

International Journal of Transgender Health



ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/wijt21

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To cite this article: Maeghan B. Ross, Tim C. van de Grift, Els Elaut, Timo O. Nieder, Inga Becker-Hebly, Gunter Heylens & Baudewijntje P. C. Kreukels (2021): Experienced barriers of care within European treatment seeking transgender individuals: A multicenter ENIGI follow-up study, International Journal of Transgender Health, DOI: 10.1080/26895269.2021.1964409

To link to this article: https://doi.org/10.1080/26895269.2021.1964409

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Experienced barriers of care within European treatment seeking transgender individuals: A multicenter ENIGI follow-up study

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ABSTRACT

Objectives: To evaluate the experienced barriers of care for treatment-seeking trans individuals (TSTG) in three large European clinics.

Methods: An online follow-up questionnaire was filled out by 307 TSTG individuals as part of the research protocol of the European Network for the Investigation of Gender Incongruence (ENIGI). Data was collected during follow-up in 2017/2018, around 5 years after participants had their initial clinical appointments in Ghent (Belgium), Amsterdam (the Netherlands), or Hamburg (Germany). Background characteristics, country, treatment characteristics and mental health were analyzed in relation to experienced barriers of care (EBOC, measured though agreement with statements).

Results: The majority of participants reported various EBOC, oftentimes more than one. The most-frequently reported EBOCs pertained to the lack of family and friends' support (28.7%, n=88) and travel time and costs (27.7%, n=85), whereas around one-fifth felt hindered by treatment protocols. Also, a significant share expressed the feeling that they had to convince their provider they needed care and/or express their wish in such way to increase their likelihood of receiving care. A higher number of EBOCs reported was associated with more mental health problems, lower income and female gender.

Conclusions: A substantial number of TSTG individuals within three European health care systems experiences EBOCs. EBOCs relate to both personal and systemic characteristics. These findings can help health care providers and centers to improve care. More research must be done to better understand the diversity among TSTG individuals and the corresponding barriers experienced.

KEYWORDS

Barriers to care; health services accessibility; transgender; transgender health care; ENIGI

Introduction

Health care access is defined as the opportunity of individuals to identify health care needs, seek health care services, and to reach, obtain or use health care services (Levesque et al., 2013). More often than not, the individual's access to care is mirrored by systemic, cultural, and individual level issues within the health care sector (James et al., 2016). In a global sense, accessing care is influenced by multiple dimensions including affordability, availability, acceptability, approachability and appropriateness (Levesque et al., 2013). Roncarolo et al. defined challenges within health

care systems as emerging and enduring problems, both personally and systemically, that destabilize the current functioning or sustainability of health care services (Roncarolo et al., 2017). On an individual level, health care access may depend on literacy, socioeconomic and identity factors (Levesque et al., 2013). For the purpose of this paper, experienced barriers of care (EBOC) will be defined as factors leading to unmet needs, or delayed, limited or prevented access to care. These factors may make accessing, maintaining, and using adequate health care services more difficult.

Generally speaking, the term "gender identity" refers to an individual's identified gender, which

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Description Supplemental data for this article is available online at https://doi.org/10.1080/26895269.2021.1964409

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is often assumed to be in line with individual's gender assigned at birth and following the normative binary categories of male or female (i.e., cisgender). Individuals who experience their gender identity as being incongruent with the gender assigned to them at birth often ascribe to identities such as trans masculine, trans feminine, non-binary, and many other gender identities (altogether frequently grouped as transgender) (Nolan et al., 2019). Compared with cisgender individuals, the prevalence of EBOCs is notably high within transgender populations (Gonzales & Henning-Smith, 2017; Seelman et al., 2017). In addition to barriers experienced in general, non-transition-related care (i.e., treatment for chronical illness, emergency medicine, visits to the general practitioner), treatment-seeking transgender individuals (TSTG) often experience specific additional barriers when accessing specialized gender-affirming psychological, hormonal and/or surgical care (Cicero et al., 2019; Roberts & Fantz, 2014; Safer et al., 2016).

Previous research has provided insight into the specific EBOC of TSTG individuals (Edmiston et al., 2016; European Union Agency for Fundamental Rights, 2020; Fuchs et al., 2012; Grant et al., 2011; LesMigraS, 2012; Loos et al., 2016). The reported barriers included financial barriers (e.g. lack of insurance and income), discrimination, lack of specialized health care providers, health systems barriers (e.g. insufficient electronic records, forms, lab references, unfit or ill-equipped clinical facilities), socioeconomic barriers (e.g. transportation) and mental health barriers (Grant et al., 2011). Additionally, a wide range of both (mostly) negative health care experiences impacting access to care have been described (Burgwal et al., 2019; Riggs et al., 2014). A few examples include being denied services, being subjected to inappropriate terminology and having one's own knowledge discounted by health professionals, poor knowledge of providers, as well as experiencing considerable waiting periods when accessing services (Puckett et al., 2018). Recent research has also looked into the differences of EBOCs within the trans population, such as the differences between binary or non-binary identifying individuals, when gender-affirming care (Burgwal & Motmans, 2021).

Yet, some barriers may be cultural or health care system-specific, and studies describing the experiences of TSTG individuals within different geographical contexts are scarce (Bauer et al., 2009; Burgwal et al., 2019; Cobos & Jones, 2009; European Union Agency for Fundamental Rights, 2020; Eyssel et al., 2017; Motmans et al., 2015; Safer et al., 2016). In contrast to the US, the European gender-affirming health care systems are often characterized by centralized multidisciplinary centers. These centers are generally dependent on broader health care systems and insurance regulations, that rely on diagnostic criteria for the provision of coverage. Comparable to US studies, a recent report by the European Union Fundamental Right's Agency (FRA), described that increased openness to health care personnel about being transgender was directly linked to more additional negative experiences and increased discrimination (European Union Agency for Fundamental Rights, 2020). Based upon the data of the FRA, when evaluating the individuals access to trans health care within the three countries, Germany scored 2nd for highest incidences of discrimination experienced by health care personnel, while the Netherlands ranked at 9th and Belgium ranked at 12th (European Union Agency for Fundamental Rights, 2020). Knowing and given the effectiveness of gender-affirming treatments, it is of great importance for transgender individuals to be able to access care with limited EBOC in order to avoid unnecessary mental and physical health problems (Bränström & Pachankis, 2020; Dhejne et al., 2016; van de Grift et al., 2017).

The aim of the study was to describe the EBOC reported within a follow-up cohort of TSTG individuals seeking gender-affirming care in three European multidisciplinary trans health care centers. The present study primarily sought to gain insights into the EBOC per center, as well as to identify characteristics of individuals at risk for experiencing barriers. A secondary study aim was to assess performative aspects by TSTG individuals to increase their access to care (e.g., behaviors/actions of TSTG individuals to increase access such as expressing themselves in specific ways).



Methods

Study procedure

This study was initiated by the European Network for the Investigation of Gender Incongruence (ENIGI), which is a collaboration between four high-volume European clinics specialized in gender-affirming care, located in Amsterdam (the Netherlands), Ghent (Belgium), Hamburg (Germany) and Oslo (Norway). The participating clinics have applied similar assessment batteries available for research. In the present study follow-up data collected by the clinics in Amsterdam, Ghent and Hamburg around 5 years after initial referral will be described. A detailed description of the ENIGI procedures can be found elsewhere (Kreukels et al., 2012), as well as the full design of the current follow-up study (van de Grift et al., 2017). Additionally, Appendix 1 provides a summary of clinic-specific care provided within each of the three centers. This study was approved by three local ethics committees—Amsterdam, Ghent and Hamburg (van de Grift et al., 2017)-and therefore, only the aforementioned three clinics participated in this follow-up study.

Eligible participants were TSTG individuals (≥ 17 years at clinical entry) who had their initial clinical appointment and participated in the ENIGI study between 2011 and 2013 (ENIGI FU Wave 2¹). Candidates were invited via telephone, email or post to fill out an online follow-up questionnaire between September 2017 and April 2018. Individuals were asked to participate regardless of whether they had received medical interventions or not. Non-responders were sent a reminder after one month. Informed consent was provided online or in written form. The online survey was provided on a secured platform and, upon providing consent, respondents received a personalized link via e-mail from their clinic. All data was stored in Hamburg, and reviewed and cleaned centrally in consultation with the including sites.

Participants

A total of 543 individuals who participated at clinical entry were invited to participate in the study of whom 349 individuals both consented and filled out the survey at follow-up (ENIGI

FU Wave 2) (64%). For the present study aim, 307 participants had data completed (Amsterdam n = 172, Ghent n = 84, Hamburg n = 51). At the time of initial data collection (clinical entry), questionnaires were still binary, and participants were categorized as trans women/feminine (assigned male at birth; n = 166) or trans men/ masculine (assigned female at birth; n = 141). Two individuals had not received any medical interventions at time of follow-up and data was missing for one individual. Furthermore, 40 participants received hormonal therapy only, two received (chest) surgery only, and 262 received both hormone therapy and surgery (Table 1).

Outcome measures

Background data

Background data at follow-up were collected using self-developed questionnaires (Kreukels et al., 2012) on gender identity, sociodemographic characteristics (education level, income level: below/around/above poverty line specified for each country), relationship status, and treatment information. Participants provided information about the gender-affirming treatments they had received until the time of follow-up on predefined lists. This data was cross-verified centrally using patient records and grouped into most common treatment combination groups. Data regarding the remaining gender-affirming treatments that participants desired had been collected within the baseline studies but was not included in the context and scope of this study. Lastly, participants filled out whether they had any remaining treatment wish (no/unsure/yes).

Additionally, the SCL-90 was used to assess participant's self-reported psychological burden on 9 symptom scales: somatization, obsessive compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoneuroticism (Derogatis, 1983). The SCL-90 was chosen as the measure for psychological burden in line with the ENIGI baseline studies.

Experienced barriers to care

Participants were provided with a closed list of questions regarding possible EBOC and were

Table 1. Sample characteristics.

	All	The Netherlands	Belgium	Germany	
	(n = 307)	(n = 172)	(n = 84)	(n = 51)	Test statistics
Age, M (SD)	36.7 (13.1)	37.5 (13.5)	34.8 (12.3)	37.1 (12.9)	F(2,293) = 1.2, P = .29
Gender identity, n (%)					$\chi^2(2) = 3.5, P = .18$
Trans feminine	166 (54.1)	94 (54.7)	50 (59.5)	22 (43.1)	
Trans masculine	141 (45.9)	78 (45.3)	34 (40.5)	29 (56.9)	
Marital status, n (%)					$\chi^2(8) = 6.4, P = .59$
Single	169 (55.8)	99 (58.2)	45 (54.2)	25 (50.0)	
In a relationship	54 (17.8)	29 (17.1)	13 (15.7)	12 (24.0)	
Married	45 (14.9)	23 (13.5)	13 (15.7)	9 (18.0)	
Divorced	14 (4.6)	6 (3.5)	7 (8.4)	1 (2.0)	
Other	21 (6.9)	13 (7.6)	5 (6.0)	3 (6.)	
Education level, n (%)					$\chi^2(4) = 7.5, P = .11$
Basic	22 (7.3)	12 (7.1)	7 (8.4)	3 (6.0)	
Secondary	160 (52.8)	85 (50.0)	40 (48.2)	35 (70.0)	
Tertiary	121 (39.9)	73 (42.9)	36 (43.4)	12 (24.0)	
Income level, n (%)					$\chi^2(4) = 9.3, P = .06$
Below poverty line	60 (19.8)	40 (23.5)	11 (13.3)	9 (18.0)	
Around poverty line	72 (23.8)	45 (26.5)	14 (16.9)	13 (26.0)	
Above poverty line	171 (56.4)	85 (50.0)	58 (69.9)	28 (56.0)	
Employment status, n (%)					$\chi^2(4) = 21.0, P < .001$
Employed	216 (71.8)	104 (61.5)	68 (82.9)	44 (88.0)	
Unemployed	82 (27.2)	62 (36.7)	14 (17.1)	6 (12.0)	
Other	3 (1.0)	3 (1.8)	_	_	
Treatments received trans masculine					$\chi^2(8) = 33.3, P < .001$
participants, n (%)					,
None	_	_	_	_	
Hormones only	5 (3.6)	2 (2.6)	1 (2.9)	2 (6.9)	
Mastectomy only	2 (1.4)	1 (1.3)	_	1 (3.4)	
Hormones and mastectomy	97 (69.3)	62 (80.5)	12 (35.3)	23 (79.3)	
Hormones, mastectomy and metoidioplasty	8 (5.7)	3 (3.9)	5 (14.7)	_	
Hormones, mastectomy and phalloplasty	28 (20.0)	9 (11.7)	16 (47.1)	3 (10.3)	
Treatments received trans feminine	, , , ,	,		, , , ,	$\chi^{2}(6) = 9.7, P = .14$
participants, n (%)					K ()
None	2 (1.2)	1 (1.0)	_	1 (4.5)	
Hormones only	35 (21.1)	17 (18.0)	10 (20.0)	8 (36.4)	
Hormones and breast augmentation	9 (5.4)	3 (3.2)	5 (10.0)	1 (4.5)	
Hormones and vaginoplasty	120 (72.3)	73 (76.8)	35 (70.0)	12 (54.5)	
Missing	. 20 (, 2.5)	1 (1.0)	33 (, 3.3)	(55)	
Further treatment wish, n (%)		. ()			$\chi^2(4) = 2.2, P = .70$
No	106 (34.5)	61 (35.5)	29 (34.5)	16 (31.4)	/ (·/, · · ·/ ·
Unsure	70 (22.8)	37 (21.5)	23 (27.4)	10 (19.6)	
Yes	131 (42.7)	74 (43.0)	32 (38.1)	25 (49.0)	
SCL-90R, GSI (follow-up), M (SD)	1.63 (.65)	1.63 (.68)	1.72 (.69)	1.50 (.44)	F(2,285) = 1.99, P = .14

SCL-90R, Symptom Checklist 90-Revised; GSI, Global Scale Index.

asked whether they had experienced this barrier during their treatments (yes/no). The list included items on: matching the treatment protocol (e.g., following the predefined/assumed treatment pathways (orders and types of treatment)-psychological, endocrinological, surgical, experiences with the treatment protocol in general, referrals for care, co-existing psychological or medical conditions, problems with relatives, travel time and costs associated with the treatment, and fear of treatment consequences (e.g., post-surgical complications, genital function). Similarly, participants were asked if they felt as though they had to perform in certain ways to secure access to care (yes/no) through answering statements on the perceived need to convince health care providers to access care, and on investigating how

to increase chances of receiving care. Lastly, participants were asked if they, looking back, would now have expressed their gender identity and treatment wishes differently when entering care.

Data analyses

To perform country-specific analysis in regression analysis, dummy variables were created. Educational level was recoded per country into basic, secondary and tertiary educational level. Descriptive statistics were used to analyze the outcome variables, including means (SD) and frequencies (%). Country differences were calculated using one-way ANOVA (continuous data) or Chi-squared tests (ordinal data) after which effect sizes were calculated accordingly. Multiple

binary logistic regressions were performed to test the predictive values of sociodemographic characteristics, country and treatment characteristics (i.e., SCL-90) on the separate barriers using a backwards linear approach. A p-value of <0.05 was considered to be significant. All analyses were performed in SPSS version 26.0.

Results

Sample characteristics

Table 1 displays the characteristics of the study sample by country. In the sample as a whole, there was slightly higher number of trans feminine participants; the mean age at participation of all participants was 36.7 years (SD = 13.1). The majority of participants were highly educated and employed with an income level above the poverty line, yet a significant number of Dutch participants reported unemployment (36.7%) when compared with participants from other countries (12 and 17%). Trans feminine participants most frequently received hormones and vaginoplasty, whereas mastectomy and hormones were the most frequently reported care path aspects among trans masculine participants. Masculinizing genital surgeries were significantly more frequently reported by the Belgian sample compared with the other countries. Two in three participants reported to (possibly) want further treatment.

Prevalence of EBOCs

A total of 189 participants reported experiencing one or more EBOC, with no participants reporting experiencing six or more. The mean number of EBOC per country differed with the Netherlands presenting the highest average number of EBOC (1.4 (SD = 1.4)), in Belgium 1.2 (SD = 1.3),whereas German participants described experiencing an average of 0.9 (SD = 1.1). Table 2 describes the participants' EBOCs ranked by the frequency in which they were mentioned. Overall, the most commonly reported EBOCs were issues with family and friends (28.7%, n = 88), travel time and costs (27.7%, n=85), treatment protocol in general (21.5%, n = 66) and fear of treatment consequences (15%, n = 46); whereas, the least

commonly reported EBOC was referral to care (4.2%, n=13). When comparing the three centers, three EBOC were statistically significantly different — barriers with travel time and costs were most frequently experienced in Belgium and the Netherlands (Cramer's V=.17), barriers with the treatment protocol in general were mostly experienced in the Netherlands (Cramer's V=.26) and barriers relating to the fear of treatment consequences were most frequently experienced in Belgium (Cramer's V=.17). With this dataset, participants from Germany never reported significantly higher rates of any of the EBOCs when compared to the other countries. For the EBOC per country we refer to Table 2. Some group differences in the total number of EBOCs had been observed. For example, trans feminine participants experienced significantly more EBOCs in comparison to the trans masculine participants (1.4 (SD = 1.5) vs. 1.0 (SD = 1.1); p=.02). Also, more EBOCs were reported when not having received genital surgery (1.4 (SD = 1.4)) compared to those who had (1.1 (SD = 1.2); p=.10). Additionally, the mean total number of EBOCs was higher in individuals with further treatment wish (1.5 (SD = 1.4) when compared to those without (.97 (SD = 1.9)) or who were unsure (1.2 (SD = 1.3); p=.01).

Performative aspects to grant access to care

Referring to the first section of Table 2, German participants experienced a low percentage of EBOC regarding treatment protocol in general. At the same time, they described significantly more often than participants from other countries that they had investigated how they could increase their chances to care (Cramer's V=.18). A substantial group (43.1%) experienced they needed to convince their health care provider that they needed care. A larger proportion of the Dutch and German participants reported that they felt the need to convince their health care providers that they required care compared to participants from Belgium (Cramer's V=.24). Regarding their gender identity and treatment wishes, the German cohort more frequently mentioned they would express their wish for specific types of transgender care differently now (Cramer's V=.14) when compared to other countries. Around one fifth of the

Table 2. Experienced barriers to care.

	All	The Netherlands	Belgium	Germany			
	(n = 307)	(n = 172)	(n=84) (n=51) Test statistics		Test statistics		
Have you experienced the following barriers during your treatment at our center? (n, %)							
My family or friends	88 (28.7)	44 (25.6)	31 (36.9)	13 (25.5)	$\chi^{2}(2) = 3.8$, P = .15, Cramer's V = .11		
Travel time and costs	85 (27.7)	50 (29.1)	29 (24.5)	6 (11.8)	$\chi^2(2) = 8.6$, P = .01, Cramer's V = .17		
Treatment protocol in general	66 (21.5)	53 (30.8)	6 (7.1)	7 (13.7)	$\chi^2(2) = 20.9$, P < .001, Cramer's V = .26		
Fear of treatment consequences	46 (15.0)	20 (11.6)	21 (25.0)	5 (9.8)	$\chi^{2}(2) = 9.2$, P = .01, Cramer's V = .17		
My psychiatric or medical condition	44 (14.3)	33 (19.2)	6 (7.1)	5 (9.3)	$\chi^2(2) = 7.7$, P = .02, Cramer's V = .16		
Match gender and/or treatment and protocol	37 (12.1)	27 (15.7)	6 (7.1)	4 (7.8)	$\chi^2(2) = 4.9$, P = .09, Cramer's V = .13		
Referral to care	13 (4.2)	6 (3.5)	3 (3.6)	4 (7.8)	$\chi^2(2) = 2.0$, P = .37, Cramer's V = .08		
Which of the following statements applies to you? (n, %)							
I feel like I had to convince my healthcare	107 (34.9)	71 (41.3)	14 (16.7)	22 (43.1)	$\chi^{2}(2) = 17.0, P < .001, Cramer's V = .24$		
provider I needed care	, , ,,			/	2/2)		
I investigated how to increase my chance of receiving care	71 (23.1)	37 (21.5)	14 (16.7)	20 (39.2)	$\chi^2(2) = 9.7$, P = .01, Cramer's V = .18		
If I would register myself today, I would express my treatment wishes differently	64 (20.8)	37 (21.5)	16 (19.0)	11 (21.6)	$\chi^{2}(2) = .23$, P = .89, Cramer's V = .03		
If I would sign myself up today, I would express my gender differently	27 (8.8)	16 (9.3)	3 (3.6)	8 (15.7)	$\chi^{2}(2) = 5.9$, P = .05, Cramer's V = .14		

Table 3. Factors associated with experienced barriers to care, odds ratio (95% CI).

	1	2	3	4	5	6	7	Total no.a
Constant B (SE)	-2.67	-2.16	-2.54	45	44	.04	-5.67	1.74
	(.96)	(.69)	(.57)	(1.09)	(1.16)	(1.23)	(1.35)	(.59)
Age	1.03							
	(1.01-1.05)*							
Gender identity	.47			.47	.44	.37		19
	(.2589)*			(.22-1.02)	(.19-1.01)	(.1591)*		(-3.15)**
Income		.72						11
		(.51-1.02)						(-2.00)*
Bottom surgery ^b				.33	.33	.38	3.88	16
				(.1571)**	(.1576)**	(.1689)*	(.96-14.4)	(-2.58)*
Further treatment wish ^c	1.34	1.76	1.36					.15
	(.97-1.86)	(1.26-2.45)**	(.95-1.99)					(2.68)**
SCL-90, FU	1.75	1.71	1.87	1.83	2.56	1.73		.29
	(1.18-2.61)**	(1.14-2.55)**	(1.21-2.91)**	(1.15-2.91)*	(1.61-4.07)***	(1.05-2.84)*		(5.15)***
Country ^d								
Netherlands vs. Belgium	1.80		.14	3.04	.31	.38		10
	(.99-3.29)		(.0538)***	(1.48-6.25)**	(.1686)*	(.13-1.08)		(-1.87)
Netherlands vs. Germany		.31	.42				3.85	
		(.1278)**	(.171.01)				(1.03-14.4)*	

^{1 –} Family or friends: $\chi^2(5) = 35.8$, $R^2 = .17$, P < .001.

Total no. – Total number of barriers experienced: F(6,277) = 11.9, $R^2 = .21$, P < .001.

participants would express their treatment wishes differently if they would enter care at this moment, regardless of the country in which they lived.

Characteristics of individuals at risk for EBOCs

The factors associated with EBOCs are presented in Table 3. The total number of EBOC was predicted by higher SCL-90 scores, a lower income, having a further treatment wish, and having a transfeminine gender identity. Regarding the separate barriers, higher levels of psychological symptoms (SCL-90) predicted EBOC related to psychiatric/medical conditions, treatment protocol (general), support from family and friends, and travel time and costs. Identifying as transfeminine predicted barriers related to family and friends

² – Travel time and costs: $\chi^2(4)$ = 32.6, R^2 = .16, P < .001.

^{3 –} Treatment protocol (general): $\chi^2(4) = 33.6$, $R^2 = .17$, P < .001.

^{4 –} Fear of consequences: $\chi^2(4) = 27.2$, $R^2 = .16$, P < .001.

^{5 –} Psychiatric/medical conditions: $\chi^2(4) = 30.5$, $R^2 = .18$, P < .001.

^{6 –} Treatment protocol (match gender/requests): $\chi^2(4) = 16.0$, $R^2 = .11$, P = .003.

^{7 -} Referrals: $\chi^2(2) = 6.2$, $R^2 = .07$, P = .05.

^a Linear regression, beta coefficients displayed (t-value).

 $^{^{\}mathrm{b}}$ None = 1, Any = 2.

 $^{^{}c}$ No = 1, Unsure = 2, Yes = 3.

 $^{^{\}rm d}$ Netherlands = 0, Belgium/Germany = 1.

CI, Confidence Interval; FU, Follow-up; SCL-90 R, Symptom Checklist- 90 Revised; SE, Standard Error.

^{*} P < .05, **P < .01, ***P < .001.

as well as the treatment protocol (matching gender/requests). Furthermore, age was a significant factor [OR = 1.03, CI = 1.01-1.05] with a higher age predicting higher levels of reported EBOC related to friends and family. Income was not a significant determinant for any of the EBOCs. In having had genital surgery, we saw that fear of consequences [OR=.33, CI=.15-.71], psychiatric/ medical conditions [OR=.33, CI=.15-.76], and treatment protocol (match gender/requests) [OR=.38, CI=.16-.89] were significant contributors to the overall number of EBOCs. In general, having no further treatment wishes significantly predicted EBOC relating to travel time and costs $[OR = 1.76, CI \ 1.26-2.45].$ When comparing countries, Dutch participants described experiencing significantly more EBOC concerning treatment protocol (general) [OR=.14, CI .05-.38] and psychiatric/medical conditions [OR=.31, CI=.16-.86], but a lower fear of treatment consequences [OR = 3.04, CI = 1.48-6.25] than Belgian participants. Experiencing a barrier due to travel time and costs was significantly more common among participants receiving care in the Netherlands [OR=.31, CI=.12-.78], but reporting issues related to referral to the center was significantly more common among participants receiving care in Germany [OR = 3.85, CI = 1.03-14.4].

Discussion

In this study we explored the EBOC within a follow-up cohort of TSTG individuals seeking gender-affirming care in three European multidisciplinary trans health care centers. Throughout the cohort, individuals experienced (lack of) support from family and friends as most-frequent EBOC. Additionally, travel time and costs were also a common EBOC, especially in the Netherlands and Belgium. With regard to the treatment itself, individuals reported the nature of the treatment protocol, and fears of treatment consequences as barriers to care.

The perceived level of support by family members and friends, or a lack thereof, was found to have an effect on the individuals access to care. When family or friends do not support the individual's gender identity, TSTG individuals may experience distress and may even be discouraged from seeking further gender-affirming care (Köhler et al., 2019). In a recent Dutch qualitative study among transgender individuals, most participants reported the perceived social support from family and partners as "indispensable" (Verbeek et al., 2020). Often times, the act of coming out is filled with fears based upon the rejection that individuals seeking gender-affirming care expect to receive from family, friends and the general population as whole (Budge et al., 2013). Moreover, the importance of perceived support in accessing care appears to be influential regardless of culture and health care system (Budge et al., 2013; Riggs et al., 2014). Also, societal knowledge and media coverage was found to influence access to transgender care. Recent scholars described how increased media coverage of transgender related topics over recent years may have promoted societal acceptance and empowered young transgender people and their families to seek clinical care (Pang et al., 2020). Although these findings may not have been unexpected, social support and acceptance by family and friends-regardless of country and cultureremain crucial factors in how individuals seek gender-affirming care.

The three study centers follow the WPATH's standards of care (Coleman et al., 2012), are organized within a multidisciplinary centralized setting with universal insurance coverage (for further description of clinic services and insurance coverage regulations, see Appendix 1). Nevertheless, reported EBOCs regarding the treatment protocol were frequent. Barriers described in these centers consisted of organizational and/or functional aspects (i.e., travel time and cost), the content of the treatment protocol in general (i.e., anticipations about requirements of one's gender, mental health functioning and/or treatment requests), and performative aspects (i.e., feeling having to present normative clothing, gestures, speech) used when seeking care (Eyssel et al., 2017). In the Netherlands and Belgium consultations with mental health care professionals were focused on diagnosis and treatment pathways, where transition unrelated mental health care options are not systematically offered, within the centers. In Germany additional mental health care is offered (Nieder et al., 2017). Across the three countries,

participants reported that the nature of the treatment protocol, was one of the main EBOCs when seeking gender-affirming care. Transgender health care in the Netherlands and Belgium was until recently primarily offered in a few large academic centers. Due to this centralization, these centers have considerable waiting times and participants may have considerable travel time to reach these centers (which is less common for patients in decentralized care systems) (Keuzekamp, 2012; Motmans et al., 2018)—both factors were reported as EBOCs as a result. Across the centers, individuals often experienced long waiting lists and mental health care diagnoses of gender dysphoria are deemed necessary in order to obtain treatment and insurance as obstacles (Grant et al., 2011; Gridley et al., 2016; Keuzekamp, 2012). Similar barriers to our cohort's EBOCs were found in an American cohort (Puckett et al., 2018), but due to universal insurance coverage and smaller travel distance in our countries, we did expect that these findings would play less of a role within our cohort.

An aspect closely related to the norms of the treatment protocol was related to interactions with health care providers. Individuals reported how they felt they needed to present themselves when seeking care was also influential in their reported levels of EBOCs. Similar to previous research (Johnson, 2019), participants described exchanging and learning strategies from one another, in order to gain access within the system. These findings imply that clients not only feel they need to fulfill a set of formal requirements to access care, but also engage in active learning of how to present oneself and one's treatment request to increase their likelihood of success. Approximately one-fifth of participants stated that they would report their treatment wishes differently now. This could be possibly related, but is not limited to, the availability of more diverse treatment options due to the advancement of care, or the fact that during transition one's perceptions regarding their gender identity and/or the importance of specific treatments had evolved. When comparing the different clinical settings, in some, participants experienced more barriers related to the formal protocol, whereas in others, participants were more actively

aware of the importance of their presentation. It is therefore important for health care providers to be aware of both norms and barriers in their procedures as well as in the clinical interactions that effectively lead to care provision.

Regardless of health care setting, we observed that not all TSTG individuals are equally likely to experience EBOCs. We found that some personal and treatment-related factors were associated with the number of EBOCs that participants reported experiencing. Participants with trans feminine identity, with lower income or with more mental health problems were more likely to experience EBOCs. When compared with trans masculine individuals, trans feminine individuals were found to experience lower societal acceptance (Connell, 2010; Glynn et al., 2016; Gonzales & Henning-Smith, 2017; Lindqvist et al., 2017; Miller & Grollman, 2015; Streed et al., 2017) as well as more problems with family and friends (Motmans et al., 2015; European Union Agency for Fundamental Rights, 2014), which both may have delayed a start of medical and/or social transition steps. Furthermore, participants with more mental health problems are likely to go through more extensive diagnostic procedures, less speedy medical transition and may have more mental health distress, all possibly contributing to more EBOCs. Lastly, TSTG individuals with lower income experienced more EBOCs, a finding which is in line with earlier studies on cis as well as trans and gender diverse populations (Burgwal & Motmans, 2021; Gonzales & Henning-Smith, 2017; Grant et al., 2011; Puckett et al., 2018), indicating lower health literacy and more difficulties navigating care. Lastly, participants with uncertain wishes or the wish for more extensive (genital) treatments, also experienced more barriers, which can partly be attributed to the more extensive clinical requirements before undergoing these treatments (e.g., Body mass index (BMI) requirements, additional mental health counseling).

In the European context, the EBOC that TSTG individuals face within gender identity clinics had yet to be studied. The present study not only shed light on EBOCs experienced by TSTG individuals from three specific centers in Europe but also provided insight into the characteristics of

these EBOC and the ways in which such barriers influenced their relationship to the current health care system. While some barriers, pertaining to socio-economic position or friends and family support, can be confirmed throughout cultures and healthcare systems, other barriers appear to be associated with models of (gender-affirming) care. It appears more likely that in countries with reimbursed, protocolled and centralized care (in contrast to countries where access to care is based on referral letters for reimbursed care and self-pay models), TSTG individuals may experience more barriers related to meeting the requirements and feel they have to fulfill certain criteria to increase their chances to receive care. In some countries, TSTG individuals may have little alternatives to obtain care outside centralized facilities. At the same time, EBOCs related to the treatment protocol are also experienced within privatized systems operating within informed consent modalities where referral letters reign (Tabaac et al., 2020). Recent scholars stated that many treatment-seeking trans people in Europe can depend on a dedicated medical team focused exclusively on their care, while their American counterpart frequently cannot rely on a supportive healthcare system (Clements et al., 1999; Kenagy, 2005; Newfield et al., 2006). While some barriers TSTG individuals experience may be similar, general access barriers due to privatized forms of insurance (i.e., health care coverage in the United States), may influence systematic and institutional access to care. But our findings demonstrate that even within the European centers, with dedicated medical staff, the individuals still experience significant EBOC. To obtain further knowledge on the different health care models, large scale quality of life comparisons between the two systems, in relation to EBOC, would provide valuable insights.

Limitations

The present study was limited by (recruitment of) the participating sample. The sample included TSTG individuals who were receiving or had received gender-affirming care at one of the three centers in the five years prior to this study, and therefore had access to care that other transgender

individuals outside of the center may not have had. Additionally, there has also been a difference in the recruitment of participants between the centers (in Ghent and Hamburg by providers versus in Amsterdam by mail). A more active recruitment may have influenced the findings. A second limitation pertains to the surveyed timeframe. Individuals were asked to report on a five-year period prior to participation, which may induce recall bias and reporting of care that is evolving. With that being said, mental health was also not assessed at time of EBOC, and experiencing EBOC's may increase mental health problems (Seelman et al., 2017). Additionally, only predefined statements on EBOCs, such as "fear of treatment consequences", were assessed. The predefined statement, "fear of treatment consequences" may refer to both medical and psychosocial outcomes. A qualitative or more well-defined follow-up study may provide additional understanding. Lastly, individuals were assessed at different time points in their individual treatment pathways. Presently, the current form of care is thought to be less binary, more decentralized and more procedures are reimbursed, possibly reducing EBOCs, which should be topic of further research.

Conclusion

The present study reports on the substantial number of TSTG individuals experiencing EBOCs when seeking gender-affirming care in three European multidisciplinary trans health care centers. Both socially and personally related EBOCs were described, as well as barriers in relation to (in)formal health care requirements (e.g., performative aspects of care). Based on personal characteristics such as lower income level and more mental health problems, TSTG individuals were more likely to experience EBOCs. TSTG individuals reported working on performative aspects of clinical encounters (i.e., presenting themselves and expressing treatment wishes) to increase the likelihood of access to care. Based on these findings healthcare providers and regulators should be aware of how both (informal) healthcare protocols and individual characteristics facilitate healthcare access. In order to be able to better

understand how exactly these systems/individual practices can be adapted to meet the needs of TSTG individuals presently, further research on system characteristics and diversity among TSTG individuals is advised.

Note

ENIGI FU Wave 1, clinical entry 2007-2009 (see van de Grift et al., 2017); ENIGI FU Wave 2 clinical entry 2011-2013 (see Kerckhof et al., 2019). In this study only participants of FU wave 2 were included.

Disclosure statement

The authors report no conflict of interest. The authors alone are responsible for the content and writing of this paper.

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