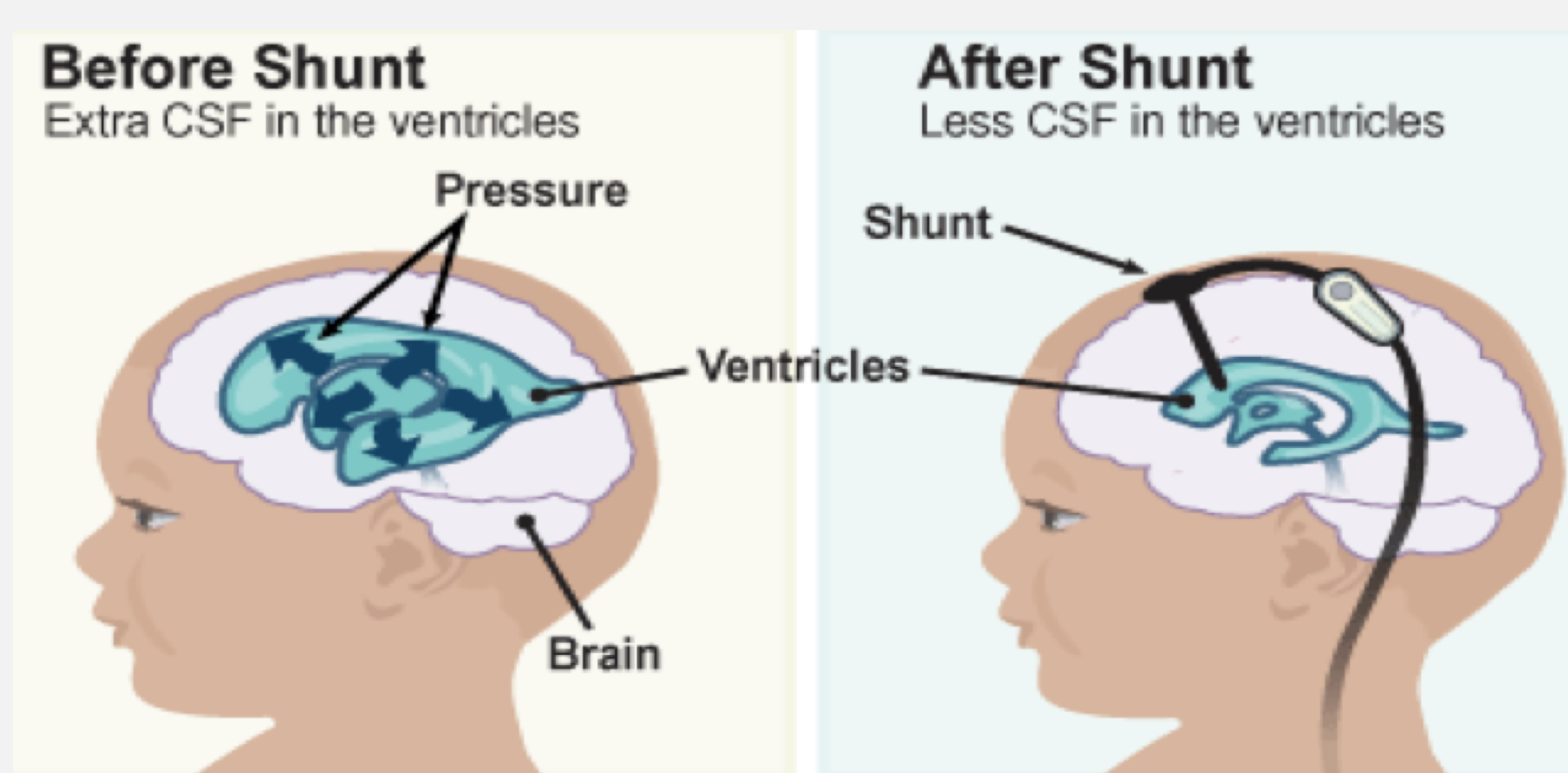


## Background

- Hydrocephalus: Chronic neurological condition that affects around 6 in 10 000 live births.<sup>1</sup>
- Ventricular dilation and increased intracranial pressure resulting from various causes (i.e. IVH,, aqueductal stenosis, tumors, etc.)
- Shunt placement and endoscopic third ventriculostomies (ETV) have increased survival rates.



## Introduction

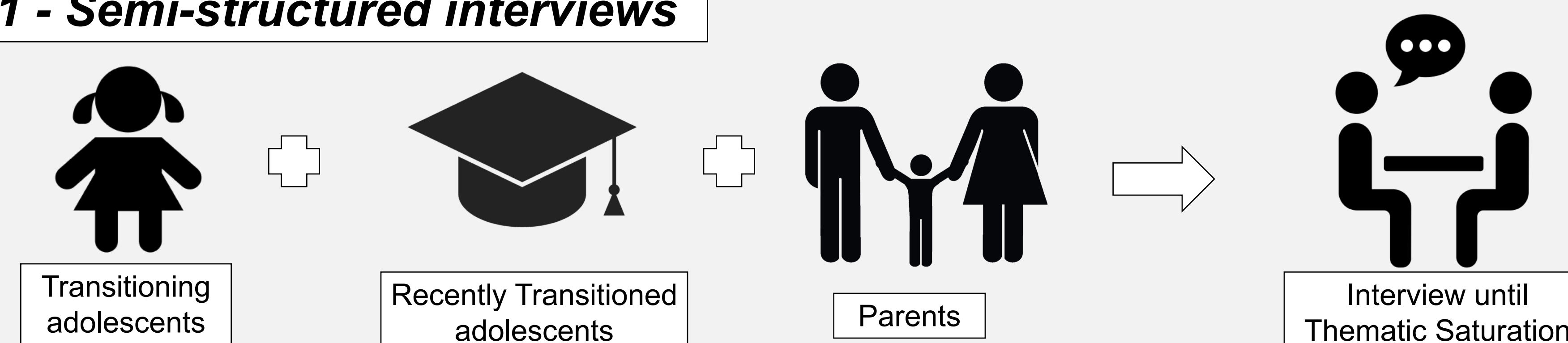
- Patients require continuous care throughout their adulthood to maintain good outcomes, as problems ranging from a shunt complication to deteriorations in social/cognitive functioning are all long-term risks that need to be attended to.<sup>2</sup>
- During transfer, patients can find it difficult to forgo familiar relationships and environment in the pediatric setting and adopt the new culture of an adult clinic.<sup>3</sup>
- Unlike other chronic conditions such as congenital heart disease, type I diabetes and rheumatic disease, transition of adolescents with hydrocephalus is often fragmented and disjointed given the lack of attention and research in establishing appropriate models.<sup>4</sup>
- The purpose of the study is to qualitatively and quantitatively identify the factors that challenge young adults with hydrocephalus as they go through this transitioning period.

## Methods

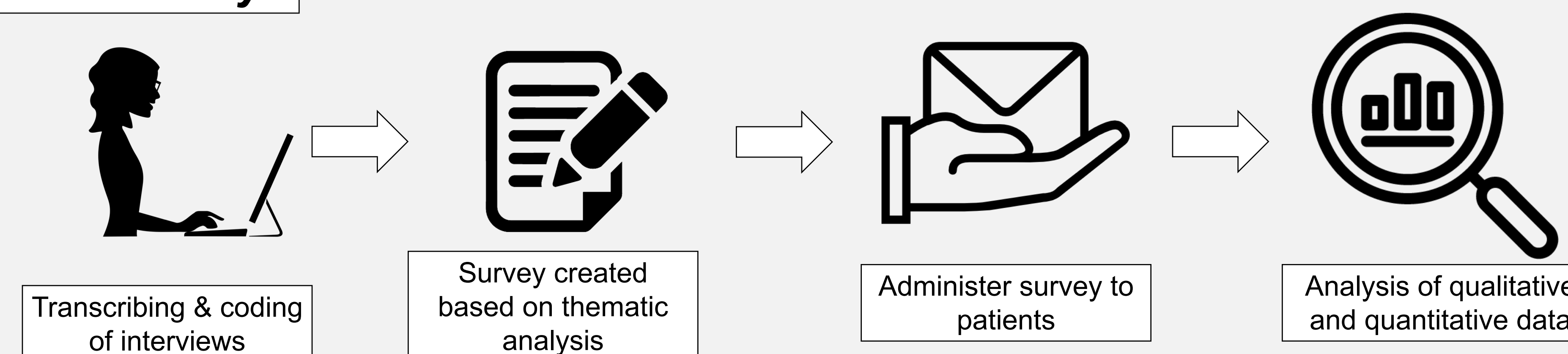
### Participants

- Patients were identified by the attending neurosurgeon, contacted by a neurosurgery research associate, and asked if they would like to participate in the research study. Participants ( $n=30$ ) between ages 15-21 (*mean age* = 18.27 years), with hydrocephalus as the primary condition were interviewed along with their parents.
- 3 Groups: Patients who are in the process of transitioning, recently transitioned patients and parents.

### Phase 1 - Semi-structured interviews



### Phase 2 - Surveys



## Results

- Analysis revealed 4 common themes that captured challenges that patients/family member faced during transition:

#### 1. Communication



"We were referred ...2 years later ... Not a word not a communication, we were completely LOST."

#### 2. Significant Relationships



"There's a real relationship with doctors at children's hospital .... that part was really hard. To say Goodbye."

#### 3. Fear of Uncertainty



"I have concerns because we don't know who these people are."

#### 4. Achieving Independence



"I didn't put too much thought into it really. But it's definitely a little bit of a concern. Like it is definitely a change in environment."

## Discussion

- Preparation for transition should start early in adolescence and should be a multidisciplinary process.
- Developing a national guideline or a transition care model requires involvement of all-party members involved in the process including patients, parents and health care professionals.
- Proposed models of practice for continuity of care for patients with hydrocephalus include Paediatric neurosurgeons running adult hydrocephalus services, Adult neurosurgeons running adult hydrocephalus services or Hybrid/joint services.<sup>5</sup>
- Limitation of this study is only exploring opinions and experiences of patients specific to Vancouver, a city that has a dedicated adult hydrocephalus clinic.
- Future studies should survey experiences of patients on a national scale, understand how to measure transition outcomes, identify factors that lead to failed transition and defining a successful transition.

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\*A full reference list is available: saman.fouladirad@alumni.ubc.ca