

Ethical and methodological challenges conducting participative research with transgender and gender-diverse young people: a systematic review.

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Introduction: Research with transgender and gender-diverse (TGD) young people is essential to understand their experiences and to be able to propose, implement and adapt 'services' in the broadest sense to meet their needs. However, research outside clinical settings on current experiences and needs of youth under the age of 18 is limited which hinders the development of knowledge on TGD, as well as the development of research informed support practices. Acquiring parental consent for participatory research may present ethical and logistical difficulties, as it could jeopardize the safety, well-being, or confidentiality of adolescent participants. This creates a tension between the adolescent's right to autonomy, privacy, freedom, and all aspects related to the consent of the underage on the one hand, and the parents' right to protect their child on the other hand. This review aims to identify the methodological and ethical challenges associated with participatory research with transgender and gender-diverse young people.

Methods: We systematically searched bibliometric databases for studies published between 2006 and 2022 and included 4 main conceptual groups: transgender and gender non-conforming, adolescence, qualitative research (including participatory research) and consent. This review was registered in PROSPERO (CRD42022368360) in November 2022.

Results: Of the 3,794 articles initially identified, 291 met the inclusion criteria and 48 were examined. The selected studies were analyzed in the light of four main ethical tensions: involving parents or a trusted person in the consent gathering process, ensuring the protection and safety of young people while respecting confidentiality, and ensuring that spaces are created for transgender and gender-diverse young people to express themselves freely as part of an empowering research process. At the same time, several methodological challenges concerning public and stakeholder participation and recruitment, data collection and analysis as well as research integrity emerged from the selected studies.

Conclusion & implications: The existing literature of participatory research involving young transgender and gender-diverse individuals underscores the intricate and conflicting aspects, especially concerning power dynamics, empowerment, and the researcher's role. The relevance of these findings extends

across various legal frameworks and is applicable to multiple contexts and countries.

Keywords: ethics; participatory research; transgender; gender-diverse; youth; systematic review

Introduction

Transgender and gender-diverse (TGD) people experience discrimination in almost all institutions and social settings, which has deleterious effects on the health and well-being of this population (Albuquerque et al., 2016; Brandes, 2014; McCann & Brown, 2017; Winter et al., 2016). Similarly, limited access to health care and quality healthcare (Noonan et al., 2018; Rider et al., 2018), substance use (Eisenberg et al., 2017), greater risk of harassment (McCann & Brown, 2017; Winter et al., 2016), homelessness and poverty (Keuroghlian et al., 2014; McCann & Brown, 2019, 2021) all contribute to the poor (mental) health of TGD people. However, these findings are often based on retrospective adult reports, and, in Europe, research on current experiences and needs of TGD youth is limited (Költö et al., 2021; McDermott & Roen, 2012; Mustanski, 2011; Tyni et al., 2024). This could be explained by the fact that adolescents are commonly seen as a vulnerable group needing protection under the law and international ethical guidelines, which tend to be closely related (Kennan, 2015).

The primary purpose of ethics committees is to safeguard the well-being and rights of research participants while upholding ethical standards throughout the research process. As adolescents are a particular population, many ethics committees require parental consent prior to their participation in medical or non-medical research (Kennan, 2015; Skelton, 2008). Although seen as an important safety barrier and good practice, requiring parental consent may discourage adolescents, particularly those who are marginalized, from participating in research (Mustanski, 2011; Panfil et al., 2017;

Schrager et al., 2019; Sims & Nolen, 2021; A. U. Smith & Schwartz, 2019; Taylor, 2008). This issue is even more pronounced for TGD youth as obtaining parental consent can compromise their safety, welfare, or privacy, for example if it is not clear whether parents know, understand, or support their child's gender identity (Cwinn et al., 2021; D'Augelli et al., 2005; Elze, 2009; Macapagal et al., 2017; Martin & Meezan, 2003; Miller et al., 2006; Mustanski, 2011; Schelbe et al., 2015; Sims & Nolen, 2021). However, it seems clear that the intrinsic vulnerability of adolescents must be balanced against the need to take account of their needs and views, especially when seeking to understand these marginalized profiles (Kennan, 2015; Pacey et al., 2020; Zeeman et al., 2017).

In this sense, participatory research methods can be particularly useful for research involving communities such as TGD youth because these approaches enable the source of marginalization to be identified, understood, and addressed in close collaboration with project partners (Bromley et al., 2015; Carney et al., 2012; Israel et al., 1998; Jourian & Nicolazzo, 2017; Pacey et al., 2020; Pain & Francis, 2003; Pullen Sansfaçon et al., 2014; Ross et al., 2010; R. Travers et al., 2014). Multiple research methodologies have been created or adjusted to promote active involvement (Foth & Axup, 2006). This has led to an expanding range of participatory approaches, such as community-based participatory research (CBPR), participatory action research, participatory rural appraisal, user-centered design, visual methods, and comparable methodologies, all falling under this overarching category. However, even if participatory research makes it possible to address issues of power inherent to the relationship between researcher and young person (James & Platzer, 1999; Powell et al., 2012), or by extension adult and young person (Bettencourt, 2020), it presents different ethical challenges that need to be carefully considered (Guta et al., 2013; McCartan et al., 2012; Robichaud & Schwimmer, 2020). Ethical considerations specific to participatory research include not

only the respect for the integrity of TGD youth and their informed consent to participate, but also the potential implications arising from the generation of knowledge concerning themselves (Hillier & Kroehle, 2021). While this production is crucial, it can either empower them or, conversely, perpetuate their marginalization (Shook et al., 2022b). Consequently, researchers need to be cautious about the application and potential misapplication of their knowledge production in study design (Cederved et al., 2021; Foucault, 1998; Khan & MacEachen, 2021; Shook et al., 2022a).

Objectives and aims

This study is part of a larger project that aims to address the unmet needs of TGD adolescents and young adults (AYAs - from 15 to 20 years) through the integration of their perspectives, knowledge, and experiences. As a precursor to this research, we aim to examine the ethical and methodological challenges related to participatory research that involves TGD individuals under the age of majority. The definition of underage used in this review is based on Article 1 of the United Nations Convention on the Rights of the Child (UNCRC), which defines minors as *'every person below the age of 18 years unless under the law applicable to the child, majority is attained earlier'* (UN General Assembly, 1989) (note that in this article, the terms adolescents and young people will be used interchangeably to define our population). This review will be then followed by a mixed methods design combining qualitative and quantitative data on the needs and lived experiences of TGD young people. We searched the literature for articles reporting research experiences with TGD young people as a target group, using qualitative methods (including participatory methods). Even though the UNCRC, in its Articles 5 and 12, advocates for the freedom of expression and competence in decision-making for young people, legally, in many countries, the age of majority (18) is the age of consent for research participation without parental authorization (Kennan, 2015; Mustanski, 2011;

Nkosi et al., 2022; UN General Assembly, 1989Art 5&12). The main objective of this study is to critically examine how ethical and methodological challenges are addressed and discussed in qualitative (including participatory) empirical research with TGD youth, who are considered minors in the eyes of the law. By identifying and highlighting the pitfalls encountered or methods used to avoid them, this study may provide relevant guidance for studies with TGD young people in particular and adolescents in general.

Methods

This systematic review of peer-reviewed qualitative research on TGD AYAs follows the steps recommended in the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (Shamseer et al., 2015), for which the checklist is available in the [Supplementary file 1](#). The protocol, methods of analysis and inclusion were pre-specified and registered in PROSPERO (CRD42022368360) in November 2022 (see [Supplementary file 2](#)).

Due to shifts in terminology over time and its occasional misinterpretation, we have adhered to the latest GLAAD terminology (GLAAD, 2021) whenever applicable, particularly in presenting findings from incorporated studies. Given our focus, the term 'transgender and gender-diverse' will serve as a comprehensive label encompassing individuals who identify as trans women/men, non-binary, gender fluid, a- or polygender.

Search strategy

The research strategy was based on the "Population - Phenomena of Interest - Context - Outcome" (PICO) model, recommended by several authors, and PRISMA (Riva et al., 2012; Sayers, 2008; Shamseer et al., 2015), who also defined our eligibility criteria. Four main groups of keywords – transgender and gender nonconforming, adolescence, qualitative research (including participatory research) and consent - were combined to

create two research equations. The first equation ("consent equation") includes the research concepts of transgender, adolescence, and consent. The second equation ("research equation") includes the first two terms of the first equation and the qualitative research design. For each research group, we employed commonly utilized synonyms, associated terms, and vocabulary specific to the database (see [Supplementary file 3](#)). The search equations were developed in consultation with a systematic review librarian and were syntactically modified according to the search parameters of each database.

For this literature review, the online bibliographic databases MEDLINE (PubMed), CINAHL (EBSCO), Embase (Elsevier), Web of Science (webofknowledge.com) were systematically searched between 14 November and 31 December 2022. During the same period, sources of unpublished studies and grey literature were also searched in ProQuest Dissertations, Theses Sciences and Open Grey. The eligibility of key articles cited in the selected articles was evaluated. The results of the 'consent equation' and the 'search equation' were then merged and de-duplicated where necessary. Two reviewers (JS and HM) first reviewed the titles and abstracts independently using EndNote data extraction in Excel. Once this initial screening was completed, they assessed the full text. A third reviewer was available for consultation at all stages in case of disagreement.

Eligibility

To provide a comprehensive overview of the ethical and methodological challenges of participatory research with TGD young people, we considered studies that used models such as exploratory description, phenomenology, grounded theory, ethnography, action research, co-creation, and transgender studies. Qualitative components of mixed methods studies were also included if they were considered relevant by both researchers (JS and

HM). Studies from any geographical region were included, but only if written in English or French. As ethical challenges may be similar under European research regulations, particular attention has been paid to studies conducted in Europe. In addition, researchers carried out a selection and full-text evaluation of publications published between 2006 and 31 December 2022. The year 2006 was chosen as the starting point because of the adoption of the Yogyakarta Principles, which enabled systematically articulation of international human rights in ways that apply to the lives and experiences of people of diverse sexual orientations and gender identities (ARC International, 2016). Although the focus was to target literature concerning minors in the eyes of the law, articles with a mixed sample (minors and adults) were considered, provided that the exclusion criteria outlined below were adhered to.

As the aim of this review was to highlight, among other things, the ethical challenges of seeking parental consent in the context of gender identity, studies that recruited their sample from a young homeless population were not included. Similarly, studies were excluded if they had 1) no discussion of the consent/assent obtained, which is the case, for example, when questions of consent have not been addressed because the parents are interviewed at the same time as their children; 2) a sample consisting exclusively or mainly of adult participants; 3) a very small number of TGD (Transgender and Gender Diverse) people in their sample (less than 5 TDG young people and/or less than a third of the sample); 4) absence of qualitative methods; and 5) recruitment bias when recruitment took place in psychiatric institutions or was carried out by a care provider, leading to a social desirability bias (see *Erreur ! Source du renvoi introuvable.*).

Data analysis

Using an analysis matrix (Excel document), the 2 reviewers (JS and HM) gathered the important summary elements to describe and identify the main conclusions in terms of ethical and methodological challenges of the selected articles.

To answer our first question (What are the ethical challenges of participatory research with transgender and gender-diverse young people?), a matrix was created to highlight the different ethical themes to categorize the selected articles. These main themes were a) the parental involvement in TGD minors consent process; b) the involvement of consent mediators; c) the protection and safety while upholding the principles of confidentiality and d) creating space and empowerment.

To answer our second question (What are the main methodological challenges inherent to participatory research with transgender and gender-diverse young people?), we structured our analysis around some of the challenges and facilitating factors of community-based research as defined by Israel et al. (1998) a) the public and stakeholders participation; b) the recruitment; c) the data collection and analysis and d) the integrity.

Results

Search results

After merging results and removing duplicates, a total of 1,350 abstracts were identified, of which 291 were selected for full-text review. Forty-eight articles, assessed for quality and included in the systematic review, were identified from the full text review. Figure 1 presents the PRISMA flow chart highlighting reasons for exclusion.

Figure 1 : PRISMA Flow chart should be placed here

Study Descriptions

[Supplementary File 4](#) lists the data evidence summary extracted from the 48 included studies. North America accounted for most studies included. Twenty-nine were conducted in the United States, ten in Canada, four in the United Kingdom, and two in Australia, while Spain, Mexico and Sweden had one study each. Eighty-two percent of the studies were published between 2017 and 2022. In the majority of articles, the age range of young people is between 14 and 18 years (see [Supplementary File 4](#)), even in articles where an adult population was also present. The main methodology of the studies can be found in Table 1 below.

Table 1: Methodology description of the 48 included studies

PARTICIPATORY RESEARCH (N=15) (Bettergarcia et al., 2022; Craig et al., 2021; Craig et al., 2017; Fontenot et al., 2020; Holtby et al., 2015; Kiperman et al., 2022; Pacey et al., 2020; Pullen Sansfaçon et al., 2018; Reisner et al., 2020; Robards et al., 2019; Sava et al., 2021; Shook et al., 2022a, 2022b; A. Travers et al., 2022; Zeeman et al., 2017)
<ul style="list-style-type: none"> • Interview (n=5) • Focus groups (n=4) • Mixed methods (n=3) • Photovoice (n=2) • Action research (n=1)
QUALITATIVE RESEARCH (N=25) (Arayasirikul et al., 2015; Asakura, 2017; Bounds et al., 2020; Budge et al., 2018; Budge et al., 2021; Cederved et al., 2021; Clark & Virani, 2021; Clark et al., 2021; Coulter et al., 2021; Fisher et al., 2016; Grossman & D'Augelli, 2006; Grossman et al., 2009; Henderson et al., 2022; Iacono et al., 2022; Lozano-Verduzco et al., 2022; Lucassen et al., 2018; Macapagal et al., 2017; McDermott & Roen, 2012; Mustanski et al., 2017; Newcomb et al., 2016; Porta et al., 2017; Romito et al., 2021; Sims & Nolen, 2021; Strauss et al., 2019; Suess Schwend et al., 2018)
<ul style="list-style-type: none"> • Interview <ul style="list-style-type: none"> ○ Face-to-face (n=11) ○ Online (n=2) • Focus groups <ul style="list-style-type: none"> ○ Face-to-face (n=8) ○ Online (n=4)
MIXED METHODS (N=4) (Harper, Jadwin-Cakmak, et al., 2019; Harper, Wagner, et al., 2019; Knopf et al., 2017; Mustanski, 2011)
<ul style="list-style-type: none"> • Interview alongside of the quantitative part (n=4)
EX-POST METHODOLOGICAL REFLECTION (N=4) (Brown et al., 2021; Panfil et al., 2017; Pickles, 2020; Taylor, 2008)

Ethical challenges of participatory research with transgender and gender-diverse young people

Parental involvement in TGD minors consent process

One of the most important principles of research ethics is the respect of autonomy. This means the provision of all information, the obtaining of consent and ensuring that the person is free to make their own decisions (Beauchamp & Childress, 2019; Coughlin, 2008). It includes, according to several international ethical statements, providing additional protection for vulnerable people such as minors (CIOMS, 2017; Gordon, 2020; World Medical Association, 2013). However, requiring parental consent from TGD young people could put young people at risk if they have not yet disclosed their lived gender identity. This issue creates a tension between the rights of young people to autonomy, privacy, and freedom on the one hand, and the rights of parents to protect their children on the other hand (Miller et al., 2006; Mustanski, 2011). While less recent articles report difficulties in obtaining ethics committee approval to waive parental consent (Mustanski, 2011; Taylor, 2008), it appears less problematic in recent years (Bettergarcia et al., 2022; Craig et al., 2017; Henderson et al., 2022; Kiperman et al., 2022; Lucassen et al., 2018; Macapagal et al., 2017; Porta et al., 2017; Shook et al., 2022a, 2022b; A. Travers et al., 2022). In this sense, although ethics committees seem to be increasingly in favor of decision power for young people, there seems to be a cut-off point in terms of age. A good practice identified in most of the selected articles is to allow young people over the age of 16 to give their consent even if, according to the legislation of their country, they are not yet old enough to do so (Craig et al., 2021; Harper, Jadwin-Cakmak, et al., 2019; Henderson et al., 2022; Iacono et al., 2022; Kiperman et al., 2022; Lozano-Verduzco et al., 2022; Macapagal et al., 2017; McDermott & Roen, 2012; Mustanski, 2011; Mustanski et al., 2017; Porta et al., 2017; Shook et al., 2022a, 2022b).

Between the ages of 14 and 16, some authors recommend using informed assent rather than formal consent to enable young people to participate, even when there is no accompanying consent of a parent/legal guardian as states by the Declaration of Helsinki (Arayasirikul et al., 2015; Iacono et al., 2022; Mustanski et al., 2017; Pickles, 2020; Romito et al., 2021; Sava et al., 2021; World Medical Association, 2013). In order for assent to be considered valid, *'the child must show evidence of understanding of the purpose of the research, what he or she can expect and what will be expected'* (Lee cited by Ireland & Holloway, 1996, p. 160), rather than simply not opposing to the research. This means that after explaining the project, the researcher must actively check the young person understands understand the objectives of the study as well as their rights, which include, among others, the right to withdraw, access to data, anonymity, and the right to confidentiality (Clark & Virani, 2021; Craig et al., 2021; Craig et al., 2017; Pickles, 2020; Romito et al., 2021). Under 14, parental consent is generally required (Robards et al., 2019; Strauss et al., 2019) unless the research team was able to demonstrate a minimal risk of taking part in the research, for which parental consent is not an appropriate protective mechanism (Fontenot et al., 2020; Shook et al., 2022a, 2022b; A. Travers et al., 2022).

Involvement of consent mediators

In order to comply with the legal and ethical guidelines and protect young minors, some researchers have called on 'Youth Advocates' instead of trying to obtain parental consent (Kiperman et al., 2022; Panfil et al., 2017; Porta et al., 2017; Shook et al., 2022a, 2022b; Sims & Nolen, 2021). While mitigating the potential risks of parental disclosure, the use of a 'Youth Advocate' provides similar protection to parental consent. The role of a 'Youth advocate' is to ensure that young people are free to participate in research without

coercion (Panfil et al., 2017; Shook et al., 2022a, 2022b; Sims & Nolen, 2021). Their help and presence can ensure that only young people who really want to participate do so. It is therefore preferable that they have no personal interest in the research to ensure their neutrality (Sims & Nolen, 2021) but they should have some experience working with young people from similar populations sampled for the research (Panfil et al., 2017). This advocate may be present for young people whose parents have consented to research participation, but are not present at certain stages of the research, which require informed decisions on the part of the young people (Mustanski, 2011; Panfil et al., 2017; Shook et al., 2022b).

Protection and safety while respecting confidentiality

To reach TGD young people, and because they are a hidden and vulnerable population, researchers need to be particularly sensitive to issues of privacy, confidentiality, and anonymity (Fisher et al., 2016; Macapagal et al., 2017; Miller et al., 2006; Mustanski et al., 2017; Shivayogi, 2013). Macapagal et al. (2017) points out the importance of adopting additional privacy safeguards to minimize the risk of privacy breaches, which could put young people at risk or inadvertently expose them to their families. According to Fisher et al. (2016), 70% of adolescents who have not disclosed their sexual or gender identity to their parents would have refused to participate in research where parental consent was needed. This share drops to 20% for young people who have disclosed their identity to one of their parents. On the parent's side, Newcomb et al. (2016) found that 74% of parents believed that parental authorization should not be a requirement for TGD adolescent health inequities studies.

Similarly, due to the sensitivity of the topic, Bounds et al. (2020) didn't request some information, such as socio-demographic background or the name of the person in

their research. Other authors have preferred to use online surveys, pointing out that they are particularly attractive to TGD young people because of the anonymity they allow by logging into a secure website with a password that they create or that the researchers give them (Brown et al., 2021; Fisher et al., 2016; Fontenot et al., 2020; McDermott & Roen, 2012). Although online methods lack the richness of face-to-face exchanges, TGD young people see them as a way of maintaining their anonymity and protecting their privacy (Brown et al., 2021; Macapagal et al., 2017; McDermott & Roen, 2012; Sava et al., 2021). However, some authors warn that participation in an online survey or interview requires 1) a safe place, away from unsupportive family or flat mates (Craig et al., 2021), and 2) an emergency protocol that allows the researcher to break confidentiality if they fear for the young person's wellbeing as a result of something they have written or said (McDermott & Roen, 2012).

Creating space and empowerment

The involvement of researchers in participatory research with TGD populations is often motivated by the desire to gain a better understanding of the experiences and expectations of these marginalized and discriminated youth and give them an active role in the research (Pickles, 2020). Community involvement in research is seen not only as amplifying the voice of the TGD young people (Bounds et al., 2020; Harper, Jadwin-Cakmak, et al., 2019; Pickles, 2020; A. Travers et al., 2022), but also as a tool to address inequalities. It allows for interventions that are more acceptable and have greater impact because they are rooted in their lived reality (Coulter et al., 2021; Mustanski et al., 2017). Including young individuals into participatory research introduces an additional layer to the study, creating a 'poly-vocal' dynamic where everyone's perspective is valued, especially those of young people on the margins (Wearing, 2015). Allowing these diverse points of view

to be heard acknowledges not only the expertise of them but also the intricacies of their experiences. According to Pickles (2020), excluding young people from research under the premise of vulnerability due to age or marginalization would result in an inconsistent ethical framework.

Empowerment, used in conjunction with giving TGD young people a real role in research, is also mentioned in some of the included studies. This empowerment is sometimes linked to the methodology used (Craig et al., 2021; Holtby et al., 2015; Porta et al., 2017; Pullen Sansfaçon et al., 2018; A. Travers et al., 2022). In other cases, it is linked to the notion of consent to research (Fisher et al., 2016; Knopf et al., 2017; Pickles, 2020). Finally, it is sometimes articulated as an outcome of the research as young people found participation in research to be empowered (Holtby et al., 2015; A. Travers et al., 2022). In any case, empowerment is a crucial construct in the experiences of TGD people and it is identified as an important factor in resilience strategies (Singh et al., 2011; A. Travers et al., 2022). One of the ethical challenges for researchers using participatory methodologies with young TGD people is to reflect in depth on the motivations of researchers to carry out their research. If these motivations stem from projected anxieties or personal questions about gender, and that the research leads to a tokenisation of young people rather than strengthening them, it may be considered unethical (Felner, 2020; Singh et al., 2013).

Methodological challenges of participatory research with transgender and gender-diverse young people

Participatory research involves stakeholders participating in the research process and recognizing each other's unique strengths (Horowitz et al., 2009). Conducting participatory research with TGD communities can therefore empower them and make their voices heard (Aldridge, 2015; Bromley et al., 2015; Carney et al., 2012; Israel et al.,

1998). Several challenges and facilitating factors for participatory research, as defined by some authors (Aldridge, 2015; Israel et al., 1998; Wilkinson & Wilkinson, 2018), were identified in the selected articles.

Public and Stakeholder participation

Leaving aside the aspect of young people's consent to take part in the research as discussed above, several authors involved communities in the creation of a 'Youth Advisory Board/Council' (YAB/Cs) in the very beginning of their research. Depending on the focus of the research, these YAB/Cs are composed solely of members of the LGBTQ or TGD communities (Bounds et al., 2020; Fontenot et al., 2020; Harper, Jadwin-Cakmak, et al., 2019; Harper, Wagner, et al., 2019; Holtby et al., 2015; Pacey et al., 2020; Pullen Sansfaçon et al., 2018; Robards et al., 2019; A. Travers et al., 2022), sometimes with the addition of people involved in these communities, such as Service Providers (SPs) and School Health Providers (SHPs) or co-researchers (Bettermann et al., 2022; Craig et al., 2017; Reisner et al., 2020; Sava et al., 2021; Zeeman et al., 2017). YAB/Cs are commonly used in research to assist in study design, participant recruitment, analysis, and knowledge mobilization. They play a role in disseminating study findings. They have been found to have a significant impact on research projects, for example by requesting researchers to increase representation of LGBTQ individuals in photographs (Holtby et al., 2015), or completely changing the design of a videogame co-created by and for trans youth (A. Travers et al., 2022). While YAB/Cs provide valuable guidance and oversight, they may not always want to assume too much responsibility. In one case, a YAB/C declined the responsibility of deciding which photovoice photographs would be showcased in a community exhibition (Holtby et al., 2015).

Recruitment

In terms of recruitment, the majority of articles (n=23) included relied on community networks, associations or clinics to reach TGD young people (Asakura, 2017; Bounds et al., 2020; Budge et al., 2018; Budge et al., 2021; Clark & Virani, 2021; Clark et al., 2021; Fontenot et al., 2020; Grossman & D'Augelli, 2006; Grossman et al., 2009; Harper, Jadwin-Cakmak, et al., 2019; Harper, Wagner, et al., 2019; Holtby et al., 2015; Lucassen et al., 2018; Macapagal et al., 2017; Pickles, 2020; Porta et al., 2017; Pullen Sansfaçon et al., 2018; Reisner et al., 2020; Romito et al., 2021; Sava et al., 2021; Shook et al., 2022a; Strauss et al., 2019; A. Travers et al., 2022). One reason cited for using these techniques is that TGD youth is a “hidden” or “hard to reach” population (Arayasirikul et al., 2015; Grossman & D'Augelli, 2006; McDermott & Roen, 2012; A. Travers et al., 2022). Eight studies use purposive sampling (Arayasirikul et al., 2015; Bettergarcia et al., 2022; Coulter et al., 2021; Craig et al., 2017; Fontenot et al., 2020; Iacono et al., 2022; Kiperman et al., 2022; Zeeman et al., 2017) which consists of asking a few people to act as key informants. These informants are TGD people and are both able and willing to share their knowledge (Tongco, 2007). Three used snowball sampling as second method of recruitment (Bettergarcia et al., 2022; Budge et al., 2018; Kiperman et al., 2022). The difference between snowball sampling and purposive sampling is that purposive sampling does not use one informant to recruit another informant (Tongco, 2007). Regardless of the recruitment procedures, the means used most are online networks, flyers, and posters to disseminate information about the research. Few studies used face-to-face recruitment only (Bettergarcia et al., 2022; Cederved et al., 2021; Clark & Virani, 2021; Clark et al., 2021; Craig et al., 2017; Newcomb et al., 2016).

Nevertheless, despite the recruitment efforts of the various networks to collect varied lived experiences, authors report an over-representation of several specific

categories. White people (Asakura, 2017; Bettergarcia et al., 2022; Budge et al., 2018; Craig et al., 2017; Fisher et al., 2016; Fontenot et al., 2020; Holtby et al., 2015; Iacono et al., 2022; Macapagal et al., 2017; Mustanski et al., 2017; Pacey et al., 2020; Pullen Sansfaçon et al., 2018; Reisner et al., 2020; Romito et al., 2021; Sava et al., 2021), trans-masculine people (Asakura, 2017; Cederved et al., 2021; Craig et al., 2017; Fontenot et al., 2020; Lucassen et al., 2018; Pacey et al., 2020; Reisner et al., 2020; Romito et al., 2021; Sava et al., 2021; Shook et al., 2022a, 2022b; Strauss et al., 2019) and/or people from urban areas (Iacono et al., 2022; Pullen Sansfaçon et al., 2018; Romito et al., 2021; Shook et al., 2022a) are often overrepresented in research.

Data collection and analysis

As participatory research is considered more as an approach than a method in itself, a variety of methodologies can be used to achieve the research goals and take account of the target audience (in this case, teenagers). As seen in Table 1, the 15 studies labelled as participatory used various data collection methods. The remaining studies gave the floor to the young people in another way as, for example, some studies engaged young people in a steering committee (Zeeman et al., 2017) or during data analysis (Shook et al., 2022a, 2022b) without involving them at all stages of research. In the same way, photovoice is seen as a participant-centered method that can encourage the TGD to identify community concerns and priorities, while ensuring empowerment and creativity (Craig et al., 2021).

Integrity

The principle of research integrity emphasizes the importance of researchers maintaining accuracy, honesty, and transparency throughout the research process (Coughlin, 2008; Kass, 2001). Reflexivity, which involves reflecting on one's own biases and assumptions, is crucial in ensuring the integrity of the research (Budge et al., 2018; Budge et al., 2021;

Holtby et al., 2015). As Katz-Wise et al. (2019) point out, in the context of participatory research, taking into account the insider/outsider status of the researcher in relation to the study population is very important and even more so when the researcher does not share the same group identity as the participants. According to the quality assessment, most of the articles selected for this review obtained the maximum score for the reflective part of their research. Nevertheless, some concerns can be raised. While some studies highlight the different identities that make up the research team and how they may have influenced the research (Budge et al., 2018; Budge et al., 2021; Henderson et al., 2022; Holtby et al., 2015; Iacono et al., 2022; Kiperman et al., 2022; Lozano-Verduzco et al., 2022; Shook et al., 2022b), in some cases this does not go beyond description and there is not much reporting on if or how these identities influenced the research (Asakura, 2017; Bettergarcia et al., 2022; Coulter et al., 2021; Craig et al., 2017; Fontenot et al., 2020; Pacey et al., 2020).

Ensuring the integrity of research also means ensuring that there is no reproduction of power relations that may exist outside the research, in particular by ensuring that participants are genuinely involved as partners within and outside the research and that they are not exploited (Guta et al., 2013; Robichaud & Schwimmer, 2020). The emphasis should be on research with participants rather than research on them (Wilkinson & Wilkinson, 2018). Some studies have discussed the power dynamics that may exist within the research team (Budge et al., 2021; A. Travers et al., 2022) or that may have influenced their methodological choices (Shook et al., 2022b).

Discussion

The aim of this literature review was to examine how ethical and methodological challenges are addressed and discussed in qualitative (including participatory) empirical

research with TGD youth. The results revealed 3 main ethical issues 1) The involvement of parents or a trusted person in the consent gathering process; 2) Ensuring the protection and safety of young people while respecting confidentiality and 3) Creating space and an empowering research process. Four methodological challenges emerged from the literature: 1) Ensuring stakeholder participation; 2) The use of community recruitment methods and its tension with the heterogeneity of the collected sample; 3) The use of participatory data collection and analysis methods and 4) Ensuring research integrity.

Ethical balancing act

As we have seen from our results, conducting research with TGD young people involves a tightrope walk in ethical terms. Historically, marginalized, and hard-to-reach groups have been excluded from research, as have young people (Macapagal et al., 2017). Research involving minors generally requires parental consent before the young person can take part. However, such consent may oblige young people to disclose their lived identity to their parents or relatives, which may put them at risk. Some authors have shown that the requirement to obtain parental consent reduces young people's willingness to take part in research, thus biasing the samples towards young people who have already revealed their lived identity (Fisher et al., 2016; Liu et al., 2017; Newcomb et al., 2016). Yet justice, as a key principles of ethics, focuses the attention on equality of opportunity, including the opportunity to take part in research (Beauchamp & Childress, 2019; Coughlin, 2008). Ethics committees' decisions that hinder research aimed at improving the well-being and support of TGD young people contradict this principle of justice (Asakura, 2017; Budge et al., 2018; Budge et al., 2021; Clark et al., 2021; Liu et al., 2017; Mustanski, 2011). Therefore, some researchers propose waiving of parental consent, arguing either that these studies entail only "minimal risk" by ensuring that the questions

posed will cause no more discomfort than these individuals encounter in their daily lives (Clark et al., 2021; Mustanski, 2011; Porta et al., 2017; Taylor, 2008); or that asking for parental consent could put these young people at greater risk (Coulter et al., 2021; Macapagal et al., 2017; Mustanski, 2011; Schragger et al., 2019); or that the benefits of the research outweigh the risks (Bettergarcia et al., 2022; Panfil et al., 2017). In surveys, researchers often address this by including a "sensitive subject" warning at the beginning or before specific survey sections, ensuring that respondents are aware that their participation may potentially cause embarrassment or distress (Fendrich et al., 2007; McInroy, 2016). Nevertheless, certain studies suggest that young people perceive minimal risks when responding to inquiries about their general and intimate lives. They even believe that participating in such research can yield substantial benefits by providing significant assistance to others facing similar situations (Fisher et al., 2016; Kuyper et al., 2012; Kuyper et al., 2014; Macapagal et al., 2017; Mustanski, 2011; Mustanski et al., 2017; Powell et al., 2013; Yeater et al., 2012). Another vital ethical principle in research, closely linked to the concept of consent, is respect for individual autonomy. This principle recognizes an individual's ability to form opinions, make choices, and act in accordance with their own values and beliefs (Beauchamp & Childress, 2019; Coughlin, 2008). In research, this entails the provision of comprehensive information, obtaining informed consent and or assent, and ensuring that individuals can freely make decisions (Coughlin, 2008). It also involves offering additional safeguards for those with limited autonomy. Since the adoption of the UNCRC, young people have been acknowledged as individuals with their own rights, including freedom of expression, competence in decision-making, the right to privacy, and the ability to access to relevant information (Powell et al., 2013; UN General Assembly, 1989Art 5&12). To enable young people to authentically share their lived experiences as genuine experts, they must have the capacity to freely express

their feelings, perceptions, and experiences or do so with the assistance of a trusted individual (Kiperman et al., 2022; Mustanski, 2011; Panfil et al., 2017; Shook et al., 2022a, 2022b; Sims & Nolen, 2021). In the selected literature, formal consent above the age of 16 is frequently emphasized and utilized, and a similar emphasis is placed on informed assent, particularly in American articles concerning young people aged between 14 and 16. The researcher's objective is to ensure that the young person fully comprehends all the information pertinent to the research, as well as their rights in relation to it. As Cocks (2006) points out, *"assent cannot be in itself sufficient in ensuring ethical integrity, rather it is complemented by the researcher operating reflexively and within a framework of ethical reflection"* (p. 249).

Privacy and confidentiality breaches can pose a significant ethical dilemma, particularly concerning TGD young individuals. This issue can be linked to the ethical principle of beneficence, which revolves around the responsibility to shield participants from harm and actively promote their well-being (Beauchamp & Childress, 2019; Coughlin, 2008). Paradoxically, some aspects of the research, which may appear innocuous (such as distributing posters or organizing meetings in popular venues), could inadvertently expose transgender and gender-diverse youth to involuntary "outing" (Macapagal et al., 2017; Mustanski, 2011). Likewise, the information disclosed by these young individuals during interviews may compel the researcher to breach confidentiality to safeguard the individual's welfare. For example, this may occur when a participant makes suicidal statements or discloses experiences of abuse. Consequently, some authors have identified the implementation of an emergency protocol as best practice for research involving these young people (Craig et al., 2021; Katz-Wise et al., 2019; McDermott & Roen, 2012; McInroy, 2016).

Degree of involvement and participation

The foundation of participatory research lies in promoting the inclusion and collaboration of both individuals and communities in the research. This involves promoting the active participation of people in the research process rather than simply treating them as research objects (Aldridge, 2015). To this end, participatory research encompasses various levels of involvement, which differ in terms of both methodology and extent (Hart, 2008). Francks (2011, p. 15) introduces the concept of 'pockets of participation' to describe the distinct participatory components that can constitute a project. These are spaces in which young people have the autonomy to decide whether or not to engage. Importantly, there exists no predetermined hierarchy or specific sequence in which participation must unfold (Treseder et al., 1997). It is not an "all or nothing" approach, as varying degrees of participation may be more suitable under different circumstances or at different stages of the research (Francks, 2011; Water, 2018). Recognizing the challenge of ensuring the continuous presence of young people throughout all research phases, some authors have employed advisory committees like the YAC/B or Community Advisory Boards. These advisory committees enable community members or those collaborating with the community to voice their concerns, express research priorities, and provide guidance on research processes that are respectful and acceptable to the community (Israel et al., 1998; Newman et al., 2011; Quinn, 2004; Singh et al., 2013; Vincent, 2018). And as some authors have pointed out, this is a particularly important practice for cisgender researchers (Goffnett & Pacey, 2020; Vincent, 2018).

Establishing advisory committees also helps to prevent tokenism and manipulation of young people and the perpetuation of power imbalances (Guta et al., 2013; Heath et al., 2009; Robichaud & Schwimmer, 2020; Water, 2018). Participatory methods pose challenges in terms of negotiating boundaries and power dynamics,

especially when involving young people (Bradbury-Jones et al., 2018; Cahill, 2007; Felner, 2020; Katz-Wise et al., 2019). Firstly, researchers must shift from their traditional role of generating results and recommendations, defining problems, to that of a facilitator, collaborating with communities to identify solutions that align with their needs (James & Platzer, 1999; Wilkinson & Wilkinson, 2018). Secondly, in order to avoid adultism, where young people are marginalized because of their age and experience, they need to re-conceptualize the relationship between adults and young people as an equal one (Bettencourt, 2020; Bradbury-Jones et al., 2018; Wilkinson & Wilkinson, 2018). To sidestep these pitfalls, some authors have employed visual methods, involving images captured by young people or provided by researchers. These approaches enable meaningful participation by young individuals and help rectify power imbalances. In fact, these techniques stimulate reflection and empowerment among young people, making them particularly well-suited for a young transgender and gender-diverse audience (Ford & Campbell; J. A. Smith et al., 2017). Nevertheless, the utilization of visual data can also give rise to ethical concerns that demand vigilance, especially concerning what gets documented, the individuals depicted, the enduring nature of the images, and the locations where they were captured, be it a public, semi-public, or private setting (Ford & Campbell; J. A. Smith et al., 2017; Water, 2018).

Benefits for participants

As the results indicate, participatory research enables young people to actively shape their lives by encouraging the articulation of their points of view and engaging in discussions related to the subject of the research. This process serves to enhance the empowerment of young individuals and frequently places a focus on achieving relational and/or collective well-being, considering it both an objective and a crucial aspect of the process (A. Travers

et al., 2022; Wagaman, 2015). Moreover, this participatory approach can foster the creation of synergistic relationships among individuals engaged in the lives of these young individuals with diverse gender identities, promoting a shared understanding of the most effective strategies for influencing systems and driving transformative change (Katz-Wise et al., 2019; Pullen Sansfaçon et al., 2018; Singh et al., 2013). Yet, as indicated by a recent exploratory study, engaging young individuals as co-researchers demands resources, time, and adaptability, and may not be devoid of potential risks, posing challenges for both the participants and the overall research project (Fløtten et al., 2021). These potential issues could encompass challenges like repurposing data originally collected for another purpose without consent, perpetuating power imbalances, or tokenization of young people (Bradbury-Jones et al., 2018; Fløtten et al., 2021; Gilchrist et al., 2013; Hillier & Kroehle, 2021). It is therefore essential to consider the interaction that the methodology used may have with the lives of young people when making methodological choices (Felner, 2020; Holtby et al., 2015).

Transparency and reflexivity

As the results and certain authors emphasize, it is crucial for researchers to maintain transparency regarding their personal narrative when conducting research involving TGD (Katz-Wise et al., 2019; Vincent, 2018; Wilson et al., 2018). Transparency entails the ability to question one's own identity, motivations for undertaking the research, research objectives, and affiliations, whether they be academic, financial, or community-based (Katz-Wise et al., 2019; Wilson et al., 2018). Concerning one's personal identity, the concept of being an insider or outsider to the research population often arises in participatory research and in the articles included. Some argue that researchers should belong to the TGD community, aligning with feminist epistemology, which posits that

individuals insider to the group are best suited to study and understand the community (Harding, 1986; James & Platzer, 1999). Nevertheless, some researchers point out that, although being an insider brings benefits to research, this dual role of researcher/insider can be complex in terms of reflexivity (James & Platzer, 1999; Misgav, 2016). Yet, when the notion of being an 'outsider' is explored in the literature, it prompts researchers to reflect on how their own identity may have influenced both the participants and the research itself (Galupo, 2017). Consequently, as addressed in some articles included in this review (Lozano-Verduzco et al., 2022; Panfil et al., 2017; Shook et al., 2022a, 2022b), the focus of researcher reflexivity should shift from a consideration of "who" they are to "how" they engage in the research and how this engagement has transformed their personal identity (Singh et al., 2013).

Limitations

This systematic review highlights the different approaches to the participation of transgender and gender-diverse young people, as well as the different tensions, in particular the reproductions of power differentials, in addition to parental consent in this type of research. However, this study has several limitations. Firstly, as the search was limited to articles in English and French, we may have missed some studies. The fact that most of the studies come from the United States or Canada is related to this, but also to other factors such as the importance of the issue in these countries and their research strength. Expanding the literature search to include other languages would make it possible to reach countries whose social norms, values and legal contexts are different from the North American context, thus highlighting different methodological and ethical challenges in participatory approaches. Secondly, this systematic review has intentionally focused on research conducted with TGD minors, given the importance of representing

the voices and experiences of young people in qualitative (and more particularly participatory) research. However, studies conducted with AYAs specifically considering the 15 to 24 age group could be relevant to advance the methodological considerations of research on TGD minors and thus contribute to the broadening of knowledge in this field. Finally, although the inclusion criteria specified in the protocol were met, it is possible that some of the literature on participatory research with TGD young people was omitted if the authors did not identify their article with the keywords that were searched. This limitation was mitigated, as far as possible, by reading the bibliographies of the selected articles in search of new articles likely to be included in this systematic review.

Conclusion

The realm of participatory research is undergoing rapid evolution, yet there remains a shortage of systematic reviews that tackle the ethical and methodological hurdles intrinsic to these approaches when minors and TGD are involved. Gilchrist et al. (2013) contend that ethical considerations in research involving young people should encompass power dynamics, issues pertaining to consent, confidentiality, and the dissemination of findings. They recognize that these concerns extend beyond research involving people under the age of 18 but emphasize that they may require particular attention in such a context. With regard to research involving young people under 18, these issues should be extended to respecting their autonomy in deciding whether or not to participate in the research or in specific segments of it, and to taking additional measures to ensure their safety and protection, such as accepting the presence of a support person designated by the young person or recruited for the research (but with no personal link to the research), or implementing a safety plan.

The researcher, for his part, must demonstrate constant reflexivity regarding his

own status in relation to the population studied and the evolution of this status, but also in relation to the balances of power that may arise during the research. All this while ensuring that the research process remains meaningful and empowering for the participants.

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List of abbreviations

TGD: Transgender and Gender-Diverse; AYAS: Adolescents and Young Adults; CBPR: Community-Based Participatory Research; UNCRC: United Nations Convention of the Rights of the Child; PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses; YAB/C: Youth Advisory Board/Council; SP: Service Providers; SHP: School Health Provider

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