009. The consultations were advertised in the Tropical Fruits newsletter, the Fruit Juice, the ACON newsletter, *Rainbow News*, the ACON website, and via a range of health and community service email lists and newsletters and by word of mouth. A media release was sent to mainstream media and the events were promoted on Northern Rivers radio.

The information sheet about advance care planning for GLBT people (Appendix 3a) was also published in the ACON newsletter, along with the invitations to attend the forums and the Explanation of Terms resource.

Exclusion criteria: It was planned that participants who were unable to understand the information statement and consent forms would be asked not to participate in the consultation forums. Plans were made for a group review of these documents at both forums, clarification if needed, and for a person in attendance to explain the documents to latecomers and gain

informed consent. For the community consultation, Auslan signers were engaged to ensure that members of the GLBT deaf community were able to participate.

The community meeting had to be cancelled due to rising floodwaters (a common occurrence in the Northern Rivers) and low response numbers. The service provider consultation went ahead. The information sheet was adapted for the service provider consultation and distributed there (Appendix 3b). Participants were asked to sign a consent form and confidentiality agreement (Appendices 4 and 6).

DATA COLLECTION

A total of 25 individuals participated in the research – 19 service providers (12 at the forum and seven via comments provided to the researcher) – and six GLBT community members who also provided comments to the researcher.

The format for the planned community and actual service provider consultations included welcomes, with lunch and/or afternoon tea provided; review of the information statement and consent and confidentiality forms, and gathering of signed forms; a brief survey of participant knowledge about the topic; a presentation about Advance Care Planning and other end-of-life issues; a scan of participant experiences in GLBT end-of-life care using a list of questions; and invitations to tell particular stories.

Seven of the twelve service providers at the forum had provided direct end-of-life care to GLBT people and could therefore give first-hand accounts of their experiences. Others had second-hand stories to contribute, or were currently working in aged care and wanted to learn more to ensure good end-of-life care would be provided to GLBT clients when the time came. With the permission of participants, the service provider consultation was recorded on audio cassette and transcribed. Following this event, transcripts were provided to participants for verification and/or clarification, and extra details and further stories were provided by some participants.

From the beginning of the research project, and as it progressed, a number of people volunteered their stories of GLBT end-of-life care. In addition, after the GLBT community consultation was cancelled, the researcher asked community members for their opinions on why the numbers of RSVPs were so low and their thoughts about advance care planning in general. The results of an additional six conversations with GLBT community members were noted and are included in this report as anecdotal evidence. An additional seven service providers provided feedback and comments which are also included as anecdotal evidence.

DATA MANAGEMENT AND ANALYSIS

A code book was set up from responses to the brief survey distributed at the service provider consultation. Data was entered into SPSS statistical software package and analysed, with reports generated. The audio cassettes from the service provider consultation were transcribed, and along with the anecdotal evidence gathered by the researcher, were manually coded. Key themes were identified.

The results of the analysis are reported in Chapter Three.

CHAPTER THREE – RESULTS

PARTICIPANT PROFILES

As this was a small scoping study, demographic characteristics of the 25 participants apart from gender and “service provider or community member” (Table 3.1) were not collected. Instead, their experiences of end-of-life care for GLBT people were gathered in order to achieve a local understanding of the relevant issues to compare with the literature on the subject.

Twelve service providers attended the service provider forum, and an additional seven provided comments to the researcher during the course of the project, a total of 19 service providers. They worked across a range of fields including nursing, home and community care, residential aged care, palliative care, allied health, social work, voluntary community care and the funeral industry. At the service provider forum, 11 of the 12 participants completed a brief survey on their knowledge about end-of-life care, and seven contributed information and stories about their actual experiences in end-of-life care for GLBT people. Despite the GLBT community consultation being cancelled, six GLBT community members provided comments to the researcher during the course of the project. A total of 17 women and eight men participated in the study. There were no transgender participants, although two of the service providers spoke about their work with transgender clients. The views of all of these participants about end-of-life care for GLBT people are reported in this chapter.

(Note: due to the high number of gay and lesbian people working in health and community services, it is likely that a significant proportion of service providers were also GLBT community members, although this information was not collected).

Table 3.1 Gender and Participant Group

Type of participant	Males	Females	Total
Service provider	4	15	19
GLBT community member	4	2	6
TOTAL	8	17	25

A profile of the range of experiences of the seven service providers who had experience in GLBT end-of-life care was gathered. Table 3.2 provides a summary of the numbers of people to whom care had been provided, and when.

Table 3.2 Number of GLBT People for Whom End-of-Life Care was Provided, and Time-Frame

Participant number	How many GLBT people have you cared for?	Time-Frame
1	200 gay men	Early HIV years (late 1980s / early 1990s)
2	1000 plus gay men A few	Early HIV years (late 1980s / early 1990s) In last 10 years
3	100 plus gay men	In last few years
4	250 GLBT people	In last 20 years
5	2 gay/lesbian people	Recently
6	1 lesbian woman, 1 transgender woman	20 years ago
7	2 gay/lesbian people	Several years ago
Total	1556 plus	

MAJOR THEMES FROM THE ANALYSIS

Failure to Acknowledge Appropriate Decision-Makers

A major theme that emerged from the analysis was the lack of legitimacy of same-sex relationships, sexual and gender identity accorded by family, health care professionals, and society, and the subsequent failure by family and health care professionals to acknowledge the appropriate substitute decision-maker/Person Responsible in end-of-life care for GLBT people.

A number of participants spoke about actual exclusion or lack of acknowledgment of same-sex partners, and the grief and loss of dignity and property that resulted from this exclusion upon the death of their partner. This was particularly salient when health professionals accorded next-of-kin status to blood family but not to same-sex partners.

One participant spoke about a client having to prove that her critically ill same-sex partner was indeed her partner to be allowed to visit her at her bedside in hospital. The hostility of a health care professional snapping “prove it” at a stressful moment was acutely distressing. Another participant responded strongly to the possibility of this scenario occurring with her own partner, acknowledging her great fear that, in a stressful situation of illness or accident, it would be challenging for her partner to have to “prove” a relationship in a health care setting.

Another participant who had cared for more than 1000 gay men in the early days of the HIV epidemic talked about families and service providers denying same-sex relationships:

I saw a few nasty incidents where families who had disowned kids stepped in. One guy had two funerals in one day. There was no recognition from anyone in authority in the hospitals of same-sex partners. The next-of-kin was usually the mother, father or a sibling. One guy who was diagnosed went downhill very quickly. His parents came the day before he died. They wanted to take his body back to the country town where they were from. They didn't want his partner or friends involved. We had a 'deviants' funeral separate to the family funeral – that was the compromise. The kid thought mum and dad would be okay but they weren't. Absolutely everything was taken from the partner.

One service provider related that her own manager had told her of her recent attendance at a community event. There she met the same-sex partner of another former client who had died five years previously in a nursing home:

... only at the [event] which the deceased's lifelong partner attended [did she] confide that during the stage of nursing home care she had been excluded and unacknowledged completely, causing her grief and loss.

Another related a story about the difficulties of providing care for a client during the early days of the HIV epidemic because of the client's mother's homophobia:

Mum was in very deep denial that a) the son was gay and ... b) that the son had had a significant relationship and a partner who had died less than 12 months beforehand and that her son was going to die.

Exclusion also occurred due to discrimination on the grounds of gender identity. One participant reported seeing a transgender person transferred from the female to the male wards in the hospital where she was nursing. The patient was very ill and dying.

This was a man who had lived as a woman since early adulthood and had been kicked out of various jobs and had a very difficult time ... and was kicked out of the female wards and put into the male wards ...

A related theme that emerged among participants was the desire for privacy on the part of gay and lesbian people. Staff at two services observed that clients who could access services locally, chose not to. They speculated that living in a small town and knowing the service providers may prevent access to services. In a small country town or rural area, the fact of small GLBT communities and the fact that many GLBT people work in health and community services mean clients and service providers may be colleagues, friends and lovers, or ex-colleagues, ex-friends and ex-lovers. This can affect service delivery. Some clients may prefer to access services in another town or city, rather than compromise their privacy or their relationships with service providers.

However, at the end of their lives, when GLBT people can be more vulnerable and dependent on others, this may mean they miss out on essential services:

Jeremy and I were lovers years ago. While he and I made our peace about that relationship years ago, I'm not sure that his friends ever forgave me for what happened. I'm a nurse working at the hospital here now. I don't know for sure, but I reckon his friends didn't want him to come into the hospital when he should have because they thought I might be there, and maybe they didn't want me taking care of him. So he just stayed at home.

An additional related theme was the decisions of some gay and lesbian people to live on the margins of society to avoid the confrontation of discrimination in the mainstream heterosexual and heterosexist world. Again, results suggest this decision may prevent access

to essential services. Participants speculated that if gay and lesbian people had lived all their lives on the margins and been self-sufficient in their own communities, they may not want or feel they need services, even GLBT or GLBT-friendly services. Part of this may be a “rebellion” against the mainstream. Much of the literature contains evidence that GLBT people do not access services for fear of a homophobic response. This scenario is more complex:

One person I know who died could have had better care at the end of his life. He'd lived for many years in an alternative community, and had a big group of community members who rallied around to take care of him when he was sick and dying. They said no to services that were there. I think his care could have been better if they'd accepted the services available.

While many service providers are supportive of GLBT people, their colleagues and families may not be similarly supportive. One service provider had a client who whenever a family member or health care worker visit was imminent, “there was a sudden need to ‘de-fag’ the house”. Another service provider told of being confronted by the husband of a care worker at a party to complain about the decorations in the home of the gay man his wife was caring for:

A gay man was living with his partner. The client was dying at home ... in his bedroom where he spent most of his time during the last few days of his life, the walls were covered in art works and photographs of semi-naked men. These were beautiful black and white artistic photos that would have been taken in the 50s. When I went to his bedroom I thought the photographs were amazing, they were not pornographic at all. All the workers who provided care for the client needed to go into the bedroom. I know one of the female workers personally as well as professionally. At a party the husband of that worker came up and told me he did not want his wife to go back to the client's home to provide services to that man - this came from out of the blue. He said she had told him about the artwork, and he did not want her to go back as he felt the artwork was porn, although he had never been to the house.

The service provider interpreted the husband's response as homophobic. Despite her husband's complaints and her own possible discomfort, the care worker continued to provide care for the gay man.

For transgender people, the lack of recognition of their chosen gender identity, or the humiliation of having to explain that they are transgender to get appropriate aged care services, were salient issues. One service provider who works with transgender people told of a transgender woman who had lived all her life as a woman, but had never had sex reassignment surgery. She now had dementia and lived in a religious aged care facility. Staff

forced her to live as a man as she retains male genitalia, leaving the client wondering about the cognitive abilities of her care providers:

She says to me 'they keep calling me 'him'. They think I'm mad or demented, but I think they're demented because they don't know I'm a woman'.

Other transgender people who have not had sex reassignment surgery, or who are left with incontinence after the surgery, have to explain their situation to care providers in order to get appropriate products. This service provider argued:

There is a phenomenal loss of dignity in having to explain and get products to match their genitalia.

Acknowledging the conservatism of staff in the aged care sector, one service provider asserted:

I will do everything I can to get supportive services for GLBT people in their own homes, rather than see them enter a nursing home.

Lack of Knowledge about Person Responsible

Medical and dental practitioners have a legal and professional responsibility to get consent before treating a patient. If the patient is unable to consent, the practitioner should seek consent from the patient's Person Responsible. The Person Responsible is not necessarily the patient's next-of-kin, but is, in order of authority: a Guardian, including an Enduring Guardian; the most recent partner, including same-sex partner, with whom the patient has a close continuing relationship; an unpaid carer (who can be on a carer payment); or a relative or friend who has a close personal relationship with the patient.

At the service provider consultation, several service providers did not know about the rights of same-sex partners to claim status as Person Responsible, and therefore to make health care decisions should their partner lack capacity. This issue is discussed further below.

Of the 11 service providers who completed the survey on this topic, the majority had heard of and had had some experience with Advance Health Care Directives, Enduring Power of Attorney and Enduring Guardians. However, while nine respondents had heard of the term Person Responsible, five had not had experience with this concept. When respondents were provided with a scenario and asked to indicate who they identified as the person with legal

rights to make health care decisions on behalf of another individual and why, most respondents indicated the individual's partner, but were unable to accurately identify the reason for this selection.

The results from this part of the survey were confirmed when later in the survey respondents were presented with the following scenario, and then asked the question: Who do you think has the legal right to make health care decisions for Georgina?

Scenario

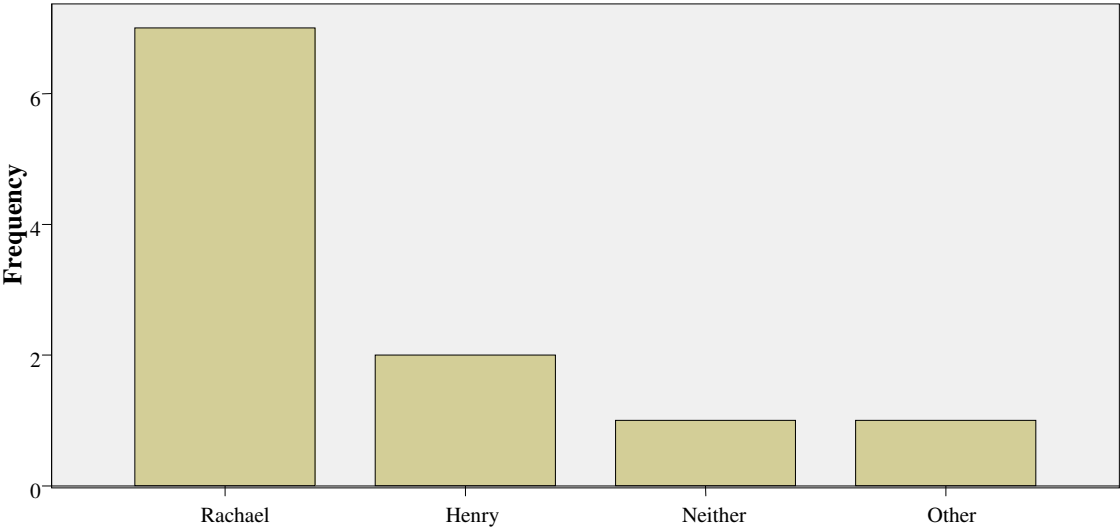
Georgina is a 37 year-old woman who has been admitted to hospital following a serious car accident. She is on life-support and in a critical condition. Her female partner of 2 years, Rachel, is by her bedside in the Intensive Care Unit when Georgina's mother Sally arrives and demands a full report on Georgina's condition from the treating medical practitioner. He asks if Georgina had ever appointed anyone to make health care decisions for her if she lost capacity, or discussed what treatment she would/would not want if she were to become terminally ill or injured. Rachel and Sally say no but Rachel says she knows that Georgina would not want her life prolonged unless she could be returned to a good level of functioning. However, Sally insists that all possible treatment be given to Georgina and that, because she is Georgina's mother – and therefore next-of-kin, she should have the right to make decisions about what treatment Georgina does or does not receive. At this point Georgina's ex-husband Henry arrives; he says that when he and Georgina were married she gave him Enduring Power of Attorney which has never been revoked, so he should have the right to make the decisions.

Seven of the 11 respondents who completed the survey indicated correctly that Rachel, Georgina's partner has the legal right to make health care decisions for Georgina (Table 3.3).

However, when asked why they thought the person chosen had the legal right, the majority of respondents were unsure. (Note: the reason that Rachel had the legal right was because, under the order of authority in the NSW Guardianship Act [1987], she was the correct Person Responsible).

Regardless of their level of awareness or experience with Person Responsible, all respondents indicated that they felt it would be helpful to know who has legal authority to make health care decisions/give consent if a client loses decision-making capacity.

Table 3.3 Who has the legal right to make health care decision for Georgina?



The Importance of Communication

Participants recounted stories that emphasised the importance of GLBT people communicating their end-of-life care wishes to family and health care professionals before they become incapacitated. If they did not, they risked their wishes and those of their close friends and partners being overridden by blood relatives and health care workers.

Based on his experiences of caring for 200 gay men in the early days of HIV, a service provider asked:

How can we get people comfortable doing these documents? ... and how do we bridge the gap so we can get people to actually communicate [the choice of a partner or friend as decision-maker] to their family if they're able to beforehand so you can avoid the fight?

In recounting his experiences, this service provider remembered that one of the ways he had found to work was to encourage clients to write down their wishes and to record them on videotape:

... to actually say what it is that they want that another family member who may arrive at a very difficult or inopportune moment can read or hear. It's very difficult, people will be irrational, but if when they are looking at the words particularly of a son or daughter, brother or sister, for them to say 'no I'm going to deny what they want and this is what's going to happen', I think that's often when it's confronting for them.

The Importance of Advocates

Participants in the study identified the importance for the dying person of advocates to help ensure their wishes are met. An advocate could be a family member who is close to the dying person and also to the rest of the family, a friend, a service provider or a volunteer carer. These people can be “buffers” between dying persons and their close friends and partners, and other people who may have an interest in the wellbeing of the person dying, usually blood relatives.

One service provider noted that although he didn't recall the term Person Responsible being used during the early days of HIV, a lead volunteer carer sometimes became the person who was making the decisions:

This was because the other partner had died, the family didn't want to - whatever the situation was - and I remember these quite clearly ... in 20 percent of those experiences all of a sudden that person became 'the person responsible'.

This participant also told of the sister of a gay man dying of HIV who was a “buffer” person or advocate in the family:

What was fabulous was that she came in early and set it all up knowing that all hell was going to break loose and she just wanted to try and find the best way through. She actually kept her brother alive a lot longer through her involvement and her love and her humour. He used to say to the care team 'Oh, I wouldn't still be here, but today's instalment between Mum and Lesley you wouldn't want to go and miss that would you?' (laughter). There were things like that that happened on a regular basis, so it was actually quite amusing.

[The sister] was pretty grounded and sensible ... as a result she asked all the right questions and ensured that her mum, who she knew was scared, was okay but didn't overstep the mark and so allowed her son to die, I guess with dignity.

Another service provider who provided care in the early days of HIV spoke about how

if a person came in late for care we would find a best friend. If it was inappropriate, we would actively push the family out of decision-making and encourage friends to come up as decision-makers ... in consultation with the client.

This participant also spoke strongly about the need for advocacy to allow gay men and lesbians to be themselves in their own homes at the end of their lives:

with my clients ... there would be a sudden need to 'de-fag' the house, because mum and dad are coming down, I'm dying, or to protect the health care workers ... [I would say to them] 'now hang on, this is where you're going to be dying, this is your life, and you shouldn't have to change those things due to family or

workers' attitudes' and let's work with the families and the workers to say 'this is your space' is one of the really important things that we did around that.

I've actually heard ... the fear is still there that gay men and lesbians have to 'de-fag' and 'de-dyke' their homes to protect the sensitivities of health care workers ... I think that's just so wrong, I think we need to work with home care providers to say 'hang on a minute that's prejudice'. We need to work with that, we need to break that down ... or we'll take them to the anti-discrimination tribunal, and I think we need to be really clear on that.

Dealing with Complex Needs

The end-of-life care of GLBT people can be more difficult when people have complex needs as a result of social isolation, and/or they are living with mental illness or misusing drugs and alcohol. Several service providers spoke about the challenges of working with these clients. In the absence of significant relationships and appropriate planning for end-of-life care, many of the responsibilities that would normally fall to the partners, close friends or family members of these clients instead fall to service providers and the state.

One participant spoke of a closeted lesbian woman and a transgender woman she had met while nursing 20 years ago. Neither had any friends or family at their hospital or nursing home bedside when they were dying. Instead, she noted, service providers such as herself took on extra roles. This was "so important for LGBTI community", she noted, because "so often we know there's a separation from the family of origin and even family friends".

The lesbian woman had worked as an unskilled labourer and lived in a boarding house for much of her life. She had then gone into a nursing home. She went into hospital where she was diagnosed with cancer, and died at the age of 72.

She just said "look I've got no one" ... I spent a lot of time listening to her ... as she got sicker and sicker I did the usual things of bringing soap and massaging her feet and so on because there was no one else except professional clinical staff ... she just wanted to shrink away. She actually said a few things like 'I wish I was strong enough to do away with myself'. And I fed that back to her nursing staff and they said 'oh yes we'll be keeping an eye on her'. Really I had this social and emotional support role rather than anything else but the nursing staff said she looked forward to me being there and so on ...

This participant also recalled a transgender woman who had had a very difficult time, living as a woman since early adulthood, finding it difficult to keep employment and living with mental illness. She had had many attempts at suicide and was very emotional:

She was kicked out of the female ward and put into the male ward and that kind of stuff and I was there to just do nursing care ... the death was actually fairly sudden ... there was fairly bad ... illness ... I could just see this person getting sicker and sicker. There was a lot of hand holding and I asked "is there anyone I can contact for you?" and "no no". There was a lot of crying about a regretful life ... People hadn't understood, basically.

Problems of social isolation can be exacerbated when clients experience mental illness or problematic alcohol or drug use. Service providers spoke informally about the difficulties of providing appropriate end-of-life care when this topic was not able to be openly discussed. An example given was clients who might be wanting to end their own lives or be seeking assistance to end their lives, but who are 'wise' to the responsibilities of some service providers to report them as suicidal if they discuss their wishes openly.

Service providers agreed that clients not wanting to be institutionalised or treated, but who nevertheless might have very pressing health issues that need attention, including mental health issues, are a very difficult group to assist and to manage in service settings. In these instances, service providers who can see deterioration in a client's health and wellbeing may do everything they can to assist, but if a client declines services or is difficult, there is little that can actually be done. These situations are exacerbated if the client is under the influence of alcohol or drugs or becomes violent.

Service providers in this situation agreed that individuals from different agencies who had a difficult client in common could meet regularly, without the client present, to discuss strategies to support each other and the client. This is normal practice when consent is granted by the client for contact to occur and confidentiality is maintained, but in some situations service providers also need to call in mental health or law enforcement agencies. In some cases, if clients are unwilling to follow services' guidelines, for example the requirement that they treat staff with respect, they are unable to be assisted by the service. Clients may have to be referred to other services to address mental health, alcohol, drug or violence issues before they can be engaged.

Benefits of Good End-of-Life Care Planning

When same-sex relationships and other important relationships are communicated to and recognised by families and health care professionals, and advance care planning is well organised and communicated to significant people, it is possible for GLBT people to experience appropriate end-of-life care.

One service provider had provided a lot of care to many gay men in the early days of HIV, and had seen many difficult situations with families and health care workers. By contrast, he remembered one friend who had got things organised:

I've seen people, when things haven't been put in place, the chaos that arises ... If you have the paperwork done, it alleviates the chaos, and makes the roles really clear ... A friend a few years ago had done all the documents, it was just so easy for his partner. They had sat down and talked about it. Then the partner could just get on with giving care. Then everything around the death went smoothly as there were defined roles and responsibilities.

Another told of a gay couple where the partner was recognised in the patient's family as having the substantive role, even though he was not nominated as Enduring Guardian:

This is a good news story: the client chose his sister as chief decision-maker ... and his request was honoured by his partner and his sister; the partner was involved in decision-making processes and acknowledged by family as part of the family, and the partner wanted what his partner (my client) wanted, and would advocate for his partner's wishes. The other staff members where I worked were supportive of this gay couple too.

EXTENT OF AWARENESS AND USE OF ADVANCE CARE PLANNING

The seven service providers consulted had between them cared for more than 1550 GLBT individuals over the past 25 years. Three had histories going back to the early days of the HIV epidemic, where they had cared for more than 1200 gay men between them from the mid 1980s to the mid 1990s, when there was no effective treatment for HIV/AIDS. However, levels of awareness and use of the legal mechanisms that assist in advance care planning varied considerably among those for whom they had provided care.

Awareness of the Legal Mechanisms for Advance Care Planning

A brief survey about advance care planning in the Northern Rivers area of NSW was distributed at the service provider consultation and completed by 11 participants.

All survey respondents (n=11) indicated that they had heard of both Advance Directives and Enduring Guardians; most had also had experiences with both mechanisms (n=9 in both cases). Nine respondents had heard of Person Responsible, but only five had had experience with Person Responsible.

Use of Legal Mechanisms for Advance Care Planning

There were extreme variations in the use of and/or experience with legal mechanisms for advance care planning among participants at the service provider consultation (Table 3.4).

Of those who had experience of end-of-life care for GLBT people:

- Between five and 100 percent of their clients had appointed an Enduring Guardian
- Between zero and 80 percent of their clients had made an Advance Health Care Directive
- Between zero and 100 percent of those who had died or been seriously ill had used the Person Responsible option.

Once again, those service providers who recalled high levels of their clients taking up these mechanisms had encouraged their clients to do so.

Other data on experiences with Advance Health Care Directives and Enduring Guardians was gathered in the survey of 11 participants at the service provider consultation.

Table 3.4 Estimates of Percentage of Clients who had used Advance Care Planning Mechanisms

Service Provider Number	How Many Clients?	Appointed an Enduring Guardian?	Completed an Advance Health Care Directive?	Used Person Responsible?
1	200 gay men in early HIV years	Less than 10%	20-30%	20% (term not used)
2	1000+ gay men but very few in last 10 years	80% as we encouraged it	80% incl. Videotape	Not often
3	100+ gay men in past few years	25%	1 %	100% of those who have died or been seriously ill
4	250 GLBT	40%	50%	10%
5	2 GLBT	100%	0 (EG used)	0 (EG used)
6	1 lesbian 1 trans-gender	Unknown	Unknown	Unknown
7	2 GLBT	Not an option in Qld at that time*	0	100%
Total	1556 plus			

*In Queensland, Enduring Guardianship is called Enduring Power of Attorney for Personal/Health Matters.

Participants were asked if they had ever been asked by a client to assist him/her to write an Advance Health Care Directive. Approximately half (n=6) indicated that they had.

Only three respondents had completed their own Advance Health Care Directive; five said they intended to and three did not want to do so.

Respondents were asked whether any client had ever told them that she/he had appointed an Enduring Guardian and the majority (n=10) indicated that a client had done so. Finally, respondents were asked whether they had ever recommended to a client that he/she should appoint an Enduring Guardian and again, the majority (n=9) indicated that they had done so. In addition to the results from the service provider consultation reported above, two other service providers reported varying levels of advance care planning for their clients. One noted

that for one very isolated client, while an Enduring Guardian had not been appointed, the client had worked with a service provider to complete an Advance Health Care Directive. The other reflected on her work with transgender clients, and the very high levels of education, advocacy and training and personal support needed to ensure clients received appropriate services from trans-friendly agencies.

FINANCIAL PLANNING

Levels of use of the legal mechanisms of wills and Enduring Power of Attorney for finances varied among the clients of service providers consulted. The seven who participated in the service provider consultation who had worked with GLBT people recalled that between 40 percent and 95 percent of people cared for had had a will (see Table 3.5). Some young gay men dying in the early days of the HIV epidemic chose not to make a will as they had debts and were concerned that people nominated in a will may be asked to pay the debts. The service providers who recollected high percentages of their clients having a will had actively encouraged the making of wills. Between 40 to 100 percent of clients had given someone Enduring Power of Attorney (Table 3.5).

Table 3.5 Financial Planning

Service Provider Number	How many GLBT people have you cared for?	How many have had a legal will?	EPA?
1	200 gay men in early HIV years	50% (some chose not to because of debts)	40% (the partner)
2	1000+ gay men but very few in last 10 years	95% as we encouraged it	80% as we encouraged it
3	100+ gay men in past few years	50%	50%
4	250 GLBT	40%	40%
5	2 GLBT	50%	100%
6	1 lesbian 1 trans-gender	50%	Unknown
7	2 GLBT	N/A	Unknown
Total	1556 plus		

The 11 survey respondents at the service provider consultation were also asked whether they had heard of or had any experience with Enduring Power of Attorney. All respondents (n=11) indicated that they had heard of an Enduring Power of Attorney, and most indicated that they had had experience with this mechanism (n=7).

ATTITUDES AND BARRIERS TO DOING ADVANCE CARE PLANNING

The community consultation scheduled for May 23 at Tropical Fruits was cancelled due to low numbers of RSVPs and an approaching flood that cut roads and threatened the area in which the consultation was to be held. This lack of interest was raised at the service provider consultation and anecdotal evidence was gathered from community members on an *ad hoc* basis as to why the community consultation had garnered so little interest.

Reasons suggested included practical matters, such as the fact that the meeting was scheduled for a weekend and that people did not want to give up their weekends; or the rising floodwaters. However other reasons suggested for the lack of interest in the GLBT community consultations and the reasons for GLBT people not engaging with advance care planning included:

- not wanting to think about the end of life;
- for gay men only, a denial of the realities of ageing and death;
- lack of time;
- lack of knowledge;
- not knowing who to appoint to significant decision-making roles.

Not Wanting to Think About End of Life

This issue was raised both as a reason for people not attending the community consultation, and in the survey given to service providers as a reason for clients not completing an Advance Health Care Directive. Its expression took a number of forms:

- fear or denial of illness and death, including cultural issues in the context of the legacy of the HIV epidemic;
- discrimination against GLBT people leading to rebellion against mainstream legal institutions;

- the differences between fearing death and normalising death;
- the differences between white Australian versus indigenous views and experiences of death and dying.

Comments included:

People don't want to think about death or dying.

Recent grief at the loss of a friend is too raw.

Is it about death? It's a bit of a worry. We're all going to go there.

One service provider speculated that GLBT people's reluctance to engage with issues of death and dying was a result of the impact of the HIV epidemic. He had worked with people with HIV/AIDS in the south-eastern states of Australia, and then moved to Queensland in 1996. He noticed a real difference in Queensland, which he felt was due to the conservative political environment there:

I found Queensland people were not so interested in end-of-life care planning. Maybe they didn't want to face their own deaths. I think it was a result of the Joh Bjelke-Petersen (conservative Queensland Premier from 1968 to 1987) legacy. There was a real divide between the positive and the negative people. To think about death was an admission that they were HIV positive. I think there is more denial of death now among HIV positive people. Back in the height of the epidemic, not a day went by when someone didn't die or you heard of someone close to death.

Another participant speculated that resistance to advance care planning was due to discrimination against GLBT people, that forced some people into living on the margins of society, and hence deciding not to participate in legal mechanisms that could protect their rights.

I see gay men living on the margins, not part of society, and rebellious: 'we don't do these normal legal things'.

Most respondents (n=9) agreed or strongly agreed that preferring not to think about end of life issues would prevent clients from making an Advance Health Care Directive, and most respondents (n=8) agreed or strongly agreed that wanting to leave it till the situation arises would prevent clients from making an Advance Health Care Directive.

One community member who had sat with many GLBT people as they had died over a long period of time was trying to get her children to understand that “dying doesn’t have to be a terrible thing”.

Another community member who had witnessed the difference between white Australian and indigenous attitudes to death and dying commented on the level of exposure to death in the two different groups. She made the point that indigenous peoples have much higher death rates, and thus higher exposure from a young age to death and the processes of dying. She had witnessed members of the GLBT community coming together to care for a dying community member, which she thought was a really positive thing:

It was the first time for a lot of people doing this. Culturally a lot of white people don’t do this. There are lots of people in nursing homes, alone. This is not the case in non-white communities. I just don’t think a lot of people are there, thinking about this for themselves or their community.

This community member was a younger person who possibly was not around at the time of high death rates in the gay community from HIV/AIDS.

Lack of Interest in Ageing and Death among Gay Men

Gay men who provided anecdotal evidence for this study suggested that many older gay men are socially isolated and alienated from the gay community because of its focus on youth and beauty. Consequently, they suggested a lack of interest, and even a denial, of the realities of ageing and death. They directly speculated a link between lack of interest in end-of-life care planning and ageism. One gay man commented:

This denial of death marries into what I call” the Peter Pan syndrome” among gay men. We might age, and we don’t want to think about this, instead of being practical and planning for it. People are scared of death: ‘it’s not going to happen to me’.

Another gay man noted that “gay men are only interested in youth and beauty, not ageing and death”.

Lack of Time / Low Priority

Several participants commented that they had not had enough time to do the paperwork for the legal document for end of life care planning. Others just had not got around to it or did not see it as necessary at present:

I know it's important but I just haven't got around to it.

I'm not ready for this one yet. I'm in good health. I'll get there. It's procrastination.

Lack of Knowledge of Where to go for Help

Several participants commented that lack of knowledge about advance care planning would prevent them from undertaking this course of action. For example, one participant simply said: "I don't know where to go". Another participant said that he would not know what decisions to put in an Advance Health Care Directive, and that this was a barrier to his completing one.

In addition, in the survey for service providers, most respondents (n=10) agreed or strongly agreed that having limited knowledge would prevent clients from making an Advance Health Care Directive.

Not Knowing Who to Appoint

Several gay male participants commented on the lack of strong connections and partnerships in the gay male community, leaving some gay men not knowing who to appoint to crucial decision-making roles:

*I can't think of who to appoint or what my AHCD decisions might be. I don't know how to figure this out. It is very personally confronting. Is it a new partner, or an old friend or family member? How do I tell the new partner if it's not him? What impact will this have on our relationship?
There is the issue of the transitory nature of friendships and relationships in the gay community. If I appoint somebody and the relationship changes, then I have to revoke it.*

HIV service providers also commented on the social isolation they had observed among some HIV-positive gay men in the Northern Rivers. Some clients, they noted, had no-one to look after them when they were ill or facing discharge from hospital.

No comments were volunteered from lesbian women or bisexual or transgender persons about this topic.

However, the results from the survey of service providers suggest that GLBT people *do* want to make advance health care planning decisions for themselves, whether they make an Advance Health Care Directive or not. Respondents indicated that preferring to leave the decision to their doctor or family and friends was *not* a factor preventing clients from making an Advance Health Care Directive.

Slightly more than half of the respondents (n=6) disagreed or strongly disagreed that wanting to leave the responsibility with their doctor would prevent a client from making an Advance Health Care Directive, three agreed or strongly agreed that it would be an issue, while the remaining two were neutral on this issue.

Responses were similar in relation to wanting to leave the responsibility with family or friends; six participants disagreed or strongly disagreed that this would prevent a client from making an Advance Health Care Directive, four agreed or strongly agreed that it would, and one remained neutral.

CONCLUSION

This chapter has presented the study findings which included: the failure by families and health care professionals to acknowledge appropriate substitute decision-makers; lack of knowledge about Person Responsible; the importance of communication of end-of-life care wishes to family and health care professionals; the importance of advocates; problems caused by social isolation, mental illness and drug and alcohol use; the benefits of recognition, good end-of-life care planning and communication; the extent of awareness and use of advance care planning and, finally, attitudes and barriers to doing advance care planning. Chapter Four discusses the findings in relation to the literature. It concludes by making some recommendations for further research and examining the implications of the study for practice in GLBT health care settings.

CHAPTER FOUR - DISCUSSION AND RECOMMENDATIONS

DISCUSSION AND ANALYSIS

Despite legal changes giving GLBT people more rights, they can be seriously marginalised in end-of-life care. The main reason for this is discrimination and lack of recognition of sexual and gender identity by health care professionals and sometimes by family members. A consequence can be the failure by patients to access health care services when they are needed, the failure by health care professionals to recognise and support partners and other important people in the patient's life, and the failure by health care professionals and sometimes by families to recognise the appropriate substitute decision-maker should the patient lack capacity.

A number of barriers were identified in this study which potentially prevent the kind of end-of-life care planning, and the implementation of that planning, that might alleviate problems. Barriers include lack of knowledge, living in the closet, and, particularly for gay men, lack of close social connections and a reluctance to think about end-of-life care issues.

Recommendations include: advocacy for additional legal rights and recognition for GLBT people and initiatives to promote better understanding of the legal rights which currently exist; education of the wider community and service providers; interventions to reduce social isolation; and the development of appropriate information resources targeting GLBT people.

The Legal Need for Advance Care Planning as a Result of Discrimination

The literature reviewed and the data gathered were consistent on the legal need for GLBT people to engage with advance care planning because of the actual discrimination and violence faced by GLBT people in health care settings. Advance care planning was seen as a mechanism that could improve end-of-life care.

On many occasions, the lack of legitimacy of same-sex relationships, sexual and gender identity accorded by society, health care professional and some family members, led to the subsequent failure by family and health care professionals to acknowledge the appropriate substitute decision-maker at the time when it was needed. Discrimination could be overt,

leading to poor or abusive service delivery, or covert. When discrimination by health services was coupled with discrimination and rejection by family members and friends, gay and lesbian people and their partners and loved ones faced difficult times at the end of their lives. For transgender people whose chosen gender identity was denied by health care professionals, this was a very difficult time.

Both the literature and the study participants stressed the need for systemic change in this area in order to achieve an end to discrimination against GLBT people at the end of life.

The failure by GLBT people to access health services, leading to problems in end-of-life care, was also found to be consistent across the literature and data gathered. Discrimination or fear of discrimination by health services is the single largest barrier to access by frail and ageing GLBT people (ACON, 2006). Discrimination and subsequent failure to access health services can lead to isolation, late presentation, the need for crisis management and premature hospitalisation or institutionalisation, and are predictors for problems in end-of-life care, including elder abuse and neglect (ACON, 2006).

However, the findings in the literature on the fear of discrimination, possibly leading to a failure to access services, and the stigma and discrimination faced by gay and lesbian people preventing end-of-life care planning for fear of being outed, leading to ‘disenfranchised grief’ and loss of entitlements for same-sex partners, were not echoed in this study. This is not to say that they do not exist: the small sample in this study in the Northern Rivers of NSW, an area of high visibility of gay and lesbian people, may mean these aspects of end-of-life care for gay and lesbian people were not issues for those consulted. A larger study, conducted over a wider geographic area, may produce different results. When relationships have been kept secret due to fear of discrimination or recrimination, specialist legal advice is needed to assist GLBT people to protect rights and property and assert their end-of-life care wishes, particularly for those living in conservative rural and regional areas and/or who might still be legally married to a current or former heterosexual partner.

Barriers to Advance Care Planning

The range of barriers to carrying out advance care planning found in this study was consistent with the literature, as was the stated need for information resources to assist GLBT people in this area. An additional barrier was identified by this study: ageism in the gay male community possibly resulting in a lack of interest in advance care planning.

Lack of knowledge about advance care planning by GLBT people

Research on older people and the law reveals that many older people do not know what the legal mechanisms that can assist in end-of-life care do, or how to access them (Ellison et al., 2004; Cartwright et al., 2006). They also face barriers due to the lengthy time and complex procedures involved in some advance care planning processes, mistrust of the process, lawyers and the legal system, and difficulties predicting future health circumstances accurately (Ellison et al., 2004; Fagerlin and Schneider, 2004). In addition to this, ACON's research for its *Healthy GLBT Ageing Strategy* (2006) could not find any evidence on whether GLBT people are aware of or are using the legal mechanisms that can assist in advance care planning. The study results are consistent with the literature in that lack of knowledge of where to go for help, lack of time, not knowing who to appoint or what to put in an Advance Health Care Directive emerged as barriers to advance care planning.

Reluctance to think about end-of-life issues

Cartwright et al (2006) found that a majority of service providers believed a reluctance to think about end-of-life issues might be a barrier to their clients completing Advance Health Care Directives, although the majority of community respondents did not agree that this would prevent them from doing so.

By contrast, in this study, service provider survey respondents answering questions about their GLBT patients and future patients, did not see this as a barrier, nor was it supported in the literature. A study from the US among GLBT communities also found a high level of engagement with, and interest in, advance care planning (Stein and Bonuck, 2001). Contrary to the literature, several GLBT community members who provided anecdotal evidence for this study speculated that a reluctance to think about end-of-life issues could be a factor that prevented engagement in advance care planning, and in this research project. This is

consistent with the findings of Ellison et al (2004) in a general survey of older people. Three reasons were put forward by participants for this:

- The first was an opinion that the high death rates in the early days of the HIV epidemic caused trauma that GLBT people, in particular gay men, did not want to revisit today. This contrasts with Stein and Bonuck (2001) who speculated that a high level of engagement in advance care planning was a result of witnessing discrimination in end-of-life care during the early days of HIV. Certainly the large number of stories in both the literature reviewed and the data gathered for this study are from the early days of HIV. However in this study, one participant, who had experience in end-of-life care for more than 1000 gay men, suggested reluctance by some gay men to engage with issues of death and dying at all after their experience of the HIV epidemic. He speculated this might be the case more in Queensland because the HIV epidemic began in the late 1980s, when Queensland had an extremely conservative State government which forced homosexuality underground.
- The second reason given for reluctance to think about end-of-life issues was a view that white Australians generally, including younger GLBT people, were not as familiar with the processes of death and dying as indigenous people, due to the high death rates in indigenous communities. As a result, they were less likely to engage in discussions about advance care planning. It is certainly the case that with better HIV treatments today, people in the gay men's communities are not dying in the large numbers that they did in the early days of HIV.
- The third reason put forward was that a lack of interest in ageing and death among gay men was due to the commercial gay scene being centred around a culture of youth and beauty. While this culture was identified in the literature on gay men's health, it was not suggested as a barrier to advance care planning. Although the literature reviewed does not draw a link between ageism and lack of interest in ageing and death, data from participants suggests there may be a connection. As a result, it warrants a separate discussion here.

Ageism in gay men as a barrier to advance care planning

A recurring theme in the literature on gay and lesbian health is the issue of ageism in the gay male community, which can lead to social isolation of older and poorer gay men who cannot fit into the gay commercial culture of youth, an ideal body type and smart clothes (Pitts et al., 2006; Chamberlain and Robinson, 2002; Ministerial Advisory Committee on Gay and Lesbian Health, Victoria, 2003; Persson et al., 2005).

Chamberlain and Robinson (2002) argue that for gay men, the experience of ageism is embedded in the dominant character of social relations in the commercial gay scene, and many gay men feel they have nowhere else to go. The experience of isolation and loneliness is felt most by single, working class gay men, although single men in other classes also draw attention to ageism in the gay sub-culture. They found most of the respondents in their Victorian study who were 'doing it tough' were single and had few friends or family ties. All were gay men. They were either working class or poorly attached to the labour force (Chamberlain and Robinson, 2002). This study found that the lesbian community is better at forging and maintaining community organisations more inclusive of older people, whereas many gay men are isolated and lacking in social support groups.

Gay men who provided anecdotal evidence for this study agreed that many older gay men are socially isolated and alienated from the gay community because of its focus on youth and beauty. Consequently, they suggested a lack of interest in, and even a denial of, the realities of ageing and death. Some directly speculated a link between lack of interest in end-of-life care planning and ageism in the gay male community.

Several gay male participants also noted the lack of strong connections and partnerships in the gay male community, leaving some not knowing who to appoint to crucial decision-making roles. This anecdotal evidence is consistent with observations made by HIV service providers about social isolation among some HIV positive gay men in the Northern Rivers region. If they do not have anyone close enough to them to look after them when they are sick, it is possible that they may also be unable to identify a suitably trusted person to be an Enduring Guardian, executor of a will, or to hold Enduring Power of Attorney.

For those people who do not have anyone they are confident to appoint to be an Enduring Guardian, it is even more important to complete an Advance Health Care Directive and to

discuss it and lodge it with their doctor and other service providers. This may assist in enabling medical and health professionals to support the kind of end-of-life care that is desired. This needs to be promoted in the GLBT community. It is also important for service providers to be proactive in raising awareness and providing information about these and other advance care planning matters.

Barriers to Appropriate End-of-Life Care: Lack of Knowledge by Service Providers

In 1987, the NSW Guardianship Act replaced 'next-of-kin' with Enduring Guardian / Person Responsible. In 1999, same-sex partners gained status as spouses as Person Responsible. Under the 1987 legislation there was a corresponding NSW Health project to update intake forms and practices in health services. Despite this, the results of this study reveal that many health professionals and health service intake forms still ask for 'next of kin' and that many health care professionals are ignorant of the legal changes and subsequently deny same-sex partners their rights.

Even among the supportive service providers attending the consultation for this project, many did not know about the rights of same-sex partners to claim status as Person Responsible and therefore to make health care decisions should their partner lack capacity.

Health services need to be aware of their legal responsibilities under the Guardianship Act (1987) and, in the absence of an Enduring Guardian, to identify and acknowledge the legally correct Person Responsible for substitute decision-making, which includes same-sex partners or other friends or carers where there is a close and continuing relationship. This may be challenging for conservative and/or homophobic health care professionals.

Given the length of time that it is taking for the legal changes to filter down to changes in practice, it is therefore crucially important that GLBT people know and can defend their rights in this area.

The Need for Advocacy

A key theme in both the literature and the data gathered was the importance of advocates to assist in the communication of end-of-life care wishes to family and health care professionals. An advocate can be a close friend or relative of the patient, or a service provider who can liaise between those at the bedside to ensure the patient's wishes are carried out.

A number of stories of difficulties in end-of-life care were resolved by advocacy. Advocates are particularly needed for those individuals experiencing social isolation and dealing with homophobic or transphobic family members or health care professionals. Social isolation may be exacerbated by mental illness and drug and alcohol use. In the absence of partners or supportive family or friends, service providers need to step in to ensure the best care for the patient. For some clients with high needs, a team or multi-disciplinary approach may be needed. Service providers may need to be proactive in assisting clients with advance care planning. Special efforts may need to be made for gay men.

Even if Enduring Guardians are appointed and Advance Health Care Directives are made, there is a risk and a well-founded fear that end-of-life care wishes will not be carried out. In all instances it is important that GLBT people have an advocate to back up their documented wishes, in the event that health care professionals do not know their legal responsibilities, and that people who do not have the right step in as alternative decision-makers.

When Advance Care Planning Works

Where possible, it is important for patients, service providers and advocates to find suitable GLBT-friendly services, either in their own homes or in safe, accepting, supportive residential facilities. It is also important that, where possible, patients communicate end-of-life care wishes to family and health care professionals in advance. When both of these things happen, it is more likely that the patient's wishes will be carried out. Respectful partnerships between patients, their loved ones and health care professionals - for example, the care provided to Thelma when she was dying at home in Melbourne (Barrett, 2008) - provide examples of what is possible when advance care planning works.

ISSUES FOR FURTHER RESEARCH

While the education of service providers to offer GLBT-friendly and appropriate care is a long-term goal, the legal mechanisms to assist people with end-of-life care planning are available now. GLBT people are well advised to know their rights and to use the mechanisms available to help prevent discrimination, loss of dignity and inappropriate care. Large scale, confident use of these mechanisms could well help educate health professionals ABOUT, and facilitate, the kind of changes needed in health services to ensure that GLBT people are treated equally to the rest of the population when accessing services.

However it is still not known the extent to which GLBT people are aware of or using these mechanisms or their experiences in so doing. A future research project could investigate this, and use the research results to generate targeted resources.

Attitudes to advance care planning and end-of-life care were not canvassed in this study but they emerged in the literature. Stein and Bonuck (2001) found a high level of interest in advance care planning and high support for palliative care versus medical intervention. Magnusson (2003) found a high level of euthanasia practice in both the US and Australia in the early days of the HIV epidemic. In a future study, attitudes to the range of end-of-life care options held by GLBT people and their service providers should be explored.

An additional issue which was not investigated in this study was the effect of whether patients hold private health insurance or are treated in the public health system. Future research should ask this question when enquiring about end-of-life care. Private health insurance is of particular importance to transgender people, as sex reassignment surgery is not available in the public health system.

RECOMMENDATIONS

The following recommendations address the barriers to advance care planning by GLBT people, and the subsequent implementation of that planning.

Systemic Change

As was found in the literature review, the first and most important change that could benefit GLBT end-of-life care would be legal and social recognition of same-sex relationships, and the diversity of sexual and gender identity. The lack of legitimacy of same-sex relationships, sexual and gender identity accorded by family and health care professionals led to a call by participants for equal rights and recognition in society and an end to discrimination. When changes at this level occur it is possible that more conservative health care professionals might be encouraged to be more supportive of GLBT people.

Information Resources Targeting GLBT People

The results of this study suggest that GLBT people do not know about and/or are not using the available legal mechanisms relating to end-of-life care, while at the same time there are compelling reasons for their use. While organisations such as ACON and the Gender Centre seek to educate health professionals and other health services staff to appropriately serve GLBT people, this is a long-term goal that requires participation from government and non-government health agencies and services. By contrast, the legal mechanisms to assist people with end-of-life care planning are available now, although not widely known about. Consequently, information resources to inform GLBT people and others of their rights in this area and how to advocate for them are an important part of advance care planning. Very specific information is required, especially for closeted rural and regional GLBT people and those still married.

Interventions to Prevent Social Isolation and Encourage Social Connection

The study found that social isolation and a lack of significant connections was a barrier to advance care planning, particularly for gay men. Interventions by health and community services and activities by GLBT community groups that promote social interactions and connections may assist GLBT people to develop the kinds of close friendships and

partnerships that might be relied upon at critical times, such as the end of life. Particular efforts may need to be made with gay men in the context of the impact of the HIV epidemic and the challenges of responding to ageism in the gay male community.

Education of Service Providers

Homophobia and transphobia among service providers can be addressed by education. While religious aged care services are exempt from anti-discrimination laws and therefore permitted to discriminate against GLBT people, some have GLBT-friendly staff and inclusive policies and practices. Education programs that raise awareness of issues facing GLBT people, and stress the benefits of diversity among staff and clients, may go some way to changing entrenched attitudes. Education may be provided by workplace consultants or GLBT agencies such as ACON and the Gender Centre.

The lack of knowledge of service providers about end-of-life decision-making, in particular about the existence of Person Responsible, requires immediate action. The Commonwealth Attorney General's Department, the Commonwealth Department of Health and Ageing, NSW Health and private hospitals and health care agencies need to provide education to health care professionals about Person Responsible. Health care professionals who need to know include doctors, nurses, social workers and pastoral care staff.

If service providers are aware of the hierarchy of people who can be alternative decision-makers for GLBT people under Person Responsible, it is more likely the appropriate person will be able to step in should the patient lose capacity. At the same time, people who are not appropriate alternative decision-makers will be less likely to be able to make decisions on behalf of the patient. The rights of GLBT people are therefore more likely to be respected and their wishes met, leading to appropriate and dignified end-of-life care for the patient and the appropriate support being available for their loved ones.

STUDY LIMITATIONS

This study contained the results of a literature review and consultations with 25 GLBT individuals and their service providers in the Northern Rivers region of NSW. A larger study, conducted over a wider geographic area, may produce different results.

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APPENDIX 1: SCHEDULE OF QUESTIONS FOR COMMUNITY AND SERVICE PROVIDER CONSULTATIONS

How many of you have provided end of life care to GLBT people? To how many people?

- Of your friends/family/clients, how many of them / what percentage had a legal will?
- An Enduring Power of Attorney?
- An Enduring Guardian?
- An Advance Health Care Directive?
- Of your friends/family/clients, how many / what percentage have you been aware where a Person Responsible has been nominated in the absence of an Enduring Guardian? In what circumstances?

Around the room: stories of end-of-life care

APPENDIX 2: BRIEF SURVEY FOR SERVICE PROVIDER CONSULTATION

ADVANCE CARE PLANNING OPTIONS

- Q1. Have you heard of, or had any experience with, any of the following?
(Please circle one number for each option for Heard of and for any that you have heard of, please circle one number for Had Experience with)

Option	Heard of		Had experience with	
	Yes	No	Yes	No
Advance Directive	1	2	1	2
Eduring Power of Attorney	1	2	1	2
Enduring Guardian	1	2	1	2
Person Responsible	1	2	1	2

- Q2. Have you ever been asked by a client to assist her/him to write an Advance Health Care Directive?

Yes	No
1	2

- Q3. Have you completed your own Advance Health Care Directive?
(Please circle one number only)

Yes	No, but I intend to	No, and I don't want to
1	2	3

- Q4. To what extent do you agree that the following would prevent **your clients** from making an Advance Health Care Directive?

Please circle one number for each statement: SA = strongly agree; A = agree; N = neither agree nor disagree; D = disagree; SD = strongly disagree

		SA	A	N	D	SD
a)	They have limited knowledge about Advance Health Care Directives	1	2	3	4	5
b)	They would prefer not to think about end-of-life issues	1	2	3	4	5
c)	They would prefer to leave it until the situation arises	1	2	3	4	5
d)	They would prefer to leave the decision to the doctor	1	2	3	4	5
d)	They would prefer to leave the decision to the family/friends	1	2	3	4	5
d)	Other (please specify	1	2	3	4	5

Section 2: Enduring Guardian/Person Responsible

		Yes		No
Q5.	Has any client of yours ever told you that s/he has appointed an Enduring Guardian?	1		2
Q6.	Have you ever recommended to a client that s/he should appoint an Enduring Guardian?	1		2
Q7.	How helpful do you think it would be for you to know who has legal authority to make health care decisions/give consent for treatment, if one of your clients loses decision-making capacity? <i>(Please circle one number only)</i>			

Very Helpful	Somewhat Helpful	Neither Helpful nor Unhelpful	Unhelpful	Very Unhelpful
1	2	3	4	5

Section 3: Scenario

Please consider the following scenario

Q.8 Georgina is a 37 year-old woman who has been admitted to hospital following a serious car accident. She is on life-support and in a critical condition. Her female partner of 2 years, Rachel, is by her bedside in the Intensive Care Unit when Georgina’s mother Sally arrives and demands a full report on Georgina’s condition from the treating medical practitioner. He asks if Georgina had ever appointed anyone to make health care decisions for her if she lost capacity, or discussed what treatment she would/would not want if she were to become terminally ill or injured. Rachel and Sally say no but Rachel says she knows that Georgina would not want her life prolonged unless she could be returned to a good level of functioning. However, Sally insists that all possible treatment be given to Georgina and that, because she is Georgina’s mother – and therefore next-of-kin, she should have the right to make decisions about what treatment Georgina does or does not receive.

At this point Georgina’s ex-husband Henry arrives; he says that when he and Georgina were married she gave him Enduring Power of Attorney which has never been revoked, so he should have the right to make the decisions.

(a) Who do you think has the legal right to make health care decisions for Georgina?

(b) Why? -----

APPENDIX 3 (A): INFORMATION SHEET FOR COMMUNITY CONSULTATIONS

Knowledge About, and Attitudes To, End-of-Life Care for Gay, Lesbian, Bisexual and Transgender People

My name is Tania Lienert. I would like to invite you to participate in a community consultation as part of a research project I am conducting at Southern Cross University's Aged Services Learning and Research Centre (ASLaRC) from May to July 2009.

To conduct this consultation, we are advertising in the gay, lesbian, bisexual and transgender (GLBT) press, the newsletters, websites and email lists of GLBT health promotion, social and support groups in the Northern Rivers area of NSW, and by word of mouth. You must be aged over 18 to participate.

The research project is on end-of-life care for GLBT people. It includes a review of the Australian and international literature; community and service provider forums like this one; writing a summary of the findings as a research report and an article to be published, and using the findings to apply for funding for a larger research project.

It is hoped that the results will lead to greater understanding by GLBT people of their legal rights in end-of-life care and how to ensure they are met, and greater understanding by the wider community and mainstream health care providers of the importance of personal relationships and community connections for GLBT people, ultimately leading to better care.

The community consultation involves asking participants about their knowledge of, attitudes towards and experiences of end-of-life care of their friends and loved ones. It will also ask about planning for care using awareness of the concept of Person Responsible, Wills, Enduring Guardianship, Enduring Power of Attorney and Advance Health Care Directives. Information on all of these topics will be available. The forum will go for approximately three hours. Everybody who wishes to share their experiences and thoughts will have an opportunity to speak in the group or to talk with me afterwards.

As the researcher, it is my responsibility to listen to your experiences and provide information. ASLaRC Director Professor Colleen Cartwright will also attend to provide information and answer questions. With the consent of participants, I will also be audio taping the forum so I can record your experiences. I will type up notes into a written document that will change names and identifying details, so you will remain anonymous. The tapes will be kept securely and confidentially at the university for seven years and then destroyed.

As a participant, you are free to attend just to listen and learn, and you are also invited to share your experiences and thoughts about end-of-life care if you wish to do so.

Because the community consultation may involve talking about people close to you who have died or who are dying, or you talking about your own end-of-life care, there is a risk that participants may become distressed. I plan to create a supportive environment in which to talk openly about these issues. To assist people who may experience grief or distress, Lismore Base Hospital social workers will be available to talk to participants at the forum or afterwards. You will also be free to leave at any time, and to contact me afterwards to ask that your information not be used.

If you are HIV positive and choose to disclose your status in the context of the discussion, there is a risk you may regret this disclosure later.

In order to join in the community consultation, and to protect the privacy of HIV positive people, all participants will be asked to sign a consent form stating that they understand the benefits and risks of

the research, and a confidentiality agreement which outlines the privacy laws in relation to HIV, and responsibility not to disclose the HIV status of any participant should it be revealed in the forum.

Some of you may know me as the manager of the ACON Northern Rivers branch, currently on secondment to ASLaRC. Your participation or your decision not to participate in this forum will have no impact on the delivery of ACON services or programs to you, and may help inform better services and programs. If you choose not to attend the forum you will still be able to access to services at ACON.

If you would like to find out more you can contact me at ASLaRC on 02 6659 3197 or email tania.lienert@scu.edu.au. You can also talk to my supervisor, ASLaRC Director, Professor Colleen Cartwright, on the same telephone number or email colleen.cartwright@scu.edu.au.

If you would like to receive a summary of the results of this research, please provide your email or postal address on the consent form. Copies of the research report and article will be available on the ASLaRC and ACON websites later in 2009.

This research has been approved by the Southern Cross University Human Research Ethics Committee (approval number ECN-09-034) and the ACON Research Ethics Review Committee.

If you have concerns about the **ethical conduct** of the research, you can write to:
The Ethics Complaints Officer
Southern Cross University
PO Box 157
Lismore NSW 2480
sue.kelly@scu.edu.au

All information is confidential and will be handled as soon as possible.

Yours sincerely,

Tania Lienert

APPENDIX 3 (B): INFORMATION SHEET FOR SERVICE PROVIDER CONSULTATIONS

Knowledge About, and Attitudes To, End-of-Life Care for Gay, Lesbian, Bisexual and Transgender People

My name is Tania Lienert. I would like to invite you to participate in a service provider consultation forum as part of a research project I am conducting at Southern Cross University's Aged Services Learning and Research Centre (ASLaRC) from May to July 2009. The project is being conducted in partnership with ACON on Knowledge About, and Attitudes To, End of Life Care for Gay, Lesbian, Bisexual and Transgender (GLBT) people.

If you care for or are likely to care for GLBT people as part of your work I encourage you to attend.

It is hoped that the results of the research project will lead to greater understanding by GLBT people of their legal rights in end of life care and how to ensure they are met, and greater understanding by the wider community and health care and community service providers of the importance of GLBT people's personal relationships and community connections, ultimately leading to better care. By attending the forum, as well as sharing your own practice experience, you may learn more about this topic and be able to improve your service delivery.

The forum involves asking service providers about their knowledge of, attitudes towards and experiences of end-of-life care of GLBT people. It will also ask about whether you have observed GLBT people planning for end-of-life care using awareness of the concept of Person Responsible, Wills, Enduring Guardianship, Enduring Power of Attorney and Advance Health Care Directives. Information on all of these topics will be available. The forum will go for approximately three hours. Everybody who wishes to share their experiences and thoughts will have an opportunity to speak in the group or to talk with me afterwards.

Along with this service provider consultation, a GLBT community consultation and a literature review will lead to a report and article and grant applications for a larger research project.

To conduct this consultation, we are advertising on the email lists and newsletters of health and community service providers in Northern Rivers area of NSW, and by word of mouth. You must be aged over 18 to participate.

As the researcher, it is my responsibility to listen to your experiences and provide information. ASLaRC Director Professor Colleen Cartwright will also attend to provide information and answer questions. With the consent of participants, I will also be audio taping the forum so I can record your experiences. I will type up notes into a written document that will change names and identifying details, so you will remain anonymous. The tapes will be kept securely and confidentially at the university for seven years, and then destroyed.

As a participant, you are free to attend just to listen and learn, and you are also invited to share your experiences and thoughts about end-of-life care for GLBT people if you would like to do so.

I plan to create a supportive environment in which to talk openly about these issues. You will be free to leave at any time, and to contact me afterwards to ask that your information not be used.

In order to join in the forum, all service providers will be asked to sign a consent form stating that they understand the benefits and risks of the research, and an agreement in which they commit to respect the confidentiality of others in the room and to not share information learned in the forum outside of the forum.

If you would like to RSVP or to find out more you can contact me at ASLaRC on 02 6659 3197 or email tania.lienert@scu.edu.au. You can also talk to my supervisor, ASLaRC Director, Professor Colleen Cartwright, on the same telephone number or email colleen.cartwright@scu.edu.au.

If you would like to receive a summary of the results of this research, please provide your email or postal address on the consent form. Copies of the research report and article will be available on the ASLaRC and ACON websites later in 2009.

This research has been approved by the Southern Cross University Human Research Ethics Committee, approval number ECN-09-034, and the ACON Research Ethics Review Committee.

If you have concerns about the **ethical conduct** of the research, you can write to:

The Ethics Complaints Officer
Southern Cross University
PO Box 157
Lismore NSW 2480
sue.kelly@scu.edu.au

All information is confidential and will be handled as soon as possible.

Yours sincerely,

Tania Lienert

APPENDIX 4: CONSENT FORM FOR COMMUNITY AND SERVICE PROVIDER CONSULTATIONS

CONSENT FORM

Knowledge About, and Attitudes To, End of Life Care for Gay, Lesbian, Bisexual and Transgender People

NOTE: This consent form will remain with the Southern Cross University researcher for their records.

Tick the box that applies, sign and date and give to the researcher

- I agree to take part in the Southern Cross University research project specified above. Yes No
- I have been provided with information at my level of comprehension about the purpose, methods, demands, risks, inconveniences and possible outcomes of this research. I understand this information. Yes No
- I agree to participate in the consultation forum knowing that the forum will be audio taped Yes No
- I understand that my participation is completely voluntary. Yes No
- I understand that I can choose not to participate in part or all of this research at any time, without consequence. Yes No
- I understand that any information that may identify me, will be de-identified at the time of analysis of any data. Therefore, any information I have provided cannot be linked to my person/ company. (*Privacy Act 1988 Cth*) Yes No
- I understand that neither my name nor any identifying information will be disclosed or published. Yes No
- I understand that all information gathered in this research is confidential. It is kept securely and confidentially for 7 years at the University (unless there are special circumstances, that have been explained to me. Yes No
- I am aware that I can contact the researcher and/or the Director of ASLARC at any time with any queries and I have been provided with their contact details. Yes No
- I understand that the ethical aspects of this research have been approved by the SCU Human Research Ethics Committee. Yes No
- If I have concerns about the **ethical conduct** of this research, I understand that I can contact the SCU Ethics Complaints Officer. All inquiries are confidential and should be in writing, in the first instance, to the following: Yes No

Ethics Complaints Officer
Southern Cross University
PO Box 157
Lismore NSW 2480 Email: sue.kelly@scu.edu.au

Participant's name:

Participant's signature:

Date:

Contact: Tel:

Email:

APPENDIX 5: END-OF-LIFE CARE PLANNING FOR GLBT PEOPLE – EXPLANATION OF TERMS

End-of-life Care Planning for GLBT People – Explanation of Terms

The care that we receive at the end of our lives – whether we have a short-term or long-term serious illness or an accident - can be planned by taking time to think about it beforehand. As GLBT people, the more planning we do, and the more we talk to our partners, friends and family about the kind of care we want, the more likely we are to receive it. If we do not plan for end-of-life care, medical practitioners and other health care professionals may provide care we would not want. It may be possible for others to make decisions not in line with ours, and people who should have a say may miss out. There are a number of ways you can plan for your end-of-life care (often referred to as Advance Care Planning).

Enduring Power of Attorney

An Enduring Power of Attorney is a substitute decision-maker of your choice who you can appoint to manage your financial and property affairs should you lose the capacity to make your own decisions at some time in the future. You can consult your local community legal centre to find out whether they can assist you with this appointment.

Advance Care Planning for your health decisions - Advance Health Care Directives, Enduring Guardianship and Person Responsible

Advance Health Care Directives: Because of accident or illness a patient may not be able to tell the doctor what life-sustaining treatments he or she wants or does not want. Some people choose to write down these preferences beforehand. This written document is an Advance Health Care Directive. Your GP can assist you in completing this document.

Enduring Guardian: An Enduring Guardian is a substitute decision-maker of your choice who you can appoint to make lifestyle and health care decisions should you lose the capacity to make your own decisions at some time in the future. You can consult your local community legal centre to find out whether they can assist you with this appointment.

Person Responsible: Medical and dental practitioners have a legal and professional responsibility to get consent before treating a patient. If the patient is unable to consent, the practitioner should seek consent from the patient's Person Responsible. The Person Responsible is not necessarily the patient's next of kin, but is, in this order, either a Guardian, including an Enduring Guardian; the most recent partner, including same-sex partner, with whom the patient has a close continuing relationship; an unpaid carer (who can be on a carer payment); or a relative or friend who has a close personal relationship with the patient.

For more information on Enduring Power of Attorney, Enduring Guardianship, and Advance Health Care Directives and forms to download, visit the ASLaRC website <http://aslarc.scu.edu.au>. For more information on Person Responsible, visit the Office of the Public Guardian website http://www.lawlink.nsw.gov.au/lawlink/opg/ll_opg.nsf/pages/OPG_glbt

Wills

The easiest way to ensure your property is distributed according to your wishes is to make a will. In your will you must appoint an Executor, preferably someone you trust, to carry out your wishes. If you don't know who to appoint, the NSW Trustee and Guardian will act as Executor for a fee. You can also direct how you would like to be buried or cremated and what sort of funeral service you would like, although these directions are not binding. You can complete a will by getting a free will form or purchasing a will kit from your local newsagent, or see a lawyer. For more information on Wills, visit the Lawlink website: http://www.lawlink.nsw.gov.au/lawlink/cpd/ll_samesex.nsf/pages/samesex_equal

APPENDIX 6: CONFIDENTIALITY FORM FOR COMMUNITY AND SERVICE PROVIDER CONSULTATIONS

CONFIDENTIALITY AGREEMENT

This agreement is specifically for all people attending the ASLaRC consultation forums on End-of-Life care.

1. I _____
(FULL NAME)

accept that as a participant in the ASLaRC research, I may learn certain facts about other people that are of a personal and confidential nature.

2. I understand that information of a personal and confidential nature includes:

- Medical conditions and treatments;
- Sexual orientation and practices;
- Relations with family members;
- Names of people with HIV/AIDS, their friends and/or family;
- Other information pertaining to participants.

3. I undertake that I will not reveal to any other person any confidential information about research participants which comes to my knowledge during the course of the research.

I further understand that this obligation:

- (a) is subject to any legal obligation to disclose the information; and
- (b) applies to me both while I am participating in the research and after I cease to be involved in the research.

4. I am aware that under section 17(2) of the Public Health Act 1991 (NSW), where a person acquires information that another person:

- (a) has been or is required to be, or is to be, tested for HIV; or
- (b) is, or has been infected with HIV,

that person must take all reasonable steps to prevent disclosure of this information.

Breach of this provision is a criminal offence. As a criminal offence ASLaRC will not indemnify me against breach of this provision.

5. I understand that if I breach an individual's confidentiality, that person is entitled to sue me for damages, and that ASLaRC will not indemnify me for such damages.

6. I accept that a breach of these conditions may result in civil and/or criminal proceedings.

7. I have read and accept the ASLaRC information statement and consent form and this confidentiality agreement as the condition of participating in the research. I also accept that other research participants are signing the same consent form and agreement.

Signed _____

Date _____