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Transgender women's experiences and beliefs about hormone therapy through and beyond mid-age: An exploratory UK study

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ABSTRACT

Background: Little is known about transgender women's beliefs and experiences of hormone therapy (HT), as part of their transition process, and particularly as they grow older.

Aims: This study aimed to investigate: (i) transgender women's experiences and attitudes to HT, and (ii) expectations of what might occur and/or what occurred after they reached "menopausal age."

Methods: Participants were recruited through invitations to an online survey sent to 138 Lesbian, gay, bisexual, transgender plus (LGBT+) support groups across the UK. Sixty-seven transgender women consented and completed the questionnaire; responses were analyzed using a mixed-methods approach. The beliefs about medicines questionnaire (BMQ) was used to assess beliefs about HT, while an inductive thematic qualitative approach was used to explore participants' personal expectations and experiences of HT and their views about the menopause.

Results: Participants were aged on average 49 years ranging from 20 to 79 years old. Most (96%) were taking HT. BMQ scores revealed strong beliefs about the necessity of HT and some concerns. Positive views about HT were expressed, with themes including treatment importance, personal and mental health benefits, but concerns about long-term effects, side effects, and maintaining access to the treatment were also mentioned. Views about menopause included uncertainty and questioning of its relevance; some mentioned changes to HT dosage, but most expected to use HT indefinitely.

Discussion: This study provides exploratory qualitative and quantitative information about transgender women's views about HT and menopause. Practical implications include improving access to HT and provision of evidence-based information about long-term use.

KEYWORDS

Expectations; hormone treatment; menopause; qualitative; trans women

Transgender is an umbrella term to describe "people whose gender identity, expression, or behavior is different from those typically associated with their assigned sex at birth" (National Center for Transgender Equality, 2016). The median age at which transgender individuals first visit a general practitioner (GP) with gender dysphoria in the UK is estimated to be 42 years (Reed, Rhodes, Schofield, & Wylie, 2009). Global prevalence data is currently limited and estimates vary depending on the specific definition of transgender identity and measures of gender dysphoria used. A meta-regression analysis of 12 recent surveys in the USA estimated a self-reported transgender-identity prevalence of 390 adults per 100,000, or approximately 1 million people across the USA in 2016 (Meerwijk & Sevelius, 2017). Research in the

Netherlands estimated incongruent gender identity rates in a Dutch population sample to be 0.8% of natal women and 1.1% of natal men (Kuyper & Wijzen, 2014). Figures were lower when combined with a dislike of their body and a wish to undergo surgery or hormone therapy (HT). In addition, a population study conducted in New Zealand found that 1.2% of participants self-reported a transgender identity in a nationally representative sample of high school students (Clark et al., 2014).

There is increasing interest in the health and wellbeing of transgender individuals; for example, in July 2017, the UK Government announced plans to review the Gender Recognition Act, with the aim of de-medicalizing the transition process, reducing discrimination, improving staff training, and removing nonessential gender enquiries in

official Government documents (Government Equalities Office, Dinanage, & Morgan, 2016). Proposals also include eliminating the requirement for a gender dysphoria diagnosis before an individual is able to apply for gender recognition (Government Equalities Office and The Rt Hon Justine Greening MP, 2017). In parallel, NHS England is conducting a review of the delivery of specialized gender identity services for adults (NHS England, 2017).

Transitioning can be a lengthy process, generally beginning with a diagnosis of gender dysphoria from a medical practitioner and consequently obtaining support through some form of suitable counseling during the transition process. Gender dysphoria is categorized in the most recent version of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, DSM-5 Task Force, 2013) as “the distress that may accompany the incongruence between one’s experienced or expressed gender and one’s assigned gender.” The recent change in diagnosis from gender identity disorder to gender dysphoria reflects an increased focus on individual experiences of discomfort and distress relating to gender incongruence. Decisions are then made with regards to having HT, living life in the preferred gender and about surgery. Updated guidelines from the World Professional Association for Transgender Health (Coleman et al., 2012) recognize that while some transgender individuals require surgery and/or HT to relieve their gender dysphoria, others may find psychotherapy or gender role changes to be adequate. Therefore, individuals may benefit from a variety of different therapeutic pathways and undergo different processes of identity affirmation.

HT is one choice within the transition process that aims to reduce gender dysphoria by increasing self-esteem, self-acceptance, and reducing feelings of distress (Ashbee & Goldberg, 2006). HT can also alter physical appearance, for example, breast development, reducing facial hair growth, and reducing muscle bulk (Gender Identity Research and Education Society, 2007). Some changes are reversible if the individual stops taking HT and the use of some hormones, such as estrogen, can commonly be a life-long

process (Ashbee & Goldberg, 2006; International Medical Advisory Panel, 2015). However, continuation or adaptation of HT use across the life-span is likely to depend on a physician’s decision related to comorbidity risks, gender affirming surgeries, patient goals, medication risks, and social or economic issues (Coleman et al., 2012). Estrogen is used to enhance physical female characteristics, while anti-androgens block the effects of testosterone; progestogens are less commonly used. Transgender individuals are encouraged to have regular medical checkups, adopt a healthy lifestyle and stop smoking before commencing the transition process, but there is little guidance about what happens when they reach the age when women typically go through the menopause. In addition, little is known about transgender women’s experience of, and attitudes to, HT, particularly long-term use, nor about their views about what might happen when they reach the age when cisgender women typically go through the menopause.

A systematic review conducted by Colizzi and Costa (2016), investigating the effect of HT among individuals with gender dysphoria found that HT is associated with improved emotional functioning and self-esteem. Despite the benefits of HT, the long-term risks and side-effects are not yet fully understood and several potential complications have been investigated, such as deep vein thrombosis, pulmonary embolisms, altered liver functioning, and changes in blood pressure (Gender Identity Research and Education Society, 2007). However, it is difficult to predict the potential for any adverse effects in an individual, and constant changes or improvements to HT medications and their administration have reduced risks. For example, transgender women with risk factors for venous thromboembolic events, such as those who are over 40 years old or obese, are no longer recommended to use ethinylestradiol (Coleman et al., 2012). Alternative recommended estrogens include transdermal estrogens and estradiol valerate (Shatzel, Connelly, & DeLoughery, 2017).

There are gaps in knowledge about transgender health within the UK medical system, with few specialists in the area and reports of transgender people feeling dissatisfied (Mackinnon, Tarasoff,

& Kia, 2016; Zeluf et al., 2016). There is also a lack of research to understand transgender people's beliefs and experiences of HT as an aspect of their transition process, particularly in the long term, as well as no clear conclusions on the adverse effects of long-term HT use (Unger, 2016).

This study uses mixed methods to address two main questions:

1. What are transgender women's personal expectations of reaching the typical age of menopause, and/or their experiences if they are over 50 years of age (the typical age of menopause)?
2. What are transgender women's beliefs and personal experiences of HT?

Materials and methods

Study design

A mixed-methods cross-sectional approach was used to investigate beliefs about menopause and HT, as well as personal expectations and experiences. Quantitative methods were used to measure beliefs about HT, while qualitative methods were used to explore participants' expectations and experiences of menopause, and beliefs and experience of HT. An online survey was developed using a standardized measure and open questions.

Participants

Transgender women were recruited by contacting transgender support groups listed by Gender Identity Research and Education Society (2017), that is, 138 groups across the UK. Of these, 29 agreed to share the online survey with their members, either through their website, social media sites or mailing lists, and 67 responses were received by the established cutoff date of 30.9.2017. Participants were also recruited through personal contacts and events targeted specifically for the transgender community. They were approached through online invitations that included the online questionnaire link, not directly by the researcher, thus ensuring anonymity. Informed consent was obtained from all individual participants included in the study through

completion of sections of the online survey and participants had the right to exit the survey at any point by simply closing the browser window.

Inclusion criteria were: aged 18 years or above, and self-identifying as a transgender female, rather than somewhere else on the gender or sex spectrum, such as gender fluid or intersex.

Measures

The beliefs about medicines questionnaire (BMQ) is a validated measure, initially developed using a sample of 524 patients with chronic illness, that is, asthmatic, diabetic, and psychiatric outpatients and cardiac, general medical, and renal inpatients (Horne, Weinman, & Hankins, 1999). The BMQ is used in the current study to measure transgender women's beliefs about HT, as it relates to gender transitioning. There are two subscales that assessed beliefs about the necessity of HT and concerns about potential harmful consequences. All BMQ items are scored on a 5-point Likert scale (1 = strongly disagree, 5 = strongly agree), with higher scores demonstrating stronger beliefs within each subscale. The BMQ has a high internal consistency (Cinar et al., 2016; Saks, Wiebe, Cory, Sammel, & Arya, 2012; Salgado et al., 2013), and has been used to assess beliefs about hypertension (Mostafavi, Najimi, Sharifirad, & Golshiri, 2016), chronic obstructive pulmonary disease (Krauskopf et al., 2015), stroke (Chambers et al., 2011), and asthma (Horne et al., 1999). All the BMQ items were modified to be HT-specific. The survey was piloted on five transgender women and minor amendments made in response to feedback, before being made available online from April to September 2017. The final survey consisted of: a participant information sheet; background information [age, ethnicity, level of education, employment status, parity, general health (poor, fair, good, very good, excellent)] and HT use; the BMQ and open questions eliciting expectations, and experiences of menopause and HT.

The study was granted ethical approval by King's College London Research Ethics Committee (LRU-16/17-4495) on 3rd April 2017.

Data analysis

The quantitative data analysis was conducted using SPSS (Version 23). Correlations and Chi square tests were used to investigate associations between background factors and HT beliefs.

Inductive thematic content analysis was considered an appropriate approach for exploring this novel research area. Braun and Clarke's (2006) thematic analysis guide was followed, which enabled exploration and identification of frequent themes and subthemes within participant responses. A researcher (Sophie Mohamed) read through all open-question responses several times to maximize familiarity with the data before initiating the coding process. All coding was conducted using NVivo 11 software, commencing with coding units of meaning for both menopause and HT-related responses within each individual questionnaire. Codes with similar meanings were then grouped together and revised to identify potential main themes and sub-themes; these were then checked by a second researcher (Myra Hunter) and amendments made.

Results

Sample characteristics

The sample consisted of 67 transgender women with a mean age of 48.67 years ($SD = 14.87$), mode = 43, ranging from 20 to 79 years old. The participants predominantly identified as of white ethnicity ($n = 64$, 96%), with a range of education levels (approximately two-thirds having education up to 16 years and one-third 18 years plus), and equal proportions were parents ($n = 33$, 49%) and non-parents ($n = 33$, 49%). More than half were employed full-time (55%), and 63% described their general health as very good or excellent. The majority were taking HT at the time of recruitment ($n = 64$, 96%), and average duration of HT was 7.20 ($SD = 8.32$) years; 96% were taking estrogen, 13% taking progestogens, and 51% taking anti-androgens (see Table 1).

Menopause: Personal expectations and experience

Thirty-three participants (49.3%) were less than 50 years old and 34 (50.7%) were aged 50 or over.

Qualitative results

Regardless of age, many participants expressed the view that menopause is not a subject relevant to transgender women, due to biological differences between them and women going through a natural menopause. For example, they mentioned that they had never considered it, that it was irrelevant, not applicable, or they did not give it much thought.

The majority of those aged 50 or over did not report having experience of the menopause. For example, "Past 50, twenty years ago! Somewhat irrelevant" (P33); "I was over 50 when I started. I'm not interested, and quite opposed, to experiments with mimicking menopause" (P4). However, some described physical changes during mid-age such as reduced energy levels, mood swings, increased emotions, and a lowering of libido. Others mentioned feeling familiar with menopause type changes because they had had hot flushes and/or mood swings when stopping HT or changing doses in the past. Nevertheless, most had continued their HT, while some had changed the dose or type of HT. For example, "I was changed from tablet to patch. This took time to balance and get the dose correct" (P31). However, there was uncertainty and concern about long-term use. "I've not changed my prescription. No one seems to know what the effect would be" (P49). "My GP and I discussed relative risks and benefits of long-term HT and on balance we were both content that I continue to take it for ever" (P58).

In terms of menopause expectations, a number of participants had no expectations of what might happen when they reached "menopausal age." Many stated they had no idea what to expect. Some expected their HT regimen to change at "menopausal age," in order to simulate the hormone changes of women going through menopause. For example "I would assume that my prescription would change to lower oestrogen levels" (P22). As a result some anticipated having menopausal symptoms such as hot flushes, lowering of libido and energy, or mood changes. Several participants mentioned that they would rely on medical professional advice: "I would not drop the target oestrogen blood level without

Table 1. Sample characteristics, treatment use, and general health.

	Sample (<i>N</i> = 67)
Age (years)	
Mean (<i>SD</i>)	48.67 (<i>SD</i> = 14.87) range = 20–79
Ethnic group	
White	64 (96%)
Mixed ethnicity	3 (4%)
Highest level of education	
No educational qualifications	11 (16%)
O level 16 years	34 (51%)
A level 18 years	12 (18%)
Degree/professional	10 (15%)
Employment	
Full-time (30+ hours per week)	37 (55%)
Part-time (<30 hours per week)	18 (27%)
Retired	6 (9%)
Unemployed	2 (3%)
Other	4 (6%)
Parent	
Yes	33 (49%)
No	33 (49%)
Other	1 (2%)
Taking HT	64 (96%)
Number of years since starting HT	7.20 (<i>SD</i> = 8.32) range 0–36.5 years
Estrogen	
Oral	28 (42%)
Transdermal	11 (24%)
Injection	4 (6%)
Gel	12 (18%)
Combination (injection + gel, injection + oral, injection + patch, gel + oral)	4 (6%)
None	3 (4%)
Progestogen	
Oral	8 (12%)
Gel	1 (1%)
None	58 (87%)
Anti-androgen	
Oral	23 (34%)
Injection	10 (15%)
Oral + injection	1 (2%)
None	33 (49%)
General health rating	
Poor	2 (3%)
Fair	5 (7%)
Good	18 (27%)
Very good	30 (45%)
Excellent	12 (18%)

expert advice from an endocrinologist experienced in these matters” (P33). Others expected that nothing would change, and argued that they intended to continue their HT regimen throughout their life. The choice of experiencing menopause as a transgender woman was also discussed, with several participants describing an awareness of their control over whether to experience menopause or not: “I have the option of never experiencing it” (P12).

Beliefs and experience of HT

Quantitative results

Mean BMQ subscale scores for the sample revealed high HT necessity beliefs across both age groups (below 50 and 50 plus) with a mean score of 20.69

(*SD* = 3.1), while the concerns about HT use proved to be relatively low (*M* = 9.48, *SD* = 3.84). Mean scores from other studies of a variety of health conditions are shown in Table 2 for comparison, including adrenal insufficiency (Tiemensma et al., 2014), acromegaly (Andela et al., 2015), asthma and diabetes (Horne et al., 1999), and HIV (Gauchet, Tarquinio, & Fischer, 2007).

Beliefs about HT, that is, BMQ scores, were not associated with age, duration of HT use, general health ratings, nor other demographic factors such as level of education, having had children, employment status ($p > .05$).

Qualitative results

Overall, the transgender women in this sample expressed generally positive beliefs and

Table 2. Means and standard deviations of BMQ scale scores for HT and a range of health conditions for comparison.

Health problem	BMQ-necessity beliefs	BMQ-concerns
HT (<i>n</i> = 67)	20.69 (3.14)	9.48 (3.84)
Adrenal insufficiency (<i>n</i> = 107)	19.62 (2.43)	18.39 (2.89)
Acromegaly (<i>n</i> = 28)	17.04 (3.54)	17.75 (2.61)
Asthma (<i>n</i> = 78)	19.67 (3.23)	15.76 (4.09)
HIV (<i>n</i> = 127)	16.06 (4.47)	10.92 (3.28)
Diabetes (<i>n</i> = 99)	21.26 (2.98)	12.91 (3.38)

experiences of HT, as part of their gender transitioning. The following main subthemes included: importance of HT, physiological changes, personal and mental health benefits, HT concerns and side effects, and social implications.

Importance of HT. Participants expressed fairly consistent beliefs that HT is a life-changing treatment and an important component of their transition. The use of the words “essential” and “vital” was strikingly common in participant responses: “HT is essential for my transition” (P15).

Physiological changes. Many participants mentioned that HT was beneficial in increasing the feminization of their appearance, such as softer skin, reduced body hair, loss of upper body musculature, prevention of male-pattern balding, as well as breast development. Other physical changes included improvements in levels of acne and gaining a younger appearance. Several mentioned that HT resulted in changes to their sexual experiences, with reduced libido proving to be a particularly common experience: “I’m much happier with my lower sex drive” (P42).

Personal benefits. Many participants expressed a belief that HT has improved their self-confidence, comfort, and connection with their own bodies: “For me, it is essential to feeling comfortable and happy in my skin” (P5). They often identified that HT was beneficial in relieving their identity issues and described a sense of satisfaction from the use of HT: “It enables me to carry out my life in a way that makes me happy” (P21).

Mental health benefits. Improvements to mental health and mood were commonly mentioned; for example, “the physical changes are actually almost secondary to the improved mental

changes” (P37), and “Without this [sic] tablets, I don’t believe 30–40% of the transgender community would be here today due to depression” (P20). Reduced feelings of gender dysphoria were also mentioned: “it gives me the chance to quell most of the dysphoria that I face” (P26). Many mentioned that they experienced a greater range of emotion, and an improved emotional state, such as feeling calmer, due to HT: “It’s made accessing my emotions in a healthy way easier” (P31).

HT concerns. Several participants (10/67) expressed concerns about the potential long-term effects of HT use, despite the relatively low BMQ concern scores overall. Others mentioned worry about being dependent on medication, getting the dose right, remembering to take life-long medication, and the expense of HT. For example, “It’s very stressful to be dependent on medications. There’s also a concern over the lack of studies on the long term effects of HT” (P1); “Increased risk of estrogenic cancers” (P24); “In the wrong dose it has a detrimental effect” (P31).

Several participants (10/67) described difficulties associated with obtaining and renewing HT prescriptions, and concerns about having access to HT: “I worry if I lose access to it I may have adverse health consequences” (P5); “Worry that it could be taken away” (P50). There was also concern about inadequate understanding and support for transgender people from health professionals, “Embarrassing questions! Why doctors qualified in giving just about anything but still can’t supply HT” (P62); “GPs need more training on transgender needs” (P42).

HT side effects. The belief that there are no negative side effects of HT was a common response among participants. Several participants reported negative emotional experiences such as mood swings, irritability and depression, especially in the early stages of HT use: “As someone with a history of mental illness, the emotional instability I experienced when commencing HT and increasing dose is something I find distressing” (P31). Physical side effects of HT use such as loss of stamina, fatigue, hot flushes, and skin irritation were common experiences.

Social implications. Positive experiences included increased feelings of blending in with society and improved gender identification from others: “lead to society being more likely to correctly gender me” (P23). Alternatively, some participants reported negative social experiences, such as increased transphobia and isolation from close friends and family members that they attributed to deciding to undergo HT.

Discussion

The use of a mixed-methods approach enabled an in-depth exploration of the beliefs, expectations, and experiences of transgender women. While the sample size was not extensive, the study included transgender women, across the age range (mean 49 years, range 20–79 years) and across educational levels, recruited from across the UK. There was also a wide range of duration of HT use with an average of 7 years and a range of 0–36 years, suggesting that HT was started when the sample were on average approximately 42 years old. These findings are consistent with the estimated median age, of 42 years, when transgender individuals first visit a doctor in the UK regarding feelings of gender dysphoria (Reed et al., 2009).

The qualitative data provided a range of views about what might happen when they reached the age of menopause. There was a general dismissal of the relevance of menopause and most participants expected to continue with HT indefinitely. However, some expected that HT dosage or regimes (oral to patches) might change at “menopausal age,” while others expressed uncertainty or believed that their experiences would depend on professional medical advice and personal choice.

The perceived necessity of HT for gender transition was clearly evident from both the quantitative and qualitative analyses. Interestingly, the BMQ scores for trans women in this sample were similar to those of diabetic patients, reflecting high necessity and relatively low concerns about the medication. There were no significant associations between BMQ scale scores and duration of HT use or sociodemographic variables, suggesting that high need and relatively low concerns are

common among transgender women, regardless of background, age, or length of HT use.

Similarly, the qualitative findings highlighted its personal benefits in improving confidence, body satisfaction, and reducing identity conflict. Most participants emphasized the importance of HT to their gender transition, and to their physical and mental health. Concerns that were expressed included uncertainty about potential long-term safety, having to correctly adhere to life-long medication, having and retaining access to the treatment and receiving appropriate information and support from health professionals. Several physical and emotional side effects were mentioned particularly at the early stages of HT use. These results highlight potential areas of improvement in transgender healthcare, such as GP training, as well as practical concerns regarding the use of HT, such as safety and access to the medication.

Limitations of the study include the use of an online survey and a self-report questionnaire, which may have introduced bias in the sample, for example, having access to computers. Although the researchers had no direct interactions with participants, their personal views may have influenced the qualitative analysis. However, the researchers do not hold any particular personal agendas in relation to this research. There was a fairly low uptake of participants to the study overall. Some transgender women made direct contact to express hesitation in participating due to a belief that transgender research does not result in changes to practice, and two participants no longer self-identified as transgender after completing gender transition. Moreover, the numbers of participants spread across a large age range spanning 59 years is a limitation, as the ideas and representations of the menopause, and its relevance, may have varied between younger and older individuals. It may be difficult for younger transgender women to imagine menopause, but it is likely to be more relevant to mid-aged and older transgender women.

The findings have some practical implications, for example, in addressing transgender women’s needs for evidence-based information to tackle uncertainty and concerns about HT, especially if used long term (Gender Identity Research and

Education Society, 2007; Gooren & Lips, 2014). The results suggest a need for improved communication and clarity around service provision of transgender healthcare, including the need for up to date information about long-term health risks and regular monitoring (Gooren & Lips, 2014), and information about what might happen when they reach “menopausal age” and about continuity of access to HT. Lack of availability of appropriate services and long waiting lists may lead to people accessing HT through online suppliers. GPs may be asked to supply prescriptions for treatments that were initiated privately or through on-line suppliers, and have expressed concern that they lack the relevant experience to prescribe hormonal drugs and to provide specialist care (Aziz, 2017; Rimmer, 2017). Greater access to treatment might be achieved by increasing the number of trained staff as well as the number of transgender health centers, or gender identity clinics, as suggested in the recent review of the Gender Recognition Act (Government Equalities Office et al., 2017) and the review of the delivery of specialist services for people aged over 17 years (NHS England, 2017).

Future research might replicate this study with larger representative samples of transgender women, across the age range. Further studies to assess the safety of both long and short-term HT use in younger and older adults are essential, and studies of cohort differences would be of interest, given the increase in numbers of younger transgender individuals. Another possible area would be to explore transgender men’s personal experiences, beliefs and expectations of menopause and HT. This might be of particular interest as trans men are likely to have different experiences, depending on the level of their transitioning and use of gender-confirmation surgery.

In conclusion, this exploratory study of transgender women provides information about their beliefs and experiences of HT and views about menopause. Menopause was generally not considered to be particularly relevant, in light of biological differences between trans and cisgender women. HT was seen as essential to gender transition, but some concerns were expressed about the long-term safety of, and access to, it. Transgender women also expressed uncertainty

regarding clinical management approaches at and beyond the “menopausal age,” as well as for those beginning HT at this age. This ambiguity reflects the lack of consensus on HT management within healthcare provision and the lack of empirical evidence relating to long-term effects after age 50.

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Conflict of interest

The authors declare that they have no conflict of interest.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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