

**DEMENTIA,
TRANSGENDER
AND INTERSEX
PEOPLE:**

**DO SERVICE
PROVIDERS
REALLY KNOW
WHAT THEIR
NEEDS ARE?**

**ALZHEIMER'S AUSTRALIA
AUGUST 2014**

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DISCLAIMER

The views expressed in this paper are the views of the author and not necessarily those of the organisation or the reviewers.

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Ms Tony Briffa

Vice President of Organisation Intersex International Australia (OII Australia) and Vice President of the Androgen Insensitivity Syndrome Support Group Australia (AISSGA)

Dr Gávi Ansara,

Manager, Policy and Research, National LGBTI Health Alliance

Ms Fiona Marriott

Project Coordinator, Better Practice Project, Aged & Community Services SA & NT Inc

Mr David Hockley

Clinical Consultant, Dementia Behaviour Management Advisory Service (DBMAS), Alzheimer's Australia South Australia

Alzheimer's Australia South Australia (AASA) LGBTI Dementia Project staff:

Liz Withall

Research Officer and author of the report

Rajiv Chand

Project Manager

Anne McKenzie

Project Coordinator

Kerry McKenzie

Training Officer

Funded by the Australian Government Department of Social Services. Visit www.dss.gov.au for more information.

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INTRODUCTION

In 2009 Alzheimer's Australia released a report it commissioned titled *Dementia, Lesbians and Gay Men*, prepared by Heather Birch. The aim of this current report, by reviewing the available literature, is to promote an informed discussion about the issues affecting transgender and intersex people with dementia or caring for someone with dementia. Many of the issues faced by transgender and intersex people will be the same as Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) people as a whole. However, do transgender and intersex people have unique needs and issues in ageing, particularly if they develop dementia? This report looks at the issues associated with accessing health or other aged care services and considers transgender and intersex people both as caregivers for those with dementia and as people with dementia. The report also aims to identify the gaps in knowledge of the needs of these communities and provide recommendations for the health professionals.

TERMINOLOGY

The importance of appropriate terminology is recognised. For the purpose of this report the 2012 National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy definitions will be adopted (see Glossary of Terms). These were developed in consultation with the National LGBTI Health Alliance Australia and through 15 community consultations.¹ However, it is acknowledged that the ways in which individuals identify is unique and one size does not fit all.

The distinction between sexuality and gender identity needs to be understood prior to reading this report as they are often misunderstood. Specifically, sexuality refers to the emotional, romantic, sexual or affection-related attraction towards others.¹ Gender identity on the other hand, relates to a person's sense of identity defined in relation to the social roles, attributes and behaviours typically ascribed by society to 'women' and 'men.'¹

Transgender and intersex are two distinct communities. Transgender is an umbrella term used to describe a diverse group of individuals who do not fit the usual culturally defined gender roles.¹

Intersex on the other hand is defined as the presence of intermediate or atypical combinations of physical features that are usually seen to distinguish female from male.¹ This may include variations in chromosomes, hormones, reproductive organs, genitals and other bodily features.¹ It is also important to understand that intersex is not about sexual orientation or gender identity, but about variations in biology that are present at birth or emerge during puberty.

DEMENTIA IN AUSTRALIA

Dementia is the third leading cause of death in Australia following heart disease and stroke, currently affecting 320,000 Australians.² Contrary to common belief it is not one specific disease; rather it is a term which describes a range of symptoms caused by disorders of the brain. It affects thinking, behaviour, memory and the ability to perform daily tasks.³ Dementia is progressive and will most likely result in the need for support services and ultimately full time care.²

Currently there is no prevention or cure³ and without a medical breakthrough the number of people with dementia is predicted to grow to 900,000 by 2050.² With this in mind, it is vital that we have an increased awareness of the impact of dementia and that persons with dementia, their family and carers have access to appropriate and timely support.

Dementia as with many other chronic illnesses does not discriminate in that it affects people irrespective of age, ethnicity and community, such as Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) people. Although dementia is not a normal part of ageing, it is more common amongst people aged 65 years and older.³ The LGBTI community make up a considerable proportion of the Australian population at an estimated 11% or 2,530,000 people.¹ By the year 2051⁴, it is expected that this will increase to 500,000 LGBTI people over the age of 65 years. Therefore the LGBTI community is a significant population that require support and access to appropriate dementia services.

TRANSGENDER AND INTERSEX COMMUNITIES

There are no reliable estimates of the actual prevalence of people who identify as transgender in the population. Available figures usually relate only to those people seeking some form of treatment or those seeking gender affirmation surgery to align their body with their gender identity. Therefore such figures are clearly an underestimate. One such commonly cited study from Sweden in the 1960's gives the figures of 1 in 30,000 men (males who have undergone gender affirmation surgery, or MtF), and 1 in 100,000 females (females who have undergone gender affirmation surgery, or FtM).⁵ A later review of these figures and a recalculation using the accumulating prevalence data in the literature indicated that the figures were indeed significantly underestimated. This later work cited a prevalence figure in the order of 1:500 males (MtF).⁵ A more recent study, found that 1.2% of high school students in New Zealand reported being transgender and a further 2.5% indicated that they were not sure about their gender.⁶ These numbers are also likely to be an underestimate as they do not include students who dropped out of high school due to gender-based bullying, and may also exclude transgender people who prefer to be identified as girls or boys rather than with the identity label of transgender.⁶

Precise estimates of people with intersex variation is also difficult to determine due to a lack of accurate data, differing medical views on what constitutes intersex and the fact that some intersex variations are not identifiable at birth. The most widely used prevalence figure for intersex is 1.7% which was derived from a review of medical literature by Fausto-Sterling.⁷ This figure is supported by the Organisation Intersex International Australia (OI).⁷

BRIEF HISTORY OF TRANSGENDER AND INTERSEX COMMUNITIES

The history of transgender and intersex communities is significant as elderly people from these communities will have been shaped by these experiences. Acknowledgement and understanding of these experiences is crucial, especially for those who are providing health care or care services

HISTORY OF TRANSGENDER

In our society many older transgender people have lived during a time when transgender was pathologised and considered a mental health disorder. The influential American Diagnostic and Statistical Manual of Mental Disorders (DSM), initially referred to it as 'transsexualism' and then later as 'gender identity disorder'. As a result it was not uncommon for transgender people to receive medical 'treatment' such as shock therapy or admission to psychiatric hospitals to 'cure' them.¹⁰ Consequently many people chose to remain quiet about their gender identity issues for fear of the ramifications. They may also have been reluctant to seek medical treatment or care of any kind for fear of further discrimination.¹⁰

I knew I was different... but the social climate was totally against it. If you came out and said that to somebody, or your parents, they would have put me in a psychiatric hospital and given me electric shock treatments - Trans woman⁸

In the 2013 edition of the DSM (referred to as the DSM 5) there has finally been a positive move away from this medical model. Gender identity disorder has been replaced by the term gender dysphoria. The word dysphoria can be defined as discomfort. Gender dysphoria is described as the clinical level of distress and discomfort people feel when their sense of their own gender does not match their birth assigned sex. So it is the clinical level of distress and not being transgender that is now a mental health issue. Whilst this shift has been welcomed by many people, the fact that it is still in the DSM means that transgender issues are still considered mental health disorders.⁹

In their lifetime, many transgender people will seek to express their gender. This is called 'transitioning' (or 'gender affirmation').

I'd gotten to the point in my life where I felt like the path I was going down was spinning wildly around in ever-decreasing circles, finally to disappear. I had to do something or die

Transitioning (or gender affirmation) is a process that involves the permanent and public adoption of the style and presentation usually of a gender that varies from that of a person's birth-assigned sex.¹ The process can take several years. It can include a change of name and personal pronouns, as well as adopting the dress and style of presentation of a person's innate gender. It can also include permanent body changes. Gender affirming hormones and surgical intervention can be used to make these changes.¹¹ Other cosmetic procedures such as hair removal, breast implants, facial feminisation and tracheal shave can be sought to assist in body changes to enhance gender identity.¹⁰

In order to receive medical assistance transgender people often face a lengthy process in which they may deal with a range of medical practitioners, a process which can be intimidating. In Australia, the World Professional Association for Transgender Health (WPATH) Standards of Care (SOC) are commonly used

by physicians assisting with medical transition, although there is no formal requirement to use one particular standard. To access hormones or surgical assistance, a person may be required to seek referral letters supporting the diagnosis of gender dysphoria and the need for medical intervention. For genital surgeries (such as vaginoplasty in MtF, and metioplasty or phalloplasty in FtM) the SOC include criteria such as hormone therapy and living in the gender role congruent with gender for a period of time prior to surgery. An individualised approach to care is promoted in the SOC and as such the requirement to fulfil criteria may vary amongst clients.¹²

BRIEF HISTORY OF INTERSEX

Intersex people, particularly those that are older, have had their bodies and natural variations pathologised. Historically the term hermaphrodite was used to refer to intersex people. This term carries with it a stigma and can be dehumanising.¹³ Whilst 'intersex' is the commonly preferred term by intersex organisations, many medical practitioners use the term 'Disorders of Sexual Development' (DSD). This terminology implies that intersex is a 'disorder' rather than variations in nature.¹⁴

There are many different types of intersex variations. However there are only a few situations in which medical intervention is actually required. For example to create a functioning urinary system or to manage an increased risk of cancer (however some people believe that the risk of cancer has been inflated and led to unnecessary surgeries).¹⁵ Predominantly, however, surgical intervention for people with intersex variations has been and continues to be for cosmetic reasons. Specifically, 'normalising' surgical procedures are performed to make a baby's genitals appear more 'normal' or in line with the binary system (that is, clearly male or female), or to remove healthy testes from infants, girls and women with Androgen Insensitivity Syndrome.

There was no medical problem with my clitoris, no disease, just an offence to somebody else. That was their problem, but I got to have my sexual part sliced up. It really stinks - Intersex person¹⁵

From the 1950s, it became widespread for surgeons to perform 'normalising' procedures on infants with ambiguous genitals.¹⁶ This medical response originated from the work of psychologist John Money. He developed the model of 'optimum gender rearing' which assumed that children are born without a gender identity. This model proposed that if a child's genitals are made to look a certain way, and they are raised accordingly that they will adopt that gender identity.¹⁶ So if the genitals are made to look female and the child is raised female, they will see themselves as a female, and vice versa.

BRIEF HISTORY OF TRANSGENDER AND INTERSEX COMMUNITIES

[CONTINUED]

There is substantial evidence to suggest that people who were subjected to the 'optimum gender rearing model' experienced psychological and physical harm.^{14, 16} Firstly, there can be surgical complications and the need for further surgeries. There can also be infertility, incontinence and reduced sexual function and genital sensation. Psychologically, the non-disclosure or secrecy of their variations by medical practitioners and even parents can create distrust and feelings that their body was not accepted the way it was. Issues such as depression and anxiety may also arise.

The lies and deception that have occurred throughout my life have taken their toll on me, making me very insecure and unwilling to trust people especially those close to me.
- Intersex person¹⁶

Intersex advocacy groups worldwide (such as the Androgen Insensitivity Syndrome Support Group Australia and Organisation Intersex International Australia) and some medical practitioners now argue that any intervention other than what is medically required to maintain health should be delayed until the child can give consent.^{14, 15, 18} However, despite this growing view, clinical practices in regard to intersex do not appear to have changed.¹⁷

For people born with intersex variations in a time when medical intervention is swiftly applied, the physical, psychological and social ramifications of such intervention need to be understood by care providers and health professionals.

AGEING ISSUES FOR TRANSGENDER AND INTERSEX COMMUNITIES

Transgender and intersex people share many of the same concerns of ageing as the wider population, and indeed with the LGBTI community generally.¹⁹ However there are some unique factors that should be considered.^{20, 21}

HEALTH AND WELLBEING

Health disparities between transgender and intersex people and the wider population have been identified.⁴ Specifically, surveys reveal lower rates of general health in transgender, and intersex communities than the wider population.²² Obesity, asthma and certain cancers have been identified as chronic health issues that affect the transgender community.^{4, 22} Mental health issues such as depression and anxiety are also dominant concerns for both transgender and intersex communities.²²⁻²⁶ These issues are believed to stem from the marginalisation and discrimination transgender and intersex people endure.^{1, 22, 24} Furthermore, LGBTI communities overall have the highest rate of suicide amongst the Australian population¹, and also internationally.²⁴⁻²⁶

LONG-TERM HORMONE THERAPY

Hormone therapy may be used by transgender people as part of their transition to maintain physical changes and support their emotional and psychological wellbeing.²⁷ Gender affirming hormones such as testosterone and oestrogen are important for bone strength.²⁸ This means that for transgender people who have undergone gender affirming surgeries²⁸, and for intersex people who were born without functioning ovaries or testes; or those who have had them removed, hormone replacement is required to maintain good health.²⁹ Long periods without hormones can decrease the level of sex hormones and consequently increase the risk of osteoporosis.²⁸ Furthermore sudden cessation of hormones can increase depression and in some cases suicidal feelings in transgender people.³¹ This can be an issue when transgender or intersex people are admitted to hospital or move into residential care.

CASE STUDY:

Shelly, a trans woman has recently moved into a residential care facility. She has been on gender affirming hormones for decades. Since moving into residential care she has not received her hormones. Staff have noticed that Shelly has become depressed and withdrawn and she has begun saying that she wants to end her life.

However, long-term use of hormones is also believed to increase the risk of other diseases such as cancer and cardiovascular disease.³⁰ Therefore this should be considered as part of care of intersex and transgender people.

PREVENTATIVE HEALTH CARE

Preventative health care is an important part of healthy ageing for transgender and intersex people as with the wider population.³² Trans men using hormone therapy who have not had a complete hysterectomy are at increased risk of endometrial and ovarian cancer.³³ Therefore screening for cervical cancer remains important.^{32, 34, 35} Similarly, for trans women, screening for breast and prostate cancer is recommended.^{32, 34}

Another consideration for preventative health care amongst transgender people may be breast implants that were carried out or performed as part of their transition. It has been found that breast implants generally have a 'life' of between 8-10 years and the longer they have been implanted the greater the risk of rupture.³⁶ Whilst studies do not suggest that there is an increased risk of cancer if implants rupture, a rupture can cause considerable pain and discomfort and it may be advised that implants are removed or replaced.³⁷ Implants may also impede the image clarity of mammogram procedures, so an alternative procedure to a mammogram may be required for people with implants, especially when there are concerns for breast cancer.³⁸

For trans men, top surgeries that involve removal of breast tissue (different from mastectomies performed for breast cancer treatment) can help affirm their gender. Whilst there is a reduction in the risk of breast cancer following surgery, screening is still recommended as the risk of cancer still remains.³²

Intersex people also require preventative health screenings especially when they have an increased risk of disease.²⁶ This is often difficult for intersex people, who have negative feelings about accessing medical treatment as a result of the inappropriate medical treatment they experienced in childhood, including repeated genital examinations, medical photography, and non-consensual surgeries.

Health professionals' understanding of how to identify and treat transgender and intersex medical problems is crucial to ensure that health concerns are not overlooked.³⁹

The discomfort of treatment and expectation of discrimination can mean that routine screening and preventative health care are avoided by transgender and intersex people over their lifetime.^{26,40} Consequently people may have undiagnosed pre-existing medical conditions upon accessing care, which can be problematic.

CASE STUDY:

An elderly post operative trans man who was a resident at an aged care facility died of ovarian cancer because it was not identified in the early stages.

PERSONAL CARE ISSUES

There will often come a point, especially if someone is diagnosed with dementia, that assistance with activities of daily living will be required. This care is likely to include assistance with showering, dressing and grooming, as it would for anyone needing assistance. However, for transgender people and intersex people there are some particular issues with this aspect of care. Transgender and intersex people may be especially wary of having their body viewed by others. So receiving personal care may be very threatening. Specifically, a transgender person who dresses and grooms themselves in accordance with their gender identity may only have had some gender affirmation surgery or none at all. This can mean that gender presentation and genitals may appear mismatched to those who have assumptions about which bodies 'belong' with which genders. Consequently carers

may not provide appropriate personal care for their client. For example a transgender resident may not be dressed in the appropriate clothes. This could also be problematic for intersex clients who may prefer to be dressed in a way which does not align with a single gender or with their genitals. In the absence of culturally appropriate training which challenges assumptions and increases awareness of transgender people and intersex people's needs, there is the risk that personal care will not be appropriate and respectful, especially if the client's capacity is declining.

Other unique forms of personal care may also be required. Transgender people who have undergone surgical treatment to assist with gender affirmation may need to undertake daily maintenance practices to keep the post surgical area healthy and functioning. For example, trans women who have undergone a procedure to create a vagina (known as vaginoplasty) require regular dilation to maintain the opening.³⁴

Furthermore in the case of dementia, people progressively lose their most recent memories. For a transgender person this could mean only remembering living in another gender, including not remembering having had gender affirmation procedures or surgery. Similarly, an intersex person might be back in their childhood during which they were receiving difficult medical interventions and examinations. These memories may be particularly distressing or challenging.

The particular personal care needs of clients such as transgender and intersex people should to be incorporated into care plans. Staff development training including cultural awareness may be required to ensure their needs are met in a respectful way.

ADVANCED CARE PLANNING

Advance care planning (including Advanced Care Directive, Enduring Power of Attorney and Enduring Power of Guardianship or Medical Power of Attorney) is important as we age. However, formalising these wishes may be even more significant for transgender and intersex people.³⁵

A real concern of many transgender people is that they will be misgendered in the event that they become reliant on others for care, especially if those carers have not been accepting of their gender identity or are uninformed about such matters. They may even fear that on death they will be buried with the wrong gender or name.

CASE STUDY:

Dave, an 80 year old trans man, had undergone some gender affirmation surgery in his sixties and lived as a man. Dave's husband and two adult daughters did not approve and gradually stopped all contact. Over the last few years, Dave's health declined, and eventually he passed away from pneumonia. Dave had a small social network and his daughters were his next of kin. They were responsible for making funeral arrangements and decided to bury him as Lucy and their mother rather than acknowledge his gender affirmation.

AGEING ISSUES FOR TRANSGENDER AND INTERSEX COMMUNITIES

[CONTINUED]

Transgender older people who are partnered or rely on a network of close friends may fear also that those people will be excluded from the care process because they are not seen as 'next of kin'.³⁵

It is important to note, too, in this context, that older transgender and intersex people are more likely not to have children or supportive family members to care for them in a health crisis.

In each of these cases, having an advanced health care directive would help address the fears and concerns.

The literature suggests that a large proportion of people from transgender communities have not put advanced care planning into place.⁵² This may also be the case for intersex communities although there is a gap in information within the literature.

For similar reasons it is important that transgender and intersex people have in place a Will which clearly outlines how the person wishes to divide their estate to ensure the individuals who are significant in their lives are provided for.⁴¹

EXPERIENCE OF DISCRIMINATION

Discrimination is a significant issue that transgender and intersex people face. For older transgender and intersex people in particular, discrimination is something that is likely to have affected many different facets of their lives such as employment and finances, social networks, personal and family relationships, and health.

Many transgender people will have experienced difficulty getting and keeping employment throughout their lives because they are transgender. People transitioning have often had to leave employment to do so. Having transitioned, they may find employment again but not be able to refer to past employment experience without revealing that they are transgender.^{21,27,42} Therefore they are less likely to be secure financially and may be more reliant on health and welfare services in retirement and ageing.

In relation to personal and social networks, transgender people often lose family and friends because their family members or friends are not able to deal with their gender affirmation.^{20,36} Family dynamics can be strained as a consequence of early medical intervention for intersex people, especially if there has been deception from family members (not revealing the person has an intersex variation).¹⁶ Social networks become particularly important as people age and for transgender and intersex people these may be limited too.

Significant rates of discrimination (such as verbal abuse, harassment and threats of violence) have been reported in surveys with transgender populations.^{22,44} In some cases threats of violence have actually eventuated into physical abuse.⁴⁵ Consequently, some elders have reported that they modify their behaviours for fear of discrimination if their identity is discovered.²² Furthermore, institutionalised discrimination in the form of structural violence in health care may be an issue. Structural violence occurs when societal structures are integrated into organisations that then deny people's basic needs. For example, a health care service that does not accommodate those who may be outside of the gender binary (male or female). Ansara⁴⁶ describes a case study of a transgender person who was unable to receive a required medical screening procedure whilst their medical record listed them as male because the 'system wouldn't allow it.' Consequently, this patient's information had to be changed to "female" – thereby misgendering the patient to allow for the procedure to take place.

Historically transgender and intersex people have been pathologised. While there has been movement to redress this, the prevailing paradigms are still linked to the medical model and to the notions of disorders and not difference, variation or diversity. Moreover the attitudes of the community at large to transgender and intersex people still reflect these pathologising attitudes. Being able to access appropriate health care from health care providers that are knowledgeable and sensitive of the needs of transgender and intersex people can be a challenge.²⁵ Often transgender and intersex people find themselves in the role of having to educate the care providers.

The author of this report would also like to acknowledge that during the development of this paper, research led by Dr Catherine Barrett (Val's Cafe at the Australian Research Centre in Sex, Health & Society, La Trobe University) into understanding and meeting the needs of older intersex and transgender people commenced. No results were available for inclusion in this report.

For further information about this study readers are encouraged to visit www.valscafe.org.au or contact Dr Barrett: c.barrett@labrobe.edu.au.

TRANSGENDER AND INTERSEX PEOPLE AND DEMENTIA

Review of various databases including PubMed, Medline, Sociological Abstracts, Web of Science and various grey literature sources revealed very limited results on the topic of dementia and transgender and intersex people. The minimal literature identified centred around the fears of transgender people in developing dementia. No literature was available on intersex people specifically.

In one study respondents who identified themselves as transsexuals reported being more concerned about developing dementia if they had a chronic illness.⁴⁷ The authors of the study offer an explanation that those identifying as transgender are already dealing with stigma and may be increasingly concerned about the possibility of developing dementia and having to deal with an additional source of stigma (i.e. the stigma that surrounds dementia). Participant's fears in relation to the development of dementia were centred around discrimination (including a lack of respect and marginalisation), being 'outed', and "not being able to find an accepting 'senior facility.'"

I have realistic concerns that I will not be treated as I would like when I am dependent on others⁴⁷

I worry that people will attempt to force me into being the wrong gender⁴⁷

In a large transgender ageing study reported in Witten⁴⁸, fears about dementia were commonly from people who had feminine gender perceptions, although they were also observed in transgender people with masculine presentation.

I am worried that I will develop dementia and will not be able to support myself and that there will be no one to take care of me. I am already becoming so forgetful and unable to concentrate at 55 yo that I worry that I will not be able to hold or keep a job at some point within the next five years or longer. I worry that I will not have the resolve to kill myself when I cannot support myself any longer.⁴⁸

Even among service providers, dementia was observed as a significant end of life care concern for transgender people. Specifically, in a qualitative study⁴⁹, service providers raised issues such as a lack of recognition of chosen gender identity and the humiliation some people feel in having to disclose that they are transgender in order to receive appropriate care.

CASE STUDY:

Pauline has lived most of her life as a woman, despite never having gender confirmation surgery. Now with dementia and living in an aged care facility, staff forced her to live as a man. – Service provider recalling story.⁴⁹

Further qualitative investigation, which included a transsexual woman respondent, highlighted the impact that dementia has on LGBTI seniors overall.⁵⁰

Issues identified included:

- The need for recognition that their experience of grief and loss was no different to that of others who have a family or partner with dementia
- Concerns regarding the disinhibition of co-residents with dementia who may make abusive or discriminatory comments
- Concerns the LGBTI person themselves with dementia may become disinhibited and consequently 'out' themselves or their partner.⁵⁰

While this research is not specific to transgender or intersex people it may be a starting point for future research into the impact of dementia on transgender and intersex communities.

To enrich this report, the author invited transgender and intersex people via intersex and transgender networks to share their experiences or concerns of ageing in the context of dementia. One transgender and one intersex person took up this offer.

There were some key concerns identified by both respondents including: the loss of control of who knew their intersex or transgender status, the lack of family to act as carers, and concerns that care staff will lack understanding and awareness of intersex and transgender people.

Some other unique concerns were also identified by the respondents. For the intersex respondent, the impact of the negative childhood experiences in relation to medical 'treatment' added to a fear of developing dementia for them:

Given my intersex variation, I am concerned I will be treated like a medical curiosity because of my intersex variation and not be able to do anything about it. I was treated that way when I was a child so I have already experienced what it's like to be spoken about as if I was not in the room, to be paraded in front of student doctors, to be prodded and poked for no medical reason, etc. I was not able to defend myself when I was a child and I will not be able to defend myself if that happens in dementia. - Intersex respondent

The transgender respondent discussed her concerns regarding how hormone therapies would be managed and about the loss of access to a trans community. Furthermore she explained that trans support groups predominantly focus on transition (such as hormones and surgeries), however do not include issues regarding physical care and support.

The importance of dignity and respect were also echoed throughout the respondents' communications, such as the excerpt below:

I am concerned about what help and support I will get when I am unable to make decisions for myself. I think I would rather die than to live without dignity or respect. I am scared about my future and quality of life if I get dementia. - Intersex respondent

TRANSGENDER AND INTERSEX PEOPLE AND DEMENTIA [CONTINUED]

Obviously further research is required to expand on these communications and provide data that is representative of the wider intersex and transgender populations. However these personal communications highlight potential areas of concern about the development of dementia by intersex and transgender people.

TRANSGENDER AND INTERSEX: CARE-GIVING AND CARE RECEIVING

There were an estimated 200,000 informal carers (family and friends) for people with dementia in the community in 2011.² Informal carers are important especially as the rate of dementia increases and demand for services grow.² It is likely that some of these carers are transgender or intersex people. However, currently this data is not recorded.

Minimal literature was identified specifically regarding care-giving by transgender and intersex for people with dementia. However there were key characteristics identified regarding Lesbian, Gay, Bisexual and Transgender (LGBT) communities with respect to the care giving role and as receivers of care. Intersex people were not generally represented within the literature, so it cannot be assumed that findings can be generalised to the intersex community without studies confirming that this is the case.

CARE-GIVERS

There is evidence to suggest that LGBT people play an important and unique role in care giving.^{51,52} Several surveys have identified that LGBT people are carers for both family of origin and 'family of choice'^{51,53,54} and in some situations, act as a dual carer (providing care concurrently to a member of their family of origin and a member of their family of choice).⁵² A family of choice is a series of supportive relationships that can be likened to that of biological family. Care for members of a family of choice is especially important in the case where there is no other support network and no appropriate services available or accessible.⁵⁵⁻⁵⁷ Also unique to LGBT carers is that unlike the general population where women have been found to be the major care providers², within the LGBT community it has been identified that males are just as likely as females to provide informal care.⁵⁶

The issues faced specifically by transgender and intersex people who act as carers have received little attention in the literature. However, those faced by LGBT carers include unhelpful assumptions, family tensions, discrimination and a lack of support services.

The assumption is often made that carers are heterosexual and from a family with a traditional structure. Heteronormativity is defined by the Oxford dictionary as 'denoting or relating to a world view that promotes heterosexuality as the normal or preferred sexual orientation.' Many carer support services are developed under heteronormative assumptions, which means that these services may be less relevant for LGBTI carers.⁵⁵ The lack of appropriate carer support further contributes to stress of carers who may already be experiencing financial, physical and emotional pressures.^{2,58}

Another issue identified in the literature as a concern for LGBT carers is tensions within family dynamics. For example, it may be assumed by family members of a LGBT person that they are 'single' and are therefore able to manage the bulk of caring duties.⁵⁹ This fails to acknowledge the importance of partnerships (which may not be legally recognised) that the LGBT person has and their role within a family that is not considered traditional such as a family of choice. This is supported in a survey of LGBT older adults in which a third of 350 participants reported that their families had greater expectations of their care-giving responsibilities due to their LGBT status and the assumption that they had fewer other family responsibilities.⁵⁶ Intersex people were not represented in this literature.

Also of concern for LGBT carers (outlined in existing literature) is that they may be asked to provide care to a family member who has not been accepting of their gender identity. This means that they may be forced to bear ongoing abuse and discrimination from those they care for and also perhaps other family members.⁵⁶ An LGBT person who is caring for their partner, may also face exclusion from decision making over formal care and end-of-life arrangements by their partner's biological family.^{21,56} No literature in relation to these issues on intersex people were found.

A further concern identified in the literature is the discrimination that LGBT carers experience when accessing residential care, medical services and other health and aged care services.^{59,60} Consequently the literature suggests that many LGBT carers may be reluctant or put off seeking support services.⁵⁹ This reluctance could be due to fear that there will be a poorer quality of services or that they will be denied services.⁵¹ Australian and international literature from Canada and the United States indicates that LGBT adults believe that they will not be welcomed or receive high quality of services if their gender identity or sexual orientation were known.^{33,61,62} The literature also suggests that even amongst service providers there is uncertainty as to whether LGBT clients would receive appropriate care.⁶³ No research was identified on intersex people as caregivers.

CARE RECIPIENTS

The progressive and terminal nature of dementia means that those with the diagnosis will ultimately become reliant on others for assistance. The literature does not include experiences of dementia from transgender and intersex people. However, in a wider sense there is limited information about LGBT people as recipients of care in general. Again, intersex people are predominantly left out of existing research.

The most recent Australian data available regarding carers for those with dementia highlights that it is commonly partners or children who act as the primary carers for people with dementia living in the community.² Whilst this data does not specifically include transgender and intersex populations, it is recognised in the literature that LGBT older people are about two and a half times less likely to have children; or a partner or spouse.^{51,52} Many people with intersex variations, especially those that received 'normalising' treatments are likely to be sterile and consequently not have biological children to provide assistance. This reality of being alone is echoed in personal communications that the author had with a transgender person and an intersex person, who made the following comments:

Infertility is an issue for most intersex people so we are often alone and don't have support from children
- Intersex respondent

Many Trans people I know have lost considerable support amongst family members. The very people – children, siblings, for instance – that aged people tend to rely on, aren't there for many Trans people. Those Trans people who never had children – and there are many – are at real risk of having no one to care for them, except for Trans friends or neighbours as they become frail and aged.
- Transgender respondent

Furthermore an Australian study found that members of LGBTI communities were twice as likely as those not from the LGBTI community to have no contact with family or have no family to rely on for serious health problems.⁶⁴ Families of choice may offer care-giving as has been identified with surveys of LGBT participants.⁶⁵ However little is known about care-giving in dementia in these situations.

FORMAL CARE

In Australia, approximately 53% of people living in permanent residential care facilities have received a diagnosis of dementia, and the majority of people living with dementia in the community (77%) need to access some level of formal services for assistance.² The main areas of support required include assistance with mobility and self care (including personal hygiene and grooming).² The literature regarding transgender and intersex people suggests that there is reluctance on their part to access needed health care and services for fear of discrimination.⁶⁵⁻⁶⁸ Furthermore given the personal nature of care commonly required it is likely that their transgender or intersex status will be discovered, and this may be another factor in the reticence to seek help. As discussed in the excerpt below:

*We most likely come to all care situations with our differences a deeply held secret. For those of us who have bodies that are unmistakably intersex the protocols and types of care provided, showering, medication, and so on, will, in all probability, "out" us.*⁶⁸

Transgender and intersex people may feel that this 'outing' leaves them vulnerable to abuse and discrimination. Another important factor is that the majority of service providers will have had little exposure to transgender and intersex people (or LGBTI people generally) and so have little understanding of their difficult history or unique needs. This can leave the care recipient vulnerable to mistreatment, as is suggested in the literature.^{48, 66-69} It is also well documented in the literature how older transgender people have been subject to a range of forms of discrimination,⁶⁹ including denial of service in some cases.^{21,65}

The literature includes several studies which highlight the concerns of transgender people becoming receivers of care (particularly formal residential care).⁴⁸ Overwhelmingly, transgender respondents in these studies are adamant that they do not want to go into residential care facilities. Whilst this is likely to be a shared concern with the wider population, these studies revealed that transgender respondents would rather end their life than become a residential care recipient:

*The day I need a caregiver, I will implement my end of life suicide plan.*⁴⁸

*I plan on committing suicide at 60 or earlier.*⁴⁸

Clearly greater awareness of transgender and intersex peoples' needs and improvement to services are required to alter the consideration of ending life as a better option than receiving care.

GAPS AND IMPLICATIONS FOR RESEARCH

The aim of compiling this report was to provide a starting point for discussions regarding the needs of transgender and intersex people in relation to ageing and dementia, in particular. What is clear is that there are significant gaps in knowledge that require further investigation to improve understanding about the needs of transgender and intersex people in relation to healthy ageing overall, and particularly in relation to dementia as it is such a significant health issue in Australia.

There is evidence to suggest that transgender people have poorer health outcomes compared with the wider population which for the main part, can be linked to marginalisation and victimisation (including violence and discrimination). For intersex people, unwanted or coerced medical intervention is linked to poor health. However the inclusion of transgender and intersex people in larger health population surveys, and further research in general, is needed to provide more information about the health and wellbeing needs and the priority areas for these communities.

Further investigation specifically into the cohort of intersex people and ageing is of particular importance as there is limited existing literature on this topic. Research led by researcher Dr Barrett at La Trobe University is currently underway to explore the needs of older transgender and intersex people which will contribute to a much needed knowledge bank on the needs of these communities.

Currently dementia is the third leading cause of death in Australia, yet we know so little about how it affects minority groups such as transgender and intersex people who are vulnerable to poor health outcomes. Inclusion of transgender and intersex people in national dementia data collection would assist in understanding how this chronic illness impacts on these communities.

The literature suggests that transgender and intersex people may play a unique role in providing care supporting not only members of their family of origin but also potentially families of choice. Research into how these communities provide care for people with dementia as well as both the enablers and barriers to accessing support services would be beneficial to improve and extend services for these carers. This is significant given that providing care for those with dementia is known to be one of the most taxing caring roles.²

The literature in relation to dementia predominately focuses on the fears transgender people have in developing dementia, whilst intersex people have not generally been represented in this literature at all. Further investigation is needed to explore their experiences of dementia both as carers and care recipients, to create a greater understanding of the key issues.

Finally, investigation into service providers' awareness and understanding of the health needs of transgender and intersex people as well as how to provide culturally safe and inclusive care for transgender and intersex people is pivotal to achieving a partnership approach towards better care and better outcomes.

LIMITATIONS

As this review identified, research on transgender and intersex people, ageing and dementia is sparse, and in the case of intersex people, virtually non-existent. Some of the reasons for this are outlined below.

Understandably, as a consequence of the stigma and discrimination that many older transgender and intersex people have faced they are likely to be reluctant to raise their hand to offer to participate in research. This must be particularly so for many intersex people who have spent years of their life being regarded as a medical curiosity and made to undergo medical tests and examinations during childhood, usually without their consent. Similarly, the culture of secrecy around intersex births may have contributed to this lack of research.

Although some transgender people identify as transgender, many view themselves simply as women and men, regardless of whether they have affirmed this gender identity socially, legally, and/or medically. Many such people view 'transgender' as an experience and not as a label with which they would self-identify. This has implications for research into transgender populations.

Furthermore it has to be acknowledged that there is stigma associated with dementia and so people who are already experiencing stigmatisation may be reluctant to want to contribute their experiences.

Notwithstanding these considerations that may have posed challenges for researchers, have researchers not been drawn to this area because it is such a small minority group? Or indeed is the absence of research another form of discrimination?

Considering the literature that was identified as part of this report, there are some methodological limitations that should be recognised. Specifically much of the literature involved studies with small sample sizes and self-selected recruitment of people to those studies. Both these factors have implications on generalising the results to wider populations. At the same time it is acknowledged that providing a representative sample, would have been particularly challenging given that accurate figures of people within these communities are not known, compounded by the fact that not everyone is willing to disclose their identity or intersex status. The differences in how researchers define sex, gender and intersex status makes it difficult to compare the results of different studies too. The validity of survey tools also needs to be considered, especially when completed by a diverse range of participants.

Qualitative investigations such as those using semi-structured interviews, identified within the literature review are not representative of the wider population and therefore cannot be generalised. However they do provide a starting point for further investigations into the experiences people may have.

Whilst studies often use the acronym LGBTI (or variations) when describing their samples, transgender and intersex people often only made up a few of the participants (or sometimes none at all) in such samples. In some cases despite contributing to the original sample, they were not always included in data because they were so few in number. Caution should be taken with extending findings of such studies to transgender and intersex people. Studies including transgender and intersex participants are required to confirm these results. Despite the limitations of the literature identified in this review, it provides a starting point for further discussions and research to investigate issues that may still be known in relation to these communities.

RECOMMENDATIONS

The 2012 National LGBTI Ageing and Aged Care Strategy (the Strategy) has identified that LGBTI ageing is a priority area that requires attention to better support the needs of people from these communities.

This literature review has revealed the importance of further research into the needs of transgender and particularly intersex people as they age, especially in the context of dementia. The following recommendations focus on increased sector support, research and development to a) increase community awareness, b) better support the individual needs of transgender and intersex ageing community and c) develop a more comprehensive and meaningful bank of contemporary research.

- National data collection into population health and also dementia should include transgender and intersex communities as a means to create a nation-wide picture of health for these communities, their current utilisation of services, and how this can be improved. This is significant as the literature alarmingly indicates that there are many people who consider ending their life the better option than receiving residential care.
- Changes in legislation namely the *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013* mean that it is now unlawful for Commonwealth-funded aged care providers to refuse to provide services to a person due to their sexual orientation, gender identity or intersex status. This is a step in the right direction.
- Service providers need resources and information to optimise culturally appropriate and inclusive care for transgender and intersex people. Cultural awareness training for service providers is also required to improve the understanding of LGBTI clients and how appropriate and respectful care can be provided. The author notes that Alzheimer's Australia in South Australia is now rolling out such training and that the National LGBTI Health Alliance has secured federal government funding to develop and roll out LGBTI awareness training nationally. Furthermore, Victorian based Val's Cafe (La Trobe University) has also developed a program designed specifically for the aged care sector on LGBTI inclusiveness called How2 Aged Care. They have already begun to encourage the take up of this program in other states. These are great initiatives but they do rely on health and aged care workers volunteering to do the training. A shift towards an accreditation model whereby some form of approved LGBTI awareness training was mandatory for all health and aged care workers may be the next necessary step to ensure LGBTI people have access to culturally safe and inclusive care.

CONCLUSION

Dementia is fast becoming one of the biggest health burdens in Australia, and internationally. The greater the awareness and understanding of the people it affects and their needs, the more responsive services can be until a cure is found.

Transgender and intersex (especially intersex) people have largely been invisible within the research literature generally not only in relation to dementia. Yet it is well documented that the experience of stigmatisation and discrimination many transgender and intersex people, indeed all LGBTI people, have encountered during their lives has long lasting effects on their health and wellbeing and often fosters a reluctance to access health or aged care support services for fear of being identified as transgender or intersex and facing further discrimination.

There is limited understanding of how transgender and intersex people are affected by dementia. The minimal evidence and anecdotes available suggest that transgender and intersex people may fear developing dementia, especially in the event that a family member has received the diagnosis.

The 2012 National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy and the 2013 amendments to the *Sex Discrimination Act (1984)* legislation are steps in the right direction. However, further exploration of transgender and intersex peoples' needs is needed. Equally important, is the need for up-skilling of service providers and health professionals in relation to these two communities.

Dementia, transgender and intersex people: do service providers really know what their needs are? There is a long way to go, but slowly things are moving in the right direction.

WHERE TO GET HELP

ALZHEIMER'S AUSTRALIA

The national peak body providing support and advocacy for Australians living with dementia, their families and carers and provides leadership in policy and services.

For more information regarding services or assistance call the National Dementia Helpline on:

1800 100 500

or look at the website:

www.fightdementia.org.au

START2TALK

Start2Talk is a new website which is funded and administered by Alzheimer's Australia to help people plan ahead for their future financial and healthcare decisions, or help others. Registration and access to the website is free and includes access to information, worksheets and planning tools. It is available in a range of languages.

Visit the website at: www.start2talk.org.au

USEFUL COMMUNITY ORGANISATIONS

AUSTRALIAN CAPITAL TERRITORY

A GENDER AGENDA (AGA)

Website: genderrights.org.au/

AGA is a community organisation which is increasing public awareness and understanding of sex and gender diversity issues. It provides advocacy and support services, information and resources as well as being engaged in human rights and law reform.

Contact: (02) 6162 1924

NEW SOUTH WALES

ACON

Website: www.acon.org.au

ACON (Aids Council of NSW) is a community-based organisation which promotes the health and wellbeing of the LGBTI community as well as supports people at risk or affected by HIV. ACON also provides health promotion, support services, policy and development and program delivery.

Contact: (02) 9206 2000

Email: acon@acon.org.au

THE GENDER CENTRE

Website: www.gendercentre.org.au

Sydney-based organisation offering a wide range of services and information to people with gender issues, their partners, families and friends.

Contact: (02) 9569 2366

Email: gendercentre@bigpond.com

QUEENSLAND

ATSAQ

Website: www.atsaq.com/new-index.html

ATSAQ (Australian Transgender Support Association Queensland Inc) is a non-for-profit, non-government funded organisation that aims to advise and assist the transgender community in Queensland. ATSAQ provides support for transgender individuals and their friends and family.

Contact: (07) 3843 5024

Email: atsaq.inc@gmail.com

SOUTH AUSTRALIA

ALZHEIMER'S AUSTRALIA SA INC. (AASA)

AASA has developed a cultural competence training programme for staff in health and aged care services as part of the AASA LGBTI Dementia Project, funded by the Department of Health and Ageing.

Contact: (08) 8372 2100

Email: sa.lgbti@alzheimers.org.au

CARROUSEL CLUB OF SA INC.

Carrousel is a social club for transgender people, their partners and families and interested professionals.

Contact: 0415 511 970

Email: carrouselclub@hotmail.com

CHAMELEONS

Based at the Positive Living Centre 16 Malwa St, Glandore, South Australia, Chameleons is an information and support service for transgender people and their families – in relation to health, HIV/AIDS education, personal care and social activities. It includes an after hours contact for emergencies.

Contact: (08) 8293 3700 or after hours (08) 8346 2516

GENDER DIVERSITY ALLIANCE OF SOUTH AUSTRALIA (GENDASA)

GenDASA is a community organisation founded to improve the living conditions of people whose gender identity/expression is different from that assigned at birth, and their friends, partners, parents and family.

Email: gendasa@gmail.com

SOUTH AUSTRALIAN IDENTITY SUPPORT ORGANISATION (SAISO)

Website: www.saiso.org.au

SAISO is an organisation to support all sexual and gender diverse people.

Contact: email via the website

TASMANIA

WORKING IT OUT (WIO)

Website: www.workingitout.org.au

WIO is an organisation funded by the Tasmanian Government which provides services designed to meet the needs of people negotiating their sexuality and/or gender identity and intersex status through individual counselling and/or support and support groups.

Contact: (03) 6231 1200

Email: info@workingitout.org.au

VICTORIA

TRANSGENDER VICTORIA (TGV)

Website: www.transgendervictoria.com/

Transgender Victoria aims to achieve justice, equity and quality health and community service provision for transgender people, their partners, families and friends. TGV educates organisations and workplaces on how to provide better services for trans* people, and seeks ways to provide direct services to the trans* community, whether in partnership with others or independently.

Contact: (03) 9517 6613 (voicemail)

Email: direct via the website

ZOE BELLE GENDER CENTRE (ZBGC)

Website: www.gendercentre.com/

Gender centre that works to address inequities of health and wellbeing of sex/ and or gender diverse people in Victoria. This includes advocating and educating issues of gender diversity and providing support, information and referrals.

Email: contact@gendercentre.com

WESTERN AUSTRALIA

GLBTI RIGHTS IN AGEING INC (GRAI)

Website: www.grai.org.au/

GRAI is a community based group that promotes and supports a quality life for older and ageing people of diverse sexualities and gender identities. This includes LGBTI sensitivity training to aged care service providers.

Contact: 0422 654 244

Email: info@grai.org.au

NATIONAL CONTACTS

ANDROGEN INSENSITIVITY SYNDROME SUPPORT GROUP AUSTRALIA INC.(AISSGA)

Website: www.aissga.org.au/

ASSIGA is a peer support, information and advocacy group for people affected by androgen insensitivity syndrome and/or related intersex variations and their families.

Email: aissgaaustralia@gmail.com

AUSTRALIAN AND NEW ZEALAND GENDER SUPPORT GROUP (ANZGSG)

Website: www.anzgsg.org/

Support group for community groups or individuals who have an interest in the general aims of ANZPATH (Australian and New Zealand Professional Association for Transgender Health).

ORGANISATION INTERSEX INTERNATIONAL AUSTRALIA (OII AUSTRALIA)

Website: www.oii.org.au/

Oii Australia is an organisation that promotes human rights and bodily autonomy for intersex people, and provides information, education and peer support.

Email: info@oii.org.au

QLIFE

Website: www.qlife.org.au/

Australia's first National counselling and referral service for people of diverse sex, genders and sexualities. Provides peer supported telephone and web based services to support Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) people of all ages experiencing poor mental health, psychological distress, social isolation, experiences of being misgendered and/or other social determinants that impact on their health and wellbeing.

Contact: 1800 184 527

Email: ask@qlife.org.au

FURTHER READING

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USEFUL WEBSITES

Alzheimer's Australia

<http://www.fightdementia.org.au>

GLOSSARY OF TERMS

BISEXUAL

A person who is sexually and emotionally attracted to both men and women.

DEMENTIA

Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease. Dementia affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person's normal social or working life.

FAMILY OF CHOICE

Due to possibly having experienced rejection from their biological families, some LGBTI people may form core relationship links with others who they may refer to as their 'family of choice.' This is similar to many other people's relationships with their biological family.

GAY

A person whose primary emotional and sexual attraction is to people of the same sex. The term is most commonly applied to men, although some women use this term.

GENDER

Characteristics that are often believed to be innate or biologically determined but include roles, behaviour, activities and attributes that a particular society considers appropriate for women and men. Note: gendered terms include man and woman.

GENDER IDENTITY

A person's sense of identity defined in relation to the social roles, attributes and behaviours customarily ascribed by society to 'women' and 'men.' For most people, biological sex and gender identity (birth assigned) are aligned, but some (e.g. transgendered) they are in conflict. Others identify as androgynous (as both a man and woman) and some reject any gender labels entirely.

INTERSEX

People born with intermediate or atypical combinations of biological and/or physiological features that distinguish females from males. This may include variations in chromosomes, hormones, reproductive organs, genitals and other physiological features.

LESBIAN

A woman whose primary emotional and sexual attraction is towards other women.

LGBTI

Acronym referring to a group of people with diverse sexual orientation, sex or gender identity, including lesbian, gay, bisexual, transgender and intersex people. It can be shortened further to individual letters e.g. T or L.

QUEER

An umbrella term that includes people who are not-heterosexual such as lesbians, gay men, bisexuals, transgender people. For some people the term 'queer' has negative connotations, however many non-heterosexual people are now reclaiming the term as a symbol of pride.

GENDER QUEER

A person who does not subscribe to conventional gender distinctions but identifies with neither, both, or a combination of male and female genders.⁷¹

TRANSGENDER

An umbrella term used to describe a diverse group of individuals who do not fit the usual culturally defined male and female gender roles. It includes all gender non-confirming people including transsexuals, cross-dressers, drag performers, and gender queer people.

TRANSITION

Describes both a public act and a process. It involves the permanent and public adoption of the style and presentation of the gender opposite to that of a person's birth-assigned sex. It usually includes a change of name, chosen style of address and pronouns, as well as adopting the dress and style of presentation of a person's innate gender. It also describes the process of changing one's lived gender by permanently changing one's body. For transsexuals this is a process of cosmetic procedures as well as cross-sexed hormone replacement therapy (HRT) and surgical intervention, usually referred to as medically assisted gender reassignment. Not all who transition undergo medically assisted gender reassignment. Some transgendered people (e.g. cross-dressers) remove facial and body hair and take cross-sexed hormones to improve their presentation.

TRANS MAN

A person who has transitioned from a woman to a man (some may prefer to be referred to as 'female to male').

TRANS WOMAN

A person who has transitioned from a man to a woman (some may prefer to be referred to as 'male to female').

SEX

The biological and physiological characteristics associated with 'female' and 'male.' The biological and physical characteristics associated with 'female' and 'male', including chromosomal configuration, hormonal profile, reproductive organs and secondary sex characteristics e.g. breasts, body hair and voice.

Note: sex terms include male and female.

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