

Experiences of transgender and non-binary youth accessing gender-affirming care: a systematic review and meta ethnography

By Seán Kearns



What is gender-affirming care?

- **“health care that holistically attends to transgender people's physical, mental, and social health needs and well-being while respectfully affirming their gender identity”**

What is a systematic review and meta ethnography?

- **“meta-ethnography is a method that allows synthesizing qualitative studies in order to achieve a new conceptual understanding of a particular phenomenon in a systematic (step by step) manner.”**

What youth and why?

- **There is a lack of research on youths experience when it comes to accessing gender care.**
- **Youth is categorised at 12-24 incorporating young adults as relevant in this sample**

Research aims

1. to systematically search, retrieve, and appraise the qualitative empirical literature on the experiences of young transgender and non-binary youth accessing healthcare.

2. to construct a new line of argument/conceptual model based on this literature

3. to synthesize and discuss the results through the lens of both this new conceptual model and Ryvicker's existing model of behavioural ecological perspective.

• **Methods:**

- A meta-ethnography and synthesis as detailed by Noblit and Hare was performed. The seven-stage method was employed to collate data and work towards the generation of new understanding.
- The project was registered on Prospero | (Registration number: CRD42020139908).
- A systematic search was completed across four databases: PsycINFO, CINAHL, EMBASE, and MEDLINE.

• **Quality Appraisal:**

- The quality of studies chosen for inclusion was assessed using the Critical Appraisal Skills Programme (CASP) checklist. This is a checklist specifically designed for the appraisal of qualitative research.

Data extraction and data synthesis

Phase one titled “getting started” relates to assessing if the qualitative synthesis is needed, assessing if you have the right people involved, and is there a clear research aim.

There is a dearth of qualitative reviews in this area and the research team involves a strong cohort of researchers from different backgrounds with expertise in this field as well as clinicians and specialist nurses who work in the area of gender healthcare.

- The second phase “deciding what is relevant” involves creating a search strategy, inclusion and exclusion criteria, deciding an appraisal tool, and implementing the search strategy and quality check. This was completed by SK and KN.

- Phase three involved “reading the studies” and identifying first order and second-order constructs. The studies were repeatedly read by SK and KN and data uploaded to the qualitative software package NVivo v11 for coding. The data uploaded consisted of all direct participant quotes from the publications reviewed.

- In phase four “how are the studies related”, a grid of concepts was made from the chosen studies extracts. Each study was reviewed and concepts were identified and juxtaposed to each other. This phase forms the initial assumptions.

- In phase five, “translating the studies”, the themes that arose across the studies are constantly compared within each other and across accounts from participants.

- Phase six involved “synthesising translations”, in this phase a line of argument and a new model was constructed. The line of argument reveals hidden meaning as a whole and is greater than the sum of any one study alone.
- The last phase is “expressing the synthesis” and this was done by comprehensively writing up the results for dissemination.

- Stages 4-6 were completed by SK and both reviewers KN and DOS were available as reviewers throughout the process. Referenced in the finding section is an example of construction of third-order constructs from first order constructs for a set theme.

Synthesis

The research team identified 141 first-and second-order constructs across the studies, which were then interpreted into third order constructs contextualised into five dimensions:

1. Disclosure of gender identity;
2. The pursuit of care;
3. The cost of care;
4. Complex family/caregiver dynamics
5. Patient-Provider Relationships.

Results

1737 studies were identified after applying a rigorous search strategy (see Prisma diagram).

10 studies were eligible for the final analysis.

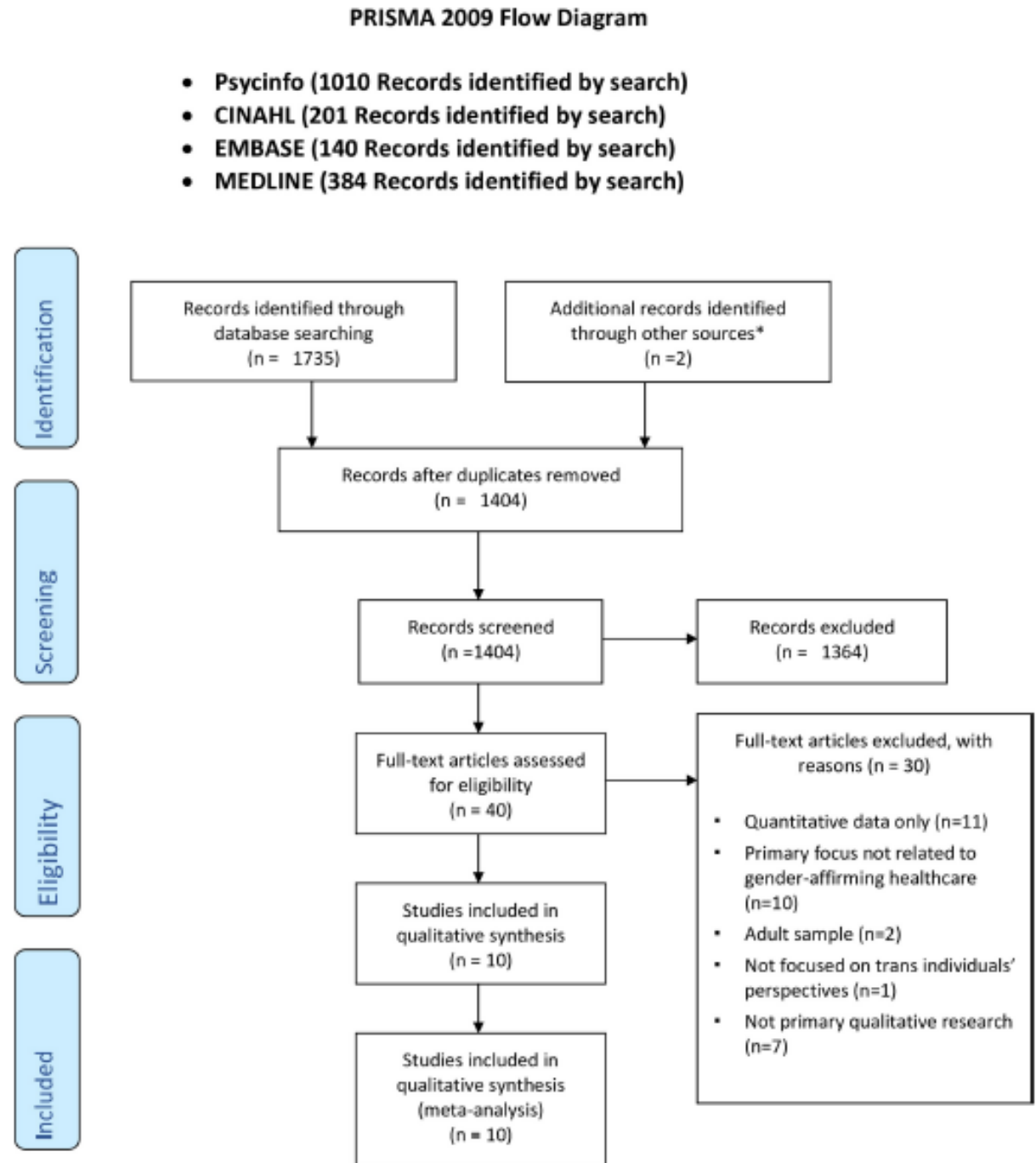


Fig 1. PRISMA flow diagram.

Characteristics of included articles:

- Six studies were conducted in the United States of America, two studies were conducted in Canada, one study was Australian, and one study was conducted in the UK.
- Eight out of ten studies were undertaken in the last 5 years.
- 188 young people and 108 parents were included in the final analysis.

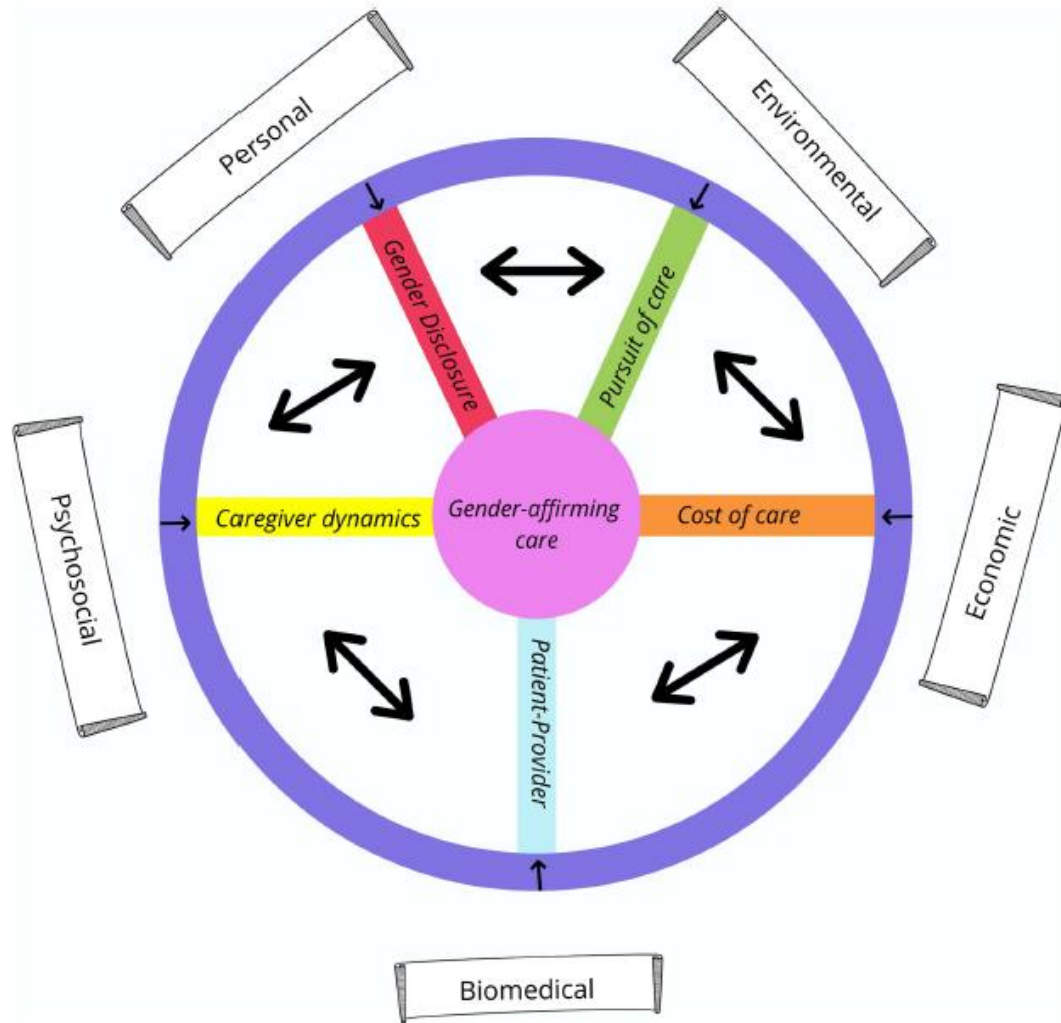
Inclusion/Exclusion:

- Studies were included if they were a primary study that was qualitative in nature with a transgender/non-binary population.
- Mixed methods were included only where qualitative direct quotes could be extracted in isolation.
- Sample age needed to be between 12 -24 years old.
- Studies were excluded if purely quantitative or sample age was not clearly defined.
- Only trans-specific studies were chosen.

Results

Disclosure of Gender Identity	The Pursuit of Care	The Cost of Care	Complex parent/caregiver perspectives	Patient-Provider Relationships
Postponing disclosure due to fear, worry, or safety	Finding a competent provider	Guilt and worry	United front	Ill-equipped
Factors encouraging disclosure	Geographical challenges	Insurance plans disparities	Insurmountable barrier	Dread fear and avoidance
	Onerous waiting times		As advocates	Need to prove gender identity
			As patients too	Pronoun or name etiquette
				Refusal of care
				Positive experiences

The authors coined the term **“Rainbow Brick Road”** as a new model. This non-linear road represents reciprocally translated dimensional obstacles that transgender and non-binary youth may experience from their initial gender questioning through their healthcare navigation.



The Lion who desires courage represents the courage needed to disclose a transgender/non-binary gender identity to oneself and others. It also represents the tenacity and ferocity needed to overcome structural, environmental and economic barriers that arise.



The Tinman who desires a heart represents the acceptance of family/caregivers who may then act as fierce advocates or insurmountable barriers.

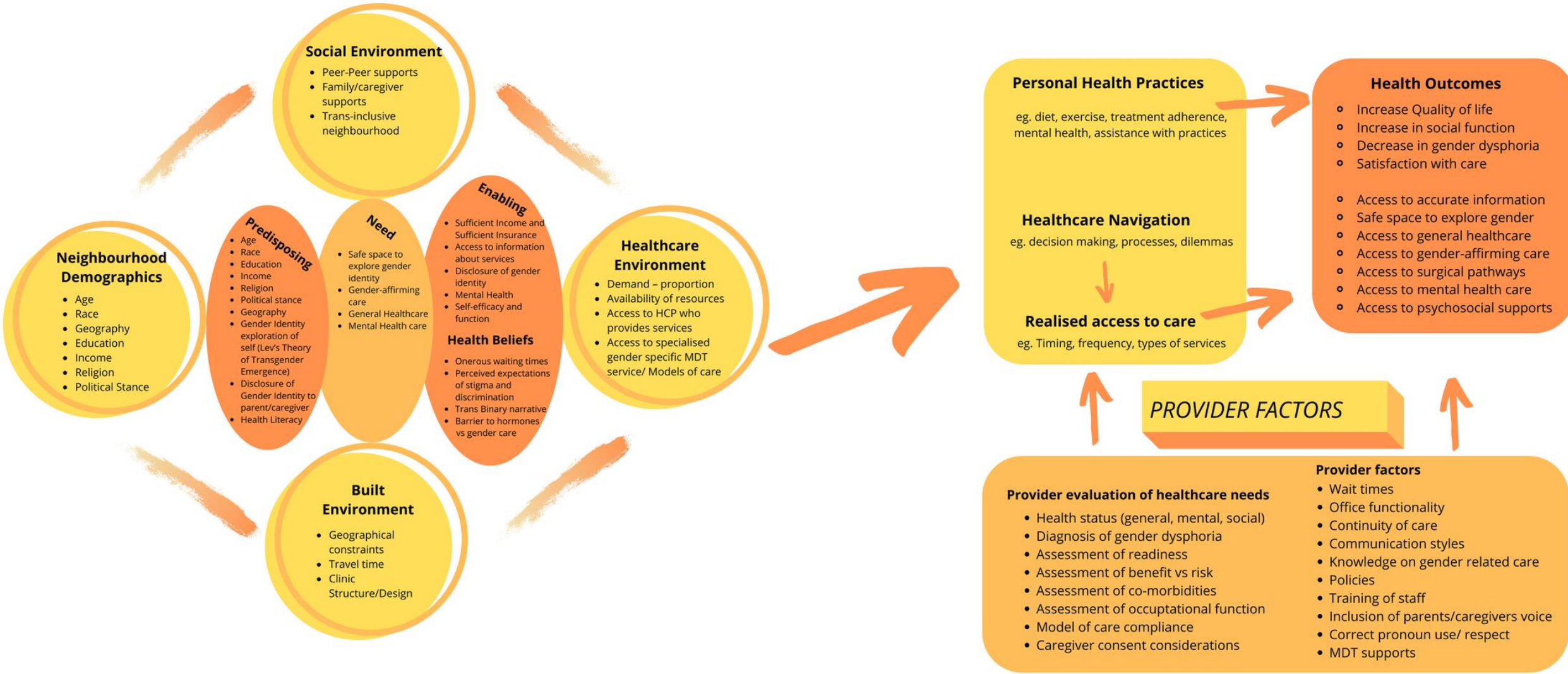


The Scarecrow who desires a brain represents healthcare providers who are ill-informed and received little training on gender-related care.

PERSON IN ENVIRONMENT

HEALTH BEHAVIOUR

OUTCOMES



RESEARCH ARTICLE

Experiences of transgender and non-binary youth accessing gender-affirming care: A systematic review and meta-ethnography

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Abstract

Objective
 Transgender and non-binary individuals frequently engage with healthcare services to obtain gender-affirming care. Little data exist on the experiences of young people accessing gender care. This systematic review and meta-ethnography aimed to identify and synthesise data on youths' experiences accessing gender-affirming healthcare.

Method

A systematic review and meta-ethnography focusing on qualitative research on the experiences of transgender and non-binary youth accessing gender care was completed between April–December 2020. The following databases were used: PsychINFO, MEDLINE, EMBASE, and CINAHL. The protocol was registered on PROSPERO, international prospective register of Systematic Reviews (CRD42020139908).

Results

Ten studies were included in the final review. The sample included participants with diverse gender identities and included the perspective of parents/caregivers. Five dimensions (third-order constructs) were identified and contextualized into the following themes: 1.) Disclosure of gender identity. 2.) The pursuit of care. 3.) The cost of care. 4.) Complex family/caregiver dynamics. 5.) Patient-provider relationships. Each dimension details a complicated set of factors that can impact healthcare navigation and are explained through a new conceptual model titled "The Rainbow Brick Road".

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... into the experience of transgender and non-binary ...
 ...aker's behavioural-ecological model of

Implication for research and clinical trials

- Further research needed into healthcare access in Europe, and specifically Ireland
- Further robust RCT evidence needed on endocrine interventions for youth
- Consideration into how to integrate trans patients into clinical trials that are often inherently gendered



Questions?

