

Qualitative Research Protocol

Title

Exploring the Hidden Burden of Living with Glanzmann Thrombasthenia: A Qualitative Study

Background & Rationale

Glanzmann Thrombasthenia (GT) is a rare inherited bleeding disorder. While clinical aspects are documented, the hidden burden including emotional, social, and practical challenges faced by individuals and families' remains poorly understood. This study aims to uncover and articulate these hidden burdens through in-depth interviews analyzed using thematic analysis.

Objectives

- Capture lived experiences that reveal the hidden emotional, psychological, and social impacts of GT.
 - Understand caregiver perspectives on managing day-to-day realities and emotional strain associated with GT.
 - Identify unmet needs and barriers to optimal care, access, and support.
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Study Design

This is a qualitative, exploratory study using semi-structured interviews. Data will be analyzed using thematic analysis following Braun & Clarke's framework.

Participants & Recruitment

- **Inclusion criteria:** Adults diagnosed with GT (male/female) and caregivers (parents, partners, family members).
 - **Sample size:** Minimum 30 interviews (10 males, 10 females, 10 caregivers).
 - **Recruitment:** Through patient advocacy groups, clinics, and social media.
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Data Collection

- Interviews will be conducted via secure video platform or telephone.

- Audio-recorded (with consent), transcribed verbatim, and anonymized.
 - Estimated duration: 45–60 minutes per interview.
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Ethical Considerations

Participants will provide informed consent. Confidentiality and data protection will be ensured. Participants may withdraw at any time without consequence.

Data Analysis

Thematic analysis will be conducted using MaxQDA or similar software. Coding will follow Braun & Clarke's six-step approach.

Deliverables

- Final interview guide
 - Protocol, consent form, and participant materials
 - Thematic report and initial analysis summary
 - Comprehensive qualitative report and final manuscript
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Semi-Structured Interview Guide

Lived Experience of GT

- Can you tell me about your experience living with GT?
- How does GT affect your daily life?
- What has been the most challenging aspect for you personally?

Emotional & Psychological Impact

- How has GT affected your emotional well-being?
- Do you ever feel anxious or fearful because of your condition?
- How do you cope with these feelings?

Social & Practical Challenges

- Has GT impacted your relationships or social life?
- Are there activities you avoid because of GT?
- How do others respond when they learn about your condition?

Caregiver Perspective

- What is it like caring for someone with GT?
- How has this affected your own emotional health?
- What support do you wish you had?

Unmet Needs & Barriers

- What kind of support or resources would make life easier for you?
- Have you faced challenges accessing treatment or care?
- If you could change one thing about the healthcare system for GT, what would it be?