


Considerations for collecting and analyzing longitudinal data in observational cohort studies of transgender, non-binary, and gender diverse people

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ABSTRACT

The health and well-being of transgender, non-binary, and gender-diverse people is receiving increasing attention from epidemiologists and public health researchers, including those utilizing longitudinal observational cohort studies. These longitudinal studies are advantageous over cross-sectional observational study designs given their scope over several timepoints rather than one, and when exposures and outcomes are prospectively measured this improves validity of causal claims. However, within these longitudinal studies, gender is often collected inconsistently (e.g. only asked at a single timepoint), or inadequately (e.g. questions that use limiting notions of gender). Due to the temporal nature of gender, this introduces potential including misclassification error and may provide an incomplete picture of gender diversity in a sample. This article considers these methodological issues and offers evidence-based recommendations to ensure longitudinal data on trans, non-binary, and gender-diverse people is treated with epidemiological rigor, while maintaining inclusivity.

KEYWORDS

Longitudinal design; data collection; data analysis; gender; trans; non-binary; gender diverse

Introduction

Many transgender, non-binary, and gender diverse people (henceforth respectfully referred to using the umbrella term, “trans”) live full and well lives. Trans people make up a considerable proportion of the population with studies estimating up to 3% of the population has trans experiences (Power et al., 2022). Accumulating research is geared toward identifying barriers and facilitators to trans health and well-being, including access to gender-affirming healthcare, freedom from stigma and discrimination, and gender euphoria and joy (Bretherton et al., 2021; Strauss et al., 2020; Tan et al., 2020). Notwithstanding this important work, a considerable body of literature has repeatedly highlighted disparities in health and well-being outcomes among trans people, including mental health (Strauss et al., 2021), substance use (Hill et al., 2021), health service access (Strauss et al., 2020), sleep (Levenson et al., 2021), and cardiovascular health (Poteat et al., 2021).

Producing rigorous public health evidence around the health and well-being experiences of trans people, including the burden, magnitude, and correlates of these issues, is critical for promoting trans health.

Traditional public health approaches posit that accurate, longitudinal epidemiological evidence, that is, longitudinal observational cohort studies following the same group of participants prospectively through time, offer one such gold standard for producing this high-quality evidence. The advantages of longitudinal studies over cross-sectional studies include the measurement of exposure and outcome variables at different times permitting increased ability to make causal claims, as well as the measurement of individual changes in outcomes over time. These design characteristics permit researchers to examine infrequent events, often with increased statistical power for these rare events (O'Neill et al., 2019). However, gender is complex and dynamic and the capturing of gender within observational studies is

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oftentimes inconsistent, and/or inadequate. For example, *Growing Up in Australia*, the first major longitudinal study of Australian children, began in 2003 recruiting a younger “B” cohort of children aged 0–1 years in 2003–2004, and an older “K” cohort of children aged 4–5 in 2003–2004 (Australian Bureau of Statistics LSAC processing team & the Australian Bureau of Statistics Household Survey Methodology team, 2020). In 2021, gender indicators were largely absent for the K cohort until Wave 8 follow-up ($N=3037$, $M_{age}=18.3$ years) and were not included in Wave 9 follow-up (Department of Social Services, 2022). These methodological decisions incorrectly assume that participants genders remain constant for any given individual across time and hence capturing gender once throughout a study period is sufficient. Similarly, whereas in previous waves gender indicators were unavailable, recent follow-up assessments within the *Growing Up in New Zealand* cohort study have included gender indicators (Growing Up in New Zealand, 2022). While these measures distinguish sex from gender, they are not without limitations however discussion of these is out of the scope of the present article.

Significant epidemiological considerations must be made by researchers to ensure this longitudinal data on trans people is treated in a manner that is rigorous, ethically sound and inclusive. This commentary explores some of these considerations with the intention of promoting improvement in this process.

Minimum standards for collecting information about gender

It is first necessary to clarify what is deemed “adequate” gender indicators in (longitudinal) observational studies. Trans people are people with a gender different to that of the gender presumed for them at birth (often termed “sex at birth”) (Transhub, 2021b). Hence a “two-stepped” approach asking people about their gender separately and in addition to their sex at birth is considered the minimum standard for gender data collection, which allows researchers to analyze trans people’s data (The Williams Institute, 2013). It is important to note that increasingly common

is a “three-stepped” approach whereby participants are first asked a “tick all that apply” item listing several gender identities. This is followed by a second “collapsed” gender item asking participants to select one of the limited gender identities (typically male/man, female/woman, non-binary), and a sex item (Bretherton et al., 2021). For the purposes of this article, we assume longitudinal observational cohort studies seeking to answer epidemiological research questions pertaining to trans people – as should all study types – include as a minimum the two-stepped approach when measuring gender.

Utilizing longitudinal data with inconsistently collected gender data

The dynamic nature of gender is evolving and formative. Often, trans people refer to their gender identities as a journey or ongoing experience which takes place across the lifespan rather than a single event isolated to a specific timepoint (Transhub, 2021a). This is also why when discussing trans people in historical context, pronouns associated with their *current* (trans) gender identity are used as opposed to pronouns associated with the gender presumed at birth (Transhub 2021c).

Despite the dynamic nature of gender, it is important to note that growing evidence highlights occurrences of de-transition or feelings of transition regret, are extremely low among trans people who have initiated medical affirmation of their gender. A recent meta-analysis of 27 studies pooling 7,928 transgender participants who underwent any type of gender-affirming surgery found that just <1% experienced regret (Bustos et al., 2021). A seminal post-hoc analysis of the United States Transgender Survey of 27,715 trans adults found that approximately 13% of participants had “de-transitioned” temporarily or permanently at some point (mostly temporarily) (Turban et al., 2021). Among trans people who do de-transition (henceforth respectfully referred to with the term, “de-trans” people), many attribute their decision to external gender minority stress and related pressures (Turban et al., 2021). Additional research suggests the majority of de-trans people do not identify as the gender presumed for them at birth (i.e. cisgender) and

are more likely to identify as non-binary or otherwise trans (MacKinnon et al., 2022).

Imputing gender into future waves

A researcher may be conducting secondary analysis of a longitudinal dataset wherein gender was only captured at one timepoint, yet their analysis spans multiple timepoints. Where gender data is limited to one timepoint, it is consistent with the theoretical framework of gender to analyze longitudinal data on trans people by imputing last-collected gender into future waves.

Gender captured across multiple timepoints

If gender indicators are however collected at multiple timepoints as opposed to a single timepoint – for example, at the start of an observational cohort study (T1) and at third follow-up timepoint (T3) – researchers must exercise further consideration.

It is useful to note there are quite stark differences in the estimated number of trans people among groups in the population. Whereas studies in younger samples from 12 to 25 years of age have found rates between 1.2% and 2.7%, population-level studies of adult general samples have found rates of between 0.3% and 0.5% (Zhang et al., 2020). However, almost all population-level studies are either of trans young people or trans adults, mutually exclusively (Zhang et al., 2020). This prohibits the examination of a “cohort effect” explanation of these varying prevalence ratios, that is, people with younger age are more likely to identify as trans whereas people with older age are less likely to identify as trans. It is plausible to posit that with recent times ushering in a host of progressive reforms around gender and trans health and rights (notwithstanding a proportionately large and increasing number of negative reforms and media (Hughto et al., 2021; Katz-Wise et al., 2021; Pang et al., 2020)), trans people are feeling more comfortable to accept themselves and share information about their gender (Zhang et al., 2020). In light of this, where gender is captured inconsistently in earlier and later follow-up timepoints within a longitudinal study, data on trans

people should be drawn from the most recent inclusion of gender to ensure optimal coverage of trans people who have shared information about their gender during the study period. Analyzing participants’ data based on last gender data reported circumvents limitations associated with loss to follow-up; however, there is one very nuanced instance where it is permissible to use gender data from an earlier timepoint.

Trans agency or trans sample size? Paternalism versus utilitarianism

Promoting and protecting trans health and well-being arguably poses one of the most critical public health challenges of the twenty first century and further rigorous, longitudinal epidemiological health research is urgently required. An important ethical consideration is faced when the sample size of trans people based on gender indicators in more recent follow-up timepoints is significantly lower than a sample of trans people drawn from an earlier timepoint/s. For example, this might occur where longitudinal studies encounter large rates of loss to follow-up or attrition such that the number of trans people identified in later follow-up waves is significantly smaller than the number of trans people identified in earlier wave/s. In the specific case of significant loss to follow-up which perhaps differentially (disproportionately) affects trans people, researchers using sample sizes drawn from those later waves might find themselves statistically underpowered for analyses compared with if they drew their sample size of trans participants from earlier waves. In specific cases such as this, we argue that it is permissible – in terms of rigor and ethics – for researchers to veto the “rule of thumb” of using gender data from later timepoints and instead use gender drawn from earlier wave points, in the interests of examining the health and well-being of trans people. This paternalistic decision to trump the rights of trans people identified in later timepoints to be included in trans-specific analyses is not to be taken lightly, however, and must only be considered when this decision results in a meaningfully sub-optimal quality of research useful for promoting health and well-being among trans

people. Typically this situation might arise where the researcher is examining precise disparities between trans and their cisgender peers or where a later timepoint yields a lesser sample size of trans participants compared with earlier timepoints. Sensitivity analyses regarding loss to follow-up should be conducted methodically with regards to this, as well as meaningful consideration of the proportion of trans people from earlier timepoints who have dropped out or been lost to follow-up at later timepoints.

Using gender data in later timepoints prevents misclassifying trans peoples' evolving genders

With this being said, a final consideration that warrants reflection is where a trans person changes gender identities and this gender identity remains different to their gender assigned at birth. For example, “person X,” a non-binary person assigned male at birth identified at T1, shares that they are a woman, at T3. Researchers faced with this scenario should consider their research question and whether other demographic or other baseline characteristics are especially relevant at specific timepoints in which case this would guide which gender indicator to use. Where the research question pertains to differences between trans people, given the evolving nature of gender, the most recent timepoint with a gender indicator should be used. Using gender data from a previous timepoint in this case risks incorrectly classifying the gender of person X which may result in measurement bias of the effect estimate, particularly where the research question examines different groups of trans people (e.g. drawing within-group comparisons between trans men, trans women, and non-binary people, for example).

Low sample sizes and statistical power

Relatedly, the exclusion of non-binary people is becoming increasingly common to see within observational studies. Specifically, researchers may decide to exclude non-binary people, often one of three levels within a gender variable, within analyses to retrieve degrees of freedom otherwise needed to make statistically significant

conclusions. This is a disservice to the rich data provided by non-binary people in epidemiological studies. Moreover, non-binary people comprise a significant proportion of trans communities (Strauss et al., 2021) and have unique experiences of health and well-being compared with their binary trans peers warranting rigorous public health research (Chew et al., 2020). A more inclusive approach is to utilize all available data on participants gender and discuss limitations on limited statistical power and sample size calculations rather than merely excluding for statistical rigor.

Finally, epidemiological studies that include “adequate” gender indicators should strive to consistently use and promote these gender indicators. Researchers involved with these studies, particularly where there is face-to-face data collection, should also seek out training and education opportunities to improve their understanding of gender diversity and ability to affirm trans people. Undergoing these trainings will strengthen and improve researchers' nuanced perspectives on reporting on gender diversity ultimately leading to higher quality research and trans health outcomes. Failing to do so may risk causing significant distress to participants, disproportionate drop-out of trans people in longitudinal studies and subsequent selection bias. This is concerning given there is already a paucity of longitudinal epidemiological research on the health and well-being of trans people and, moreover, trans people represent a relatively small proportion of the population, and hence may result in an underestimation of an effect estimate.

Recommendations and conclusions

In summation, analyzing longitudinal data on trans people raises several considerations for researchers. Gender is dynamic and evolving and there are no hard and fast rules about which timepoint to use to determine your trans sample size; however, generally, analyzing longitudinal data on trans people based on gender indicators at later/more recent waves is in keeping with the theoretical parameters of gender, may yield larger sample size/increase statistical power, and avoids misclassifying changing gender identities. Increased conscientiousness of

collecting and using longitudinal data on gender should commence ideally in the study conception and design phase and take place throughout the study process through to reporting and dissemination of results, to ensure that this data and its interpretation is treated with a high degree of epidemiological rigor and ethical soundness. Researchers employing these principle? recommendations for handling longitudinal data on trans people will optimize the likelihood their research will benefit the health and well-being of trans people and thus society more broadly.

Author contributions

SB led the conception, design, and drafting of the work. NN, YP, LG, SS, and EB all revised the work for important intellectual content. All authors approved the final version to be published.

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