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.

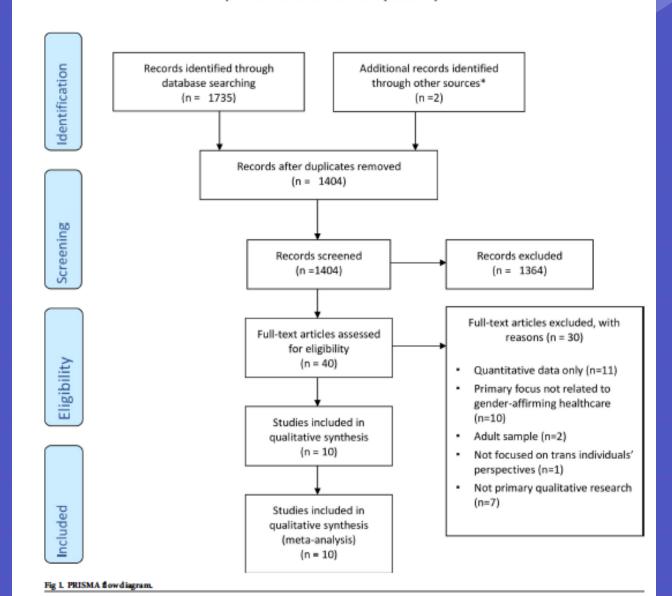
Results

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

10 studies were eligible for the final analysis.

PRISMA 2009 Flow Diagram

- Psycinfo (1010 Records identified by search)
- CINAHL (201 Records identified by search)
- EMBASE (140 Records identified by search)
- MEDLINE (384 Records identified by search)



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:

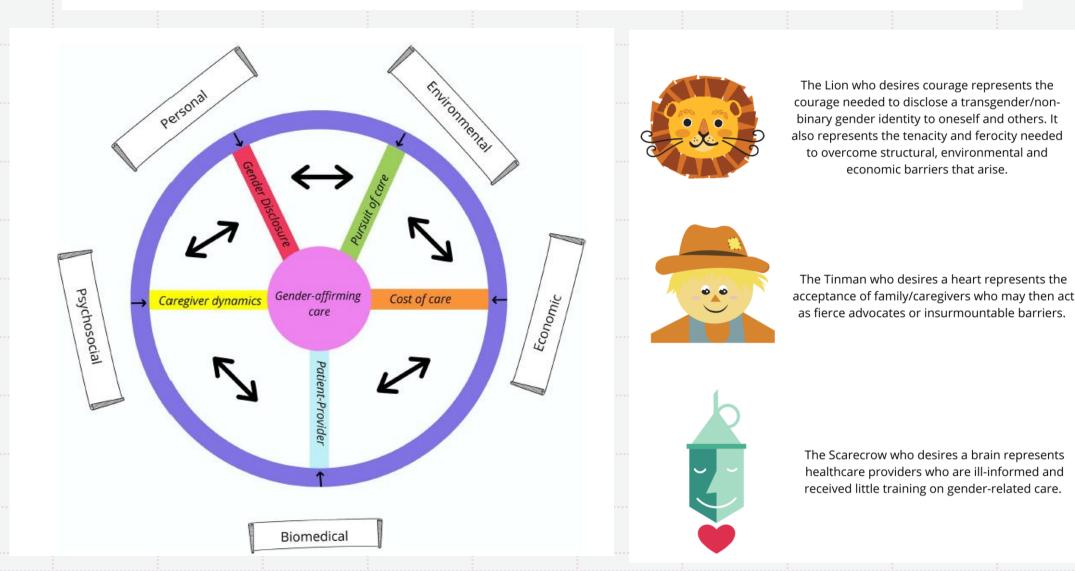
- Studies were included if they were a primary study that was qualitative in nature with a transgender/non-binary population.
- Mixed methods were included only where qualitative direct quotes could be extracted in isolation.
- Sample age needed to be between 12 -24 years old.
- Studies were excluded 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	III-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.



PERSON IN ENVIRONMENT

HEALTH BEHAVIOUR

OUTCOMES

Social Environment

- · Peer-Peer supports
- Family/caregiver supports
- Trans-inclusive neighbourhood

Neighbourhood Demographics

- Age
- Race
- Geography
- Education
- Income
- Religion
- Political Stance

· Age Age Race

- Race
 Education
 Income
- ReligionPolitical stanceGeography
- Gender Identity
 exploration of
- exploration of self (Lev's Theory of Transgender Emergence)
- Disclosure of Gender Identity to parent/caregiver
 Health Literacy

Need

- Safe space to explore gender identity
- Gender-affirming care
- General Healthcare
 Mental Health care

Sufficient Income and

- Sufficient Insurance
 Access to information
 about services
- about services
 Disclosure of gender identity
- Mental Health
- Self-efficacy and

Health Beliefs

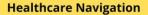
- Onerous waiting times
- Perceived expectations of stigma and discrimination
- Trans Binary narrative
- Barrier to hormones vs gender care

Healthcare Environment

- Demand proportion
- · Availability of resources
- Access to HCP who provides services
- Access to specialised gender specific MDT service/ Models of care

Personal Health Practices

eg. diet, exercise, treatment adherence, mental health, assistance with practices



eg. decision making, processes, dilemmas

Realised access to care

eg. Timing, frequency, types of services

Health Outcomes

- Increase Quality of life
- Increase in social function
- Decrease in gender dysphoria
- Satisfaction with care
- Access to accurate information
- Safe space to explore gender
- Access to general healthcare
- Access to gender-affirming care
- Access to surgical pathways
- Access to mental health care
- Access to psychosocial supports



PROVIDER FACTORS



Built Environment

- Geographical constraints
- Travel time
- Clinic
 Structure/Design

Provider evaluation of healthcare needs

- Health status (general, mental, social)
- Diagnosis of gender dysphoria
- Assessment of readiness
- Assessment of benefit vs risk
- Assessment of co-morbidities
- Assessment of occuptational functionModel of care compliance
- Caregiver consent considerations

Provider factors

- Wait times
- Office functionality
- Continuity of care
- Communication styles
- Knowledge on gender related care
- Policies
- · Training of staff
- Inclusion of parents/caregivers voice
- Correct pronoun use/ respect
- MDT supports

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Abstract

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Transgender and non-binary individuals frequently engage with healthcare services to Transgender and non-binary individuals frequently engage with frequent services to dain gender-affirming care. Little data exist on the experiences of young people accessing and make particular and make particular and make particular and make particular and another particular and make opain genoer-animing care. Line data exist on the expenences of young people accessing gender care. This systematic review and meta-ethnography aimed to identify and synthesis and the data on the expension of the data of the expension of the ex sise data on youths' experiences accessing gender-affirming healthcare.

A systematic review and meta-ethnography focusing on qualitative research on the experi-A systematic review and meta-etimography locusing on qualitative research on the experiences of transgender and non-binary youth accessing gender care was completed between ences or transgenoer and non-binary yourn accessing genoer care was completed by April-December 2020. The following databases were used: PsychiNFO, MEDUNE, April-December 2020. The following databases were used: PsychiNFO, International April-December 2020. The newtonal ways realists and on DD CODED international appropriate the particular appropriate the property of the property April-December 2020. The following databases were used: PsychiNFO, MEDUNE,

EMBASE, and CINAHL The protocol was registered on PROSPERO, international prospedive register of Systematic Reviews (CRD42020139908).

Ten studies were included in the final review. The sample included participants with diverse gender identities and included the perspective of parents/cate/givers. Five dimensions gender loantries and included the perspective of parents/caregivers. Five dimensions (third-order constructs) were identified and contextualized into the following themes: 1.) Unitro-proet constructs) were identified and contextualized into the rollowing mames: 1.) Uis closure of gender identity. 2.) The pursuit of care. 3.) The cost of care. 4.4.0 complex family. cosure of gender identity. 2.) The pursuit of care. 3.) The cost of care. 4.) Complex tamily caregiver dynamics. 5.) Patient-provider relationships. Each dimension details a complicaregiver dynamics. 3.) Patient-provider relationships. Each dimension details a compile cated set of factors that can impact healthcare navigation and are explained through a new conceptual model titled "The Rainbow Brick Road".

Variable experience of transgender and non-binary

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?

