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# LGBT people's knowledge of and preparedness to discuss end-of-life care planning options

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## **LGBT people's knowledge of and preparedness to discuss end-of-life care planning options**

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### **Abstract**

Despite the devastating impact of HIV/AIDS, end-of-life care planning among lesbian, gay, bisexual and transgender (LGBT) communities is relatively under-researched, especially in Australia. This paper reports findings of a survey of 305 LGBT people living in New South Wales, which examined their knowledge of and attitudes towards end-of-life care. The focus of this paper is their preparedness to discuss with health care providers any end-of-life care plans. The results highlight that while the majority of respondents were aware of three of the four key end-of-life care planning options available in New South Wales – enduring powers of attorney, enduring guardians, and person responsible (only a minority had heard of advance health care directives) – a much smaller number of people had actually taken up these options. Only a minority of respondents were able to identify correctly who had the legal right to make treatment decisions for a person who is unconscious following a car accident. A small proportion of people had discussed end-of-life care options with general practitioners or another main health care provider, and only in very few cases were these issues raised by the practitioner themselves. Those most likely to not feel comfortable discussing these issues with practitioners included younger people, those not fully open about their sexuality to family members, and transgender people and others who do not define their gender as male or female. The paper highlights the importance of education strategies to raise awareness of the end-of-life care planning options among LGBT people, as

well as strategies for increasing health providers' preparedness to discuss these issues with LGBT patients.

### **What is known about the topic**

- LGBT people's partners, ex-partners and friends are sometimes not fully recognized as having a legitimate role in end-of-life decision making by biological family members and health care providers.
- Despite the existence of legal options that can protect the rights of LGBT people in relation to end-of-life care decisions, there is some evidence that there is limited understanding of these options.

### **What this paper adds**

- While there was a high level of understanding of enduring power of attorney, understanding of other end-of-life care planning options was less common, and there were relatively few people who had actually taken up these options.
- Only about one quarter of people could identify the legally correct decision maker in a scenario involving a woman and her same-sex partner who had been in a car accident.
- Very few people had discussed end-of-life issues with GPs or other health care practitioners, even though most would feel comfortable if the practitioners raised these issues.

**Keywords:** LGBT people, end-of-life care; advance care planning; sexuality; aged; palliative care; health care communication

## Introduction

For many years the end-of-life experiences of lesbian, gay, bisexual and transgender (LGBT) people were viewed through the lens of HIV/AIDS (Ward *et al.* 2010). Increasingly, researchers are exploring these experiences within the context of ageing, and/or alongside the other life-limiting conditions which affect the whole population. Key issues for LGBT people at the end of life include the availability of personal support networks, which may include same-sex partners, ex-partners and friends ('families of choice'), as well as biological family members (Almack *et al.* 2010, Smolinski & Colón 2006). Almack *et al.* (2010) highlight the ways in which these chosen families can be disenfranchised because they may not be fully recognized by biological families or by health and other care providers. Concerns have also been expressed that LGBT people may delay seeking health care support because of fears of discrimination or may choose to hide their identity (going back in the 'closet') when in contact with service providers (Rawlings 2012).

The legal rights of LGBT people as they approach the end of life have been a source of contestation both in Australia and around the world. Despite the amendment in 2009 of 85 pieces of Federal legislation to protect the rights of same-sex couples and their children, because same-sex couples cannot be legally married in Australia there remains confusion among some people about their legal status. In the UK, Westwood (2013) draws attention to the limited legal recognition of friends, particularly in Wales and England, especially in relation to making treatment decisions. Of particular concern is the confusion expressed by some about the legal rights of same-sex partners and friends when LGBT people lose legal decision-making capacity (e.g. because they are unconscious or have dementia) and are no longer able to communicate their views to health professionals (Cartwright *et al.* 2012). Yet

in Australia and in most other western countries there are advance care planning and other legal options available, which can be used to ensure LGBT people's views are accommodated even after they lose legal capacity. In Australia these legal options are under state government jurisdiction, and in New South Wales, the site of this study, for people who have lost capacity they include:

- enduring power of attorney: where an attorney is appointed to make financial decisions on a person's behalf;
- enduring guardian: where a guardian is appointed to make personal decisions, such as in relation to accommodation and medical treatment;
- person responsible: a person, not necessarily 'next of kin', who is sought by medical or dental practitioners to give consent to treatment if the patient is not able to provide this consent (the legal 'order of authority' for person responsible is: the patient's guardian; spouse or defacto spouse (including same-sex partner); an unpaid carer providing support; or a relative or friend who has a close personal relationship with the patient);
- advance health care directive: a document completed prior to the loss of legal capacity, whereby a person sets out their wishes for care and treatment beyond the point where they are able to make those decisions themselves.

Evidence from Australia and overseas (Jackson *et al.* 2009) suggests that the general population has limited understanding, and makes limited use, of these legal options. This is particularly the case for older people (Cartwright *et al.* 2006), and especially those living in residential aged care facilities (Bezzina 2009). A key source of information about the legal options available to them is health care professionals who are providing support towards the end of life. However, such discussions do not always occur. For example, a study of 158 United States primary care medical practitioners revealed that they provided this

information to only 43% of patients with life-limiting illness, despite 97.5% of patients saying that they would feel comfortable discussing this with their doctors (Snyder *et al.* 2012). Barriers to effective take-up of end-of-life care planning options for the general population and for health care practitioners include, but are not limited to, lack of knowledge; difficulties accessing, understanding and completing the legal documentation; difficulties for practitioners knowing when to time discussions about end of life care; and emotional reactions related to these issues and confronting one's mortality (Boddy *et al.* 2013).

Given the significance of these legal options in promoting the rights of LGBT people towards the end of life, it is important to understand if there is a similar lack of knowledge and take-up of these legal options for LGBT people, as well as what some of the barriers might be. Thus far, there has been no study in Australia that has investigated LGBT people's knowledge of and preparedness to take up such legal options. However, based on one of the only studies worldwide to examine this issue (Metlife *et al.* 2006), it is possible that the results for LGBT people do reflect those of the wider population. Of the 1000 LGBT people aged 40 to 61 who were surveyed in the Metlife *et al.* study, 72% reported that they had discussed end-of-life preferences with someone, while only 42% had completed an advance care directive. In further analysis of a subset of this sample (n=793), de Vries *et al.* (2009) identified that people who were in a legally-recognised same-sex relationship were more likely to have completed a living will (advance health care directive) (58.7%) than those who were not (34.0%), similarly they were also more likely to have completed a durable power of attorney for health care (also referred to as health care surrogate or proxy) (60.4% versus 26.1%).

As with the general population, LGBT people's knowledge of and preparedness to take up end-of-life care planning options may also rely on health and other care providers' ability and willingness to discuss these issues in the context of the provision of or planning for care. In one of the few studies to address this issue, Stein & Bonuck (2001) revealed that 79% of the 575 lesbians and gay men they surveyed in New York had not discussed with their health care provider what should happen in the event of them needing to be resuscitated and, of these, 73% would like their health provider to know their views. Similarly while 75% had considered advance care options, only in 23% of cases had their doctors discussed this with them. While there was a high level of awareness of some advance care legal options – 72% knew of health care proxies and 90% of living wills – the actual take-up of these options was much less (42% for health care proxies and 38% for living wills).

Based on their systematic review of sexual minorities and end-of-life care, Harding *et al.* (2012) report the need for more research into the issues faced by LGBT people in relation to end-of-life care, and they highlight in particular the lack of data on transgender people's experiences. While the legal options in different jurisdictions vary (both within and across countries), LGBT people are afforded legal protection in relation to end-of-life care in many places. Research into the extent to which these options are known about, whether or not they are taken up, and the role of health and other care providers in increasing awareness of these options is therefore required.

This paper reports on such a study in New South Wales, Australia. It was decided to select one state as the focus of research given the complexity of surveying people across different jurisdictions that have different legal options and use different terminology. This state was identified as appropriate given it is likely to have the largest number of LGBT people of any state in Australia. For example, in the 2011 census, while NSW comprised about one third of

Australia's population, it had 41% of the nation's (publically identifying) male cohabiting same-sex couples, and 34% of female cohabiting same-sex couples (ABS 2013). Any conclusions drawn from the research must bear in mind this geographical context.

## **Aims**

- To examine LGBT people's understanding of the end-of-life care planning options available to them.
- To investigate LGBT people's capacity to access information about these options, including their preparedness to discuss end-of-life issues with their GP or other main health care provider.

## **Methods**

This study comprised a survey of LGBT people residing in the state of New South Wales, Australia, and was modeled on surveys previously developed by Steinberg *et al.* (1996) and Cartwright *et al.* (1998). The design of the survey was informed by a steering committee, which comprised relevant stakeholders from LGBT community organisations and community legal services. It was also informed by the results of an earlier exploratory qualitative study which examined the needs of LGBT people and service providers in relation to end-of-life care (Cartwright *et al.* 2012). Ethics approval was obtained from Southern Cross University and key community organisations. Following approval, the survey was piloted with two older gay men, with subsequent minor amendments made.

## **Sampling**



Accessing representative samples of LGBT people is notoriously difficult (Stein & Bonuck 2001) and thus the constraints of this research meant that a convenience sample was necessary. This was generated through wide-spread distribution of the online survey link and hard-copy questionnaires by LGBT community organisations. Hard copy questionnaires (with reply paid envelopes) were also enclosed in newsletters and were available at drop-in centres and other agencies. It was intended that the survey be completed by self-identifying LGBT people, resident in New South Wales. However, post-code analysis of completed questionnaires revealed that the survey had been completed by residents of other states. For the purposes of this paper, these cases have not been included in the sample set.

#### Data collection

The survey mainly comprised forced-choice questions, with the option of providing additional information where needed. The online version of the survey was generated by Survey Monkey. Key demographic variables reported in this paper – including gender, sexual orientation, age and relationship status – were measured categorically. A question about openness about sexuality to family members provided the options: ‘Yes to all’; ‘Only to some’; ‘No’.

Knowledge of end-of-life care planning options was examined by asking respondents 1) if they had heard of each of the relevant legal options and 2) if they have had experience with each of these options. The legal options presented to respondents were: enduring power of attorney, enduring guardian, person responsible, and advance health care directive. An explanation of each of the legal options was provided in the questionnaire.

Knowledge of these legal options was also assessed through responses to the following scenario, which was included in the questionnaire, and followed the questions about knowledge and experiences with end-of-life legal options. This scenario involved the rights of a same-sex partner to make health care decisions after her partner's loss of legal capacity as a result of a car accident:

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.

Respondents were asked to identify who, from the people in the case study, had the legal right to make the decision on behalf of the patient. A further open-ended question asked why the respondent thought this person had the legal right.

In addition, two five-point Likert Scales were developed to assess the degree of comfort respondents felt 1) in them raising end-of-life issues with their main health care provider and 2) their main health care provider raising these issues with them.

#### Data analysis

Responses from the hard copy surveys were entered into Survey Monkey. Initial frequencies of variables were calculated using this software. Data were then exported, via a Microsoft Excel spreadsheet, into the Statistical Package for the Social Sciences (SPSS) version 19 (International Business Machines Corporation, USA). Crosstabulations and chi-square analysis were then conducted to facilitate bi-variate analysis. The alpha was set at 0.05. Responses to the open-ended question were coded thematically.

#### **Results**

In total, 305 people completed the survey (202 in hard copy and 103 online). Table 1 presents the characteristics of respondents.

PLEASE INSERT TABLE 1 ABOUT HERE

#### Knowledge of end-of-life care planning options

Respondents were asked if they had heard of or had experience with four legal options related to end-of-life care planning. While there was a relatively high rate of awareness of enduring powers of attorney (87% had heard of it), awareness of the other legal options was much lower, with 59% aware of enduring guardians, 52% of person responsible, and only

38% of advance health care directives (Table2). Despite the awareness of the availability of enduring power of attorney it was notable that, of the people who answered the question, only 59% had had experience with it. Experience with the other legal options was similarly relatively low.

PLEASE INSERT TABLE 2 ABOUT HERE

When asked to identify the person in the scenario who had the legal right to make health care decisions for the patient, only 27% of respondents correctly identified that her same-sex partner had this legal right (n=297). Fifty-one percent incorrectly identified her ex-husband, while 15% incorrectly identified the patient's mother. Of the 277 respondents who provided a reason why they chose this person, only 13% identified the correct legal reason – that the same-sex partner is the 'person responsible' (as she is her de-facto partner).

#### Discussion of end-of-life care with health care providers

Of the 300 respondents who answered the question, 87% reported that they had a regular general practitioner (GP), while of those who did not, 90% identified another health practitioner (e.g. naturopath, HIV/AIDS specialist) as being a main health provider.

Compared to the older groups in the sample, younger people (those aged 29 and under) were significantly less likely to have a regular GP – with only 47% reporting this, compared to 100% of those aged 70 and above ( $\chi^2 (6, n = 300) = 37.425, p \leq 0.01$ ).

Thirteen percent (38) of respondents reported that they had discussed end-of-life issues with their GP or main health provider (n=300). Of these, 92% had raised the issues themselves. When asked how comfortable they would be with their health care provider

raising these issues with them, 76% (225) said that they would be comfortable or very comfortable, while only 8% said that they would be uncomfortable or very uncomfortable with this (n=298) (Table 3).

PLEASE INSERT TABLE 3 ABOUT HERE

Bivariate analysis revealed that people aged 29 and younger were significantly less likely than older people to feel comfortable with a GP or other health care provider raising the issue – with 37% reporting that they would feel comfortable or very comfortable with this, compared to 82% of those aged 70 and above ( $\chi^2 (12, n = 289) = 29.469, p \leq 0.01$ ). Notably, respondents who identified their gender as transgender or ‘other’ were also significantly less likely to feel comfortable if a GP or other health care provider raised the issue of end of life care. Fifty two percent of those who identified their gender as other than male or female reported that they would feel comfortable or very comfortable with the issue being raised, compared with 78% of those who identified as male or female ( $\chi^2 (4, n = 285) = 10.380, p \leq 0.05$ ). People who were not fully open to all family members about their sexuality were also significantly less likely to feel comfortable or very comfortable with health care providers raising end-of-life care issues (81%) than those who were full open (60%) ( $\chi^2 (4, n = 288) = 17.181, p \leq 0.01$ ).

## **Discussion**

When LGBT people approach end of life and make decisions about end-of-life care it cannot be taken for granted that they are able to exercise their rights in the same way that non-LGBT people can (Powell & Neustifter 2012). This is especially the case in relation to the rights of LGBT people to ensure that same-sex partners and nominated friends are not

excluded by biological family members, or by health care providers who may assume that biological family members' views should be pre-eminent. In the Australian state of New South Wales, as in other parts of the world, there are legal provisions available that protect and promote the rights of LGBT people when making end-of-life decisions, including advance care planning decisions. Knauer (2010, p. 7) argues that for LGBT seniors these legal mechanisms can 'serve as a partial bulwark against many of the inequities they experience.'

However, as this study has demonstrated, there is a relatively low level of awareness of these provisions among LGBT people, and also a low level of experience using these provisions. These findings are comparable with those of studies of the general population. For example, it has been estimated that only between 18% and 30% of Americans have completed an advance directive (Wilkson *et al.* 2007). There has been little research of the take-up of this option in Australia. What is of particular concern in relation to LGBT people is that these important legal options – that protect people's rights – are not being systematically employed. In our study this point was highlighted by the fact that only 27% of those surveyed knew that, in the scenario provided, a same-sex partner (as the 'person responsible') did have the right to make treatment decisions on behalf of her partner, and only 13% knew why. Although it is notable that in a study of NSW GPs and medical specialists a similar proportion (19%) did not know who the 'person responsible' was in a scenario involving an older heterosexual woman (Cartwright *et al.* 2009).

For LGBT people, being open about one's sexual or gender identity is positively associated with a range of benefits, including increased self esteem and life satisfaction (Fredricksen-Goldsen & Muraco 2010). While it is not necessarily possible or desirable to be open about this aspect of one's identity to all people all of the time, being open about one's LGBT status has particular benefits when in contact with health care providers, such as GPs (Klitzman &

Greenberg 2002). However there is substantial research which evidences health care professionals' difficulties in communicating with people about sexuality and in recognizing people with diverse sexual and gender identities (Pennant *et al.* 2009). Of concern in the present study is that people who were not open about their sexual identity were significantly less likely to feel comfortable talking to their health provider about end-of-life issues.

That transgender people and others who did not identify their gender as either male or female were significantly less likely to feel comfortable having end-of-life issues raised by health providers is a major concern. It is possible that this is a reflection of the ongoing difficulties transgender and intersex people have had in engaging with the medical and other health care professions. In a study of 385 self-identified transgender people in Virginia, USA, 25% (n=94) reported that they had experienced discrimination in health care (Bradford *et al.* 2013). This is supported by qualitative findings from Australia which pointed to a wide range of discriminatory behaviours, ranging from curiosity and novelty to outright hostility and ridicule (Pitts *et al.* 2009). The particular issues faced by transgender people highlight how crucial it is that, when engaging with LGBT people, health care providers recognize the diverse needs, identities and community affiliations of all LGBT people, and that they are not treated as all the same.

The findings of this research highlight the need for training of health care professionals both in the options available for end-of-life care planning, and in communicating effectively with LGBT patients. This can be achieved relatively easily. For example, a study by Reygan & D'Alton (2013) highlighted the impact of a 50 minute training module for health and social care practitioners on providing oncological and palliative care to LGB people. Key outcomes included increased confidence in providing care to LGB patients, feeling more comfortable

using LGB-related terminology, and greater knowledge of the particular health-care issues of LGB people. The current efforts by the Australian Government to increase the responsiveness of community and residential aged care staff to LGBT people would be strengthened by a similar program targeting general practitioners. Clearly both programs would benefit greatly by including modules on end-of-life care and advance care planning.

This research highlighted the potential for increasing knowledge among LGBT people of end-of-life care planning options, including enabling GPs and other health providers to raise these issues with their LGBT patients. There were, however, a number of limitations to the study which need to be borne in mind when interpreting the findings. Like other studies of the LGBT population, this research relied on a convenience sample, and thus caution needs to be taken in extrapolating the findings to the wider LGBT population. Similarly the use of inferential statistics to draw conclusions from a non-probability sample, while common, is also a clear limitation (American Association for Public Opinion Research 2013). Because respondents were accessed via connections with LGBT community organisations and through advertisements in LGBT media, it is likely that the survey over-represented people who were more open about their sexuality or gender identity, than those who were not.

An additional limitation was the possible pre-empting of responses to the scenario by having respondents first answer questions regarding the legal options available (including an explanation of what these legal options were). Without such pre-empting it is possible that the accuracy of the responses to the scenario would have been even lower. Further, it is important to acknowledge that the study was limited to one state in Australia, due to variations in legal options available in other jurisdictions, and thus it is possible that knowledge of these alternative options in other states or countries may be different to that reported in New South Wales, although research with general population groups has found



similarly low levels of knowledge and experience across jurisdictions (Cartwright *et al.* 1998, Steinberg *et al.* 1996).

More research is needed into the experience of LGBT people in planning for end of life. This project has highlighted a lack of understanding and take-up of the legal options available. However, it has not been able to investigate in depth the meaning that people ascribe to these decision-making options, to the ethical and personal questions they raise for them, nor to the informal arrangements they have made within their own families and communities. A next stage of the research reported in this paper could be in-depth interviews and focus groups to assist in interpreting the survey's findings. This kind of qualitative research would help explore the contextual factors at play for different individuals, such as the extent to which biological family members are supportive of same-sex relationships, and the nature of people's social support networks.

## **Conclusion**

Legal options exist within New South Wales and other jurisdictions around the world which can be used to protect and promote the rights of LGBT people as they move towards the end of life. However, a central concern remains the considerable gaps between 1) the legal provisions available, 2) awareness among LGBT people of these provisions, and 3) the actual take-up of these legal options. General practitioners and other health care providers are in a unique position to ensure that LGBT patients can access information about these options. However, this relies on health care providers being able to communicate effectively with patients about their gender or sexual identity (so that people may be recognized as LGBT), as well as being able to talk about end-of-life issues. As Stein & Bonuck (2001) argue, health

care provider-initiated discussions may help in translating patients' knowledge about the legal options into actual take-up of these options.

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**Table 1: Demographic characteristics of participants**

<b>Age (N=292)</b>	<b>&lt;40</b>	<b>40-49</b>	<b>50-59</b>	<b>60-69</b>	<b>70+</b>
% (n)	17 (51)	22 (65)	26 (74)	22 (64)	13 (38)
<b>Gender (N=288)</b>	<b>Male</b>	<b>Female</b>	<b>Transgender</b>	<b>Other*</b>	
% (n)	51 (148)	40 (116)	4 (10)	5 (14)	
<b>Sexual identity (N=292)</b>	<b>Gay**</b>	<b>Lesbian</b>	<b>Bisexual</b>	<b>Hetero-sexual</b>	<b>Other***</b>
% (n)	48 (140)	25 (74)	12 (36)	6 (18)	9 (24)
<b>Open to significant others (N=291)</b>	<b>Yes, to all</b>	<b>Only to some</b>			<b>No</b>
% (n)	75 (219)	16 (45)			9 (27)
<b>Relationship status (N=288)</b>	<b>Single</b>	<b>Partnered****</b>			<b>Grieving loss of partner</b>
% (n)	45 (131)	51 (145)			4 (12)

\*Includes self-identified terms: transsexual and intergender

\*\*2 women identified as Gay, rather than as Lesbian

\*\*\*Includes self-identified terms: queer and transvestite

\*\*\*\*Of those in a partnership, 67% were cohabiting.

**Table 2: Proportion of respondents who had heard of and had experience with end-of-life care planning options (N=305)**

Option	Heard Of			Had Experience With		
	N	Yes	No	N	Yes	No
		% (n)	% (n)		% (n)	% (n)
Enduring Power of Attorney	276	87 (239)	13 (37)	160	59 (94)	41 (66)
Enduring Guardian	272	59 (160)	41 (112)	105	57 (59)	43 (45)
Person Responsible	262	52 (135)	48 (127)	88	59 (52)	41 (36)
Advance Health Care Directive	269	38 (101)	62 (168)	56	57 (32)	43 (24)



**Table 3: Degree of comfort if health care provider raised end-of-life issues (N=298)**

<b>Degree of comfort if health care provider raised the end-of-life issues</b>	<b>N</b>	<b>%</b>
Very Comfortable	126	43
Comfortable	99	33
Neither Comfortable nor Uncomfortable	47	16
Uncomfortable	16	5
Very Uncomfortable	10	3
Total	<b>298</b>	<b>100</b>