“I Feel a Lot More Vulnerable”: Exploring Unmet Psychosocial Care and Recovery Needs in Young Survivors of Stroke

Syeda Hashmi, MD
Department of Psychiatry
University Health Network
Toronto, Canada

Presentation Roadmap

Introduction & Rationale

Methods (Qualitative Focus)

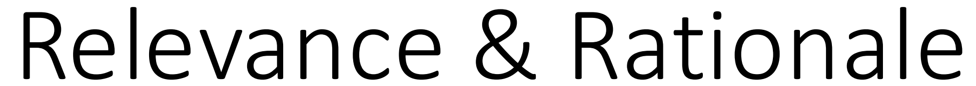
Findings (Key Themes & Illustrative Quotes)

Discussion & Implications

Conclusion, Limitations & Future Directions

Introduction

- Stroke incidence in <65 y/o adults has doubled over the past decade (Feigin et al., 2021)
- Younger survivors often experience disproportionately high psychosocial challenges compared to physical deficits
- Traditional stroke care is primarily designed for older populations



Relevance & Rationale

- Underexplored psychosocial impacts: identity disruption, stigma, role conflict
- Younger adults juggle career, education, or parenting responsibilities
- Standard tools (e.g., Neuro-QOL) may miss nuanced psychosocial complexities (Cella et al., 2012)
- Need for age-specific approaches and integrated care models

Existing Literature Gaps

- Primarily biomedical focus on physical/cognitive recovery (Holloway et al., 2022)
- Limited qualitative research addressing life-stage-specific psychosocial experiences (Amoah et al., 2023)
- Inconsistent stroke care for younger adults: minimal mental health screening, few guidelines on vocational rehabilitation

Study Objectives

1

Explore unmet psychosocial needs of y-stroke survivors (≤65 years old)

2

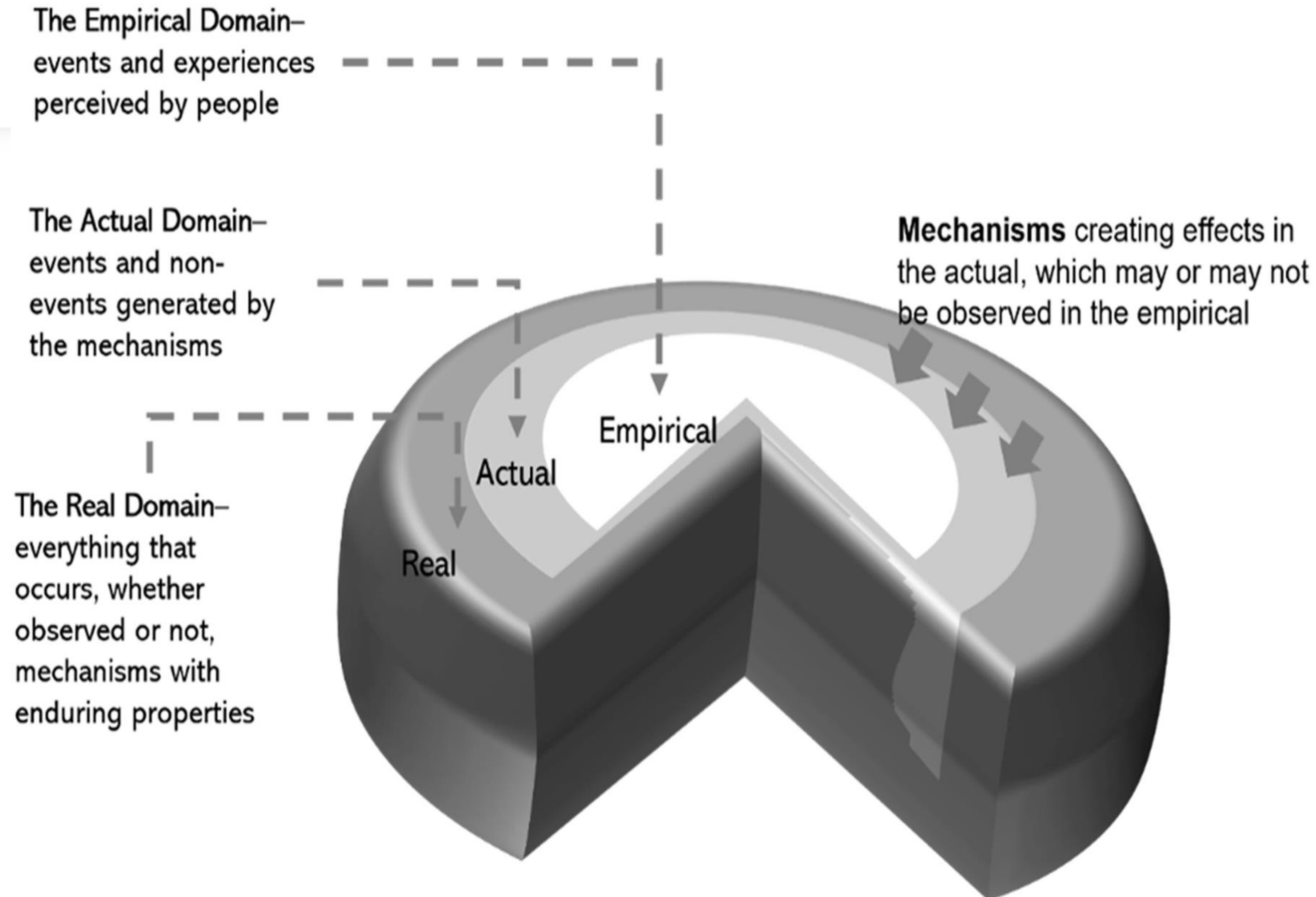
Identify barriers/gaps in stroke care pathways, especially during transitions

3

Inform policy & practice by suggesting tailored interventions for younger adults

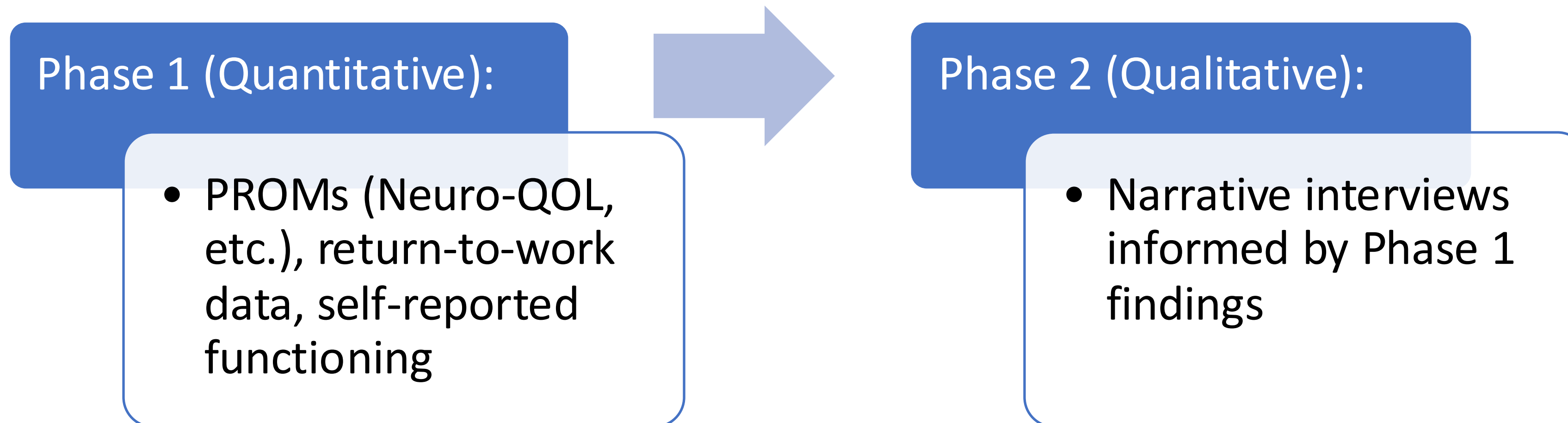
Conceptual & Theoretical Lens

- **Critical Realism:**
  - Recognizes objective reality (stroke pathology) + subjective experiences (Zachariadis et al., 2013)
- **Reflexive Qualitative Approach:**
  - Iterative coding, sensitivity to researcher bias
- **Intersectionality:**
  - Considers age, gender, language, socio-cultural background



Methods: Study Design

- Sequential Explanatory Mixed-Methods (Y-Stroke Needs, YSN Study)



Methods: Participants & Setting

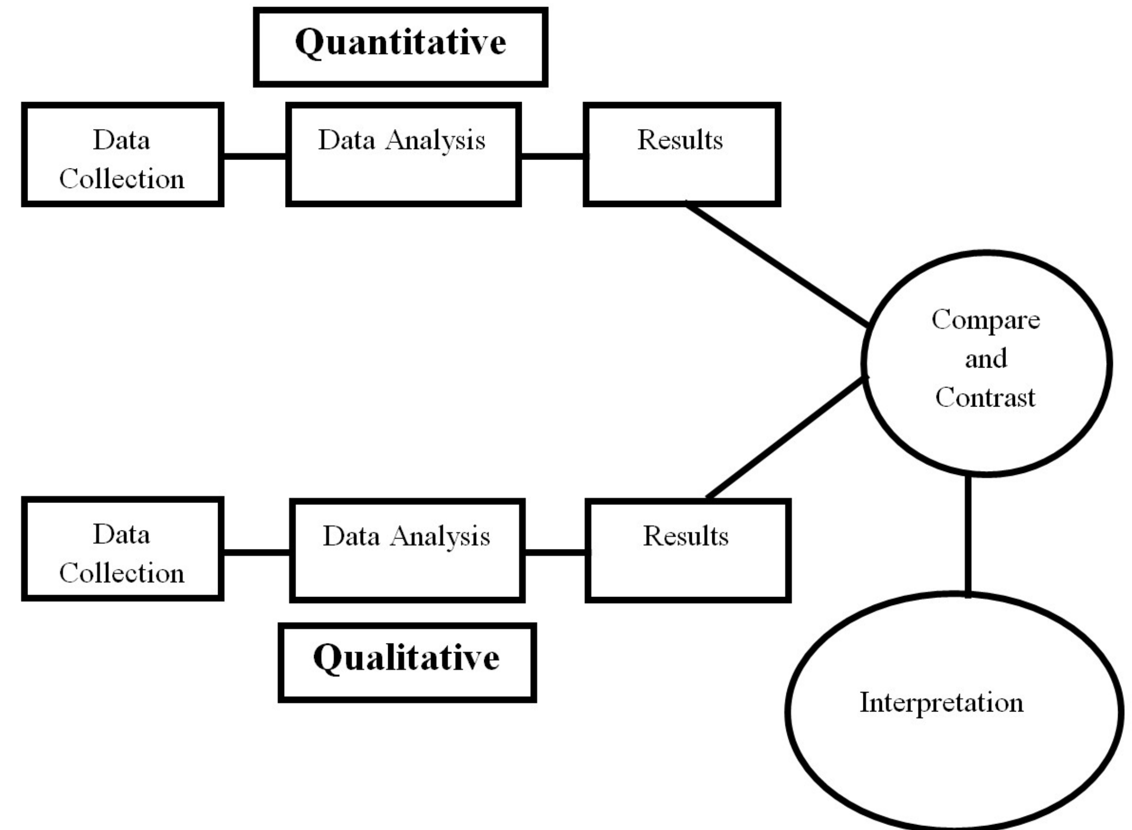
- Inclusion: Adults <65, ≥90 days post-ischemic or hemorrhagic stroke, mild-to-moderate deficits, English proficiency
- Exclusion: Severe aphasia, advanced cognitive impairment, subarachnoid hemorrhage or trauma-related stroke
- Sample: 22 participants (88.2% first-time stroke) from Toronto Western Hospital's Stroke Prevention/Rehab Clinics
- Reasoning: Focus on a relatively homogeneous group (mild–moderate impairment) to capture psychosocial nuances

Methods: Data Collection

- Narrative Interviews: ~1.5 years post-stroke to capture longer-term psychosocial transitions
- Semi-Structured Topics: Identity, emotional/mental health, role transitions, rehab experiences
- Audio-recorded & Transcribed Verbatim: Additional follow-ups for clarification as needed

Methods: Analysis

- Reflexive Thematic Analysis (Clarke et al., 2015)
  - Inductive coding → categories → overarching themes
- Triangulation:
  - Cross-check with quantitative data (Phase 1)
  - Multidisciplinary team (psychiatry, neurology, nursing, social sciences)
- Software: NVivo 12



Reflexivity & Ethical Considerations

REFLEXIVITY: REGULAR TEAM DISCUSSIONS TO ADDRESS RESEARCHER BIAS, ENSURE INTERPRETIVE RIGOR

CONFIDENTIALITY: DE-IDENTIFICATION, PARTICIPANT ANONYMITY

Study Participants

Age Range: Early 30s to mid-50s

Majority were first-time stroke survivors

Varied work statuses: Many not returned to work at time of interviews (Ibrahim et al., 2024)

Typically well-resourced, English-speaking → Implications for generalizability

Key Findings

Three Core Domains of unmet psychosocial needs:

Explicit unmet needs (financial, vocational, role transitions)	Negative care experiences (age bias, misdiagnosis, "too well for rehab")	Self-advocacy (filling gaps in psychosocial support)

Evolving Needs across acute, sub-acute, and chronic phases

Domain 1: Explicit Unmet Needs

- Financial Strain & Vocational Challenges
  - Disability payments often insufficient; hamper social life, returning to school/work
- Role Transitions
  - Identity shift as parent, spouse, student, or breadwinner
  - Desire for stroke-specific peer networks
- Academic or Workplace Accommodations
  - Some participants faced refusals or skepticism from institutions

Domain 1 Example Quotes

- *"...the money [from disability] is so low. You just don't have enough to do anything besides basics."*

(ID#015, male, age 41)

- *"I wanted to go back to school, but they wouldn't accommodate my slower pace."*

(ID#010, female, age 36)

Domain 2: Negative Care Experiences

- Age-Related Bias
  - Misdiagnosis or delayed recognition: “You’re too young for stroke”“
- Too Well for Rehab”
  - Younger survivors sometimes discharged early, rehab not tailored to their potential capacity
- Emotional Consequences
  - Distress, mistrust in healthcare system; feeling dismissed or invalidated

Domain 2 Example Quotes

I tried telling them my right side was numb. They didn’t believe me...like I was exaggerating.”

(ID#004, female, age 43)“

They said I looked fine. Meanwhile, I was exhausted, dizzy, anxious.”

(ID#009, female, age 51)

Domain 3: Self-Advocacy

- Independent Resource-Seeking
  - Private counseling, peer forums, reliance on family/friends
- Health Literacy
  - Participants proactively researching stroke, meds, rehab strategies
- Equity Concerns
  - Not all survivors have time, finances, or social capital to self-advocate effectively

Domain 3: Example Quotes

“I joined an online forum to talk with people my age who had strokes…that helped more than official rehab.”

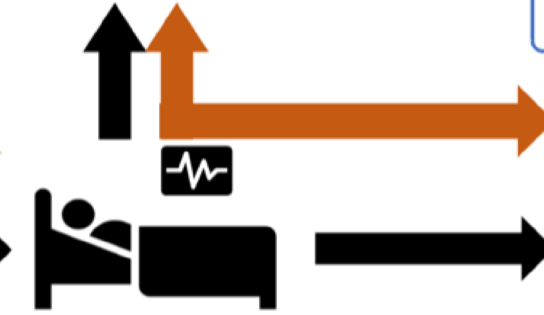
(ID#003, female, age 53)

“My boss was amazing—let me work shorter hours so I could attend therapy sessions.”

(ID#009, female, age 51)

Evolving Needs Across Recovery

Acute (First 48 hrs)	Sub-Acute (~90 Days)	Chronic (>90 Days)
• Symptom recognition, immediate psychosocial crisis, lack of educational resources	• Balancing desire for normalcy with medical advice, navigating new identity • Some participants reported depressive symptoms yet did not seek care	• Identity redefinition, fear of recurrence, financial/work instability, sustained isolation

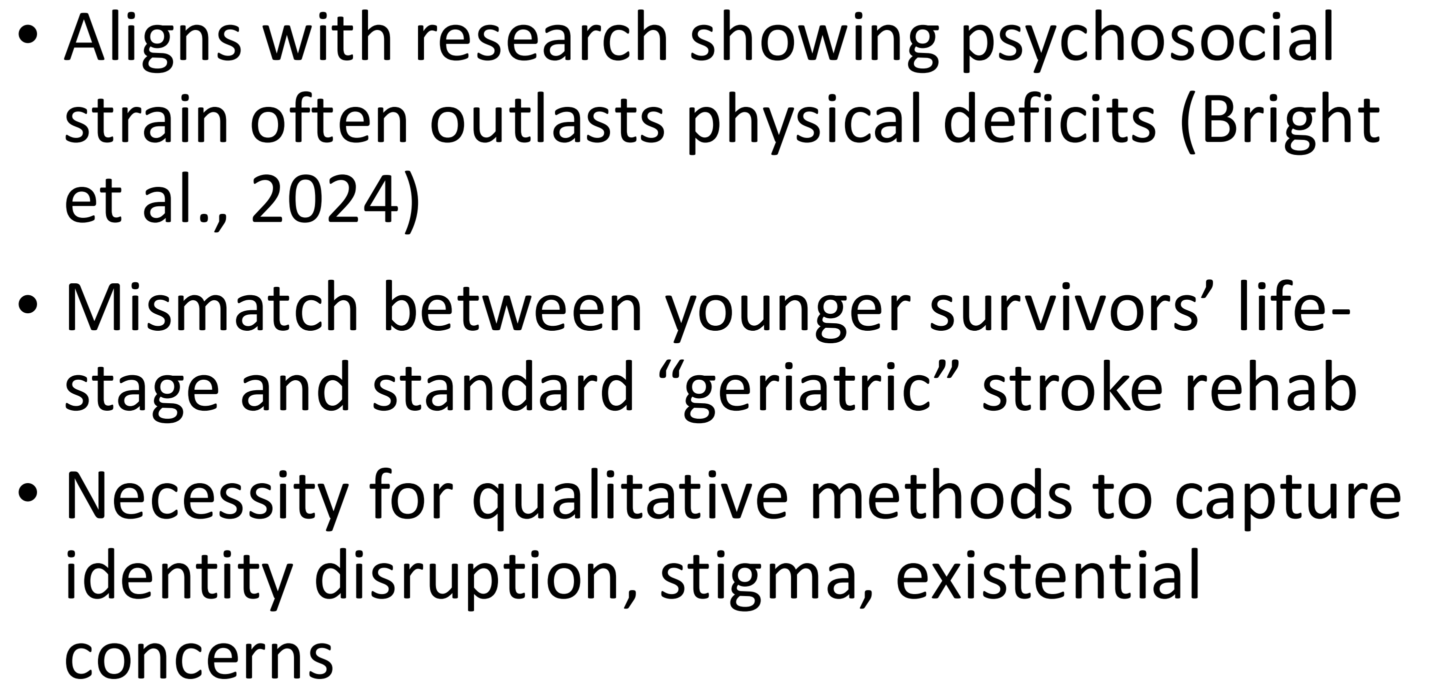


"I didn't realize that headaches was one of the symptoms of stroke... I would have gone to the hospital sooner."
You're anxious.
"But woman to woman, when you have a period... you want to wash at least once a day... it was just that feeling of powerlessness..."
Errors/omissions in discharge & follow up
"...no follow-up and they only gave me enough blood thinners for seven days, but I needed to continue for two weeks...."
One size doesn't fit all.
Limited awareness of stroke in younger populations
Misidentification of symptoms in acute settings
Loss of identity, agency & unclear recovery expectations
Age-related mis-matches in rehab opportunities and practices
Context Matters: Age & Life Stages, Gender, Language

Intersectional/Contextual Factors

- Age & Life Stage: Career-building, childrearing, relationship transitions
- Gender Roles: Burden of childcare, household management can differ by gender
- Language/Cultural Barriers: Communication challenges, unfamiliar healthcare norms
- Stigma: “Disability” label influencing employability, social acceptance

Discussion: Integrating Findings



Significance for Stroke Care

- Holistic Care: Integrate mental health, vocational rehab, peer groups with physical therapy
- Early & Ongoing Psychosocial Screening: Routine checks for anxiety, depression, social isolation
- Life-Stage-Specific Interventions: Parenting resources, flexible rehab programs

- Tailored Rehabilitation
  - Age-appropriate intensity, bridging “too well for rehab” gaps
- Integrated Mental Health Services
  - On-site or embedded mental health clinicians to address emotional distress early
- Peer Support & Community Programs
  - Y-stroke-specific social groups, online forums, or local meetups

Policy Implications

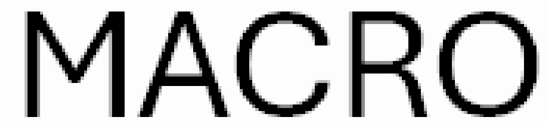
- Workplace Accommodations: Legislation or guidelines for flexible hours, role modifications
- Extended Insurance Coverage: Psychosocial therapies, vocational rehab often underfunded
- Public Awareness Campaigns: Challenge "older adult stroke" stereotype; encourage younger people to recognize stroke symptoms

Recommendations for Practice

Multidisciplinary Teams: Neurology, psychiatry, nursing, social work, vocational rehab

Culturally Sensitive Approaches: Interpretation services, tailored education materials

Long-Term Follow-Up: Chronic phase support to address identity shifts, fear of recurrence



- Policy/system-level changes such as vocational and financial support programs.
- Advocacy for societal change to support young stroke survivors.

MESO

- Organizational and community-level initiatives, such as peer support networks and integrated care pathways that combine mental and physical health services.

MICRO

- Individual patient care, focusing on patient-centered plans and personalized rehabilitation.

Multilevel Care Recommendations for Young Stroke Survivors.

Limitations

- Sample primarily mild-to-moderate stroke, English-speaking, well-resourced
- Exclusion of severe aphasia → underrepresents communication barriers
- Single-center, urban setting (Toronto) → may not reflect rural or more diverse contexts

Strengths

- In-depth Narrative Interviews: Rich data on lived experiences
- Reflexive, Interdisciplinary Team: Minimizes single-researcher bias
- Temporal Aspect (1.5 years post-stroke): Allows insight into evolving psychosocial challenges

Conclusion

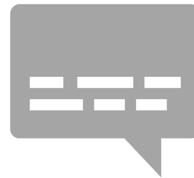
- Younger stroke survivors face distinct, evolving psychosocial needs often unmet by current frameworks
- Fragmented care pathways → survivors must self-advocate, leading to inequities
- Integrating mental health, vocational support, and tailored rehab can significantly improve outcomes

Future Directions

- More Diverse Inclusion: Survivors with aphasia, severe impairments, non-English speakers
- Longitudinal Research: Track psychosocial trajectories 2+ years post-stroke
- Pilot RCTs: Testing integrated psychosocial + physical rehab interventions for y-stroke

Thank You - Q&A

Thank you for listening!



Questions, comments, or suggestions?

Contact:
Syeda.Hashmi@mail.utoronto.ca

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