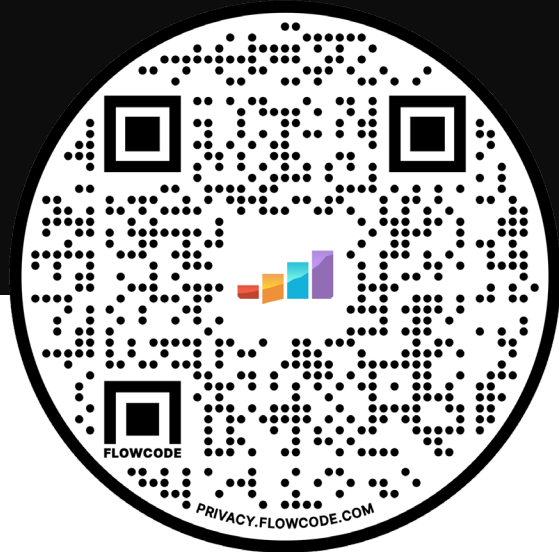# Mapping the Rare Caregiver Journey in Hypoxic-Ischemic Encephalopathy Using Real-World Insights From Social Media

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INTRODUCTION

Hypoxic-Ischemic Encephalopathy
Hypoxic-ischemic encephalopathy (HIE) occurs in approximately 2 to 3 out of 1000 live births and up to 26 out of 1000 births in developing countries.[1,2] The event leading to HIE usually occurs at or around the time of delivery and results from low oxygen levels and inadequate blood flow to the brain and other organs.[3]
Caregivers of individuals living with HIE experience high levels of stress at the time of the birth or event and beyond, resulting in a substantial risk for mental health (MH) challenges. These MH difficulties are not fully characterized from the caregiver's perspective.
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Caregiver-Reported Outcomes
- Caregiver-reported outcomes (CROs) are typically captured through surveys and interviews and are included in data explored in clinical trials.
- Rare and emerging diseases pose a particular challenge regarding CRO data collection.[4]
- Real-world data (RWD) can be a resource for gathering CROs regarding caregiver experience with rare disease in a more time- and cost-effective manner.[5]

Social Listening
Social listening is the process of using and analyzing RWD available on social media networks. Patients tend to share their experience within social networks, and the resulting data can provide information regarding **symptoms associated with disease** and **disease impact on daily life.**

METHODS

Aim	To evaluate the caregiver journey in HIE using a new method of real-world data collection: social listening

Social listening data were collected from 5 Facebook groups: (1) Hope for HIE Support Parent Hub, (2) New to HIE, (3) The In Between in HIE, (4) More Severe Outcomes, and (5) Pregnancy after HIE.

Data were analyzed using Krystie™, the TREND Community analytics engine. This social media listening method follows the FDA Guidelines for Patient-Focused Drug Development.[6]

CONCLUSIONS

TREND Community identified key MH and emotional wellness touchpoints along the HIE caregiver journey through an analysis of the HIE community's real-world conversations taking place within online support groups.

This data exploration aimed to understand the HIE community lexicon. The perspectives and experiences of caregivers led to the identification of different touchpoints in their journey. Each of these touchpoints was illustrated by specific MH challenges. Further, the emotional weights of specific terms and phrases highlight the emotional impact of the patient experience. These insights could begin to help MH professionals understand how this community talks about MH issues and support collaborative health initiatives to address the MH needs of caregivers in this community.

In the context of rare disease, for which real-world information is often limited, the ability to interrogate social media conversation data can be valuable to patients and their caregivers, physicians, researchers, and pharmaceutical developers.

RESULTS

We used Krystie to identify discussions in the early stages of the caregiver journey that were related to MH and isolated statements with a high probability (>0.80) of discussing MH (approximately 10% of all statements in Early Stages). The touchpoints identified from the analyses included Birth or Event, Post-Event & Acute Care, Transition Home, Milestone Moments & Transitions of Care, Adulthood & Independence, and Loss (Fig. 1). Figure 2 depicts the frequencies for MH terms (e.g., anxiety, depression) in conversations for each subgroup after isolating high-MH statements.

To understand emotional impact more comprehensively, we characterized the emotional affect of statements by exploring the "emotional weights" of language in MH-related conversations in each group (Fig. 3).

Using Krystie, we isolated statements that were most related to MH (approximately 10% of all data available). Anxiety and stress mentions are relatively high in the More Severe group, whereas anxiety tends to be dominant in the In Between cohort (Fig. 4).
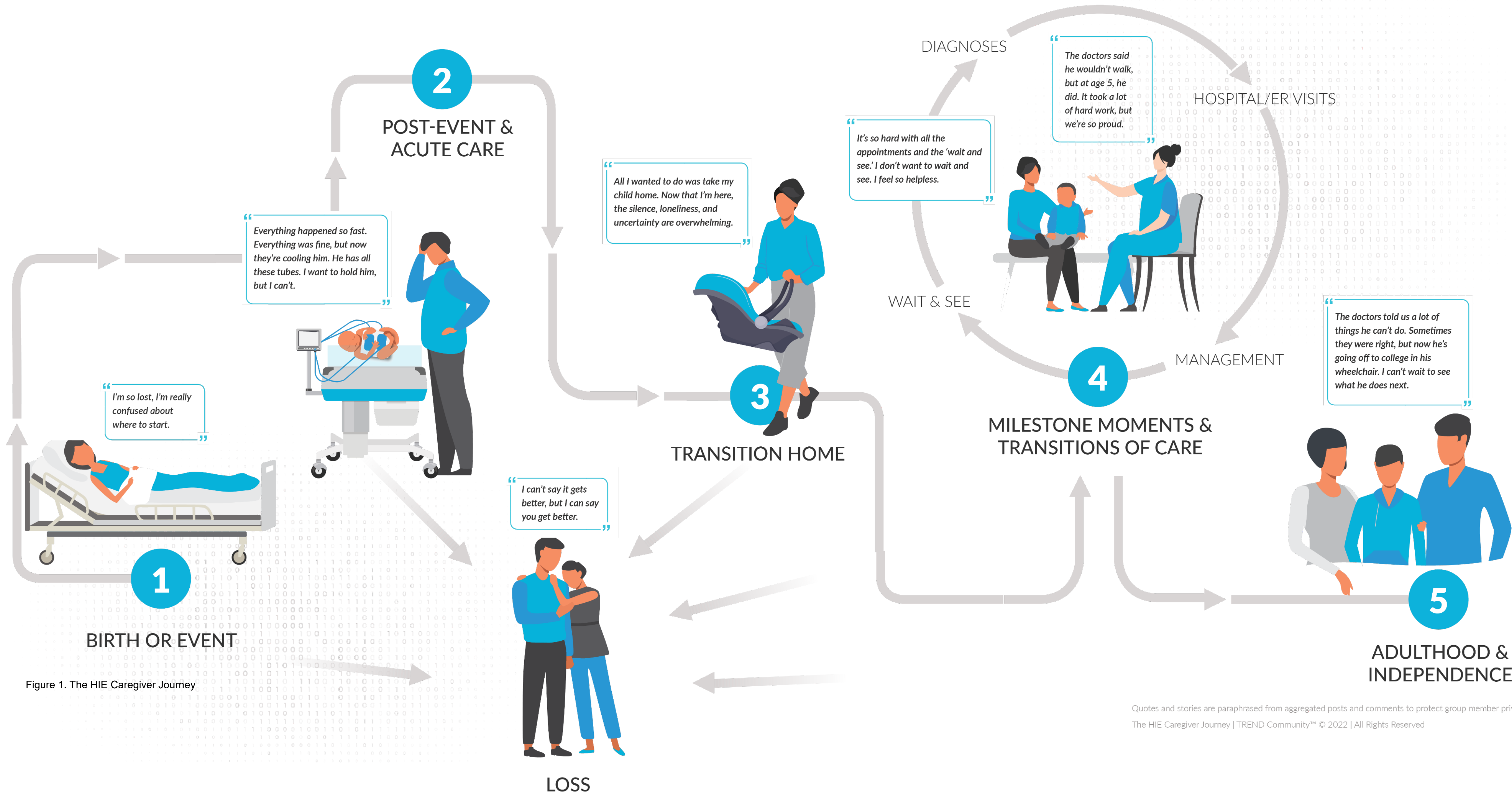

Figure 1. The HIE Caregiver Journey

Quotes and stories are paraphrased from aggregated posts and comments to protect group member privacy.
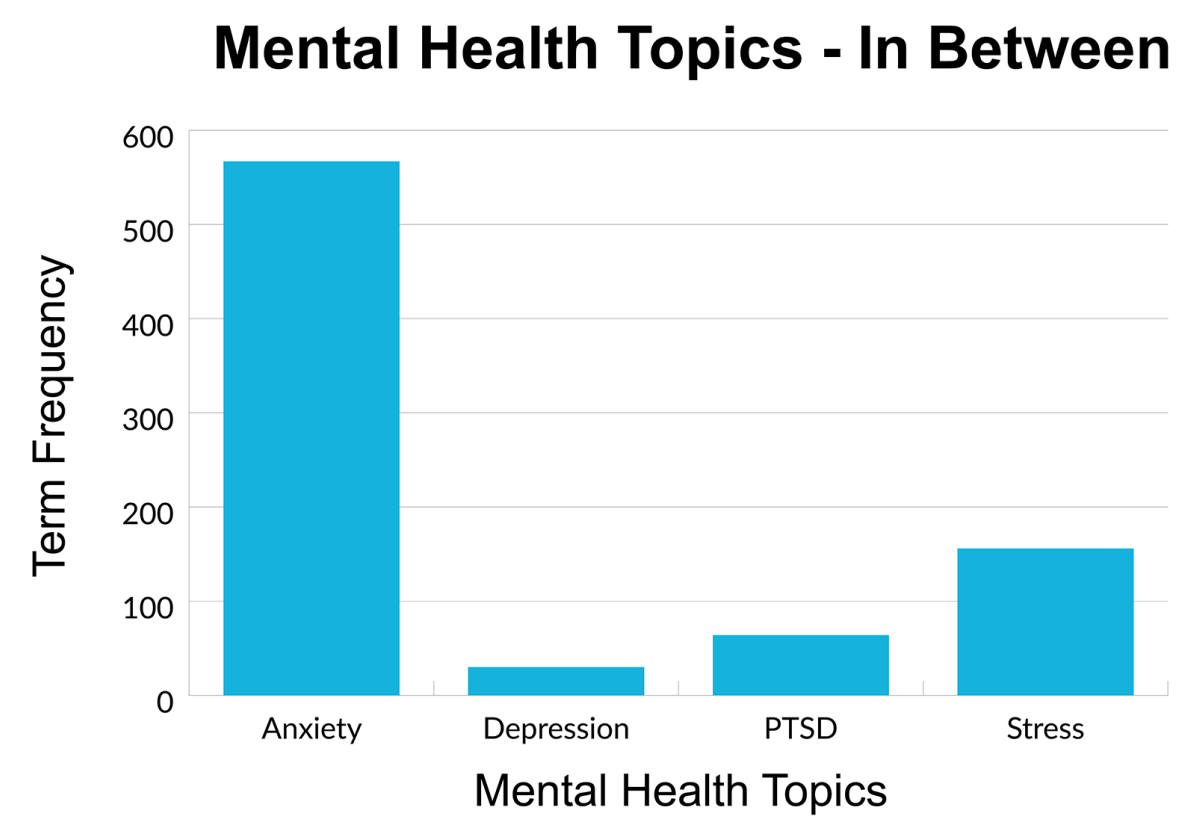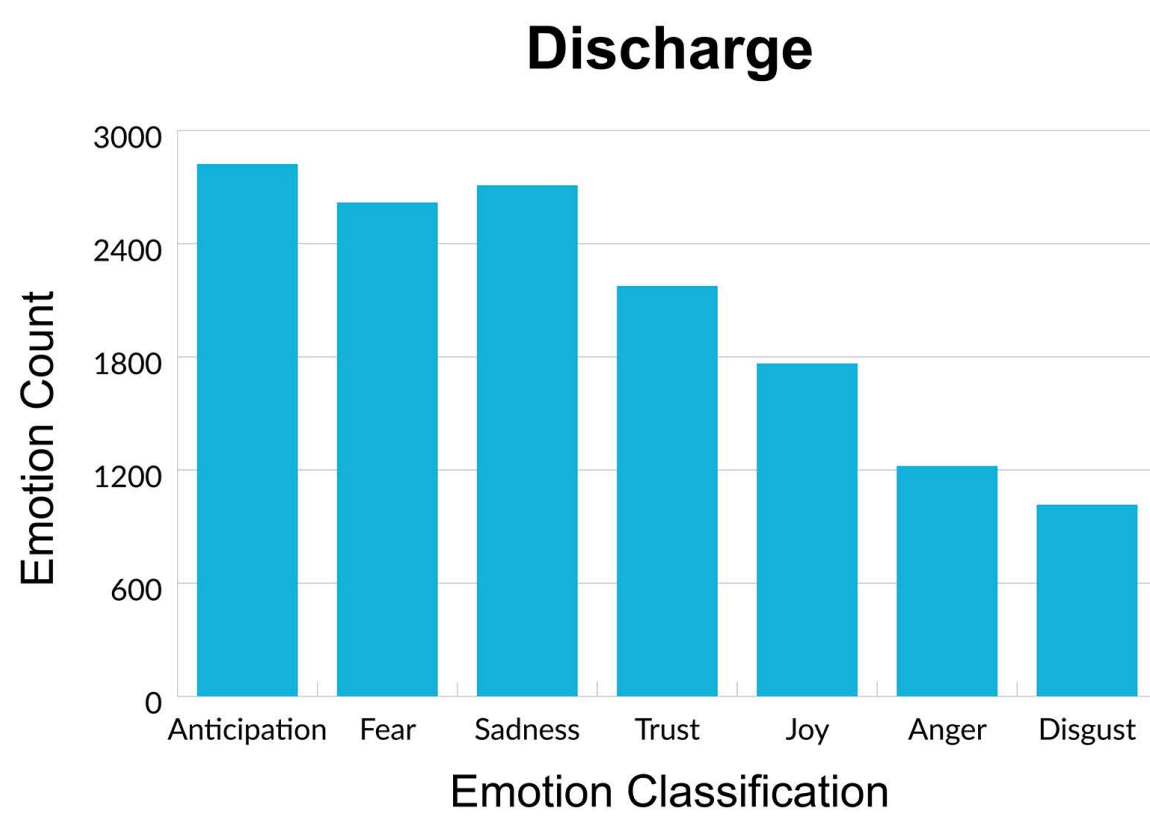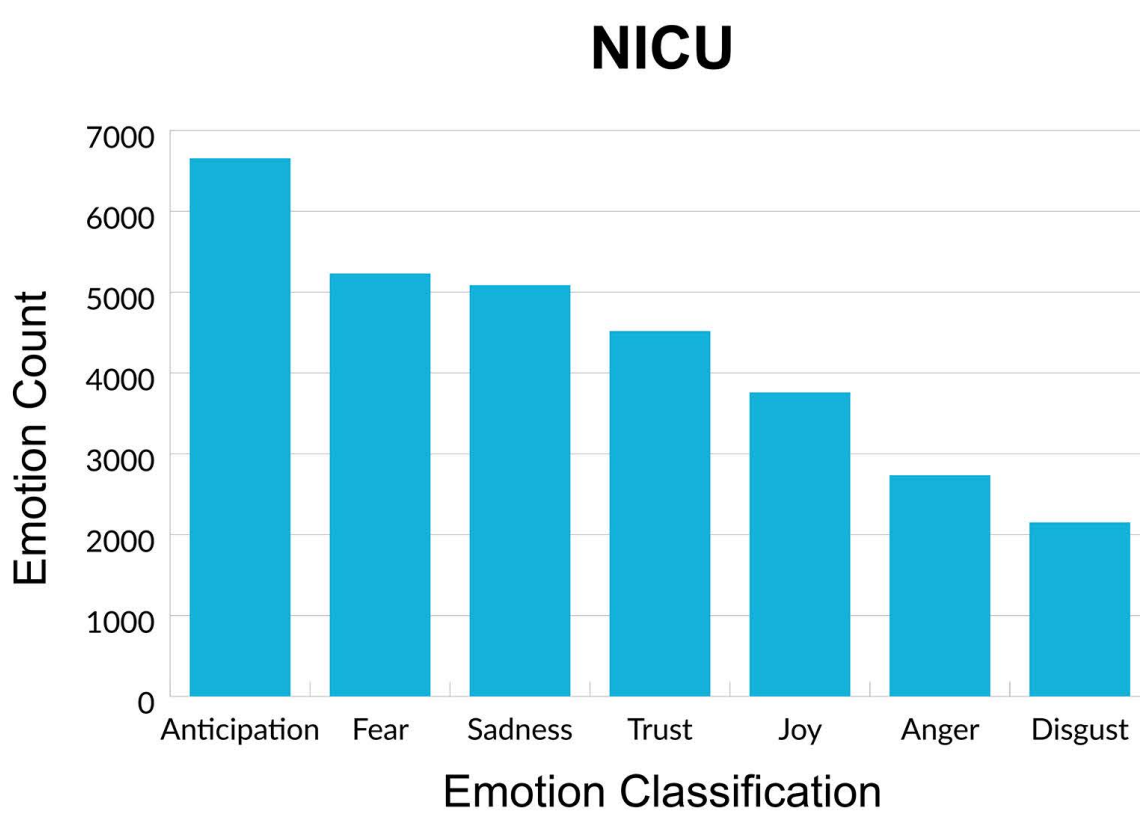The HIE Caregiver Journey | TREND Community™ © 2023 | All Rights Reserved
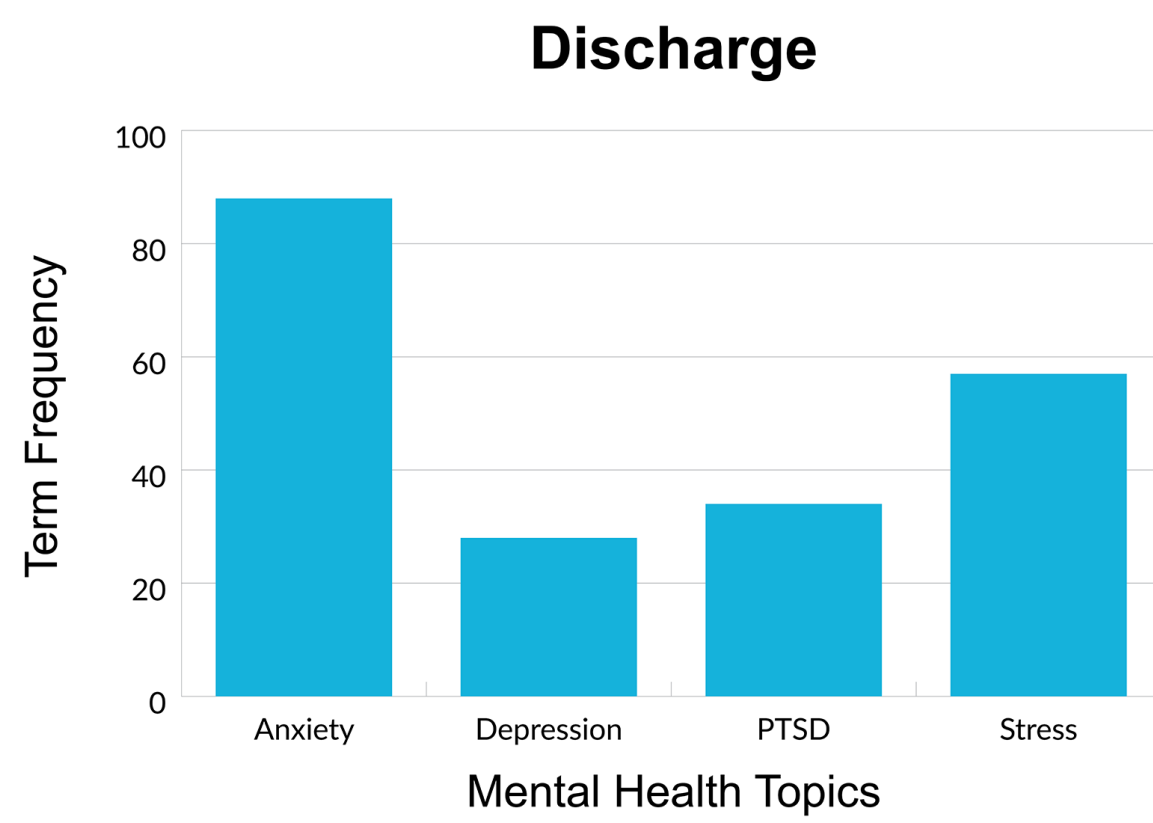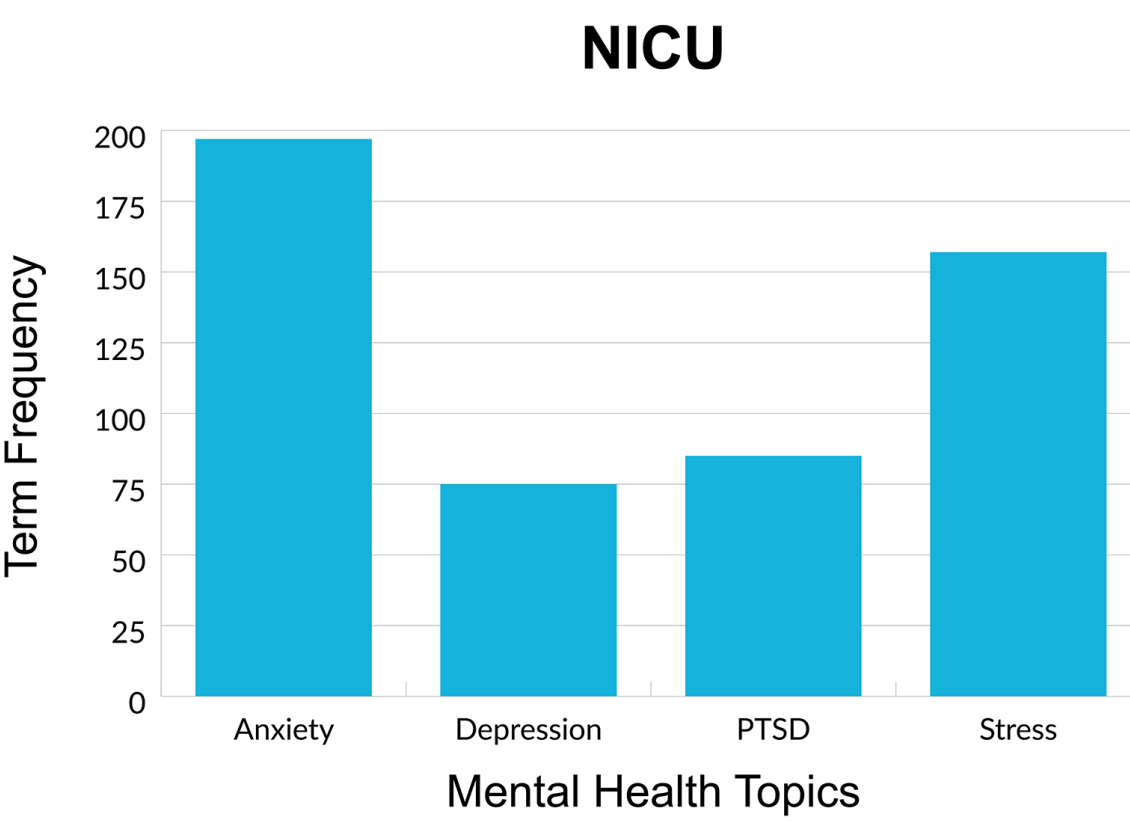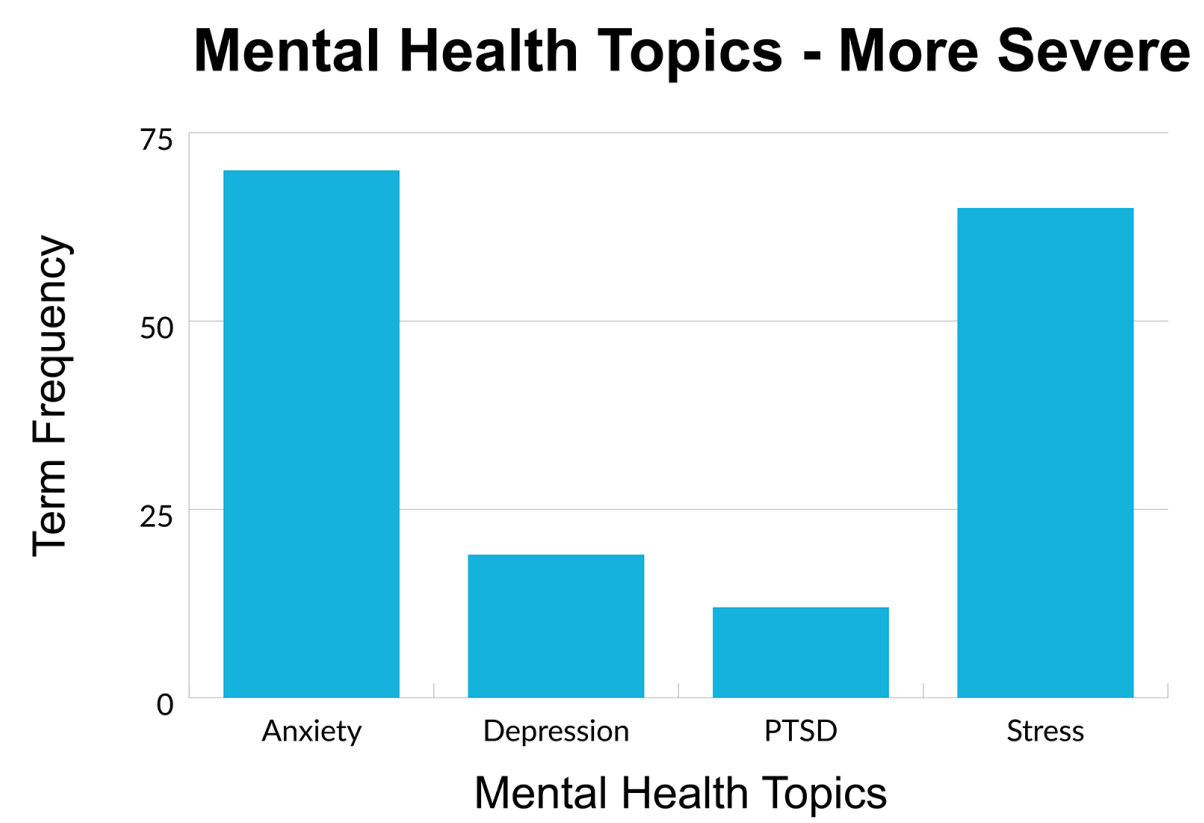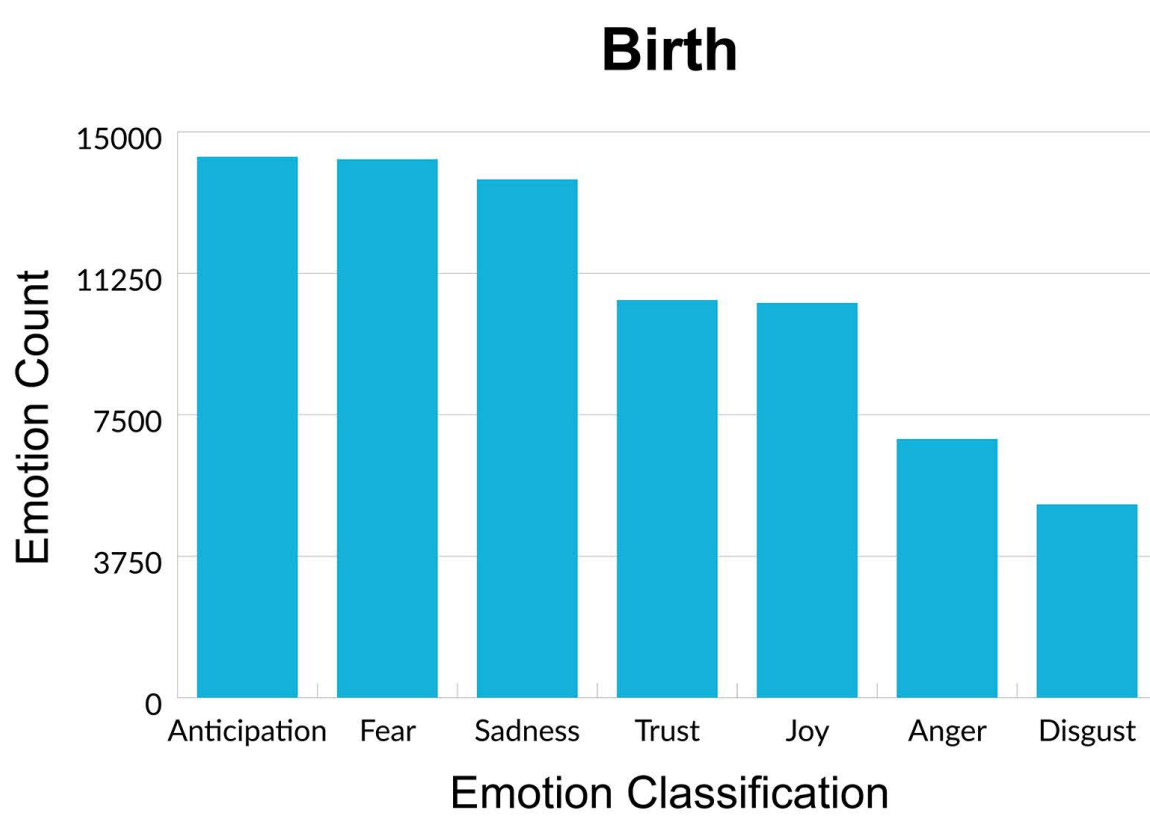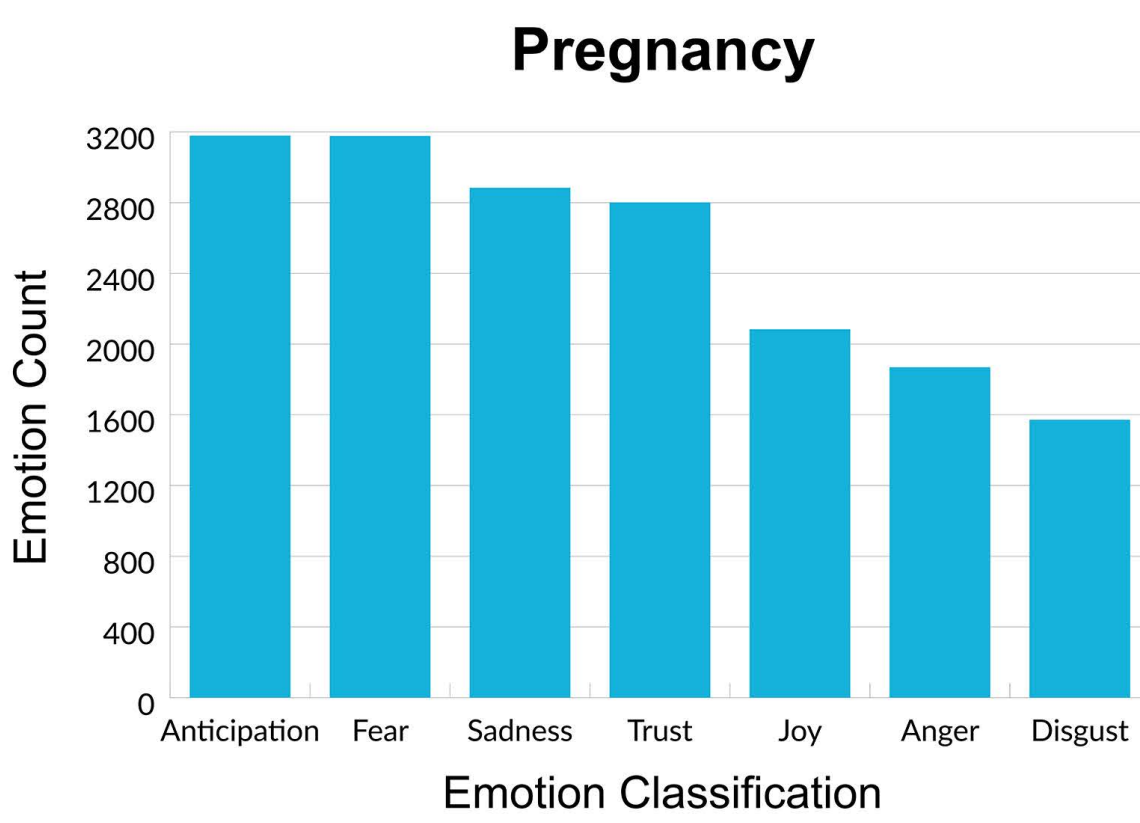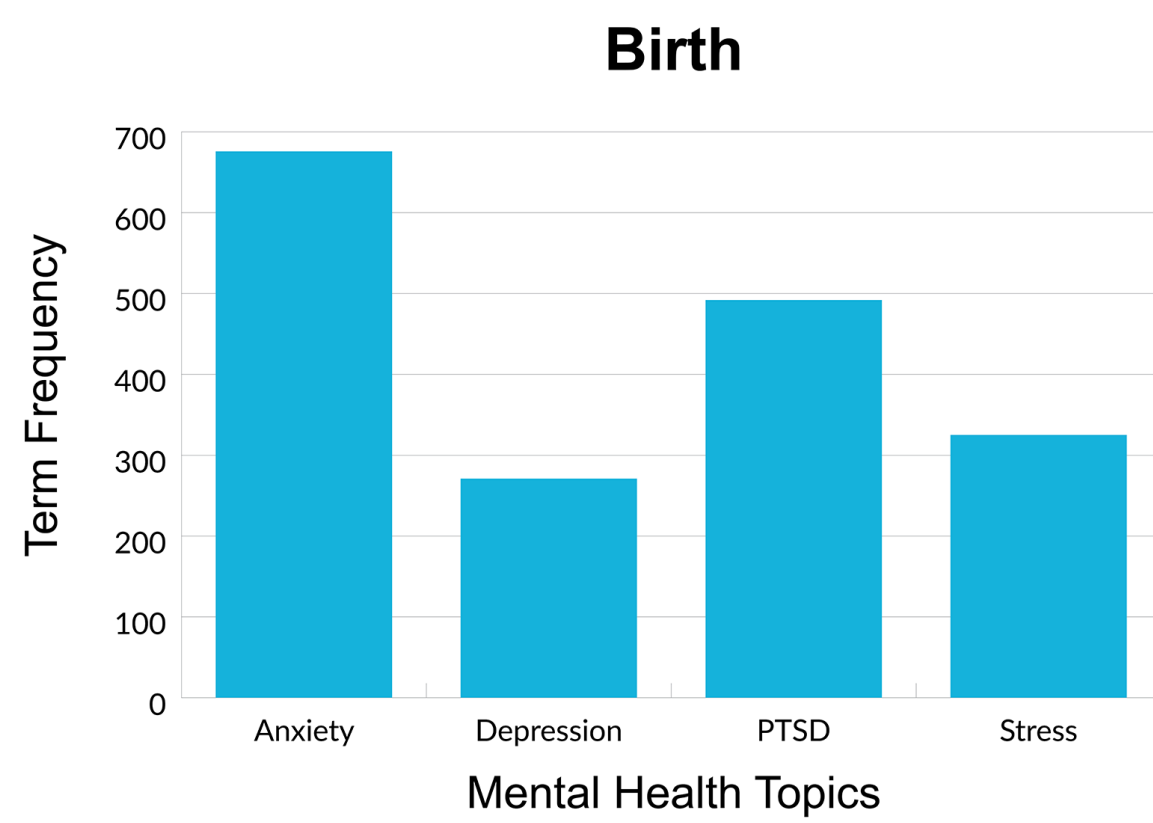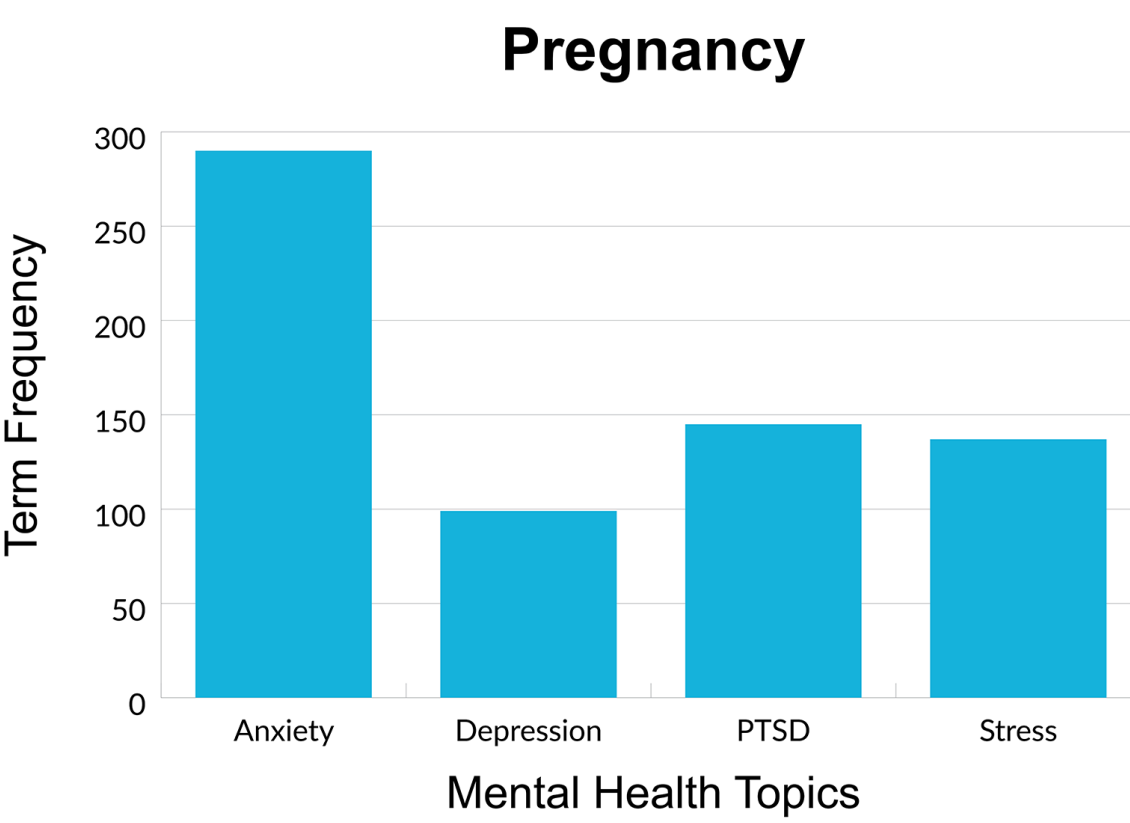

Figure 2. Mental Health Language

Figure 3. Emotional Weights on Conversation by Subgroup

Figure 4. Mental Health Topics in More Severe and In Between

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