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PROFESSIONAL DOCTORATES

Choice in Life (transgender older adults' mental health) and in Death (UK GPs' euthanasia discourses)

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Award date:
2017

Awarding institution:
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CHOICE IN LIFE (transgender older adults' mental health)

AND IN DEATH (UK GPs' euthanasia discourses)

Emily Maddock

Bangor University

Submitted in part fulfilment of the final degree award

Doctorate in Clinical Psychology

June 2017

Contents

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Acknowledgements

Firstly, a huge thank you to Carolien, whose energy and enthusiasm has been inspiring. Your support has been invaluable, especially when I could no longer see the wood for the trees!

Danny, thank you for your patience, encouragement and grounding. I could not have come this far without you.

And finally, thank you to the research team, who provided guidance along the way.

CHOICE IN LIFE (transgender older adults' mental health)

AND IN DEATH (UK GPs' euthanasia discourses)

Literature review: Transgender older adults' mental health needs are poorly understood. A systematic review of the literature revealed that transgender older adults' mental health is affected by three types of factors; socioeconomic, psychosocial and biomedical. Transgender older adults may have unique mental health needs that differ from the general older adult population, transgender adults and youth. Fear of victimisation and discrimination, and a lack of social support result in transgender older adults being less likely to engage in end of life planning. **Empirical paper:** The debate in the United Kingdom (UK) regarding the legalisation of euthanasia (EU) and assisted suicide (AS) is ongoing. However, the views of UK GPs regarding the legalisation of EU/AS are not well understood. Six white British GPs participated in semi-structured interviews. Their discourses were analysed using Foucauldian discourse analysis. While the GPs' factual knowledge regarding EU/AS was limited, they revealed three discourses: 'palliative', 'medicine is limited, is EU/AS the answer?' and 'Patients have the right to EU/AS, but do not count on me'. **Implications for theory and practice:** Both papers highlighted the influence of societal norms and related discourses on individuals and on services, the need for open communication, staff training and for services to be sensitive to personal choice, both for patients and staff. Many influential models of aging are underpinned by normative assumptions. The use of these models by services and in research may be perpetuating these assumptions through the lack of consideration of those who do not meet such assumptions, including transgender older adults.

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The Gerontological Society of America (GSA), the publisher of The Gerontologist, was founded in 1945 to promote the scientific study of aging, to encourage exchanges among researchers and practitioners from the various disciplines related to gerontology, and to foster the use of gerontological research in forming public policy. The Society's 5,500+ members

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(2011) 51(3): 281–284). Qualitative manuscripts should avoid the subheading "A Qualitative Study."

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Factors that impact on the mental health of transgender older adults: A systematic review of the literature

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This paper is part of the Doctorate in Clinical Psychology

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Abstract

Purpose: This review provides an update on the limited body of research examining the factors that impact on the mental health of transgender older adults. Factors reported in the transgender aging literature are identified and considered in relation to the broader adult and youth transgender literature, taking into consideration the shifting social climate.

Design and Methods: The databases PsycINFO, ProQuest Social Sciences Premium Collection, Social Science Database, Political Science Database and Science Direct were searched for studies published between 2000 and 2017. The following terms were used: (Transgender*), male-to-female, female-to-male, gender identity, gender expression, (old*) adults, elder, mental health and successful aging. Eight articles were identified that met the criteria for inclusion in the review. ***Results:*** Three factors were identified. Socioeconomic factors included employment, education and income, and military service. Psychosocial factors included relationship status, victimisation and discrimination, gender identity disclosure, social support and community belonging, internalised stigma, development of a cohesive self and self-acceptance, and spiritual/religious activity. Biomedical factors included physical health and health related behaviours, and transition related health care.

Implications: Transgender older adults may have unique mental health needs that differ from the general older adult population, transgender adults and youth. These needs and cohort effects should be taken into consideration by health and social care organisations involved in the mental health care provision for transgender older adults.

Key Words: Lesbian, Gay, Bisexual and Transgender (LGBT), Quality of life (QOL), Gender identity

Transgender older adults' mental health needs continue to be poorly understood and are understudied. Although there has been a recent increase in research focusing on the mental health of transgender individuals, much of this focus has been on transgender youth, health care access, socio-demographic characteristics and rates of mental health difficulties. Little research has attempted to understand the factors that influence the mental health of transgender individuals, and even fewer studies focus on older adults who identify as transgender. In this review, mental health is conceptualised as a subjective state of cognitive and emotional wellbeing that encompasses, quality of life (QOL), satisfaction and contentment. Psychological distress, suicidal ideation and mental health diagnoses such as depression and anxiety are referred to as indicators of mental health difficulties (Fredriksen-Goldsen, Kim, Shiu, Goldsen, & Emlet, 2015; Hoy-Ellis et al., 2017; McCann et al., 2013).

The term 'transgender' is used to describe individuals whose gender identity, expression or behaviours do not match those usually associated with their biological sex (Persson, 2009). Biological sex is categorised as either female, male or intersexed according to an individual's anatomy. Traditionally, gender has been dichotomised as either male or female and assigned at birth according to biological sex. However, gender identity is increasingly being understood as a more complex and multidimensional construct that refers to an individual's 'sense of self' as being male, female or a sense of self that does not conform to this traditional dichotomy.

Population estimates are difficult both because many official documents do not include data on gender identity (e.g. the United States [US] & United Kingdom [UK] Census) and because many transgender individuals prefer not to disclose their gender identity (Meerwijk & Sevelius, 2017). There is currently no validated estimate of the population of transgender adults in the UK. Based on survey data from 1998, Reed, Rhodes, Schofield, and Wylie

(2009) estimated that in 2007 there was likely to be a minimum of 10,000 transgender individuals over the age of sixteen in the UK, who had sought transition related health care. Transgender individual are estimated to make up 0.5% of the American adult population (Conron, Scott, Stowell, & Landers, 2012). Slightly higher prevalence rates have been reported for transgender youth. In a school based survey, 1.2% of 8,166 students in New Zealand reported being transgender and 2.5% were not sure about their gender (Clark et al., 2014). Similar rates of 1.3% of 2,730 middle school students reported identifying as transgender in an American school based survey (Shields et al., 2013).

Transgender individuals report higher rates of anxiety (40.4% for transgender women & 47.5% for transgender men; Budge & Adelson, 2013) and depression (48-62%; Nemoto, Bodeker, & Iwamoto, 2011) than the general population (28.8% & 16.6% respectively; Kessler, Berglund, Demler, Jin, & Walters, 2005). The National Transgender Discrimination Survey (Hass, Rodgers, & Herman, 2014) conducted in America reported lifetime suicide attempts of 45% for 18-44 year olds, 33% for 55-64 year olds and 16% for over 65s. Like other minority groups, transgender individuals can find themselves in a social context that does not provide adequate support or health care to meet their physical and mental health needs.

Stigma-related discrimination and victimisation have long been recognised as having a profoundly negative impact on the mental health and wellbeing of minority groups. Transgender individuals are at greater risk of experiencing discrimination and victimisation than the general population (Bradford, Reisner, Honnold, & Xavier, 2013). Prevalence estimates of transgender-related discrimination have been reported to exceed 60% among adults (Clements-Nolle, Marx, & Katz, 2006).

It is clear that transgender individuals across the life span are at higher risk of experiencing mental health issues. Yet, although the mental health needs of transgender individuals are increasingly being recognised, there continues to be a lack of understanding of the factors that impact on mental health, particularly for transgender older adults. In addition, understanding transgender older adults' mental health is complicated by the fact that what constitutes an "older adult" is culturally defined. In most western societies it is generally accepted to be retirement age (63 for women and 65 for men in the United Kingdom [UK]) but can include people as young as 50 (Department of Health, 2001). The term older adult will be used in this review to reflect this common definition and will refer to individuals aged 50 and over. This paper reviews the limited research on the factors that impact the mental health of transgender older adults. Factors are discussed in comparison with the experience of non-transgender older adults, transgender adults and youth as reported in the literature.

Method

The databases PsycINFO, ProQuest Social Sciences Premium Collection, Social Science Database, Political Science Database and Science Direct were searched using the following terms: (Transgender*), male-to-female, female-to-male, gender identity, gender expression, (old*) adults, elder, mental health and successful aging. As the transgender older adult population has been 'invisible' and the focus of little research until approximately the year 2000 (Witten, 2016), the search was limited to studies published between 2000 and 2017. The search and selection process was completed by the first author.

The search produced 272 articles of potential relevance. The resulting abstracts were assessed for relevance and excluded if they were duplicates, not available in English, were not exclusive to older transgender adults or did not include factors specific to mental health

or wellbeing (see Figure 1). Qualitative and quantitative studies that assessed mental health

factors as variables in statistical models and questionnaires were included.

Eight articles were identified that met the criteria to be included in the review (see

Table 1). Although these studies ranged in quality from rigorous large scale quantitative

designs (e.g. Fredriksen-Goldsen et al., 2015) to discussions of case vignettes (e.g. Ettner &

Wylie, 2013), all eight studies were included due to the limited amount of studies available.

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│                         Databases                           │
│  PsycINFO, ProQuest Social Sciences Premium Collection,     │
│  Social Science Database, Political Science Database and     │
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              │        Search results        │
              │            N = 272           │
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│                         Exclusion process                           │
│                                                                     │
│  Duplicates = 0                                                     │
│  Not involving older adults = 106                                  │
│  Articles unrelated to transgender = 72                            │
│  Articles involving transgender older adults unrelated to mental   │
│  health = 59                                                        │
│  Articles involving transgender older adults related to mental     │
│  health but not including factors = 25                             │
│  Not available in English = 1                                      │
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              │       Full text reviewed     │
              │             n = 9            │
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│                           Excluded                                  │
│  n = 1 (Referred to LGBT but the sample didn't include any          │
│         transgender participants)                                   │
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              │          Included            │
              │            n = 8             │
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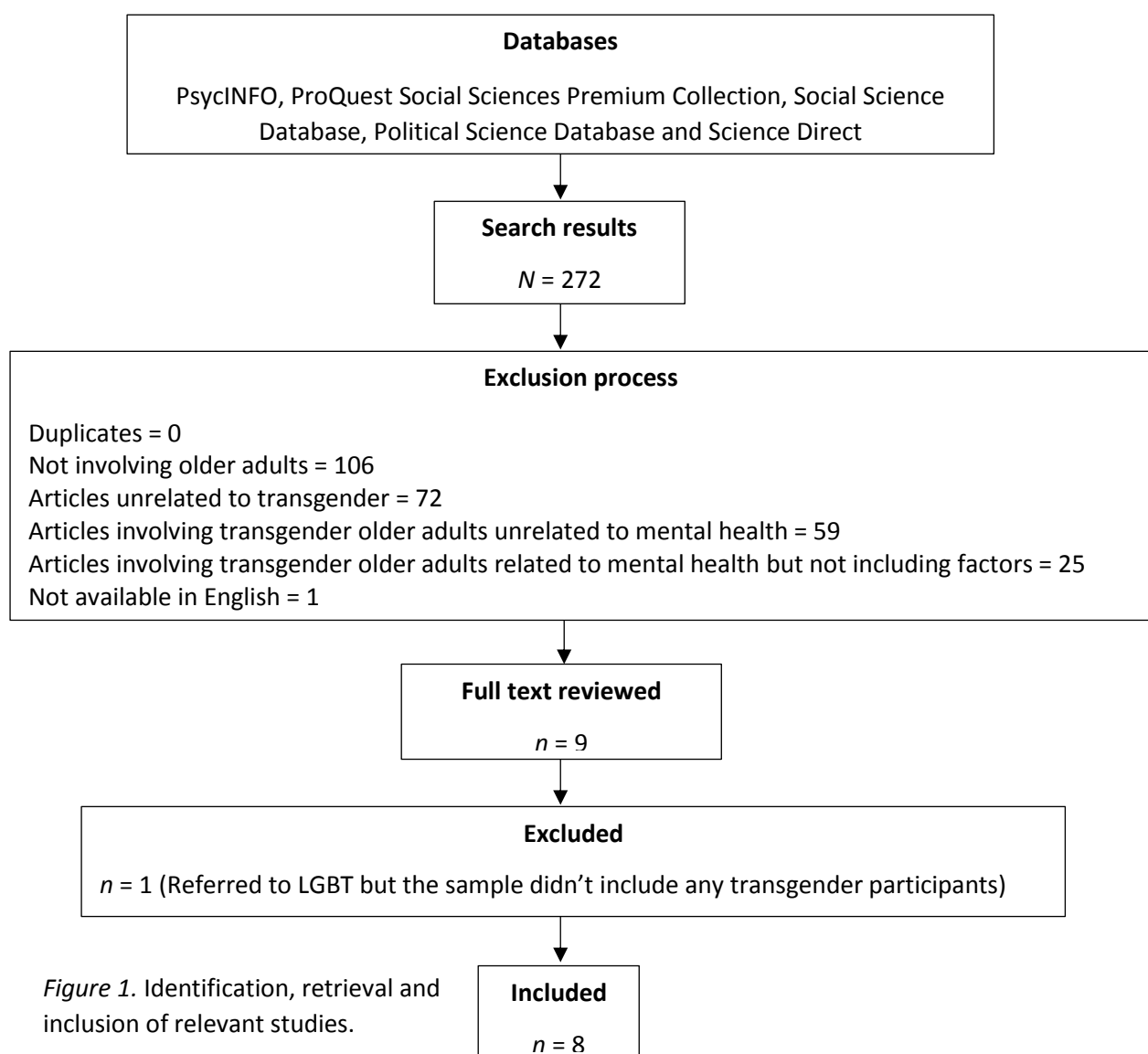
Figure 1. Identification, retrieval and inclusion of relevant studies.

Factors that affect the health and wellbeing of transgender older adults have been categorised in the literature as biomedical, psychosocial and socioeconomic (Ettner & Wylie, 2013; Witten 2016). Therefore, each article was reviewed and factors that impacted on the mental health of transgender older adults were identified (see Table 1 for summary) and presented under the following headings (1) socioeconomic factors, (2) psychosocial factors and (3) biomedical factors.

Results

Although the literature base is currently limited, the available studies provide an initial indication of the factors that impact on transgender older adult's mental health. Under the socioeconomic category, the following factors were identified: employment, education and income, and military service. Under the psychosocial category, the following factors were identified: relationship status, victimisation and discrimination, gender identity disclosure, social support and community belonging, internalised stigma, development of a cohesive self and self-acceptance, and spiritual/religious activity. Under the biomedical category, the following factors were identified: physical health and health related behaviours, and transition related health care. Each of the factors is summarised and reviewed in comparison to the general older adult, transgender adult and youth literature where appropriate.

Socioeconomic Factors

Employment, education and income

In the general population, employment and higher levels of income are associated with lower levels of psychological distress, depression and anxiety compared to unemployment

Table 1
Summary of studies included in the review and factors identified.

Study	Year	Data collection	N	Age group	% transgender	Mental health outcomes	Factors identified Positive	Negative
Elder	2016	Semi-structured interviews	10	60+	100%	Subjective reports of experiences (suicidal ideation, depression, loneliness & low self-esteem)	Gender transition, advocating/teaching & raising awareness of transgender issues, community connectedness	Historical victimisation/discrimination, rejection/loss & discrimination in religious community
Ettner & Wylie	2013	Case vignettes	5	60+	100%	Subjective reports of depression, anxiety & wellbeing	Self-acceptance	Hormone deficiency
Fabbre	2015	Interviews & participant observations	22	50+	100%	Subjective reports of wellbeing & experiences of emotions	Prior military service, development of a cohesive self & self-acceptance	Heteronormative societal gender expectations & internalized stigma
Fredriksen-Goldsen et al.	2013	Cross-sectional survey	2,560 LGBT	50+	7% (174)	Depressive symptomatology & perceived stress	Social support & community belonging	Internalised stigma, victimisation, fear of accessing health services, obesity, lack of physical activity & concealment of gender identity
Fredriksen-Goldsen et al.	2015	Cross-sectional survey	2,560 LGBT	50+	7% (174)	Physical & mental health related QOL	Positive sense of sexual identity, social network size, social support, income, employment, health promoting behaviours	Victimisation & discrimination, gender identity disclosure & chronic health conditions

Author	Year	Design	N	Age	%			
Hoy-Ellis et al.	2017	Cross-sectional survey	183	50+	100%	Depressive symptomatology & psychological health related quality of life	Prior military service	Identity stigma
McCann et al.	2013	Survey & semi-structured interviews	144 LGBT	55+	7% (10)	Mental health status, suicide & self-harm & substance misuse	-	Victimisation & discrimination (physical violence/verbal insults), loss, rejection, gender identity disclosure & substance misuse
Porter et al.	2013	Cross-sectional survey	289	51+	100%	Subjective experience of successful aging	Religious affiliation	Discrimination by religious groups

and lower levels of income (<$20,000; Frech & Damaske, 2012; Hergenrather, Zeglin, McGuire-Kuletz, & Rhodes, 2015; Prause & Dooley, 2001; Robert et al., 2009; Van Gorp et al., 2007). The positive impact of employment and income on mental health is also consistently demonstrated in the transgender adult population (Rotondi et al., 2011). Retirement has been associated with reduced levels of depression, including when compared to those in employment in the general population (Mandal & Roe, 2008).

Employment and income were reported to have a positive impact on the mental health QOL of transgender older adults (Fredriksen-Goldsen et al., 2015). However, an elevated rate of suicide attempts has been shown for those who have experienced discrimination in the work environment, particularly those who had experienced physical violence (n = 209; 65%; Hass et al., 2014). The Fredriksen-Goldsen et al. (2015) study was of high quality and used multivariate linear regression to assess the independent contributions of variables, including age (*Young-old* = 50-64 years, *n*= 1,078; *Middle-old* = 65-79 years, *n*= 1,138; & *Old-old* = 80+ years, *n* = 247), on mental health QOL. While the positive impact of income was consistent across age groups but strongest in the young-old group, education was not reported to have a positive effect on mental health QOL. This finding is consistent with the general older adult literature (Robert et al., 2009) which suggests that income is a stronger predictor of mental health QOL than education for older people, regardless of gender orientation.

Military service

Within the general older adult population, military service has been associated with poorer mental health in the short term following service compared with those without prior military service (Wilmoth, London, & Parker, 2010). However, recent research shows

positive impacts of prior military service on older adults' mental health in the longer term (Spiro, Settersten, & Aldwin, 2016). In a recent study, the negative impact of identity related stigma on the mental health of transgender older adults was attenuated by prior military service. Prior military service was a significant predictor of lower depressive symptomatology and higher psychological health related QOL in transgender older adults (Hoy-Ellis et al., 2017).

Furthermore, in a study by Fabbre (2015), male-to-female transgender older adults reported that the desire to fulfil societal gender expectations during youth and adulthood led them to consider or enrol in military service. Participants hoped that the masculine military environment would reduce their transgender feelings and reduce taunting for being feminine. Although military experience was reported to constrain gender identity, in later life it was viewed as a positive experience which contributed to the process of self-acceptance.

The Hoy-Ellis et al. (2017) study provides initial evidence that the negative impact of identity related stigma on the mental health of transgender older adults can be attenuated by prior military service. This was a good quality study that employed a rigorous method and analysis, using weighted multivariate linear models to evaluate the relationship between health related QOL, depressive symptomatology, identity stigma and prior military service. Prior military service is a potentially protective factor that warrants further investigation, especially considering 41% of transgender older adults reported previous military service in an American national community based survey (Fredriksen-Goldsen et al., 2013).

Psychosocial Factors

Relationship status

A negative impact of being partnered (married or in a relationship) was reported for transgender older adults in the old-old group (80+ years), but not for the middle-old or young-old groups (Fredriksen-Goldsen et al., 2015). This finding is not consistent with the positive impact of being partnered in the general older adult population (Namkee & Jung-Hwa, 2011) and the lesbian, gay, bisexual and transgender (LGBT) older adult population, when age group distinctions are not made (Williams & Fredriksen-Goldsen, 2014).

Victimisation and discrimination

The studies that examine the mental health of transgender older adults consistently identify victimisation, particularly physical violence, as negatively impacting on mental health (Elder, 2016; Fredriksen-Goldsen et al., 2013; Fredriksen-Goldsen et al., 2015; McCann, Sharek, Higgins, Sheerin, & Glacken, 2013). The rates of victimisation and discrimination were highest among the young-old and lowest among the old-old participants. However, the negative impact on mental health was stronger in the young-old and old-old than in the middle-old (Fredriksen-Goldsen et al., 2015).

Those who had experienced victimisation were at higher risk of attempting suicide, according to survey data and qualitative interviews. In the McCann et al. (2013) study, 11% of the survey respondents had considered suicide in the previous year and 4% had self-harmed. Nineteen percent of survey respondents reported experiencing physical violence and 47% had experienced verbal insults related to their LGBT identity. Interview participants discussed suicidal ideation and self-harm as being related to victimisation and discrimination.

Victimisation and discrimination, as well as the fear of these experiences, was specifically linked to the social context of the 1940-50s in which many transgender older adults grew up (Elder, 2016). In this good quality thematic qualitative study, participants reported fearing being committed to an institution, being beaten or killed, throughout their adolescence/adulthood as society was not accepting of transgender people. Some participants spoke about attending vigils for transgender friends who died violent deaths, and linked these experiences to trauma and suicidal feelings.

The negative impact of victimisation and discrimination on transgender older adults' mental health is consistent with the broader literature relating to transgender adults and youth. Transgender individuals across the lifespan experience wide spread discrimination (housing, work, education & health care; Bradford, Reisner, Honnold, & Xavier, 2013).

Gender identity disclosure

Gender identity disclosure was consistently identified as negatively impacting on the mental health of transgender older adults, the impact was highest among the young-old and old-old age ranges (Elder, 2016; Fredriksen-Goldsen et al., 2015; McCann et al., 2013).

Findings from qualitative interviews seem to suggest that this could be linked to the potential or actual rejection and loss experienced following disclosure (McCann et al., 2013). Rejection by family members was also associated with higher rates (57%) of lifetime suicide attempts compared to those who did not experience rejection by family members (33%; Hass et al., 2014). Furthermore, gender identity concealment was shown to be associated with increased depressive symptomatology and perceived stress for transgender participants when compared to LGB older adults (Fredriksen-Goldsen et al., 2013). The emerging literature is suggestive of a 'catch 22' situation, where disclosing gender identity

could result in rejection and negatively impact on mental health, while at the same time concealing gender identity may be stressful and increase depressive symptoms. Gender identity disclosure might be further complicated by perceived recognition by others as transgender. Higher rates (45%) of suicide attempts were reported among transgender females (male to female) who perceived others could 'most of the time' tell they are transgender compared to those who perceived others could 'never' tell they are transgender (36%; Hass et al., 2014).

For transgender adults, the literature is less suggestive of a consistently negative impact of gender identity disclosure on mental health. Reports suggest a mixture of both positive and negative experiences, primarily influenced by the type of response received when the disclosure is made. In Galupo, Krum, Hagen, Gonzalez, and Bauerband's (2014) study, 55% of adult participants reported positive and supportive experiences of gender identity disclosure to friends that had a self-affirming effect. Negative experiences were reported by 25% of the participants, responses included believing the transgender identity was not genuine and refusing to use the chosen pronoun or name. Twenty three percent of adult participants reported indifferent responses to their disclosure. Positive impacts on mental health such as increased self-acceptance, self-confidence and higher levels of well-being have been reported when the disclosure was received positively (Lepore, Ragan, & Jones, 2000; Rodriguez & Kelly, 2006).

Awareness of transgender identity is developing at increasingly younger ages (Floyd & Bakeman, 2006). However, many studies show that the younger youth are less accepting of LGBT peers (Heinze & Horn, 2009; Poteat, Espelage, & Koenig, 2009). Despite this, gender disclosure during adolescence has been shown to be associated with lower levels of depression and higher levels of satisfaction and self-esteem. Although many transgender

youth experience school based victimisation that has a negative impact on their mental health, this may be outweighed by not having to conceal gender identity, which was also associated with higher levels of depression (Russell, Toomey, Ryan, & Diaz, 2014). For today's transgender youth, disclosing transgender identity during adolescence is associated with better mental health in early adulthood (Russell et al., 2014).

Social support and community belonging

Social support and a sense of community belonging were consistently found to have a positive impact on the mental health of transgender older adults and were significantly associated with lower levels of depressive symptomatology and perceived stress (Elder, 2016; Fredriksen-Goldsen et al. 2013; Fredriksen-Goldsen et al., 2015). Further insight was provided by the Fredriksen-Goldsen et al. (2013) study that compared transgender older adults to LGB older adults. Transgender older adults were shown to report lower levels of social support and community belonging than the LGB older adults, despite reporting larger social networks. There were inconsistent findings on the impact of social network size on mental health. Fredriksen-Goldsen et al. (2015) reported a positive impact associated with larger social network size while others found no effect. One possible explanation for the inconsistent findings is that while social network size is considered a measure for social support, it is more likely to be the quality and support provided by the social relationship that is important.

Active involvement in advocacy and teaching others in a variety of settings (churches, courts, hospitals, schools & conferences) about transgender related topics and issues was reported to be linked to resilience and had a positive impact on mental health (Elder, 2016). This linked to a sense of community involvement, especially when transgender older adults

were integrated with younger transgender individuals at events such as transgender marches.

Family, peer and community support have also been shown to be protective factors against suicide attempts and associated with better mental health outcomes for both transgender adults and youth (Budge & Adelson, 2013; Liu & Mustanski, 2012; Moody & Smith, 2013; Snapp, Watson, Russell, Diaz, & Ryan, 2015). Family acceptance has been shown to be a particularly important predictor of self-esteem for youth (Snapp et al., 2015). In a longitudinal study (McConnell, Birkett, & Mustanski, 2016), younger people who received support from their family and peers reported significantly lower levels of psychological distress than those who did not receive support from family or peers. Youth who received support from peers but not family, reported higher levels of psychological distress than those who did receive family support. However, they also reported increasing levels of family support throughout adolescence into early adulthood, and reduced psychological distress associated with the increase in family support.

Additionally, in a study by Witten (2014) transgender individuals over the age of 18 reported concerns and worries about lacking social support in later life. Concerns included reduced independence and that if later life care was required their gender related choices and wishes would not be respected; for example, their preferred pronoun and name would not be put on their death certificate or gravestone. Other concerns included not being able to live the final years of their lives as their true selves and suicide or euthanasia was spoken about as preferable to returning to a non-gender affirming identity. These concerns resulted in a lack of end of life preparation, such as the use of advance directives, wills and power of attorney options.

Internalised stigma

Although only addressed in two studies, higher levels of internalised stigma were found to be significantly associated with higher depressive symptomatology and perceived stress (Fabbre, 2015; Fredriksen-Goldsen et al., 2013). In one study (Fredriksen-Goldsen et al., 2013) transgender older adults were compared to non-transgender LGB older adults. While internalised stigma had a negative impact on the mental health of LGB older adults, the rates of internalised stigma were higher among transgender older adults.

Internalised stigma has been conceptualised as resulting from minority stressors, such as exposure to high levels of victimisation and discrimination due to transgender identity. Given that transgender older adults may have been exposed to victimisation and discrimination for many years, and have lived during a time when being transgender was less accepted than it is today, it seems likely that internalised stigma is a relevant factor that warrants further exploration.

Development of a cohesive self and self-acceptance

The development of a cohesive self and self-acceptance has been reported to have a positive impact on the mental health of transgender older adults (Ettner & Wylie, 2013; Fabbre, 2015). In a good quality extended case qualitative study by Fabbre (2015), transgender older adults reported being acutely aware of how their gender identities did not match the heteronormative expectations of Western society. They reported spending many years trying to 'fit' into expected gender roles and feeling as though they had failed when this was not achieved. This was associated with feelings of anger, and frustration and reported to negatively impact on mental health. However, 'failing' to fulfil society's expectations was seen as an important step towards self-acceptance and living authentically

according to their own expectations. This self-acceptance was associated with improved

mental health, self-confidence and a sense of peace. Transgender older adults reported the

development of a cohesive self that integrated previous attempts to 'fit' societal gender

expectations with their self-accepted gender identity. As well as self-acceptance of gender

identity, a positive sense of sexual identity was reported to be associated with better mental

health QOL among transgender older adults (Fredriksen-Goldsen et al., 2015).

Spiritual/religious activity

Spiritual/religious activity was not found to have a significant impact on depressive

symptomatology, perceived stress or successful aging for transgender older adults

(Fredriksen-Goldsen et al., 2013; Porter, Ronneberg & Witten, 2013).

Although little research has addressed religion and spirituality among transgender

adults and youth, the available literature suggests both benefits and risks to mental health.

In a qualitative study by Westerfield (2013), transgender adults reported a connection with

a higher power and viewing themselves as being made as transgender by God. They also

reported concern regarding how others with religious beliefs would perceive them and had

experienced both supportive and discriminatory responses. In another qualitative study

(Dahl & Galliher, 2012), transgender youths reported mixed experiences of religious

involvement. Negative experiences included feelings of inadequacy, religious-based guilt,

depressive symptoms and social strain. Positive experiences included building resilience,

increased sense of self, enhanced acceptance of others, religious values and social support.

Similarly, religion has been reported to be both protective and a risk factor among LGB

individuals. Religion has been associated with higher levels of internalised homophobia,

resulting in a negative impact on mental health and wellbeing (Kralovec, Fartacek, Fartacek,

& Plöderl, 2014). Two-thirds of sexual minorities have reported experiencing conflict between their religious and sexual identities (Dahl & Galliher, 2009).

It is widely accepted that religion and spirituality have a positive impact on the wellbeing, physical and mental health of the general older adult population. Religion and spirituality have been reported to impact on relationship satisfaction (Cohen & Koenig, 2003), to bring meaning to life (Emery & Pargament, 2004) and to help adjustment to changes associated with aging (Sadler & Biggs, 2006). Religion has also been shown to be a protective factor against suicide in the general population (Colucci & Martin, 2008; Gearing & Lizardi, 2009).

Biomedical Factors

Physical health and health related behaviours

Chronic health conditions were shown to negatively impact on mental health QOL (Fredriksen-Goldsen et al., 2015). This negative impact was highest among the young-old and old-old participants. This is consistent with the general older adult population (Braden et al., 2008).

Fear of accessing services and lack of physical activity were shown to mediate the relationship between gender identity and depressive symptomatology and perceived stress in transgender older adults (Fredriksen-Goldsen et al., 2013). This was consistent with a follow up study by Fredriksen-Goldsen et al. (2015) that showed physical activity and routine health check-ups were positively associated with mental health QOL. Leisure activity and no substance misuse were also shown to positively impact on mental health QOL which

was consistent with qualitative interviews that suggested substance misuse negatively impacted on the mental health of transgender older adults (McCann et al., 2013).

Transition related health care

Higher rates of lifetime suicide attempts were reported by older participants who had received or wanted to receive transition related health care like hormone treatment and surgery (Hass et al., 2014). However, this study had several methodological limitations and it was unclear what percentage of attempts occurred before or after transition related health care. This finding is not consistent with the broader literature that suggests the use of transition related health care is associated with improved mental health and reduced suicide risk for transgender adults (Bailey, Ellis, & McNeil, 2014; Wilsen, Chen, Arayasirikul, Winzel, & Raymond, 2015). Furthermore, in a qualitative study by Elder (2016), transgender older adults reported waiting until they were in their 50s before pursuing transition related health care due to the extreme levels of stigma, discrimination and victimisation that they experienced in the 1940-50s. Older participants associated delaying, having to wait to transition and the increased physical complications with transitioning later in life with poorer mental health (Elder, 2016).

Ettner and Wylie (2013) discussed that male-to-female transgender older adults who are not receiving hormone treatment may be at risk of untreated testosterone deficiency, which can lead to depression. Although testosterone decline is a typical part of aging, testosterone deficiency in male-to-female transgender older adults may be missed by health care professionals. This bio-medical factor warrants further exploration.

Discussion

Today's transgender older adults aged in a social context that viewed them as mentally ill and subjected them to brutal treatments such as castration, lobotomies and involuntary institutionalization. Extreme victimisation and discrimination began to reduce in the 1970's and society has gradually become more supportive and accepting over the last few decades. This historical social context has had primarily negative implications for today's transgender older adults. This is key for understanding the factors that may impact on their mental health, and how this may differ from transgender adults and youth developing in a more accepting society. This review highlights the complex nature of the mental health of transgender older adults. There are likely to be many factors that directly or indirectly affect the wellbeing and mental health of this group. There is a complex web of interactions between factors for individuals identifying as transgender and this review has aimed to begin to identify some of these factors rather than explore interactions in great detail.

The finding that being partnered had a negative impact only on the old-old transgender older adults is perhaps better understood when considered in relation to historical social context. It may be that the social context in which the old-old group grew up in, had an influence on their decisions to conceal their gender identity and get married or have a relationship that fitted with the social expectations associated with their birth sex. This may have been less likely to happen for younger generations who grew up in a more accepting social context and were more able to have gender affirming relationships. The lower rates of victimisation and discrimination among the old-old group but higher levels of negative impact on mental health might be related to this. There are numerous potential explanations that require further investigation. This finding perhaps indicates differences in

coping between the age groups, different types of victimisation or different support availability. Another possible explanation is that reluctance to disclose gender identity in the old-old group due to historic social context, has protected them from some victimisation.

A negative impact of gender identity disclosure was consistently identified for transgender older adults, which was at odds with the mixed but generally more positive experiences reported by transgender adults and youth. This important difference is again better understood by considering the less accepting historic social context. It could be that due to the extreme levels of discrimination and victimisation experienced by transgender persons in the 1940-50s, transgender older adults' experiences of disclosing their gender identity have been generally more negative.

The positive impact of social support and a sense of community belonging on the mental health of transgender older adults was consistent with the positive impact of social support reported in the transgender adult and youth literature. However, the more extensive transgender adult and youth literature includes more specific findings, such as the positive impact of family acceptance and support that exceeds the positive impact of peer support. The impact of different forms of support (e.g. family, peer, partner, community & combinations of support) on the mental health of transgender older adults has yet to be investigated.

Limitations

This review includes only a small number of studies that use a range of methods, including selective recruitment methods from which the results cannot be generalized. Study samples may be biased to transgender older adults who are more confident and feel able to disclose their gender identity. Those who are the most at risk or who are

experiencing mental health difficulties may be under represented in study samples, particularly the old-old age group. Although the factors have been categorised as biomedical, psychosocial and socioeconomic according to conceptualisations in the literature (Ettner & Wylie, 2013; Witten 2016), some of the factors are complex and interlinking and could be conceptualised as fitting into more than one of the categories.

It was beyond the scope of this review to critique the theoretical underpinnings of the research that addresses the mental health of transgender older adults, such as heteronormative models of aging and social theories that pathologise non-normative gender identities. However, it is likely that the structuring of services, health interventions and research based on these heteronormative models also impacts on the mental health of transgender individuals.

The broad umbrella term 'lesbian, gay, bisexual and transgender' (LGBT) is used to describe a diverse group of individuals whose sexual and/or gender identity does not match that which is usually associated with the individual's birth sex. Some of the studies included in this review used LGBT samples without distinguishing between gender identity and sexual orientation. Although the more extensive LGB literature has proved to be a valuable starting place for research focusing on transgender related issues, it is increasingly becoming apparent that there are important differences between transgender individuals' and LGB individuals' mental health. These differences warrant independent research and potentially have implications for clinical practice.

Clinical implications and directions for future research

This review identifies and summarizes some of the factors identified in a small number of studies that appear to impact on the mental health of transgender older adults. It

highlights that transgender older adults may have unique mental health needs that differ from the general older adult population and transgender adults and youth, such as the impact of delaying transition until later in life due to the experience of extreme discrimination and victimisation in the 1940-50s. These needs and cohort effects should be taken into consideration by health and social care organisations involved in the mental health care provision of transgender older adults. Staff working with transgender older adults need to be aware that their views on transitioning might differ from their clients and that a common ground needs to be found for developing a therapeutic relationship. Factors such as religion and being in a partnership, which are considered to be protective in most general older adult research (Emery & Pargament, 2004; Sadler & Biggs, 2006), might not fulfil this role in transgender older adults. Specific issues raised by transgender adults about end of life care require attention in health care provision as well as care settings.

Identifying factors that have a positive impact on the mental health of transgender older adults specifically is crucial for tailoring interventions that promote good mental health and successful aging. Potential positive factors i.e. a positive sense of sexual identity, advocacy, and prior military service, require further exploration. Additional research to verify the impact of these factors on the mental health of transgender older adults (and transgender individuals of all ages) would be beneficial and could have useful implications; for example, health and social services may be able to facilitate their involvement in advocacy.

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Fitness for purpose

Are the methods of the research appropriate to the nature of the question(s) being asked, i.e.

- Does the research seek to understand social processes or social structures &/or to illuminate subjective experiences or meanings?
- Are the settings, groups or individuals being examined of a type which cannot be pre-selected, or the possible outcomes not specified (or hypothesised) in advance?

Methodology and methods

- All papers must include a dedicated methods section which specifies, as appropriate, the sample recruitment strategy, sample size, and analytical strategy.

Principles of selection

Qualitative research is often based on or includes non-probability sampling. The unit(s) of research may include one or a combination of people, events, institutions, samples of natural behaviour, conversations, written and visual material, etc.

- The selection of these should be theoretically justified e.g. it should be made clear how respondents were selected
- There should be a rationale for the sources of the data (e.g respondents/participants, settings, documents)
- Consideration should be given to whether the sources of data (e.g people, organisations, documents) were unusual in some important way
- Any limitations of the data should be discussed (such as non response, refusal to take part)

The research process

In most papers there should be consideration of

- The access process
- How data were collected and recorded
- Who collected the data
- When the data were collected
- How the research was explained to respondents/participants

Research ethics

- Details of formal ethical approval (i.e. IRB, Research Ethics Committee) should be stated in the main body of the paper. If authors were not required to obtain ethical approval (as is the case in some countries) or unable to obtain attain ethical approval (as sometimes occurs in resource-poor settings) they should explain this. Please anonymise this information as appropriate in the manuscript, and give the information when asked during submission.
- Procedures for securing informed consent should be provided

Any ethical concerns that arose during the research should be discussed.

Analysis

The process of analysis should be made as transparent as possible (notwithstanding the conceptual and theoretical creativity that typically characterises qualitative research). For example

- How was the analysis conducted
  - How were themes, concepts and categories generated from the data
  - Whether analysis was computer assisted (and, if so, how)
  - Who was involved in the analysis and in what manner
- Assurance of analytic rigour. For example
  - Steps taken to guard against selectivity in the use of data
  - Triangulation
  - Inter-rater reliability
  - Member and expert checking
  - The researcher's own position should clearly be stated. For example, have they examined their own role, possible bias, and influence on the research (reflexivity)?

Presentation of findings

Consideration of context

The research should be clearly contextualised. For example

- Relevant information about the settings and respondents/participants should be supplied
- The phenomena under study should be integrated into their social context (rather than being abstracted or de-contextualised)
- Any particular/unique influences should be identified and discussed

Presentation of data:

- Quotations, field notes, and other data where appropriate should be identified in a way which enables the reader to judge the range of evidence being used
- Distinctions between the data and their interpretation should be clear
- The iteration between data and explanations of the data (theory generation) should be clear
- Sufficient original evidence should be presented to satisfy the reader of the relationship between the evidence and the conclusions (validity)

- There should be adequate consideration of cases or evidence which might refute the conclusions

General Practitioners and the euthanasia and assisted suicide debate in the United Kingdom: A Foucauldian exploration of their discourses

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Abstract

The debate in the United Kingdom (UK) regarding the legalisation of euthanasia (EU) and assisted suicide (AS) is ongoing. While EU/AS are not legal in the UK, doctors use palliative sedation and high doses of painkillers to manage the end of life stages. However, were EU/AS to become end of life choice options, UK General Practitioners (GPs) are likely to be involved in assessing and assisting in these choices. The purpose of this study was to gain an understanding of the discourses of UK GPs regarding EU/AS. Six white British GPs participated in semi-structured interviews. Their discourses were analysed using Foucauldian discourse analysis (FDA); a form of discourse analysis based on the philosophy of Michel Foucault, which is primarily concerned with revealing the knowledge and power relationships in discourse. While the GPs' factual knowledge regarding EU/AS was limited, they revealed a comfortable 'palliative' discourse, in which GPs hold a powerful 'expert' position but in which EU/AS did not feature. However, a less comfortable 'medicine is limited, is EU/AS the answer?' discourse emerged, where GPs were no longer the 'experts'. From the 'medicine is limited, is EU/AS the answer?' discourse, GPs moved to a further discourse where EU/AS could be a patient's right, however most GPs settled on a 'someone else should do it' discourse. In this discourse where EU/AS was legalised, the GPs returned to the comfortable 'palliative' discourse and 'expert' position, and considered EU/AS not necessarily as part of the role of a GP. Increased factual knowledge of EU/AS is necessary for UK GPs to engage in an informed debate, and would allow GPs to develop new, alternative discourses. Future research should take their discourses and gaps in knowledge into consideration.

Keywords: Euthanasia, Assisted dying, Foucault, Palliative care, Physician assisted dying

The way that death and dying are thought about, spoken about and subsequently responded to is specific to the cultural context at any given time (Strazzari, 2005). As medical knowledge and technology advanced throughout the latter half of the twentieth century in the United Kingdom (UK), dying shifted from an accepted, natural part of life (Callahan, 2009) to a medical challenge, with the aim to prolong life as long as possible (Clark, 2002). Dying increasingly took place in hospices, hospitals and other medical/care settings and people could be kept alive beyond the point at which death would naturally have occurred. These advances have contributed to an increase in end of life care options, such as palliative sedation and the use of high doses of pain killers to control physical symptoms. This is often referred to as the 'medicalization of dying' (Karsoho, Fishman, Wright, & Macdonald, 2016).

The medicalization of death and the prolonging of life beyond its natural end point has contributed to debates about the medical decision making process regarding the point at which it is decided that interventions are stopped, treatment is withdrawn or life supporting equipment is turned off. These decisions ultimately determine when death occurs (Karsoho, Fishman, Wright, & Macdonald, 2016). Several public and patient groups in the UK have been campaigning for the legalisation of euthanasia (EU) and assisted suicide (AS) so that the dying person can be given the option to determine the endpoint of their life rather than a doctor.

While EU and AS are not legal in the UK, the options available to doctors to manage the end of life stages are palliative sedation and high doses of painkillers. Palliative sedation is the intentional administration of sedative drugs to a terminally ill patient with the aim of reducing consciousness to a level that provides relief from physical symptoms and pain that

cannot otherwise be managed (Broeckaert & Nunez Olarte, 2002). The use of high doses of

pain killers to control otherwise unmanageable physical symptoms may have as an

unintended side effect the shortening of life, often referred to by medics as 'the double

effect' (Marcoux, Mishara, & Durand, 2007). Both practices have been hotly debated in the

UK, with critics claiming that they are forms of 'soft euthanasia' (Ten Have & Welie, 2014;

Howland, 2005).

In contrast, EU is the deliberate ending of a competent person's life, at their request,

for the purpose of relieving suffering (Deliens & Van der Wal, 2003). In assisted suicide, a

competent patient ends their own life using means (e.g. lethal drugs) provided by a medical

practitioner (Wilson et al., 2007). Legislation supporting EU and AS has been in place in the

Netherlands and Belgium since 2002, in Luxembourg since 2009 and in Colombia since 2015.

Several other countries and states of America also have legislation permitting either EU or

AS, with Canada passing legislation legalising Physician assisted dying in June 2016.

In the Netherlands, GPs perform EU more frequently than any other medical specialists

(Onwuteaka-Philipsen et al., 2003). Research into the views and experience of Dutch GPs

has revealed both positive and negative impacts of being involved in the EU/AS process. A

mixture of anxiety, loss and relief were reported by GPs in a study by Van Marwijk,

Haverkate, Van Royen, and The (2007). Open patient-GP communication regarding EU has

been highlighted as particularly important (Borgsteede et al., 2007). Opinions about who

should initiate EU discussions differed between GPs and many reported finding it difficult to

judge the 'right' time to discuss EU. Having a good patient-doctor relationship has also been

shown to be important, with many GPs saying they are only willing to perform EU if they

have a good relationship with the patient (Van Marwijk, Haverkate, Van Royen, & The,

2007). Norwood (2007) interviewed patients and GPs revealing that conversations about EU changed the patient-GP relationship. Open discussions resulted in a deepening and strengthening of the relationship.

If EU/AS were to be legalised in the UK, UK doctors, including GPs, would be directly affected by this ruling. Doctors are currently involved in decisions about the use of palliative sedation and pain management, which acknowledges the risk of 'the double effect'. However, the views of UK GPs regarding the legalisation of EU/AS are not well understood (Seale, 2009b). The available research suggests that the majority (32-63%) of GPs are opposed to the legalisation of EU/AS in the UK, but less so than geriatricians (80%; Market Research Services, 2004). A survey by Seale (2009b) that included 1073 GPs, also showed UK doctors (79.9%) to be opposed to EU/AS. Those who were in support of EU/AS stated a strong need for safeguards, that GPs should have the right to 'opt out' of involvement with EU/AS and that non-medical practitioners should be able to be involved. Of those who opposed EU/AS, 35% agreed that withholding life sustaining treatment in the interest of relieving suffering, or providing treatment that might also have a life shortening effect, was acceptable.

Given that there have been (and are likely to be future) attempts to pass EU/AS legislation in the UK, a better understanding of the views of GPs regarding EU/AS is essential, as the implementation could be hampered by a lack of willingness of GPs to be involved in carrying out EU/AS. To gain a deeper insight into the discourses of UK GPs regarding EU/AS, the same methodology to Lamers and Williams (2015) will be used, who explored the discourses of older people in the UK regarding EU/AS. Foucauldian discourse analysis (FDA) will be used to address two research questions:

1. What knowledge and power underlies general practitioners discourses in relation to the EU/AS debate?

2. What is the position of general practitioners in the EU/AS debate?

Method

Methodology

Discourse analysis (DA) is a social constructionist approach that is concerned with the relationship between language and social processes (Bryman, 2001). A discourse is the narrative of a phenomenon constructed through speech, writing and practice (Wetherell, Taylor & Yates, 2015). FDA is a form of DA based on the theories of the French philosopher Michel Foucault and is primarily concerned with power relationships in society as revealed through discourses. As the EU/AS debate centres around the questions as to who has the power to decide when and how to end a life, this methodology seemed suitable to answer the posed questions.

Foucault conceptualised discourses as constitutive, constructing what is considered to be 'real', 'correct' or the 'truth' at any given time in a particular culture (Gutting, 2005). This 'truth' is constructed through the process of normalization, when a particular discourse becomes dominant and considered 'correct'. Through this discourse, implicit and explicit 'rules of behaviour' (e.g. social norms and legislation) are created and this influences how individuals and institutions think and act. Existing discourses can be consolidated or indeed challenged. When changes in the knowledge of a particular phenomenon occur, this can produce new conceptualisations of a phenomenon and an alternative discourse gets created. With a change in knowledge as the catalyst for the development and evolution of discourses, knowledge is also fundamental to power relationships (Wetherell, Taylor &

Yates, 2004). Power relationships are developed when people who have different aspects of knowledge, are divided into social positions of 'experts', those who have knowledge about the 'objects', who in turn become the 'subjects' based on knowledge as it is expressed through discourse. Foucault theorised that the position of 'subject' is itself produced and defined by the discourse. The 'subject' is an individual who personifies the knowledge created by a particular discourse.

As discourses are ever evolving; what is considered to be 'true' or 'correct' evolves over time. Thus, FDA does not seek to reveal one single definitive 'truth' relating to a phenomenon, instead FDA seeks to reveal the power relationships created by discourses at any given time in a particular culture.

Medical, illness and end of life care discourses position medical practitioners, such as GPs, in the 'expert' position. They hold specialist knowledge regarding illnesses and treatments, and use associated medical and diagnostic language. Subsequently, the experience of an individual becomes the 'object' of the GP's knowledge and their discourse. Through these discourses, the position of 'patient' (subject position) is created and associated behavioural 'norms' are established. The patient (subject) conforms to the 'rules' defined by the medical discourses and behaves accordingly, a process Foucault referred to a 'subjectification' (Wetherell, Taylor & Yates, 2004). Institutions, such as hospitals, also hold authority and power, as through and in these institutions the 'experts' (medical practitioners) monitor the 'objects' (patients) treatment and progress. This experience of surveillance leads to the 'subject' (patients) engaging in self-surveillance (self-monitoring), a process that Foucault believed to be the most powerful mechanism of control.

In the UK, through the frequent legal challenges and media discussions, the dominant discourse that EU/AS is unacceptable and could lead to a 'slippery slope' is being challenged repeatedly. Discourses about possible inadequacies of current end of life care and a cultural shift to self-determination, contribute to an emerging discourse that EU/AS is needed and beneficial (Lamers & Williams, 2015). Nevertheless, the discourse to maintain EU/AS as an illegal act remains dominant, and is supported by a legal framework that sets out how GPs and other medical professionals are allowed to act when providing end of life care, and as such operates as a surveillance system for the doctors. These six Foucauldian concepts; knowledge, power, surveillance, expert, object and subject will be used to understand the GPs' discourses around EU/AS.

Research Ethics

Ethical approval for this research was obtained from both the School of Psychology Ethics Committee at Bangor University and from the Betsi Cadwaladr University Health Board Research and Development West Department.

Sampling

FDA is a social constructionist approach and is therefore concerned with gaining an in depth understanding of participants' construction of reality through language. As it does not aim to generalise results, random sampling is not required. Therefore, recruitment was opportunistic and via adverts (see Appendix E) distributed through GP meetings to GPs currently employed by Betsi Cadwaladr University Health Board and those who have retired. The information available to prospective participants included the advert, an information sheet (see Appendix F) detailing the purpose of the research, the process, data protection

procedures and researcher information and contact details. Initial contact with prospective

participants was via e-mail or telephone, and consent to participate was discussed.

Participants

Participants were six white British GPs aged between 35-73 years, three were currently

practising and three had retired. Length of time in practice ranged between 3-41 years.

Demographic details were recorded (see Table 1).

Table 1
Participant Demographic Details

Participant	Gender	Age	Professional status	Years in practice	Length of retirement
Grace	Female	60	Retired	35	1 month
John	Male	73	Retired	41	8 years
Peter	Male	67	Retired	32	8 years
Sarah	Female	39	Practicing	15	-
William	Male	58	Practicing	30	-
Jane	Female	35	Practicing	3	-

Note. Participant names are pseudonyms.

Interviews

Interviews were conducted by the first author at Bangor University or at the GPs' home.

The interview process began with confirmation that the GP had read and understood the

information sheet. The information sheet addressed the action that would be undertaken

were a GP to describe a clinical practice that might cause concern. If this were to happen,

the supervisory team would be informed and appropriate action taken. The opportunity was

given for the GPs to ask questions or raise concerns. The informed consent form (see

Appendix G) was completed at the beginning of the interview. The interview was recorded

using a Dictaphone.

The interviews were semi-structured and followed an interview schedule (see Appendix

H) that was based on that used by Lamers and Williams (2015). The interview schedule was

altered to incorporate questions that would distinguish between the GPs' professional and

personal views. The interview began with externalising questions with the aim of

establishing GPs' knowledge and understanding of EU/AS, e.g. "Can you tell me in your own

words what euthanasia means?" This was followed by personalising questions with the aim

of accessing the language used by GPs to describe their views and personal meaning of

EU/AS, and finally, specifying questions regarding the circumstances under which they

would consider EU/AS. GPs were given the opportunity to discuss or add comments they felt

were relevant or important that had not been addressed in the interview. Explorative

prompts were used throughout the interviews to facilitate naturally occurring speech as

much as possible. Interviews lasted 30-45 minutes and ended with a debrief.

Analysis

As there is no single agreed method for conducting FDA, in keeping with Lamers and

Williams (2015), the analysis followed the procedure outlined by Georgaca and Avdi (2011).

The analysis consisted of the following stages:

1. The interviews were transcribed by the first author (see Appendix I for example

   transcript). Transcription included vocal tones and pauses (bold = said loudly/with

   emphasis; underlined = said quietly/softly; (.) = pause for 1-2 seconds; (..) = pause for

   3+ seconds).

2. Transcripts were read and reread to identify the main discourses relating to each of the two research questions. This included identifying and examining implied or explicit expressions of the GPs' views on EU/AS, and how they positioned themselves in the debate, keeping in mind the Foucauldian concepts of knowledge, power, surveillance, expert, object and subject. In addition to the main discourses, other interrelated discourses were identified and examined.

3. The dynamics of the interaction were examined, focusing on the GPs' discursive agenda and interaction with the interviewer (e.g. seeking agreement).

4. The GPs' position (expert, object or subject) within each discourse was established.

5. The way in which each discourse maintained or challenged current practices and power structures was identified.

6. The impact of the discourses on the GPs behaviour was explored.

Results

First Author's Declaration

The first author has no previous research, clinical or personal experiences with EU/AS and does not hold strong views either way related to EU/AS. The first author's interest in EU/AS came from the increase in media coverage of the EU/AS debate in the UK.

Interpretations

As FDA seeks to reveal the power relationships associated with discourses, rather than seeking to reveal one single definitive truth, the results are presented as interpretations. It should be acknowledged that both the author's and the reader's own discourses influence

the interpretation of the discourses revealed by the GPs. All identifying details have been anonymised and GPs' quotes are presented under pseudonyms.

Throughout the interviews, GPs' discourses regarding EU/AS drew on three types of knowledge; their knowledge about what EU/AS is and the law in the UK, professional knowledge about illness and treatment, and personal knowledge about societal norms, expectations and their own values. As Foucault theorised, this knowledge and the associated discourses have developed and evolved over a number of years.

> Sarah: "*I think God my views have changed so much from perhaps 20 years ago, I think perhaps 20 years ago I was far more kind of **yes**, absolutely, everyone should be given the right to do it and I feel so much more uncomfortable about it now*".

GPs' factual knowledge regarding EU/AS was confused. Although they described EU as the intentional ending of a patient's life with the aim of relieving suffering, there was confusion around who made this decision, the patient or the medical practitioner. No GP referred explicitly to the fact that the patient had to be competent. Most GPs described EU as being primarily a doctor initiated decision, and several of the GPs engaged in checking or seeking agreement from the interviewer: *"We talk about euthanizing animals, don't we?"* (Jane).

There was also some confusion regarding the difference between EU and AS "*Erm (..) I'm not sure whether I've thought of there being a difference (.) erm (..)*" (Sarah). Most GPs described AS as helping someone to die by providing the means, e.g. a lethal drug that the person takes themselves. In contrast with EU, all GPs described AS as being initiated by, and a decision made by, the patient not the medical practitioner. However, GPs were unable to accurately differentiate between EU and AS, being confused about who makes the decision

and who carries out the procedure. With this confusion around the nature of the acts, their discourses were based on inaccurate knowledge.

> Grace: *"I suppose they are slightly different in that assisted suicide suggests that the person is making the plans and simply requires help with the actual process of **doing**, whereas euthanasia would suggest that others have more of a say in the initiation and carrying out of the act. That for me is the difference".*

Palliative care

The GPs revealed a dominant 'palliative' discourse that was underpinned by the GPs' professional knowledge of illness, illness trajectory, treatment options and symptom management. They talked about managing end of life situations effectively with medication in such a way that patients were able to have 'a good death' and EU/AS was not viewed as necessary or part of the GPs' treatment repertoire.

> Sarah*: "At the moment with things like syringe drivers we write up the drugs but we don't actually administer (.) it's district nurses generally that do it, erm so yes you might alter doses and say yes they need more at the moment, they're more distressed or restless or this needs to be added to the driver".*

Here, GPs were in the 'expert' position and held the power to make medical decisions that might have the side effect of hastening somebody's death: "*what you do all the time as a doctor is make judgments about things that aren't black and white*" (Jane). It is worth noting that it is not usually the GP who implements their own decision, it is often the district nurses. The patient's experience was the 'object' of the 'palliative' discourse: "*I don't think there has been one where we've just left them without, where it hasn't been sorted out*"

(Sarah). Within this discourse, the GP 'sorted out' the 'object' (i.e. 'one') by using their expert knowledge and medical decisions, thus creating a 'subject' that gets 'sorted out'.

The 'palliative' discourse was comfortable and safe for the GPs, who spoke confidently and fluently. Within this discourse the GP makes decisions for the patient, thus taking the expert position and creating the 'subject' who complies accordingly.

> Jane: "*When it's palliative care and its people who are dying anyway, then there is a massive overlap between (.) treatments that are going to kill someone and treatments that are going to help someone. So I feel much more comfortable discussing in those situations 'well this is what we are doing with your medication*".

> Sarah*: "Erm, and I think we are all well aware that by increasing pain medication (.) that potentially can shorten life because of the side effects but it's a very, they are in those last few days anyway so by increasing, actually it's more important that their pain is controlled".*

The 'palliative' discourse also has a 'covert' strand, where the GPs acknowledge the risk of the 'double effect' and where medical decisions might begin to move closer to the acts of EU/AS. GPs quote medical colleagues who are seen as more knowledgeable and therefore more powerful, implying an internal level of surveillance.

> Jane*: "A couple of senior doctors I've worked with have said things like (.) they talk about a palliative patient and you say at least they aren't in any pain and you sort of see them go but mmm but if they were at least we could then (.) offer some morphine that might then cut things down a bit. Because actually it's dragging on for*

them and it's dragging on for the family. But actually if someone isn't in any pain

(..)".

While palliative care creates a safe discourse, with the GPs using their expert knowledge with the aim of alleviating pain and suffering, they allude to an awareness that at times their intervention might come close to the 'double effect' and the challenge of surveillance emerges.

Medicine is limited, is EU/AS the answer?

However, GPs began to acknowledge that for a minority of patients a 'good death' was not always possible; palliative treatment and pain management options had been exhausted or were ineffective at relieving symptoms. In describing the limitations of medicine, their own knowledge and skills, a much less comfortable discourse emerged.

> Jane: "*Erm, we love to think we've got loads of options in medicine and actually sometimes you just don't. And actually for some people dying is going to be bad. So I think it's naive isn't the right word but I think to say oh you know, modern medicine can make it better, I don't think that is true".*

GPs were themselves beginning to challenge the previous 'palliative' discourse. They described these situations as "*difficult because they [GPs] are used to being in control of a situation like that*" (Peter), and themselves as feeling "*helpless*" (William). These words are inferring a shift from being and feeling powerful to becoming powerless. In these situations, the knowledge and power had shifted away from the GP, with the patient experiencing the limitations of the medical knowledge. When the patient and GP were confronted with the 'medicine is limited' discourse, EU/AS was considered to be an alternative. William was

aware that he might have different views about EU/AS from his colleagues, and he senses some level of surveillance.

> William: *"I've got fairly (.) well I think positive views but other people would disagree. Strong views on euthanasia from my experience of seeing people suffering and I don't think that's because (..) I don't think that's because we don't, haven't made reasonable attempts to relieve suffering I think some things are just (..) beyond science and society to help individuals and so I think euthanasia and assisted suicide should be an option".*

When confronted with the discourse 'Medicine is limited, is EU/AS the answer?', GPs described engaging in two behaviours that were interpreted as attempts to avoid the vulnerable position that this discourse would put them in, as this could potentially lead to 'risky' EU/AS conversations. Jane commented that "*the words [EU/AS] (..) make everyone very edgy*". The first behaviour was to attempt to shut down any conversations the patients may initiate regarding EU/AS.

> Jane*: "I think for me a conversation like that would always start off with 'wow ok, this is medically a really difficult area because this is not something that I can help you with'".*

The second behaviour was to call in the experts, as the GPs questioned their own knowledge and power.

> Peter: *"You could call an expert in when things were getting out of (.) getting slightly out of control, you weren't sure what to do. And we had a good one round here and I'd just ring him up and say look er, I've got this problem and der der der*

der and you don't have to come and see it, but erm, the patient, but can you tell me what to do, or very often I'd ring him up and say look, erm I'm getting out of control with this and I need you to actually come and talk to these people and say look these are the options, I don't think they are believing me because I'm only a general practitioner so to speak. And we just need a little more authority or something and that would work in that way, er, erm and things would settle down".

In this strand of the 'medicine is limited' discourse, Peter moved out of the 'expert' position, and into a subject position. Peter's comment "*I'm getting out of control with this*" reflects a level of self-surveillance regarding his expertise and ensuring that his own behaviour was in line with the law. By inviting an 'expert', Peter also invited in external surveillance. By gaining the perspective of an authoritative expert, he was able to regain control and re-establish his position in a 'palliative' discourse.

Despite attempts to remain in the 'palliative' discourse, the 'medicine is limited' discourse frequently re-emerged as GPs knew that there would be situations when a good death was not possible. The discourse was underpinned by the GPs' knowledge of the limitations of treatments and medicines as well as their experience of end of life care not always being able to meet the needs of patients. Based on this professional knowledge, the 'medicine is limited' discourse was unavoidable and the possibility of EU/AS as an alternative discourse emerged.

Patients have the right to EU/AS, but do not count on me

In this "*vulnerable position*" (Grace) where the dominant 'palliative' discourse was challenged by the 'medicine is limited, is EU/AS the answer?' discourse, the possibility of a 'patients should have the right to EU/AS' discourse was considered.

Grace: *"At the moment it's kind of by the back door by let's put in DNAR [do not attempt resuscitation] orders on people, well what are we really saying in that situation? You know, in the event of something happening we are not actually going to give you active care, well that's one step along the road to actually having that conversation with relatives which would be (.) I really do think we are reaching the point where quality of life is really dreadful here and we now say to them I think it would be counterproductive in the event of something happening to try to resuscitate this person, if their heart stopped or whatever. Maybe we would need to be more brave and say, you know do you feel that we should be looking at the option of ending this person's life. I don't think it's a massive step because if we really looked inside what we are doing we are probably not that far away now".*

In Grace's description, the confusion in the knowledge about the exact nature of EU/AS is noted, where she proposes to engage in conversations with family and friends about the patient's quality of life and the futility of treatment, rather than the patient themselves. Grace alludes again to the 'covert' strand of the 'palliative' discourse, and makes reference to the 'double effect'.

Peter: *"We just said helping people to die and that sort of thing. And we'd talk about it, but in the time I was there, there was no doctor who would say yeah I do it or I would do it because it's actually illegal. Maximum 14 years in prison?! It's something like that, it's something fairly heavy. So, we would touch on it and this sort of thing and we would talk about erm, again, this er, the ethics of the double effect, so in fact you're actually talking about euthanasia without actually mentioning it maybe or calling it by the name".*

Here, Peter also refers to a 'covert' strand known amongst doctors, reflecting an awareness of the power they exert over medical decisions, while also exhibiting a shared self-surveillance, and an awareness of the surveillance of the legal system. The GP moved between the position of 'expert' and being powerful, to the 'subject' under surveillance. Sarah expressed her concerns about the risks related to naming an act in terms of EU/AS.

> Sarah: "Erm, and I think we are all well aware that by increasing pain medication (.) that potentially can shorten life because of the side effects but it's a very, they are in those last few days anyway so by increasing, actually it's more important that their pain is controlled. But to actually say, right, to purposefully, yes, we are actually going to make sure that is that. That is obviously life ending".

The discourse that 'patients should have the right to EU/AS' was generally described in positive and collaborative language. While the patient was seen in the 'expert' role with knowledge about their own life, there was also a tension noted with the patient in a position of power and control, leading to a reversal of positions held under a 'palliative' discourse.

> Grace: "We give choice in medicine on so many issues, we involve people in choice more. And therefore my view now is that people probably have the right to choose for themselves whether or not their life should be ended".

> Jane: "I think by the time you are having conversations about it [EU/AS], they [patients] know what position they are putting you in".

However, when GPs attempted to define when EU/AS could be seen as a potential option, the 'patients should have the right to EU/AS' discourse seemed to be challenged. All GPs

spoke about EU/AS as only being acceptable "*if somebody just had a few months to go and was suffering a lot*" (John) and for "*a clear physical condition not a mental health problem, clear physical condition (.) that is (.) unbearable for the individual (.) that is very resistant to any sort of palliative treatment*" (William). Their attempt to define the criteria for when EU/AS could be considered, brings the GPs' knowledge about health and illness back as a central player in the decision making, thus reinstating their position of power. They challenge the 'subject's' knowledge and expertise to judge when their own life would no longer be bearable.

> Sarah: "*That's what sits really uncomfortably, the what if, because I don't want to be at a point where I'm going to be incontinent or I'm gonna be this or this and therefore on this day I want my life to end. Erm, well what if it never happens or what if when you get there it's not how you think it might be, or it might be*".

Sarah starts to introduce the word 'I', beginning to bring her personal ideas and experiences to the EU/AS debate. This third type of personal knowledge regarding one's own values and experiences, informed this discourse further, as well as societal discourses about when death is acceptable.

> Grace: "*As society becomes less comfortable with the concept of death and wants to keep people as long as possible and we are not supposed to be age discriminatory, the care that we're now offering people is probably worse than it was many years ago when we were rather more pragmatic about not treating chest infections or other things*".

Possibly, Grace was referring to a discourse around an aged death (Lamers & Williams, 2015), which might be valued differently to a death in younger people or from non-age

related conditions. However, when exploring the consequences of a 'patients should have the right to EU/AS' discourse, GPs found themselves not only no longer positioned as the 'expert', their actions related to EU/AS, would also become the 'subject' of strict legal surveillance as well as scrutiny by their colleagues, patients and the public. GPs expressed concerns about being known as "*the death doctor*" (Jane) and no longer being trusted by their communities; "*You know, it's not great to have a reputation as the one who will bump you off if you get a bit too problematic*" (Grace).

In exploring the implications of the 'patients should have the right to EU/AS' discourse, GPs developed a 'someone else should do it' strand as a response. They excluded themselves from an active involvement with EU/AS, if this end of life choice were to be legalised in the UK. They felt that EU/AS required a legislative framework which should offer GPs the option to 'opt out', with the proviso that they would refer on to a colleague who was prepared to undertake EU/AS. They drew on a familiar pregnancy termination discourse, where a similar practice exists. It is worth noting that in the 'palliative' discourse, perhaps GPs had also 'opted out' when they described the practice of prescribing an increase in medication, but other professionals administering it.

> Grace: "*I don't think the Swiss model is a bad one that it is not doctors administering the (.) treatment. I actually think there is an important distinction between doctors supporting euthanasia and assisted suicide and being the agents there of. Erm, I suppose it could work if you had the equivalent that we have in termination clinics. Where you have doctors who simply work there (..) or nurses who work there. Erm, equally, (..) in terminations you know, doctors have the right to opt out. Erm, and I'm not sure that that should necessarily be doctors or whether it should be practitioners*

who are simply there to administer the means. I'm not even sure that I would want to be the person writing the prescription".

Although all GPs stated that patients should have the right to access EU/AS, only William anticipated being willing to have an active role in EU/AS, should it be legalised. This strand of the 'patients should have the right to EU/AS' discourse provided a comfortable position for GPs regarding EU/AS, resolving the vulnerabilities and issues evident in the 'medicine is limited' discourse, but that GPs 'shouldn't be the ones to do it'. The GPs returned to the 'palliative' discourse, as the most viable alternative, and one which also allowed them to remain in the 'expert' position.

Discussion

The GPs engaged in multiple and conflicting discourses before settling on a 'Patients should have the right to EU/AS, but someone else should do it' discourse. This discourse positioned the GPs as supporting the legalisation of EU/AS in the UK, provided that they did not have an active role in the EU/AS process. However, the question remains whether their lack of accurate knowledge and understanding of EU/AS has disadvantaged them in engaging with alternative discourses.

It is possible that GPs were referring to other concepts associated with EU/AS, which not only confuses discourse, but might have made the discrepancy between palliative care and EU/AS more nebulous; the 'covert' strand. When the law talks about EU/AS carried out in a competent person, this is also referred to as 'voluntary'. If the decision is made by someone other than the patient and the patient is incapable of making the decision themselves, this is referred to as 'non-voluntary' (Strazzari, 2005). The way in which EU/AS is achieved can be classified as either 'active', e.g. the administration of a lethal drug, or

'passive', the withholding of life sustaining treatment (Strazzari, 2005). The latter might resonate with the palliative care practice of withdrawing treatments or interventions.

A more accurate understanding of EU/AS, the distinctions between other end of life practices and the 'double effect', is necessary in order for UK GPs to engage in an informed debate. The impact that this lack of knowledge regarding EU/AS had on their discourses and ability to engage in an informed debate, highlights the need for improved training and education on end of life options, EU/AS and the associated laws.

In the 'palliative' discourse, GPs held medical and illness related knowledge which positioned them in the 'expert' position, from which they made legal end of life care decisions, such as when to increase painkilling medication. Patients were able to have 'good deaths', as unpleasant symptoms and pain were successfully controlled. The knowledge, 'expert' position and power of GPs expressed in this discourse, reflects the medicalization of dying.

When confronted with the 'medicine is limited' discourse, one of the behaviours that the GPs described engaging in was to attempt to shut down any conversations the patients may initiate regarding EU/AS, thus limiting the patient's access to the discourse. The positioning of the GPs in this debate mirrors the findings in Lamers and Williams' (2015) study, where older people stated that the medical profession seemed not willing to engage with them in the EU/AS debate.

Although the GPs' reluctance to engage in discussions regarding EU/AS is understandable given that EU/AS remains illegal in the UK, this behaviour is problematic in that it may negatively impact the patient-GP relationship and inhibit the patient from expressing concerns or difficulties regarding their end of life care. The importance of

communication in healthcare, and in palliative care specifically, has long been recognised (Royal College of Nursing, 2014). Open patient-doctor discussions regarding a number of end-of-life topics has been shown to result in greater concordance between patient end of life care goals and those documented by medical practitioners, as well as increased patient satisfaction with care (You et al., 2014).

Decisions about end of life care can be influenced by patient-doctor end of life care discussions (Mack et al., 2012). In countries where EU/AS is legal, open patient-GP communication regarding EU has been highlighted as particularly important (Borgsteede et al., 2007), even when the patient does not ultimately choose an EU/AS death. Norwood (2009) interviewed patients and GPs in the Netherlands (where EU is legal) and reported that conversations about EU had a positive impact on the patient-GP relationship. Open discussions resulted in a deepening and strengthening of the relationship. The GPs' concerns about actively engaging in EU/AS might be a reflection of their lack of knowledge regarding EU/AS and are potentially amplified by their reluctance to engage in discussions with their patients and colleagues regarding EU/AS.

However, with patient-GP communication essential and impacting not only on end of life decisions but also the patient-GP relationship, it will be beneficial for GPs to begin to engage in end of life care discussions with their patients, regardless whether they have raised EU/AS. This communication will enhance the GPs' understanding of the patients' concerns and reasons for raising EU/AS, help to protect the patient-GP relationship whilst also being able to address the patient concerns or difficulties.

It is possible that the six GPs have felt under 'surveillance' by the interviewer, who had indicated at the start of the interview that any concerns regarding the GPs' practice would

be reported to the relevant authorities and regulatory bodies. This surveillance, along with the GPs' knowledge of legal prohibitions, could have led to the 'covert' strand noted in the 'palliative' and 'medicine is limited' discourses. Therefore, it should be acknowledged that the context may have influenced the GPs' discourses. Also, GPs whose practices might be harder to distinguish from EU/AS would have been unlikely to have volunteered to take part in the study. As discourses are ever evolving, the results can only be considered within the socio-political context at the time of the research. Furthermore, the interpretation of the GPs' discourses by the authors will have been influenced by the authors' own knowledge, views and discourses.

The discourses may have been influenced by demographic factors. All of the GPs were white British, practising in the UK and they will have reflected western discourses regarding illness, care of the dying, EU/AS and the role of a GP. The GPs varied in age and length of time in practice and will have experienced different training and practice approaches that have changed and developed over time. This study does not address the possibility that younger, newly qualified GPs may hold different discourses from older, more experienced or retired GPs. Indeed, some of the GPs discussed that length of time in practice was a factor that had shaped their views regarding EU/AS.

The methodology itself brings limitations, as FDA assumes that reality is discursively constructed and contingent, it can minimise the non-semantic aspects of reality, particularly the material structuring of economic and political reality. FDA does not take into consideration the impact of such non-semantic factors on the construction of the 'object', which is conceptualised as being entirely discourse constructed (Reed, 2000). FDA has also

been criticised for minimising the significance of human agency in the construction, evolution and function of discourse.

This study has revealed that the GPs' discourses regarding EU/AS are complex, at times conflicting and based on three different types of knowledge. Future research that aims to understand GPs' views on EU/AS may need to take these complexities and deficits in knowledge into account.

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Contributions to personal development, clinical practice and theory

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This final paper focuses on three areas. Firstly, my personal reflections on the project are discussed, followed by the clinical implications of the literature review and empirical paper, and finally the contributions of both papers to theory development and future research.

Personal reflections

Choosing topics

My interest in euthanasia (EU) and assisted suicide (AS) has developed over a number of years with the growing debate and media coverage in the United Kingdom (UK). Lamers and Williams (2015) used Foucauldian Discourse Analysis (FDA) to explore the discourses of older adults in the UK regarding EU/AS. This study provided the starting point for the development of the ideas for both the literature review and the empirical paper. Given that older adults' discourses revealed General Practitioners (GPs) as being in a position of power when it comes to making end of life decisions (Lamers & Williams, 2015), exploring the discourses of UK GPs themselves regarding EU/AS was the next logical step. This previous study, along with the fact that the views of UK GPs regarding EU/AS are not well understood (Seale, 2009), led to the development of the research questions addressed in the empirical paper.

My initial ideas for the literature review developed from considering Foucauldian power concepts in relation to my own clinical practice. One particular experience that had evoked strong feelings for me stood out. I had been left feeling very frustrated when I attempted to utilise the gender reassignment referral pathway for a service user, but was met with resistance from another professional who, despite clear guidelines, felt it was not part of their role to make the referral and engaged in obstructive behaviours such as not responding to my correspondence. I was struck by the amount of power that this

professional held and how it left me feeling frustrated, although not as frustrated as the service user. Given that in the discourses of older adults, medical professionals were seen to be in the 'expert' position and holding the power in medical and end of life decisions (Lamers & Williams, 2015), I began to think about the position of transgender older adults and how, as a minority group, they related to powerful medical professionals.

This thinking led me to explore the literature on transgender older adults, however, it quickly became apparent that there was very little research available and none that addressed their discourses or relationships with professionals (perhaps reflecting a lack of power). From this, the idea developed to focus on what factors are implicated in the mental health of transgender older adults.

Having now completed the research project, I have considered how the findings might influence my perception of the experience that initially led me to consider the mental health of transgender older adults. I feel that there are several similarities between the power relationships revealed in the empirical study and those that were at play in my experience.

GPs' discourses around EU/AS revealed their position as the powerful 'experts' and the patient as the 'subject'. This indeed also seemed to be the case in the experience that I had, the service user and I were both in the 'subject' position, lacking power over the referral process. Similar to the GPs who shut down uncomfortable EU/AS discussions, the professional concerned in my experience also engaged in shutting down communication, perhaps indicating a lack of knowledge regarding transgender related issues and the referral process. Interestingly, the professional also engaged in a 'someone else should do it' discourse and did not see the gender clinic referral as part of their role.

For me, these similarities highlight how a possible lack of knowledge that many professionals have around transgender related issues, can lead to certain discourses and related behaviours, which can impact on the service user and their mental health. Indeed, this lack of knowledge amongst professionals was apparent in the discussions I had with Sophie[1], a 70 year old woman who identifies as transgender. She agreed to meet with me to discuss my literature review. Although these comments are my own reflections, and no research has been done that investigates the discourses of transgender older adults or medical professionals regarding transgender related issues, I do feel that these reflections have been beneficial in raising my awareness of potential power relationships, related discourses and the way this impacts on my behaviour and role, as well as the impact of these discourses on service users.

Doing qualitative research

Having previously only used quantitative research methods, I made the decision to undertake a qualitative research project, based in part on the idea that the experience would be more beneficial to my professional development. Although I feel that this has indeed been the case, the process of understanding and using an unfamiliar methodology such as FDA, whilst juggling the pressures of being a Trainee, has been challenging.

I began by reading studies that had used FDA and researching Foucauldian philosophies in a hope to 'get my head around' FDA reasonably quickly. However, the more I researched the more it became apparent that Foucault's writings are extensive, complex, and at times contradictory. My understanding of FDA seemed to consolidate through the process of

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[1]Sophie is a pseudonym

actually applying it (and realising that there is no agreed 'it') to my own data. Through this process I was able to understand FDA as bringing a unique perspective to interpret data.

The experience of applying FDA to my data has developed my ability to think flexibly whilst maintaining a particular 'stance' based on the philosophy of Foucault. Taking a Foucauldian perspective locates the experience of the individual in power relationships as they exist in institutions and society as a whole. However, the Foucauldian philosophies that underpin FDA can be criticised for the absence of an agreed methodology, and potentially being based on Foucault's own personal life experiences.

While it is widely accepted that too little is known about Foucault's private life to be able to say with any certainty to what extent it influenced his philosophical work and writings (Gutting, 2005), it is conceivable that his early exposure to powerful academics, his authoritarian father and receiving psychiatric care could have influenced his ideas about power and knowledge.

It has been speculated that Foucault attempted suicide in his early adulthood due to struggling with his homosexuality, resulting in him receiving psychiatric care. It is possible that this experience contributed to his ideas about sexuality, the medical profession holding power, surveillance and control. Foucault posed that with changes in knowledge, came new power relationships that were played out in peoples' behaviour. Thus ever evolving discourses created new realities in which power was executed though institutions such as prisons, schools and hospitals through modes such as surveillance. Foucault can be criticised for taking a negative stance that focuses on how institutions can use power to control the 'subject' and not acknowledging the positive aspects of knowledge and power within

institutions such as hospitals e.g. the power to keep somebody safe. Perhaps this negative stance reflects his perception of his own life experiences.

The use of FDA to analyse the GPs' discourses regarding EU/AS was appropriate given that power relationships are prominent in EU/AS and the ongoing debate in the UK. However, the potential impact of my power as the researcher in relation to data creation, analysis and interpretation should be acknowledged. Discourse analysis is primarily applied to naturally occurring discourses, but due to the lack of availability of any records or texts reflecting the discourses of UK GPs regarding EU/AS, it was necessary to generate data through semi-structured interviews. Through developing and using an interview schedule I created an artificial structure that may have influenced the GPs' discourses. Furthermore, the GPs may have felt under 'surveillance' by me, as the researcher, with the power to report any concerning practice to the supervisory team. This may have influenced the GPs' discourses.

Although my own views and power could potentially have influenced the GPs' discourses, discourse analysis is not concerned with revealing one definitive truth but instead provides an account of a reality, as constructed by discourse at any given time. Therefore, the potential impact of my own views and power on the GPs' discourses, and the interpretation of these discourses, must be acknowledged and considered. Through this acknowledgment and consideration, the potential impact can be minimised and contextualised.

Although I do not hold strong views regarding EU/AS and do not take a position of either supporting or opposing its legalisation in the UK, it was noted that several of the GPs engaged in seeking my approval when giving their views in the interview. Furthermore, one

GP commented at the end of the interview "I've used terminology to you today because you're a Psychologist that most lay people wouldn't have understood" (Peter), indicating an assumed level of knowledge and power associated with my profession that influenced Peter's choice of language. Despite these limitations, FDA provides an alternative way of understanding and conceptualising a phenomenon such as EU/AS through discourses, power and knowledge as they are executed in a particular social context.

The interface between 'real life' and academic research

My experience as a 'scientist-practitioner' has been that there is sometimes a mismatch between the 'real world' and the academic literature. Therefore, having reviewed the literature on the factors that impact on the mental health of transgender older adults, I was fortunate enough to be able to meet with Sophie, who has identified as female since her teens and transitioned from male to female 11 years ago. I met with Sophie to discuss how the literature review matched her lived experience of identifying as transgender. Sophie has extensive knowledge and experience of transgender related issues and is involved in running transgender support groups, networks, delivering diversity training to health boards, schools, police services and is involved in large scale research projects across the UK. Although Sophie's experience cannot be considered to be representative of other transgender older adults, she provided some very useful insights and contributed greatly to my learning experience and contextualising of the literature.

Sophie felt strongly that academic research generally focuses on the negative experiences of transgender individuals, such as being victimised and experiencing stigma, and neglects the positive experiences. She highlighted that quantitative questionnaires as well as qualitative studies often ask questions regarding the experience of victimisation

without clarifying or reporting when this experience happened. She explained that in her experience, most transgender adults, and particularly older adults, will have experienced some form of victimisation, but for most this will have happened 20 or maybe 30 years ago. Sophie felt that the lack of consideration in research of when the victimisation took place results in a disproportionately negative representation of the experience of being transgender in current society. Furthermore, she felt that this has a negative, fear inducing impact on those who are experiencing confusion regarding their gender identity.

Sophie spoke about the difficulties she, and others she knows, have experienced when accessing physical and mental health care, and that it is not uncommon for people who identify as transgender to experience additional end of life difficulties. This included the impact of dementia on gender identity, where people might forget that they have transitioned from one gender to another and become confused and distressed. She spoke about how families, who have been reluctant to accept the gender identity of a loved one, often revert to calling the person by their birth name and sex once they have died, including at their funeral. Thus disregarding the person's wishes about how they are remembered. Sophie felt the literature review was important, especially as there are many aspects of transgender aging and mental health that are not yet sufficiently addressed in the literature.

Implications for clinical practice

The clinical implications of both papers are discussed in relation to the person, clinicians, training, service level, and on a societal level.

Implications for the person and clinicians/professionals

Both papers highlight the influence and impact of societal norms as reflected in discourses on individuals and on services. For GPs, the discourses around EU/AS led to a fear of being labelled the 'doctor of death' if EU/AS were to be legalised in the UK. This led GPs to respond with a 'someone else should do it' discourse, disengaging from the consequences of a possible change in legal status of EU/AS. For some transgender older adults, the discourses and stigma associated with not conforming to societal gender norms influenced their decisions to disclose their gender identity, and even to join military service in the hope that it would reduce their transgender feelings (Fabbre, 2015).

It is important for health and social care professionals who may be working with transgender older adults to be aware of how societal norms/discourses, such as gender expectations, may impact on transgender older adults; for example, they may be less willing to disclose their gender identity for fear of rejection (McCann, Sharek, Higgins, Sheerin, & Glacken, 2013). It is also important for professionals to be aware of how such discourses may influence their own behaviour, e.g. making assumptions or decisions based on biological sex.

Both papers have emphasised the challenges in communication and bringing views into the open. Foucault proposed that this type of behaviour is directly influenced by the related discourses (Wetherell, Taylor & Yates, 2004). This was evident in the empirical study when the GPs were confronted with the uncomfortable 'medicine is limited' discourse. One of the behaviours that GPs described engaging in, to avoid the 'medicine is limited' discourse that highlighted their lack of knowledge, was shutting down any conversations the patients tried to initiate regarding EU/AS. This can be problematic given the importance of patient-GP

communication in developing a good patient-GP relationship and patient satisfaction (You et al., 2014). It may be more helpful for GPs to explore patient concerns regarding end of life issues, despite limited options, rather than shutting down communication. This may help to protect the patient-GP relationship and address patient worries.

Training implications

Both papers highlight that a lack of knowledge about a particular issue can result in reluctance to engage in discussions. Therefore, offering staff training that addresses end of life issues may be an effective way of enhancing and encouraging patient-professional communication. GPs and other staff who are involved in delivering palliative and end of life care also need to be aware of the specific needs of minority groups, such as transgender older adults. Awareness of gender related issues may contribute to staff feeling more confident in discussing and delivering appropriate care to transgender older adults. Training on transgender terminology may also facilitate communication around transgender related issues. Although not specific to older adults, the importance of staff training on transgender related issues and mental health has been recognised in the 'LGBT People & Mental Health: Guidance for Services and Practitioners' produced by the National LGB&T Partnership (2015a).

Incorporating research findings, such as that the factors that impact on the mental health of transgender older adults may differ from transgender adults and youth need to be incorporated in psycho-education for multi-disciplinary teams who are directly involved in the care and support of transgender older adults, and for service users themselves. Regular supervision for staff who are delivering mental health and end of life services may also be a useful way to ensure diversity needs are being met.

Service level implications

GPs' discourses regarding EU/AS revealed that GPs are usually in the 'expert' position and have the power to make end of life decisions, such as when to increase pain killing medication. However, in the 'medicine is limited' discourse GPs had reached the limits of their knowledge and skills to manage end of life situations. Therefore, they 'called in' colleagues who were seen to have more expertise and medical authority. This highlights the importance of multi-disciplinary team meetings in palliative care, where responsibility and knowledge can be shared. Furthermore, there is a need for services to be transparent and openly discuss end of life options, what is and what is not available, with patients, without fear of repurcussions for the professionals. Services involved in end of life care need to promote the use of end of life planning and advance directives, as this can give patients a sense of control over the end of their life. Indeed, in the GPs' discourses, patients raised the possibility of EU/AS, and this may have been an attempt at gaining control over the end of their life.

Services also need to be aware that transgender older adults are more likely to identify friends as potential care givers and for the role of the next of kin, than the general older adult population (De Vries & Gutman, 2016). This can be problematic as friends are often not recognised in service policies that are based on normative family structures and care provision (Barker, 2002). Indeed, it was noted in the empirical paper that GPs often addressed family members regarding end of life decisions. Transgender older adults may lack important social support networks (Fredriksen-Goldsen et al., 2013), which makes them less likely to have discussed or made end of life plans, such as living wills (De Vries &

Gutman, 2016). Services may need to consider the role of patients' friends when developing service policies related to end of life care.

Although information sheets, such as the 'Trans Health Factsheet on Ageing – Rising to the challenge' (The National LGB&T Partnership, 2015b) have recently become available (see Appendix J), the literature reviewed and Sophie's comments would suggest this information is not yet being used routinely. Furthermore, services need to be sensitive to and facilitate personal choice, both for patients and for staff. This was highlighted by GPs in the 'patients have the right to EU/AS, but do not count on me' discourse, where GPs expressed that they should have the option to opt out of practices that are not in keeping with their personal values.

On a societal level

The debate regarding the legalisation of EU/AS in the UK is ongoing. However, as reported in the empirical paper, GPs have confused and limited knowledge regarding EU/AS which may hinder their ability to successfully engage in the debate. Opinions of the medical profession have previously been considered in parliament during debates (The Commission on Assisted Dying, 2012), and have contributed to decisions not to legalise EU/AS in the UK. Therefore, there may be a need, on a societal level, for a critical evaluation of the opinions that contribute to this decision making process. Both papers highlight the need for the recognition of individuals' values and rights to make life choices, whether that is related to gender expression or the right to opt out of providing a service that is not in line with personal values.

Implications for theory development and future research

Research philosophy

Many psychological and societal theories and models of aging, such as the successful aging paradigm, are underpinned by normative assumptions, including heteronormativity (Fabbre, 2015); the assumption in western cultures that biological sex, gender and sexuality have a 'natural' alignment (e.g. the expectation that females are feminine).

Models that are based on normative assumptions, such as heteronormativity, are perpetuating these assumptions through researching and describing people against these assumptions, and through the association of successful aging with people who meet these assumptions. The successful aging paradigm has been criticised for lacking consideration of inequality, gender and race (Fabbre, 2015). This criticism is particularly relevant for transgender people who might not meet the criteria of heteronormativity. Transgender older adults are more likely to experience victimisation, discrimination, a lack of social support and physical health problems associated with transition. They are therefore more likely to experience poor mental health, be reluctant to engage with professionals and are less likely to make end of life plans. Given these difficulties, heteronormative models would conceptualise transgender older adults as not aging successfully. This can also lead to a lack of specialist service provision for minority groups such as transgender older adults, as the services are aimed at people who meet the normative assumptions.

This perpetuating of normative assumptions and lack of service provision can further contribute to an internalised stigma (Maylon, 1982) of not meeting the expected behaviours and outcomes for one's grouping. Therefore, it is important to critically evaluate the use of these models in underpinning research and service provision.

While it must be acknowledged that transgender older adults are more likely to experience additional difficulties than the general older adult population, the question must also be asked; how helpful is it for research and services to be underpinned by models that are based on, and perpetuate, normative assumptions that may contribute to internalised stigma and that fail to consider positive aspects of transgender aging such as the development of a cohesive self? Indeed, Sophie stated that in her opinion academic research has a tendency to focus on the negative aspects of transgender aging and that this can be fear inducing.

The GPs' discourses regarding EU/AS also seem to be influenced by dominant research and care models that have normative assumptions. For example, within the palliative discourse, GPs spoke about the need for patients to have a 'good death'. GPs' descriptions of what a 'good death' would involve, appeared to be based on normative assumptions such as heteronormativity, the importance of independence and productivity. There was no reference made to gender, race or cohort effects. Furthermore, the impact of such normative assumptions was apparent in Lamers and Williams (2015) study of the discourses of older adults regarding EU/AS, who spoke about becoming dependent on others as an undesirable position.

Both studies, and Sophie's comments, suggest the need for increased development and use of models and theories of aging, communication, identity and social support that are not based exclusively on normative assumptions such as heteronormativity, independence and productivity. The development and use of such models and theories in research and service provision could in itself contribute to reducing (internalised) stigma as well as improving servicing provision for all, including minority groups.

Future research

While the 'palliative' discourse was consistent with the current UK legal position on EU/AS, the GPs' discourse that 'patients should have the right to EU/AS' is not consistent with the views of the majority of the GPs in other studies. One possible explanation for this inconsistency is that previous research, primarily large scale questionnaires, asks questions regarding GPs' views on EU/AS from the perspective that the GPs holds an active role in EU/AS. For example, a question in Seale's (2009b) study asks: 'A person with an incurable and a painful illness, from which they will die, for example, someone dying of cancer. Do you think that, if they ask for it, a doctor should ever be allowed by law to end their life, or not?' Such questions do not allow for the complexity of GPs' views.

When a survey included the option to make qualitative comments, (Seale, 2009b) those GPs who were in support of EU/AS stated that GPs should have the right to 'opt out' of involvement with EU/AS and that non-medical practitioners should be able to be involved. These added qualitative comments are consistent with the 'someone else should do it' discourse revealed by the GPs.

Furthermore, the wording used in questionnaires and the respondents' knowledge of EU/AS can bias responses (Hagelin, Nilstun, Hau, & Carlsson, 2004; Marcoux, Mishara, & Durand, 2007; Seale, 2009a). The finding that the GPs were not able to accurately define or distinguish between EU/AS, and that they were not opposed to EU/AS per se but rather opposed to their role in it, might bring a different perspective to the UK GPs' responses to such questionnaires regarding EU/AS.

When GPs considered that patients might have EU/AS as a potential end of life choice option, they felt that EU/AS was only acceptable if somebody was close to death, was

suffering a lot, and had a physical illness. They did not explicitly refer to the age at which death would occur nor the type of illness the patient would have. Future research investigating GPs' discourses regarding EU/AS when considering age or health condition might be worth exploring, as the older adults revealed an 'aged death' discourse (Lamers & Williams, 2015), where death was considered as the natural order and uneventful, and distinguished from untimely deaths in younger people. The discourses of other medical specialisms (e.g. oncology) and health professionals such as nurses, might reveal different discourses. The latter group might hold a very different discourse regarding EU/AS, as they seem to be the ones carrying out the decisions of their medical colleagues and are likely to be present when death occurs.

GPs described dementia as a 'tricky area' regarding EU/AS, due to patients' lacking the capacity to make end of life decisions. Dementia is also a concern for transgender older adults, who fear they will become confused about their gender and that professionals will deliver care based on their previous gender. Both studies highlight the need for further research into dementia and its impact on end of life decisions.

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Appendix A

School of Psychology Ethics Application

Appendix B

School of Psychology Ethical Approval Letter

Dear Emily,

2016-15670 General Practitioners and the euthanasia and assisted suicide debate in the United Kingdom: A Foucauldian exploration of their discourses

Your research proposal number 2016-15670
has been reviewed by the Psychology Ethics and Research Committee
and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

Appendix C

Betsi Cadwaladr University Health Board Research and Development West

Department R&D approval application

Appendix D

Betsi Cadwaladr University Health Board Research and Development West

Department approval letter

Appendix E

Advert

Appendix F

Information Sheet

Appendix G

Informed Consent Form

Appendix H

Interview Schedule

Appendix I

Example Transcript

Appendix J

Trans Health Factsheet on Ageing – Rising to the challenge

Appendix K

Word count statement