

Nurturance
Appreciation
Admiration
Support

My People

Acceptance
Tolerance
Pity
Repulsion

Interim Findings from a Study Exploring the Experiences of GLBTI Seniors in Aged Care Services



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January 2008



Funded by the Reichstein Foundation

Contact and Enquiries

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This Project is proudly supported by the Matrix Guild of Victoria, Vintage Men Inc, The Reichstein Foundation, The Brotherhood of St Laurence, Victorian Gay and Lesbian Rights Lobby, Gay and Lesbian Health Victoria, The Also Foundation, Women's Health East, Women's Health in the South East, Women's Health West, The Australian Lesbian Medical Association, The School of Health Sciences: The University of South Australia, The Victorian Council on the Ageing and Victorian Equal Opportunity & Human Rights Commission, Victorian AIDS Council, Australian Lesbian and Gay Archives

Background

The past two decades in Australia has seen widespread socio-political reforms challenging the general perspective of heterosexual experience as the only view of the world. Despite these reforms there remains an assumption of heterosexuality in aged care. Such an assumption fails to create a climate in which non-heterosexuals are prepared to disclose sexual or gender identity, life history or care needs. This failure to disclose results in a cycle in which health professionals are unaware of their GLBTI clients and their particular needs (Harrison, 2004*). To achieve appropriate change in the provision of services to older people, in line with the general changes in society, the Matrix Guild has outlined a four-stage program. The aim of the Program is to reduce health disparities in society by redressing the unmet health needs of GLBTI seniors.

Stage 1 (2007): Exploring the Experiences of GLBTI Seniors in Aged Care: Created an in-depth understanding of the experiences of GLBTI seniors in aged care services by interviewing GLBTI seniors receiving these services.

Stage 2 (2008): Determining Strategies to Enhance Aged Care Services: This project aims to identify strategies to improve aged care services in response to the needs identified in Stage 1. This will be achieved by inviting aged care service providers to participate in interviews and focus groups to explore the provision of services to GLBTI seniors.

Stage 3 & 4 (2009 -): Implementing Change: Data gathered from Stage 1 and 2 will be utilized to challenge policy and legislative officers at all levels of government with a particular focus on the State Government Department of Human Services (the Aged Care Branch and the Ministerial Advisory Committee on Gay, Lesbian, Bisexual Transgender and Intersex Health and Wellbeing); and the Department of Planning and Community Development (Ministerial Advisory Council of Senior Victorians and the Office of Senior Victorians). The data will also be utilized to inform the development of resources to assist in improving aged care services for GLBTI seniors.

Methodology

The methodology for the study was developed in conjunction with an expert steering committee of stakeholders and ethics approval was obtained from the Victorian Aids Council. Participants were recruited over a seven month period through steering committee networks and paid advertisement. The project consisted of two phases; the first involved gathering stories of aged care experiences through interviews with 14 aged care recipients, a transsexual woman and three gay and lesbian aged care workers. These interviews were analyzed to identify themes around what worked and what could be improved. To explore these themes in greater depth a second phase involved more in-depth interviews with three GLBTI seniors and their carers and/or family.

*Harrison, J (2004). *Towards the recognition of gay, lesbian, bisexual, transgender and intersex ageing in Australian gerontology*. PhD Thesis. School of Health Sciences, Division of Health Sciences, The University of South Australia.

Participant Characteristics

Phase One interviewees were receiving aged care services including home care, residential aged care and day care services. Interviewees had an average age of 70.4 years and included seven females and eight males who identified as lesbian (7), gay (6) and bisexual males (2). Most participants lived in the Melbourne area (13) and almost half had a current partner. The case studies conducted for Phase Two included interviews with: a 64 year old gay man living in a nursing home, a 74 year old lesbian caring for her dying partner at home; and a 79 year old transsexual woman living in a catholic supported accommodation unit/aged care hostel.

Issues Emerging from Thematic Analysis

The interviews conducted in Phase One of the Project identified that some older GLBTI people:

- 1 Have endured discrimination for many decades and consequently expect discrimination to continue and feel powerless to achieve the social justice that they deserve.
- 2 Are prohibited from expressing themselves in a sexual way in aged care services by families and staff
- 3 Perceive that they re-enter the 'closet' when they enter shared aged care services
- 4 Feel that they re-enter the 'closet' when they invite carers into their home
- 5 Have internalised homophobia/transphobia
 - Respond to homophobic/transphobic comments from carers or co-residents with a reinforced belief that they needed to hide their sexual/gender identity to be safe
 - Use demeaning language to describe their sexual identity
 - Perceive it would not be fair to expose their carers to their sexual identity
- 6 Are dependent on the good will of carers and feel vulnerable in that relationship because of their sexual/gender identity.
- 7 Are isolated, lonely and vulnerable
- 8 Are concerned that disclosing their sexual identity would 'sour' relationships with carers and lead to diminished standards of care.
- 9 Feel that many health professionals can 'recite a mantra' around non-discrimination whilst maintaining homophobic/heterosexist practices.
- 10 Had more difficulty protecting themselves from homophobic or transphobic abuse when they were cognitively impaired/had dementia
- 11 Had little privacy in residential aged care and consequently struggled to protect their sexual/gender identity:
 - from staff who did not respect their privacy
 - from cognitively impaired residents who invaded their space
 - particularly when they were transsexual (and did not pass) or were cross dressers (and were clearly identifiable)
 - when they were cognitively impaired
- 12 Could cue aged care service providers to treat them in a respectful manner

Why Not Take All of Me?

Précis from interviews with: a) Tom a 64 year old gay man living in a nursing home; b) Lizzi his Community Support Officer with the Victorian AIDS Council and c) Kathleen, Tom's 85 year old mother.

Tom: My name is Tom and I have been in a nursing home since I had a stroke four years ago. I had the stroke because I've got HIV. I've got two brothers and one sister, but we don't talk because I'm gay and I've got the HIV and they disapprove. I've got no-one in my life now that loves me. Except the old girl, she loves me. When mum goes I'm done. Because I'm gay I'm a lonely man. Oscar Wilde said: City life, millions of people living lonesome together.

When I came here I told the staff I was married and they started asking to see the pictures of my wife. Of course I didn't have any and because they knew I had HIV they worked out that I'm gay. I can't talk to the staff about being gay because I am worried my care will be worse. I'm not able to live a gay man's life here because there is no privacy, and there are rules and some people think gay is disgusting. I keep my mouth shut. I have to be careful how I act and be careful what I say.

I'm only 64 but I am an old man. The HIV makes me feel old and this place makes me feel old. I've got no-one to talk to here because the residents sleep all day and they have dementia. My mind is still good, but I have no conversation. I talk to Lizzi; she's my Community Support Officer from the Victorian AIDS Council. I talk to her about how much I miss sex, touch and intimacy but I can't talk to the staff in here about that. When I realised there was nothing for me in here; that I had to forget about a sexual relationship with a male, my libido was extinguished. For a few years I rallied against this place, then I got depressed and I succumbed to it. I need to meet interesting people to make me feel alive for a while. Then back to this deadness. What else is there? I can't talk to them. I am a reasonably intelligent man. It's been depressing being in here so I started antidepressants. They're called happy pills. I had to go on them when I came in here, it's depressing.

I've got extra services because of the HIV. People who know about HIV come here to help the staff look after me. I have Lizzi who organises volunteers to take me out for a latte, a beer or a drag show. They have helped with my HIV and they have changed the way staff treat me. See they are used to gay men and I can be a gay man when I'm with them. They've educated staff about how to care for me so I get better care. They check that I'm getting the right care. The staff here know that there are people who are interested in what happens to me, that makes a difference.

The services that come in for my HIV have made some staff take interest in gay culture; one nurse wants to come to a drag show with me. That's good because a lot of straight people don't understand gay people. The other benefit is that the services understand gay men, so it's my chance to be with my kind of people, when I am with them I come alive. We can talk about old times and I can be myself. Lizzi says there are more gay men like me with HIV who are going to need aged care. Can you tell them my story so that they get looked after well and don't get lonely like me?

** Special thanks to Lizzi, Community Support Officer from the Victorian AIDS Council for her assistance with and feedback relating to this case study.*

Show a Little Fight Girls, Don't Be Too Polite.

Précis from interviews with: a) Maureen, a 74 year old lesbian who cared for her dying partner at home with home based support services and b) Jean, a friend and carer.

Thelma, she was born in 1956 and was diagnosed with cancer in 2002 and died six months later. We were together for 17 years. Thelma was, is and always will be the love of my life. She was a wonderful woman and a very strong lesbian. She went in all the marches, spoke on the steps of parliament house and chained herself to the arbitration buildings for equal pay for women.

Thelma was able to be cared for at home because of this wonderful chain of lesbians who stick together and give support because we love each other and are committed to each other. The chain also allowed me to survive after her death. If they weren't around I think I would go mad. Caring for Thelma at home was the greatest blessing for both of us. Every day was a new day for us. I could see her nearly every second of the day. I could look at her, I could smile at her and I could talk with her. I could spend my time with her and I had all the help I needed.

We had three close friends who were nurses that we trusted to care for Thelma. They were trusted because they were friends and they were lesbians. They knew us both. We had a palliative care service come in and the district nurse. When they came to see Thelma I said: "We are lesbians and we would like to be recognised as a couple and we ask for your respect and I don't want any male nurses coming here to wash Thelma or whatever you people are going to do." They agreed. The case manager used to sit out the back and have a yarn with us. She knew we were lesbians. She told me afterwards that she knew immediately she came in because there was this beautiful sense of eyes looking at each other, the way I looked at Thelma, the way that Thelma looked at me. She knew but she said that she appreciated me coming out to her. She would go to Thelma and kiss her on the top of the head. That was really nice. On Christmas day the palliative care nurse came dressed as a rainbow fairy, which was amazing.

The palliative care service was there for advice, support and they were very much in the background to let Thelma die the way she wanted to die with the people around her that she wanted to have care for her. We were surprised at how supportive they were of us as a lesbian community. They said to us that they had never come across this kind of support before. After Thelma's death, the case manager asked whether there anything else that they could have done for us as a community. They used the word 'community' and 'your community'.

The lesbian chain becomes more important as you get older. In your area there's always a lesbian, you know what I mean? There is always a lesbian for a little bit of a talk, a little bit of a smile, a little bit of a joke. That is part of the wonderful chain of lesbians caring for and loving one another. That is more important as you get older, it is very, very important. If older lesbians do not have the support we had, and if they are not going to speak up then they are going to lose a chance of having a wonderful life on their last years. If you don't talk up you die very lonely. You might have got some flack but who cares? You have to talk up, ask for help. If the worst comes to the worst, well you are not a murderer, you are not a thief, you are just a very great lesbian who loves women.

I Am Who I Say I Am

Précis from interviews with: a) Nancy, a 79 year old trans woman living in a Catholic Supported Accommodation Unit/Aged Care Hostel and b) Maggie a nurse who had been caring for Nancy for 15 years.

Nancy: Me name is Nancy, I was born a boy in 1928 and me parents called me Brian. I worked as a female impersonator with Les Girls and I went into the navy during the Second World War. In 1959 I had a sex change operation. I could only have the breasts done; they couldn't do the change below. I'm not a pure male any more; I'm a trans; both; fifty-fifty. Staff here know who I am.

Me life is hard. Its hard being in here. The people here are a lot of **bludgers**. I should keep away from them. That's why I never leave me room except for some meals. See! I've got me bags packed. I'm leavin'. They're not my kind of people, they're not sociable people. One of the other residents wants to flatten me because I'm a transsexual. Had I been a normal sex it would have been a different story then. People judge me because I've got a penis, I'm a transsexual. If I didn't have the penis, if I was a full female, then it would be a different story. They wouldn't know I was a transsexual then. Sometimes I don't want to funk' eat. Sometimes I feel like I wanna die. Me life's too fuckin hard.

Maggie: When I first met Nancy my heart went out to her. To me Nancy was Nancy. Sometimes she would pee standing up with the toilet door open and I would walk past and do a double take and then go: "Oh! That's right!" Nancy dressed very inappropriately when I first met her. The staff used to think it was funny when she walked out in a bikini with half her genitals falling out the bottom of her bikini pants. They thought it was funny to watch her get around like that. When I took over the place I fired the lot of them and helped Nancy to feminise herself. We were teaching her how to be feminine and she blossomed.

Nancy was married to Frank for 18 years. When Frank was dying they took him to hospital. Frank's family told Nancy that she couldn't visit him because it was 'family only'. Well that was the wrong thing to say to me, I said to Nancy: "You go upstairs, tidy yourself up, put a bit of lippy on and get your coat; I'm going to take you to the hospital. Nancy stayed with Frank for about an hour before he died, she was so happy.

I was at home the day after Frank died and the staff rang me to say that Frank's nephew had just arrived and was taking everything out of Frank and Nancy's bedroom. They were trying to take the rings off Nancy's fingers. I reckon I must have broken all the speed rules to get there. I went flying up the stairs and into the bedroom and I said to him: "Get out of here, before I ring the police; how **dare** you! She hasn't even had time to mourn and you're trying to wipe out every memory she's got. Get out of the building before I call the police."

Since Frank died Nancy has been lonely, she would talk to anybody and everybody. She is very vulnerable, especially now. The staff here are so great, we are all very protective of her. I try to teach my staff that what you see is what she is. Don't think that's Brian; that's Nancy. That's Nancy through and through and to you she is a woman. If you get that through to them there's no dramas after that. **She is a woman.** That's how I have always treated her.