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Review

The phenomenology of gender dysphoria in adults: A systematic review and meta-synthesis

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HIGHLIGHTS

- A systematic review of all papers on the lived experience of gender dysphoria
- Twenty papers with 1606 participants were included in a meta-ethnographic synthesis.
- Distress was due to gender and sex incongruence, as well as social factors.
- Results give new insights into the relationships between factors causing distress.

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ABSTRACT

Gender dysphoria is distress due to a discrepancy between one's assigned gender and gender identity. Adults who wish to access gender clinics are assessed to ensure they meet the diagnostic criteria for gender dysphoria. Therefore, the definition of gender dysphoria has a significant impact on the lives of individuals who wish to undergo physical gender transition. This systematic review aimed to identify and synthesize all existing qualitative research literature about the lived experience of gender dysphoria in adults. A pre-planned systematic search identified 1491 papers, with 20 of those meeting full inclusion criteria, and a quality assessment of each paper was conducted. Data pertaining to the lived experience of gender dysphoria were extracted from each paper and a meta-ethnographic synthesis was conducted. Four overarching concepts were identified; distress due to dissonance of assigned and experienced gender; interface of assigned gender, gender identity and society; social consequences of gender identity; internal processing of rejection, and transphobia. A key finding was the reciprocal relationship between an individual's feelings about their gender and societal responses to transgender people. Other subthemes contributing to distress were misgendering, mismatch between gender identity and societal expectations, and hypervigilance for transphobia.

1. Introduction

Transgender is an umbrella term used to describe individuals who have a gender identity which does not align with their assigned gender. Gender dysphoria in adolescents and adults is defined in the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013) as marked incongruence between an individual's gender identity and assigned gender with associated distress or impairment; see Table 1 for further details of DSM-5 criteria for gender dysphoria in adolescents and adults. A UK survey found that 1% of adults were gender diverse, or transgender, but it is not known what proportion of these had gender dysphoria (Reed, Rhodes, Schofield, & Wylie, 2009). This is in line with a recent review which suggested that between 0.5 and 1.3% of children, adolescents, and adults self-report a transgender identity (Zucker, 2017). In the Netherlands the prevalence of gender dysphoria was 0.6% in adult natal males, and 0.2% in adult natal females, while 3.2% of adults assigned female at birth and 4.6% assigned male at birth reported an equal identification with each gender or "ambivalent gender identity" (Kuyper & Wijsen, 2014).

The DSM-III (3rd ed.; *DSM–III*; American Psychiatric Association, 1980) was the first edition of the DSM to include a gender-related diagnosis, called Transsexualism located within the "psychosexual disorders" category. The adult diagnosis of transsexualism referred to "discomfort and inappropriateness" of one's biological sex alongside the

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Table 1
Definitions.

Gender dysphoria (DSM-5)	Diagnosis made if the individual experiences two or more of these experiences: • a marked incongruence between gender identity and sex characteristics • a desire to be rid of one's sex characteristics • a strong desire for the sex characteristics of the other gender • a strong desire to be the other gender (or an alternative, i.e. non-binary gender) • a desire to be treated as being the other gender (or an alternative, i.e. non-binary gender) • a conviction that one has the same feelings and responses as the other gender (or an alternative, i.e. non-binary gender) This should be associated with significant distress or functional impairment for a diagnosis to be made
Gender identity	An individual's felt sense of their identity being masculine, feminine, a combination or none of these
Gender expression	How an individual behaves, interacts with others, dresses, and otherwise displays their gender identity to others.
Gender norms	Societal expectations about how an individual will behave and express their gender. Therefore someone born female is expected to act in a stereotypically feminine way and someone born male is expected to act in a stereotypically masculine way.

wish to be rid of one's genitals and live in one's gender identity. Many changes have been made to the diagnostic criteria since this time (Beek, Cohen-Kettenis, & Kreukels, 2016). In the DSM-IV (4th ed.; *DSM–IV*; American Psychiatric Association, 1994), the diagnostic terminology was changed and transsexualism became "Gender Identity Disorder", but the focus on distress in relation to one's assigned gender remained a core component of diagnosis, as it continues to be in the DSM-5. Corneil, Eisfeld, and Botzer (2010) state that it is important to differentiate between transgender individuals who experience distress and those who do not. They argue this helps to normalize transgender identities and highlight that these cause distress in some, but not all cases. Significantly, the DSM-5 gender dysphoria diagnosis now accommodates a spectrum of gender identities, although the wording remains binary, referring to the *other* gender. This means that non-binary individuals who experience distress in relation to their gender identity can now be diagnosed and more readily receive support for gender dysphoria within the standard healthcare model. See Zucker et al. (2013) for a detailed description of the justification of changes to the diagnostic criteria from DSM IV to DSM-5.

The most recent DSM-5 classification for Gender Dysphoria published in 2013 is contentious (Davy & Toze, 2018). Critics state that including gender dysphoria in the DSM implies that having a transgender identity is a mental health problem, although the DSM is clear that only cases where there is distress or impairment would meet criteria for a diagnosis, while proponents highlight that in current medical practice, diagnosis is a requirement for access to appropriate medical support (Drescher, 2010). Indeed, in most settings a diagnosis of gender dysphoria is a prerequisite for receiving gender-focused support from healthcare services. This is in line with the World Professional Association for Transgender Health (WPATH) Standards of Care (Coleman et al., 2012), although some authors have argued an assessment but not necessarily a diagnosis of gender dysphoria is required according to these guidelines (Ashley, 2019). Therefore, the way in which gender dysphoria is defined affects service provision and availability. Intervention for gender dysphoria ranges from the provision of psychological support to explore gender identity or to make the social transition to live as one's affirmed gender identity, to medical interventions to enable the biological affirmation to one's gender identity through hormone treatment or gender affirming surgery (Coleman et al., 2012).

Gender diversity is not considered a mental health problem. However, transgender people are more likely to experience mental health problems than the general population (Downing & Przedworski, 2018). Individuals with gender dysphoria are also more likely to experience mental health problems, most commonly anxiety and depression (Dhejne, Van Vlerken, Heylens, & Arcelus, 2016). In terms of well-being following transition, a study using the Amsterdam Cohort of Gender Dysphoria from 1972 to 2015 found that of individuals who received a gonadectomy, 0.6% of transwomen and 0.3% of transmen experienced regret (Wiepjes et al., 2018). A meta-analysis investigating mental health quality of life in treatment-seeking transgender adults supported Dhejne et al.'s findings, as mental health quality of life was lower in the transgender population compared to controls (Nobili, Glazebrook, & Arcelus, 2018). The authors then investigated quality of life following cross-sex hormonal treatment; seven studies were included, and mental health quality of life was found to significantly improve following treatment (Nobili et al., 2018).

Some researchers have suggested that higher rates of mental health problems in the transgender population are linked to gender minority stress, or the experiences of stigma and discrimination transgender and gender nonconforming individuals experience which contribute to poor mental health (Meyer, 2015; Testa, Habarth, Peta, Balsam, & Bockting, 2015). This has been supported by studies which have found associations in the transgender population between mental health conditions and level of social stigma experienced by participants due to their gender identity (Bockting, Miner, Swinburne Romine, Hamilton, & Coleman, 2013). One example of a social stressor experienced by some transgender individuals is "misgendering" or being treated as or labelled a different gender to their own gender identity. Frequency of experiences of being misgendered, as well as feelings of being stigmatized, have been found to be positively associated with psychological distress in the transgender population (McLemore, 2018).

These high rates of mental health problems need to be better understood through an investigation of the mechanisms contributing to distress in this population. Described above are two distinct conceptualizations of the experience of gender-related distress in individuals with gender dysphoria. There is the diagnostic conceptualization of dysphoria related to a discrepancy between assigned and experienced gender, as defined in diagnostic manuals such as the DSM-5 (5th ed.; DSM-5; American Psychiatric Association, 2013), and a more social, stigma focused understanding of distress as described by gender minority stress theory (Meyer, 2015). It is not currently clear how these two forms of distress relate to one another. Zucker, Wood, and VanderLaan (2014) highlight that there is a lack of research investigating distress which is a direct result of gender dysphoria in children and adolescents, and we argue that the same gap is apparent in the adult literature. Given the rapidly increasing societal awareness of transgender identities (e.g. Steinmetz, 2014), and substantial increase in referrals to gender clinics (e.g. Aitken et al., 2015; Wiepjes et al., 2018), it is important to have an up-to-date understanding of the experience of gender dysphoria as described by the individuals themselves. This will help to guide care in clinical settings where an unprecedented number of referrals are being received, and ensure that the current understanding of gender dysphoria according to rigorous research findings is current. Therefore a contemporary systematic review of the phenomenology of gender related distress is critical to improve, update and develop coherence around our understanding of the experience of gender dysphoria, to ensure that it is conceptualized in a consistent way and in line with the current social context.

Scientific research has played an important role in clearly defining gender dysphoria and investigating the efficacy of various treatments for this group. There has been an emphasis on opinion pieces and narrative reviews compared to original empirical studies. A review of

primary published literature on gender dysphoria from 1970 to 2011 found that the most common study type published was narrative review at 29% or 479 articles and that commentaries made up a further 7.5% or 124 papers (Eftekhar et al., 2015). Empirical studies based on original data made up a smaller proportion of research at 34% or 555 articles, including qualitative studies, cross-sectional studies, cohort studies, case control studies and clinical trials. The least common method employed was systematic review at 0.4% or 6 articles. Narrative reviews allow authors to select the research they feel has the most value and to summarize this research, which increases the risk of bias in the review (e.g. Littell, 2008). There have not been any systematic reviews focused on the phenomenology of gender related-distress, despite distress related to gender identity being a central criterion for individuals hoping to access gender clinics. Given the high level of controversy and emotive nature of this particular research area, it is especially important that more systematic methods are utilized in order to reduce the likelihood of researcher bias and to improve the quality of evidence available.

Systematic reviews employ a replicable search strategy, with a clearly defined screening method to select papers relevant to the review question following predefined inclusion and exclusion criteria (Moher et al., 2015). This significantly reduces the likelihood of bias in terms of studies included in the review. When qualitative evidence requires synthesis, standardized protocols can be followed such as meta-ethnography (Noblit & Hare, 1988), a widely used method of qualitative research synthesis, which ensures a high level of methodological rigor in the synthesis of qualitative results.

1.1. Aims

This study aims to systematically review and synthesize existing qualitative literature regarding the phenomenology of gender dysphoria in adults. This will result in a deeper and empirically informed understanding of the lived experience of gender related distress, focusing on the cognitive, psychological and physical experiences associated with gender dysphoria.[1]

2. Methods

The methods section was developed using the ENTREQ guidelines (Tong, Flemming, McInnes, Oliver, & Craig, 2012), which aim to standardize the reporting of qualitative syntheses. A protocol for this study was pre-registered on PROSPERO (CRD42019140899). The theoretical basis for the qualitative synthesis was interpretive constructivism (Rubin & Rubin, 2012). Interpretive constructivism acknowledges that the findings regarding the phenomenology of gender dysphoria from the studies reviewed will have multiple and at times conflicting perspectives, which can exist alongside one another.

A meta-ethnography approach was selected for the current study (Noblit & Hare, 1988). This entailed conducting a structured analysis for synthesising research about the phenomenology of gender dysphoria in transgender individuals. This methodology allowed for a" line-of-argument" synthesis, which allowed for the development of an integrating scheme which furthered understanding of the phenomena under investigation. A systematic search and screening against pre-defined criteria preceded a thorough synthesis of qualitative studies investigating the experience of gender dysphoria.

[1] An original stated aim of this systematic review, as published on PROSPERO, was to compare the experiences of binary and non-binary transgender individuals' experiences of gender dysphoria. Following searches and screening, there were not enough data regarding the non-binary experience of gender dysphoria to keep this as an aim of this review.

2.1. Inclusion criteria

The inclusion criteria were developed in order to identify in-depth qualitative data about the experience of gender dysphoria in transgender individuals (see Table 2). Gender-related distress was operationally defined as any negative emotions directly related to gender identity in transgender individuals. This broad definition of gender dysphoria was selected rather than attempting to apply diagnostic criteria in order to include a wide range of studies, and also in acknowledgement of the rapidly changing cultural understanding of gender diversity.

2.2. Search strategy

We developed a pre-planned search strategy, using MEDLINE, PsycINFO, Embase and Web of Science and the search terms in Table 3. A preliminary search on PubMed with the following terms: (((((((qualitative) OR interview) OR "focus group") OR experience) OR phenomenolog*)) AND (((((((((distress) OR "mental health") OR depression) OR "low mood") OR discomfort) OR dysphoria)) AND (((((((Transgender) OR "gender nonconforming") OR "gender atypical") OR "gender variant") OR non-binary) OR genderqueer))) OR (((transsexual*) OR "gender identity disorder") OR "gender dysphoria"))).

The searches were conducted in July 2019, and 1741 records were identified, reducing to 1370 once duplicates were removed. The searches were updated and run again in October 2019. This identified 121 new papers since the July search. Non-published "grey" literature was not included in the present study. The reference sections of included papers were scanned for further published studies that might meet inclusion criteria.

2.3. Screening

A total of 85 studies went to full text review. See Fig. 1 for further details of the identification, screening, and eligibility assessment of papers in this study. The first round of screening involved reading the title and abstract of identified references to assess whether papers met the above criteria. Where further information was required, the full text was assessed in the second screening round using the same method.

Twenty studies were included in the analysis, which included 1606 transgender participants in total. All studies which met the inclusion criteria were published from 2009 onwards. See Appendix A for details of each included study.

2.4. Inter-rater reliability

The first author screened studies using the inclusion and exclusion criteria, and a second researcher screened 10% of these. Discrepancies were resolved using a pre-defined strategy. Any disagreements between the two screeners were resolved by discussion. Where an agreement could not be reached, the final author was consulted. Agreement between the two researchers was measured; there was 99.3% agreement between the two researchers (Cohen's Kappa = 0.85), indicating near perfect agreement.

2.5. Data extraction

A data table was developed for the purpose of this study. As well as including data for the qualitative synthesis, the following data were collected: Author name(s); Year published; Title; Journal; Setting; Participant group (i.e. binary or non-binary participants, transgender women etc.); Number of participants; Qualitative methodology; Interview type (see Appendix A). Data in the results and discussion section of the study pertaining to the inner experience of gender dysphoria were extracted. Specifically, data regarding the thoughts, feelings, and sensations that come with having a transgender identity and

Table 2
Inclusion and exclusion criteria.

	Inclusion	Exclusion
Participants	• Participants are over the age of 18 years old. • Participants are transgender i.e. have a gender identity which is different from their assigned gender.	• Participants include Lesbian, Gay and Bisexual participants as well as transgender participants • Participants include those under the age of 18
Types of study	• Qualitative or mixed-methods studies. • Study involved primary data collection comprising first person accounts through interviews, focus groups, open-ended surveys etc. • Study focused on (i.e. asked about or found a theme relating to) participant's experiences of distress in relation to their gender identity i.e. the thoughts, feelings, and sensations associated with gender related distress. • Published in a peer-reviewed journal. • Written in English. • Any time period. • Any geographical region.	• Observational or secondary data studies. • Quantitative studies • Reviews or commentaries

Table 3
Planned search terms and criteria for review.

Field		Search terms
Abstract		Transsexual* OR "gender identity disorder" OR "gender dysphoria"
Abstract	OR	(Transgender OR "gender nonconforming" or "gender atypical" or "gender variant" OR non-binary OR genderqueer) AND (distress OR "mental health" OR depression OR "low mood" OR discomfort OR dysphoria)
Any field	AND	Qualitative OR interview OR "focus group" OR "lived experience" OR phenomenolog*

being distressed about this were included, but not broader data about the experience of accessing healthcare or education experiences. Once analysis had begun and the initial concepts were identified, a table was constructed to look at whether and how each study represents data pertaining to each concept (Britten et al., 2002).

2.6. Quality assessment

The widely used CASP checklist (Critical Appraisal Skills Programme, 2018) was used to assess the quality of studies included in the review (see Appendix B). All studies were included in the synthesis irrespective of quality, but the CASP checklist results were considered carefully when conducting the data coding and synthesis. The CASP checklist was used to assess whether each included study had a clear statement of aims; used an appropriate methodology; had an appropriate research design and recruitment strategy; considered data collection, research relationships and ethical issues; analyzed data rigorously; stated findings clearly; and had value. Each item was given a score of 0–2 dependent on the quality of information provided in each category, see Duggleby et al. (2010), with 2 representing higher quality and 0 lower quality. 10% of the studies were inter-rated by the final author, following the process outlined in the "screening" section, and inter-rater reliability was good (Cohen's Kappa = 0.67).

2.7. Data analysis

Data were coded and translated inductively based on Noblit and Hare (1988), commencing with familiarization with each of the papers. The experiences of gender dysphoria in transgender individuals were the focus of the analysis. It is important to note at this stage the relationship between the following concepts:

- First order constructs, or participant responses
- Second order constructs, or how the original authors interpreted these responses
- Third order constructs, or how the review authors interpret the second order constructs

Line-by-line coding was conducted to search for first order and second order concepts related to the target phenomena, i.e. inner experiences of gender dysphoria (e.g. Rice, 2002). Each study was analyzed in this way until the concepts from each paper were identified. This was done by the first author and the final author coded a subset of included papers. The second order constructs were used for the meta-synthesis, but the first order constructs were noted in order to ensure that the second order constructs accurately represented what the participants had said and demonstrated significant depth of description. In cases where the first order construct was not thought to align well with the corresponding second order construct, the second order construct was not included in the analysis.

Next concepts which recurred across multiple studies were used to translate the findings between each study (e.g. Britten et al., 2002). Concepts which were shared among studies were grouped together when their themes were similar to one another. This was done through an iterative process of grouping concepts together and reading and re-reading the included studies to ensure that concepts that were grouped together were done so in a meaningful way (Toye et al., 2014). A summary of the concept from each relevant paper was written in the format of either a quote from the source paper or a summary written by the research team. Summaries used the original authors' words where possible.

A translational synthesis was undertaken, whereby included papers had sufficiently similar themes to be grouped together and resulted in a line of argument synthesis. At this stage, third order constructs were created to synthesize the findings of all the papers. The third order constructs were developed by the first author and then discussed in depth with the other authors. The authors discussed any differences in their understanding of the concepts and second order constructs of the included papers, and the third order constructs were refined until the authors reached agreement. Third order constructs would be divided into two types; subordinate themes and overarching themes which shaped the overall synthesis and findings. These over-arching themes represented the line of argument stage of the synthesis. At this point the synthesis was written in narrative form by the first author, and this synthesis described the concepts, second order, and third order constructs identified in the meta-synthesis. The narrative synthesis was then read and agreed upon by all the authors.

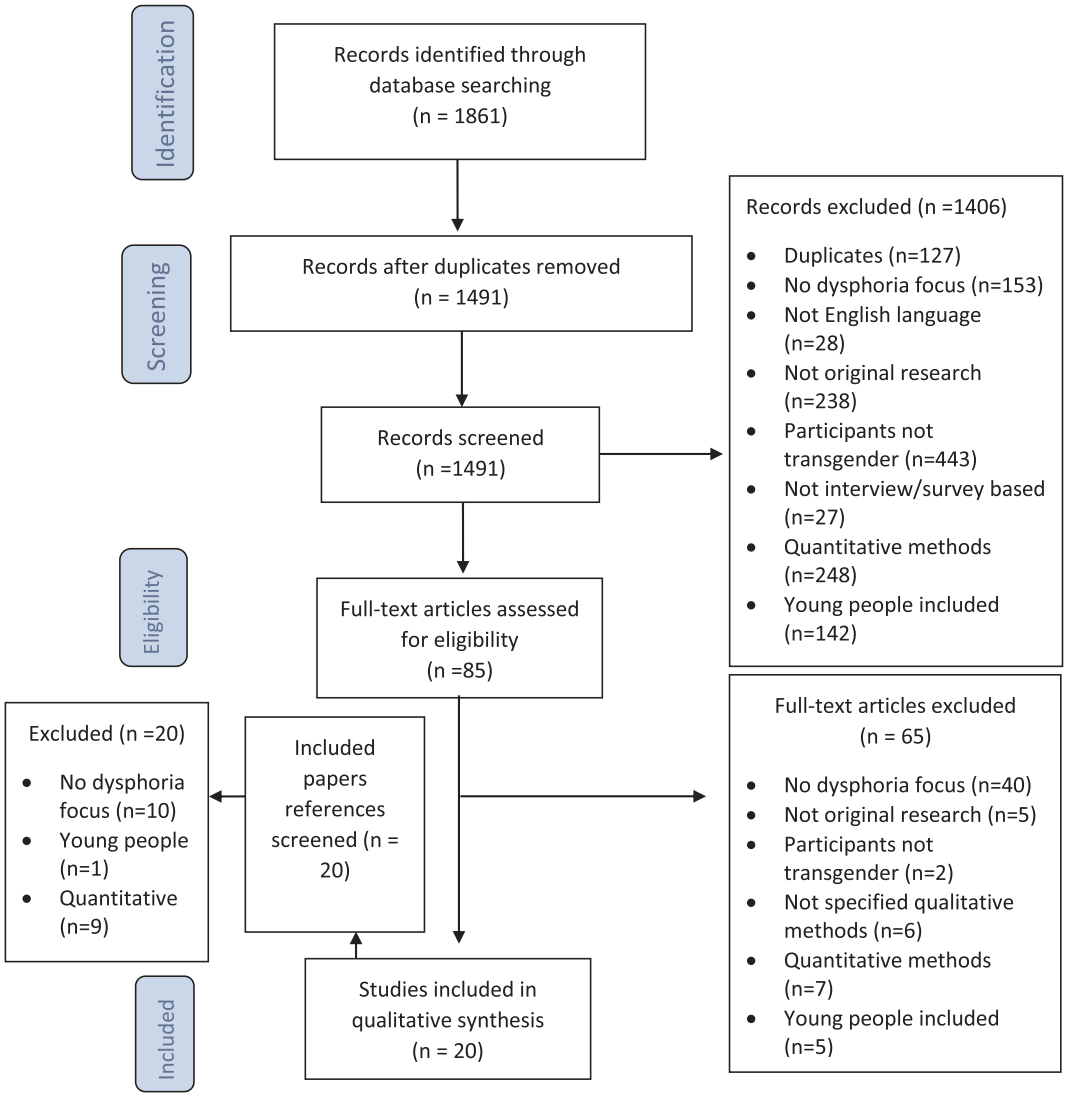

Fig. 1. Identification, screening and eligibility of studies in the systematic review.

3. Results

We identified four key concepts in the analysis, with twelve subthemes. The overarching concepts identified were" distress due to dissonance of assigned and experienced gender"', "interface of assigned gender, gender identity, and society"," negative social consequences of gender identity" and" internal processing of rejection and transphobia". See Table 4 for an overview of the third order constructs we identified.

3.1. Distress due to dissonance of assigned and experienced gender

The first concept we identified was participants' negative feelings about the mismatch between their gender identity and body. These feelings included gender-focused and body-focused distress which were interrelated. Participants experienced distress, conflict, confusion, and denial related to their gender identity, and as well as body dysphoria and disconnection. These feelings had consequences such as suicidal ideation and fear for the future.

The most prominent sub-theme we identified was body dysphoria, which included the unease, dysphoria, hatred, and disgust participants felt towards their bodies. The focus was frequently on the genitals and secondary sex characteristics such as the chest and body and facial hair, with some attempts to suppress these features. Studies identified a range of negative feelings towards the body from being troubled, experiencing discomfort, a destabilized sense of self, to disgust, hatred, and existential crisis. These feelings sometimes led to participants' attempts to suppress their femininity or masculinity, for example through restricting food intake to minimize the appearance of breasts. Some individuals also experienced detachment from the body. This referred to the sense of disconnection from the physical self which resulted from body and gender dissonance. The word" disembodiment" was used in two of the three studies which referred to detachment, and underlines the force of this feeling for participants, who felt such a powerful sense of gender dissonance that they experienced a total break between their sense of self and physical body. For some participants, this feeling of disgust towards their body led to suicidal thoughts or self-harm; individuals felt that death was preferable to continuing to live in their body.

The next subtheme was gender distress, which refers to distress relating to participants' gender identity, which in some participants extended to thoughts of death and suicide. Multiple papers described distress following conflict between participants' gender assigned at birth and self-concept, with the sense that this could be destabilizing and cause an existential crisis. Emotions reported included depression, anxiety, disappointment, and self-hatred, and these feelings could be overwhelming and tumultuous. One paper looked at the experience of transgender individuals undergoing transition and found that negative emotions were particularly experienced pre- and during transition,

Table 4
Overarching concepts and sub-themes.

Third order concept	Sub-themes	Example quote
1. Distress due to dissonance of assigned and experienced gender	• Body dysphoria	"Beards and pubic hair caused trouble to many of the respondents, and penile erections were a source of embarrassment and shame" (Giovanardi et al., 2019).
	• Gender distress	"Disappointment and an internalized hatred in having to live each day in the wrong gender" (Goodrich, 2012).
	• Conflict of body and gender	"Experiences of internal conflict and gender dissonance had a strong presence in all interviews" (Mullen & Moane, 2013)
	• Confusion	"Some participants felt suicidal because they were confused about their gender and did not have the information and support they needed to help them process their feelings" (Bailey, Ellis, & McNeil, 2014).
	• Denial and suppression	"It was common for the participants in this study to describe a complete denial of their transgender identity" (Budge et al., 2013).
	• Fear of future	"A second subtheme, 'fear of the future,' captures the anxiety about life-changing decisions and acceptance by others" (Applegarth & Nuttall, 2016).
2. Interface of assigned gender, gender identity, and society	• Distress due to misgendering	"An inability to pass/blend would likely be associated with general disappointment, feeling sad, and, for some, even suicidal ideation" (Rood et al., 2017)
	• Mismatch between gender identity and societal expectations	"Some degree of conflict existed between the internal sense of self and dominant social norms" (Ellis et al., 2015)
3. Negative social consequences of gender identity	• Isolation	"Participants reported feelings of sadness and loss when friends and others in their social network were not supportive." (Smith et al., 2018)
4. Internal processing of rejection and transphobia	• Fear of rejection, and sadness following rejection	"They pointed to how encountering rejection or invalidation of their gender identity … had led to proximal or internalized stress processes" (Goldberg, Kuvalanka, Budge, Benz, & Smith, 2019)
	• Hypervigilance for transphobia	"Participants reported that the expectation of rejection often is associated with distinct feelings of fear and worry for their personal safety" (Rood et al., 2016).
	• Internalized transphobia	"…one's own body might become persecutory for some TGNC individuals who feel themselves constantly looked by others. This might have a heavy price in psychological terms, as it can cause shame and self-hatred if internalized, or rather internalized transphobia" (Scandurra, Vitelli, Maldonato, Valerio, & Bochicchio, 2019)

becoming less prominent post-transition.

The sense of conflict between participants' body and gender was a prominent sub-theme, with studies describing a mismatch between individuals' gender identities and anatomy, leading to feelings of dissonance, conflict, and distress. A range of vocabulary was used to describe this dissonance, demonstrating a spectrum of feelings from discomfort to significant distress and struggle. This use of the words" struggle" and" conflict" suggests that some people experienced the difference between their gender identity and bodies as something to be struggled against and overcome, with the implication that an internal conflict could lead to changes that would resolve the struggle. One paper highlighted that the distance between a person's gender identity and their experiences of their own body contributed to the intensity of gender dysphoria. Some papers conceptualized the dissonance as being between body and mind, whereas other focused more specifically on body and sense of self or gender identity. This dissonance was identified by non-binary participants as well as binary-identified participants.

The next subtheme we identified was confusion or uncertainty about gender identity which is experienced as distressing. Participants reported that they needed more support from society or from family members in order to understand their feelings about their gender. There was an implication that there are societal norms around being "certain" of one's gender identity or that one should conform to gender norms, and that transgressing societal expectations was therefore experienced as confusing and disorientating. It is of note that even a sense of uncertainty was experienced as distressing in contexts where the dominant narrative is that gender identity is fixed and in line with one's sex, and therefore certain.

Denial and suppression were another prominent feature of the studies, with denial of an individual's true gender identity leading to attempts to suppress it. This brought participants feelings of stress and of not being true to one's identity. In all the studies which discussed this theme there was the sense that transgender identities caused feelings of shame in participants due to negative views of transgender identities in society, or that suppressing one's gender identity was necessary to be accepted by others. Participants also felt shame around the suppression of their gender identity, implying that they felt caught between two contradictory ways of conceptualizing and expressing their gender identity, on the one hand conforming to traditional gender norms and suppressing their identity, and on the other hand fully embracing their gender identity.

The last sub-theme we identified within this concept was fear of the future. This referred to participants' difficulties envisaging how to navigate their gender identities, with a sense of hopelessness or fear for the future. This theme encapsulated the lack of control and anxiety transgender individuals felt about making life-altering decisions when they became more certain about their gender identity. Considering the earlier themes of death sometimes feeling preferable to continuing in one's current body, and the confusion or denial and suppression that comes with dissonance of assigned and experienced gender, huge emotional weight was associated with future-decision making for this group. While many participants were desperate to change their bodies and gender expression, for some this was associated with a fear of stepping into the unknown and of transgressing social norms.

3.2. Interface of assigned gender, gender identity, and society

The second concept we identified was the interface of assigned gender, gender identity, and society. This concept acknowledges the social nature of gender identity. Gender norms are culturally defined expectations about how gender-related behaviors and gender expression are interpreted. An individual's gender expression is interpreted by others using gender norms to work out their likely gender identity. The dissonance that the transgender individual experiences around their assigned gender and gender identity may be experienced by those they interact with, who may be unsure how to label the transgender person. The transgender individual who is undergoing transition wants to be seen as belonging to their experienced gender group and treated as such. In order to achieve this aim, individuals may wish to change others' perceptions of their body, and therefore others' perceptions of their gender expression. This concept underscores the effect of binary gender norms (i.e. the idea that gender is binary, either male or female)

on the transgender individual, who may struggle with having a different gender journey to the dominant narratives around gender. These experiences of the interface of body, personal identity, and societal norms and responses to the individual led to a sense of not fitting in and transgressing societal norms, and a fear of others shaming or misgendering the individual. There are reciprocal relationships between feelings about the body, gender expression, and reactions of others. For example, an individual who is misgendered may then begin to feel higher levels of body dysphoria and conflict between their assigned and experienced gender. Moreover, feelings of anxiety or confusion around one's gender identity could affect an individual's gender expression, thereby shaping the social responses of people the transgender individual interacts with.

The first sub-theme was distress due to misgendering. This related to participants' fear of others misreading their gender identity and experiencing distress when this occurred, with a feeling of responsibility to ensure misgendering did not occur. A number of the studies identified feelings of fear, distress, embarrassment, anxiety, and stress at the thought or reality of being identified as belonging to a gender group which does not align with one's identity. Studies identified anticipatory fear of being misgendered or placing pressure on oneself to “pass” as one's gender identity, with some participants reporting suicidal ideation if they were not successful in this aim. This was linked with the earlier theme of body dysphoria and conflict of body and gender, as participants would measure their success in changing their bodies or gender expression by the reactions of others. Participants expressed fear of being labelled as transgender by others, with an implicit sense that this is a shameful, negative label. Moreover, participants wanted to be affirmed in their gender identity by others. This theme linked with the sense of struggle identified within the first theme, with misgendering being something that participants aimed to overcome. This demonstrates the complex interplay between gender identity, gender expression, and social interactions with others, with an individual's own sense of dissonance and negative feelings about their bodies and gender identity potentially being exacerbated by the reactions of other people. This theme has an emphasis on emotions linked to anxiety, suggesting that participants would spend time trying to predict and control the reactions of others.

The second sub-theme was the mismatch between participants' gender identity and societal expectations. This theme captured the dissonance between the individual's gender and societal expectations, rather than dissonance around the individual's own body and gender identity. Dominant social narratives that gender identity and biological sex should align did not fit the transgender person, which resulted in conflict and sadness. This links to the earlier theme of confusion, whereby participants were unsettled by their gender identity not aligning with societal expectations. Studies described participants' experience that they had been socialized to the incorrect gender, which caused dissonance and distress. This relates to the earlier theme of participants' suppression or denial of their gender identity, which happened as a result of not fitting societal norms. Furthermore, social interactions triggered gender dysphoria, and participants experienced shame and self-hatred when they perceived that others were looking at them and assessing their gender. Transgender individuals expected to be rejected due to the prevalence of binary gender norms, and so did not feel able to share their thoughts and feelings about their gender, even with close family members. Transgender men who chose to become pregnant felt isolated by the gender binary, as they did not conform to gender norms around parenthood. Therefore, societal expectations that assigned gender and gender identity should align, and that others should act in a gender conforming way, led participants to experience more negative feelings about their own gender identity, with shame being an important emotion in this process.

3.3. Negative social consequences of gender identity

The third concept was the social consequences of gender identity, primarily a sense of isolation due to the individual's gender identity. Transgender individuals felt and were cut-off from society and communities due to their gender identity. Participants reported that they felt outside of society due to their differences in gender identity, and the lack of acceptance in society for people who do not conform to traditional gender norms. Studies referred to a lack of community, reduced sense of belonging, invisibility, invalidation, and loneliness. Participants were clear that this was associated with their gender identity and that this caused distress, particularly loneliness. This concept highlights the loneliness of belonging to a group which can be ostracized by society. It is worth noting that some studies also referred to positive social consequences of gender identity, such as becoming close to other transgender people, however the negative social consequences came alongside these. The positive consequences are not reported here due to this paper's focus on distress in relation to gender identity.

3.4. Internal processing of rejection and transphobia

The final concept was the internal processing of rejection and transphobia, with hypervigilance for rejection due to gender identity and an internalized sense of shame and fear about one's gender. The focus of this concept was on the individual's internal cognitive processes and making meaning of their negative experiences as a transgender person in the world, with the difficult feelings that come with this including sadness, loss, and anxiety. This theme is conceptualized as resulting from the earlier theme of negative social consequences of gender identity; if participants had not either experienced or seen examples of rejection due to being transgender or transphobia, then they would not have developed internal narratives and processes to make sense of these experiences.

The most prominent sub-theme for this concept was fear of rejection, and sadness following rejection. This theme focused on how participants feared future rejection and ruminated on previous incidents of rejection, and these experiences were heightened by a high rate of previous rejections and awareness of negative societal attitudes towards transgender people. A high number of included studies discussed participants' fears of rejection, judgement or other negative responses from others, including family and friends. The range of emotions included fear, anxiety, loneliness, discomfort, frustration, pain, anger and depression. Participants experienced a sense of loss when rejected by people close to them such as friends or family. Participants wanted to fit in and hoped that others would not judge them, fearing rejection and judgement of others.

The next sub-theme was hypervigilance for transphobia, where an individual's expectation that they would be discriminated against or harmed due to being transgender was associated with attentional biases for threat and danger when out in public, with an understandable fear about leaving the home. Studies described participants' feelings of being unsafe due to fears of discrimination, violence or harassment. Such fears led to individuals looking out for signs of danger when out in public, in the hope of keeping themselves safe, presumably resulting in individuals spending long stretches of time in a state of high psychological arousal and anxiety, even at times when no threat is present. This was associated with a range of negative feelings such as anxiety, embarrassment, and depression.

The final sub-theme for this concept was internalized transphobia, or feelings of shame as negative external narratives about transgender people were internalized. Studies identified that individuals were highly aware of social stigma about their gender identity, and of transphobic narratives, and that for some people these became

internalized, resulting in a sense of shame about their gender. One study highlighted that social messages about transgender people directly led to self-hate, confusion, and shame (Rood et al., 2017). These feelings had consequences such as difficulties affirming gender identity, finding satisfaction with physical body, and hiding at home.

4. Discussion

This systematic review and meta-ethnographic study synthesized all the available qualitative studies about the lived experience of gender dysphoria in transgender adults. Twenty studies were included, all published since 2009, providing a rich dataset for the synthesis. Four overarching concepts were identified; distress due to dissonance of assigned and experienced gender, interface of assigned gender, gender identity, and society, social consequences of gender identity and internal processing of rejection and transphobia. These concepts demonstrated that distress caused by the dissonance of assigned and experienced gender is closely intertwined with distress due to the reactions of others to one's gender identity, whether that is reflected by strangers misgendering the individual, or rejection by close family or friends. This can then feed into the individual's thinking pattern and behaviors, for example through hypervigilance for transphobia, and fear of rejection due to being transgender. This demonstrates the complex relationships between an individual's feelings about their body, their gender identity, gender expression, and how outsiders interact with the individual, often guided by cultural gender norms and lack of awareness or acceptance of the transgender individual's experience. These findings are concordant with the quantitative literature available in this field. Participants described experiencing significant psychological distress in this study, in line with previous quantitative work (Downing & Przedworski, 2018). Participants frequently reported experiencing anxiety and low mood in relation to their gender, and anxiety and depression are the most commonly reported conditions in this group (Dhejne et al., 2016). While not a focus of this study, some studies included in this review did highlight the improved psychological wellbeing post-transition, in line with quantitative reviews about the effects of physical transition (Nobili et al., 2018).

The first overarching theme we identified was dissonance of assigned and experienced gender. This concept aligns most closely with the DSM-5 definition of gender dysphoria (American Psychiatric Association, 2013), particularly the sub-themes of body dysphoria, gender distress, and conflict of body and gender. These clearly align well with the criteria such as incongruence between gender identity and sex, the desire to be rid of one's sex characteristics and to have those of the other gender, a desire to be the other gender and the conviction that one has the feelings and responses of the other gender. This finding of significant distress in relation to the body supports the findings of quantitative outcome studies which find high levels of distress in those with gender dysphoria pre-transition (Nobili et al., 2018). This is further supported by studies demonstrating that transgender people identify more with images of their body which are edited to be in line with their gender identity, compared to cisgender people who identify with unedited images of their body (e.g. Majid et al., 2019). The only part of the DSM-5 criteria which fits with another theme is the desire to be treated as the other gender, which aligns with the interface to assigned gender, gender identity, and society concept. The sub-themes which do not fit with the DSM-5 criteria are confusion, denial, and suppression and fear of the future. These features also contribute to distress but are not captured by the current DSM criteria, due to the focus of the DSM on intra-individual rather than societal and inter-individual processes. One explanation for these discrepancies is that they are not indicators of gender dysphoria, and rather are associated features. Another possible explanation for these discrepancies is the different types of gender related distress. The experience of gender distress which is alleviated through physical transition may diverge from the experience of gender distress which does not lead to a physical transition. There is limited research available in the adult population to further explore this at present.

This study provides further evidence for the concepts of negative social consequences of gender dysphoria and internal processing of rejection and transphobia, which fit within the framework of gender minority stress (Meyer, 2015; Testa et al., 2015), as well as the rejection sensitivity model (Downey & Feldman, 1996; Feinstein, 2019). Testa et al. (2015) developed a measure of gender minority stress in the transgender and gender nonconforming community. In their paper they highlight the role of difficult social experiences in the experience of psychological distress in gender nonconforming and transgender individuals. As well as experiences of discrimination, rejection and victimization, they measured internalized transphobia and gender non-affirmation, or misgendering, as well as negative expectations for future events, and nondisclosure. Their scale measuring these constructs was found to be valid for use with transgender people, providing quantitative support for the utility of these constructs. Our study has found a number of overlapping sub-themes, such as misgendering, isolation, internalized transphobia, and fear of rejection and sadness following rejection and so provides support for the gender minority stress framework. Further, Feinstein (2019) proposes an extension to minority stress theory using the rejection sensitivity model, which includes "anxious expectations of rejection", "perceptions of rejection", and "cognitive affective reactions" which contribute to distress following adverse social experiences (Downey & Feldman, 1996). While Feinstein applied this model to sexual minority groups, other authors have proposed its potential relevance to the transgender population, if adapted to this group and supported by rigorous research evidence (e.g. Wells, Tucker, & Kraines, 2019). Our findings provide some support for these cognitive factors contributing to distress in the transgender population, with the “internal processing of rejection and transphobia” theme highlighting pre-emptory and post-hoc emotional responses to rejection due to transgender identity which are in line with components of the rejection sensitivity model. These similarities provide preliminary support for Feinstein's proposal that internal processing of rejection is central to distress, and suggests that this occurs in the transgender population as well as in sexual minority groups. While rejection sensitivity as a model to account for emotional distress has intuitive appeal and some evidence to support it, fluctuations in the level of rejection sensitivity in other groups, perhaps with social and interpersonal contexts playing a role, highlights the need for careful longitudinal research to establish rejection sensitivity as a valid theoretical framework for transgender people.

Our paper further extends the established understanding of gender dysphoria, and gender minority stress, to better understand the relationship between these two experiences. We found that societal expectations and gender norms caused participants to experience gender dysphoria when comparing their own gender experiences to those of others, or when sensing that their body and gender expression were being judged by others. On top of these factors, experience of actual rejection and social isolation due to gender caused significant distress. This led to increased body dysphoria, gender distress, conflict of body and gender, confusion, denial, and suppression and fear of the future, alongside internalized transphobia. All of these experiences in turn increased difficulties in leaving the home and hypervigilance when interacting with others. A strength of this study was the relatively recent publication of all the included studies; the oldest was from 2009. While the searches were not constrained by year, it appears that researchers have only recently begun investigating the lived experience of adults who experience gender dysphoria. Older studies were often excluded due to using quantitative or case study methods, rather than employing systematic qualitative methods. This means that this synthesis is highly relevant to current presentations of gender dysphoria and given the rapidly shifting context of this field (e.g. Aitken et al., 2015). A limitation was the relatively low number of studies that recruited non-binary participants, and none of the studies analyzed these

data separately. Therefore, it was not possible to understand the similarities or differences in the experience of gender dysphoria between these groups. A further limitation is that our inclusion criteria restricted the synthesis to peer-reviewed, qualitatively analyzed studies. This means that the rich narratives of transgender individuals included in books or other non-peer reviewed sources were not included in the current study. This may have led to selection bias for the narratives which researchers have chosen to focus upon. Finally, we included papers which investigated the experiences of adults, and so the findings may not be transferrable to children. Systematic reviews focused on the experiences of children with gender dysphoria are therefore warranted.

We propose that the DSM definition of gender dysphoria requires increased conceptual clarity in its definition of distress. This is particularly important given the role of gender dysphoria diagnosis in current gender clinic practice (Coleman et al., 2012). Our review demonstrates that significant distress is experienced by those with gender dysphoria as a result of social factors, which vary over time and age cohorts. Future quantitative research could compare the experience of gender dysphoria in individuals within more accepting cultural contexts versus less accepting contexts. This would help unpack the effects of the social environment on distress in gender dysphoria. Further research should investigate the relationships between distress due to dissonance of assigned and experienced gender, as well as processes such as: internal processing of rejection and transphobia including internalized transphobia; the interface of assigned gender, gender identity, and society, including misgendering or non-affirmation of gender; and negative social consequences of gender or discrimination, rejection, and victimization. Longitudinal studies investigating these processes over the course of coming out as transgender or transitioning would be well placed to elucidate the relationships between these concepts. Furthermore, research into the experience of non-binary individuals of gender dysphoria to understand how this relates to the experience of binary-identified transgender individuals is needed. This is particularly important given the flexibility of gender identities included in the DSM-5 criteria for gender dysphoria. Finally, the experience of distress in those who choose to physically transition versus those who choose another option is currently not known. This study provides further evidence for the need for society to accommodate people with different gender identities and journeys. It is clear from our findings that such societal shifts will improve the well-being of transgender people. Furthermore, societal responses to transgender people such as misgendering can exacerbate their negative feelings towards their body and their gender, adding further distress to the existing experience of gender dysphoria. Significantly, additional experiences of dysphoria than those in the DSM-5 came from the analysis. It is worth noting that confusion around gender identity, and suppression and denial of gender identity were often reported in relation to distress around gender identity. This study provides support for both the DSM-5 criteria for gender dysphoria and gender minority stress theory, while providing an important insight into how these experiences of distress are related to one another.

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Contributors

KC, AR, WM and CB designed the study and KC wrote the protocol. KC conducted literature searches and screening. All authors contributed to the analysis. KC wrote the first draft of the manuscript and all authors contributed to and have approved the final manuscript.

Declaration of Competing Interest

None.

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Appendix A. Studies included in the meta-ethnography

	Author/Year	Title	Journal	Country	Setting	Participant group	Participants	Qualitative methods	Data collection method
1	Algars et al., 2012	Disordered eating and gender identity disorder: a qualitative study	Eating disorders	Finland	Support organisations	Transgender and undergoing gender reassignment (16 with diagnosis of GID)	20	Grounded theory	One-to-one interview
2	Applegarth & Nuttall, 2016	The lived experience of transgender people of talking therapies	International Journal of Transgenderism	UK	Community support groups and online	Transgender participants including non-binary people	6	IPA	One-to-one interview
3	Bailey et al., 2014	Suicide risk in the UK Trans population and the role of gender transition in decreasing suicidal ideation and suicide attempt	Mental Health Review Journal	UK	Support organisations and services and online	Transgender	889	Narrative analysis	Self-report survey
4	Budge et al., 2013	Transgender emotional and coping processes: facilitative and avoidant coping throughout gender transitioning	The Counselling Psychologist	USA	LGBT community centres	Transgender participants including non-binary people	18	Grounded Theory	One-to-one interview face-to-face
5	Charter et al., 2018	The transgender parent: experiences and constructions of pregnancy and parenthood for transgender men in Australia	International Journal of Transgenderism	Australia	Community support groups and online	Transgender men	25	Thematic analysis	One-to-one telephone interview

6	Ellis et al., 2015	Conception, pregnancy and birth experiences of male and gender variant gestational parents: it's how we could have a family	Journal of Midwifery and Women's Health	USA	Health care and social services plus snowballing	Transgender and non-binary (assigned female at birth)	8	Grounded Theory	One-to-one interview via online video call
7	Ganju & Saggurti, 2017	Stigma, violence and HIV vulnerability among transgender persons in sex work in Maharashtra, India	Culture, Health & Sexuality	India	Health providers, NGOs and snowballing	Transgender (hijra)	68	Thematic analysis	One-to-one interview face-to-face
8	Giovanardi et al., 2019	Transition memories: experiences of trans adult women with hormone therapy and their beliefs on the usage of hormone blockers to suppress puberty	Journal of Endocrinological Investigation	Italy	Gender clinic	Transgender women	10	Consensual Qualitative Research	One-to-one interview face-to-face
9	Goldberg et al., 2019	Health care experiences of transgender binary and nonbinary university students	The Counselling Psychologist	USA	Support organisations and services and online	Transgender, GNC, gender questioning, genderqueer, non-binary, agender	430	Thematic analysis	Self-report survey
10	Goodrich, 2012	Lived experiences of college-age transsexual individuals	Journal of College Counselling	USA	Support organisations and services and online	Transsexuals	4	Grounded Theory	One-to-one interview (phone and face-to-face)
11	Levy and Lo, 2013	Transgender, transsexual, and gender queer individuals with a Christian upbringing: the process of resolving conflict between gender identity and faith	Journal of Religion & Spirituality in Social Work: Social Thought	USA	Support organisations and online	Transgender, transsexual and gender queer	5	Grounded Theory	One-to-one interview face-to-face
12	MacDonald et al., 2016	Transmasculine individuals' experiences with lactation, chestfeeding, and gender identity: a qualitative study	BMC Pregnancy and Childbirth	North America, Europe & Australia	Online recruitment	Transmasculine individuals	22	Interpretive description methodology	One-to-one interview on skype or telephone
13	Mullen & Moane, 2013	A qualitative exploration of transgender identity affirmation at the personal, interpersonal, and sociocultural levels	International Journal of Transgenderism	Ireland	Support organisations	Transgender	7	Thematic analysis	One-to-one interview face-to-face
14	Peitzmeier et al., 2017	"It Can promote an existential crisis": factors influencing pap test acceptability and utilization among transmasculine individuals	Qualitative Health Research	USA	Support organisation, health services and online	Transmasculine individuals	32	Grounded Theory	One-to-one interview face-to-face
15	Rood et al., 2017	Identity concealment in transgender adults: a qualitative assessment of minority stress and gender affirmation	American Journal of Orthopsychiatry	USA	Online recruitment	Transgender; Non-cisgender/other	30	Consensual Qualitative Research	One-to-one interview on skype
16	Rood et al., 2017	Internalized transphobia: exploring perceptions of social messages in transgender and gender nonconforming adults	International Journal of Transgenderism	USA	Online recruitment	Transgender; Non-cisgender/other	30	Consensual Qualitative Research	One-to-one interview on skype
17	Rood et al., 2016	Expecting rejection: understanding the minority stress experiences of transgender and gender nonconforming individuals	Transgender Health	USA	Online recruitment	Transgender; Non-cisgender/other	30	Consensual Qualitative Research	One-to-one interview on skype
18	Scandurra et al., 2019	A qualitative study on minority stress subjectively experienced by transgender and gender nonconforming people in Italy	Sexologies	Italy	Personal contacts/ snowballing	Transgender and genderqueer	8	Thematic analysis	Semi-structured focus group
19	Schrock et al., 2009	Emotion work in the public performances of male-to-female transsexuals	Archives of Sexual Behaviour	USA	Support organisations	MtF transsexuals (Transgender women)	9	Inductive analysis	One-to-one interview face-to-face
20	Smith et al., 2018	Determinants of transgender individuals' well-being, mental health and suicidality in a rural state	Rural Mental Health	USA	Support organisations and services and online	Transgender, non-binary and Two-Spirit	30	Community Based Participatory Research	One-to-one interview

Appendix B. CASP quality assessment for included papers

Study number	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1. Clear statement of aims?	2	2	1	2	2	1	1	2	2	2	1	2	0	1	2	2	2	2	1	2
2. Is a qualitative method appropriate?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
3. Research design appropriate for aims?	1	2	1	2	1	2	1	1	1	1	1	2	1	1	1	1	1	1	1	2
4. Appropriate recruitment strategy?	1	1	2	1	2	1	2	1	1	1	1	1	1	2	2	2	2	1	1	2
5. Data collected appropriately?	1	0	1	2	1	0	2	2	1	1	1	1	2	1	1	2	2	2	1	2
6. Relationship between researcher and participants considered?	0	1	0	2	2	0	0	0	0	2	0	0	0	1	1	1	1	0	0	2
7. Ethical issues considered?	2	0	2	2	2	2	1	1	1	1	0	2	2	1	1	1	2	2	1	2
8. Data analysis rigorous?	0	2	0	2	2	1	1	1	2	2	0	0	1	1	2	2	2	1	0	2
9. Clear statement of findings?	1	2	1	2	1	1	1	1	1	2	1	1	2	1	2	2	2	1	1	2
10. How valuable is the research?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Average	1.2	1.4	1.2	1.9	1.7	1.2	1.3	1.3	1.3	1.6	0.9	1.3	1.3	1.3	1.6	1.7	1.8	1.4	1	2

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