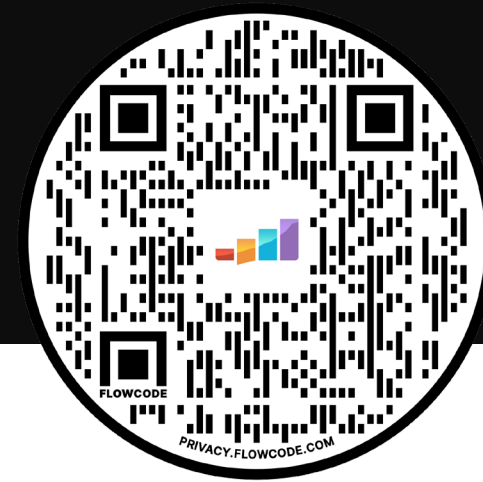# Mapping the Rare Caregiver Journey in Hypoxic-Ischemic Encephalopathy Using Real-World Insights From Social Media

Monica Converse[1], Maurice Flurie[1], Rachelle Cook[1], Matthew Horsnell[1], E. Robert Wassman[1], Betsy Pilon[2], Christopher DeFelice[1], Maria Picone[1]

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INTRODUCTION

Hypoxic-Ischemic Encephalopathy (HIE)
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 hypoxic-ischemic encephalopathy using a new method of real-world data collection: social listening

Social listening data were collected from 5 sources: **(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] Scan QR code for methodology.

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 at understanding 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 where 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.

Scan QR code for **Methodology**, **Disclosure & Limitations**, **Acknowledgments**, and **References**.

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 "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).
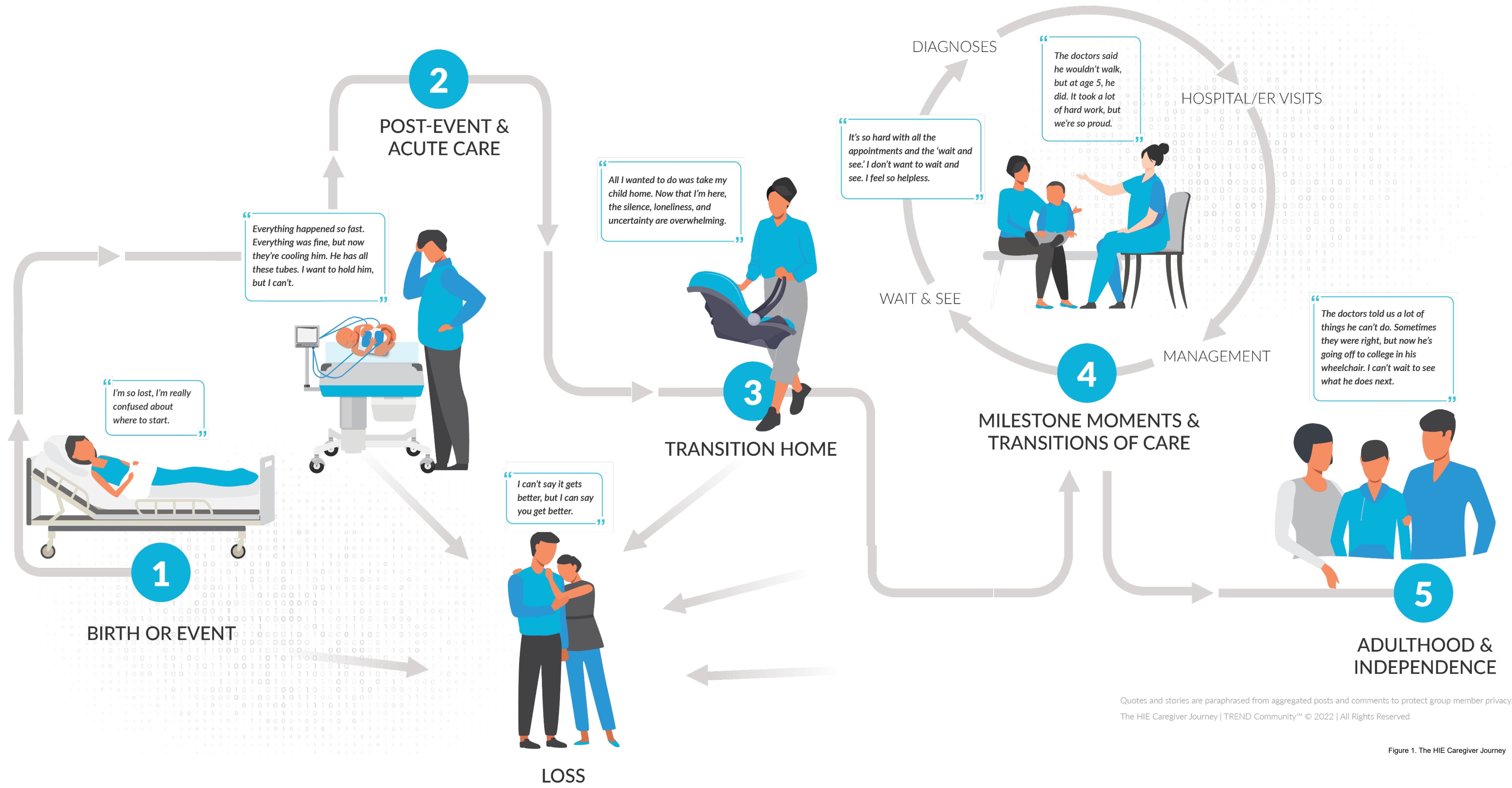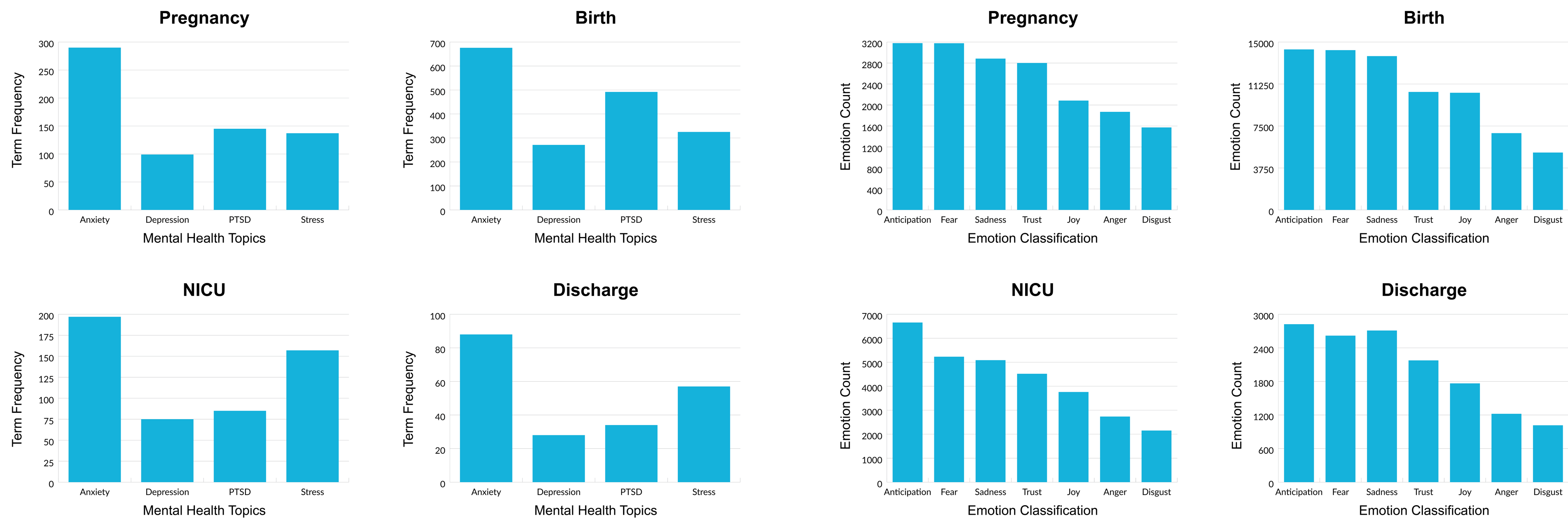

Figure 1. The HIE Caregiver Journey
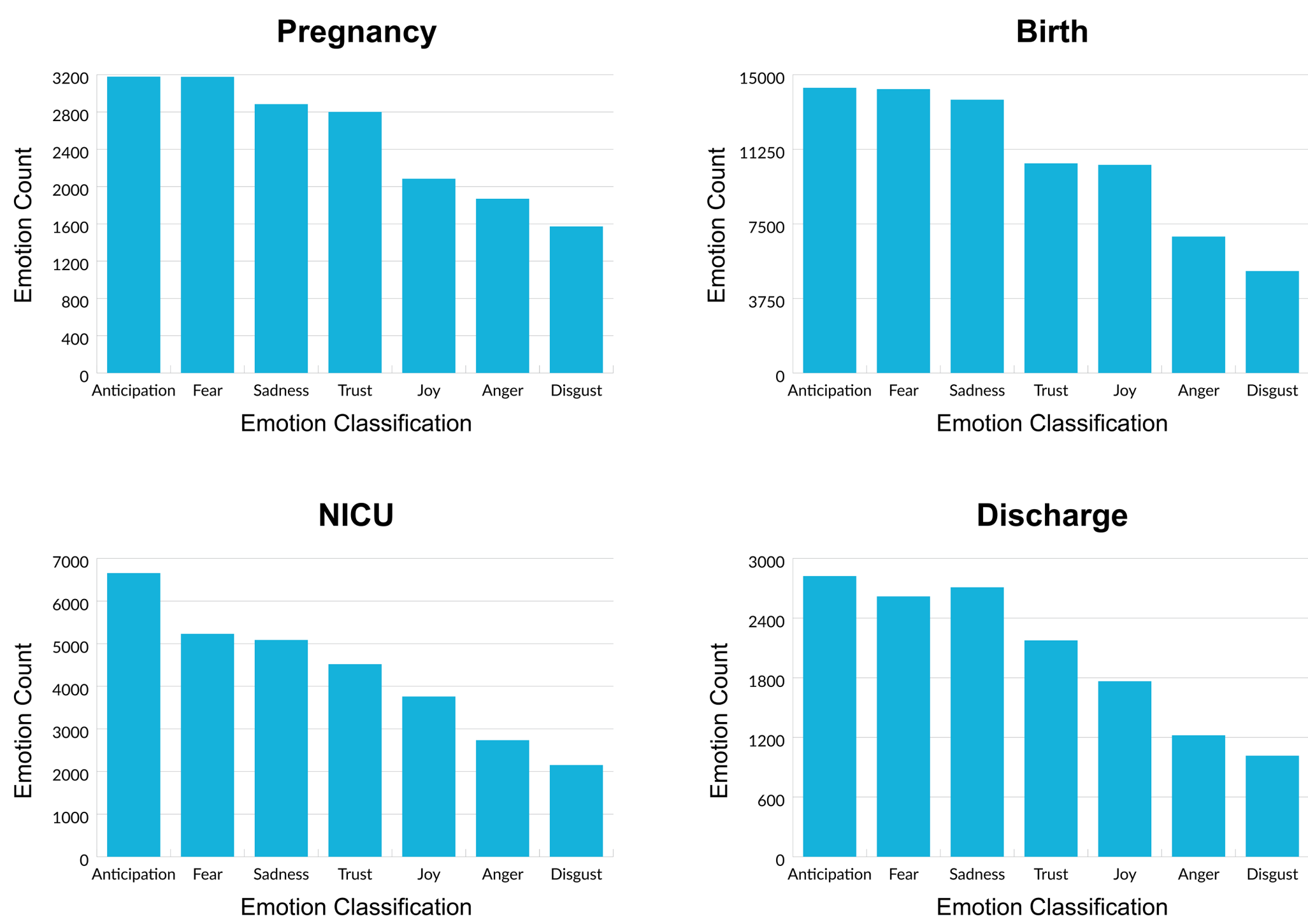

Figure 2. Mental Health Language

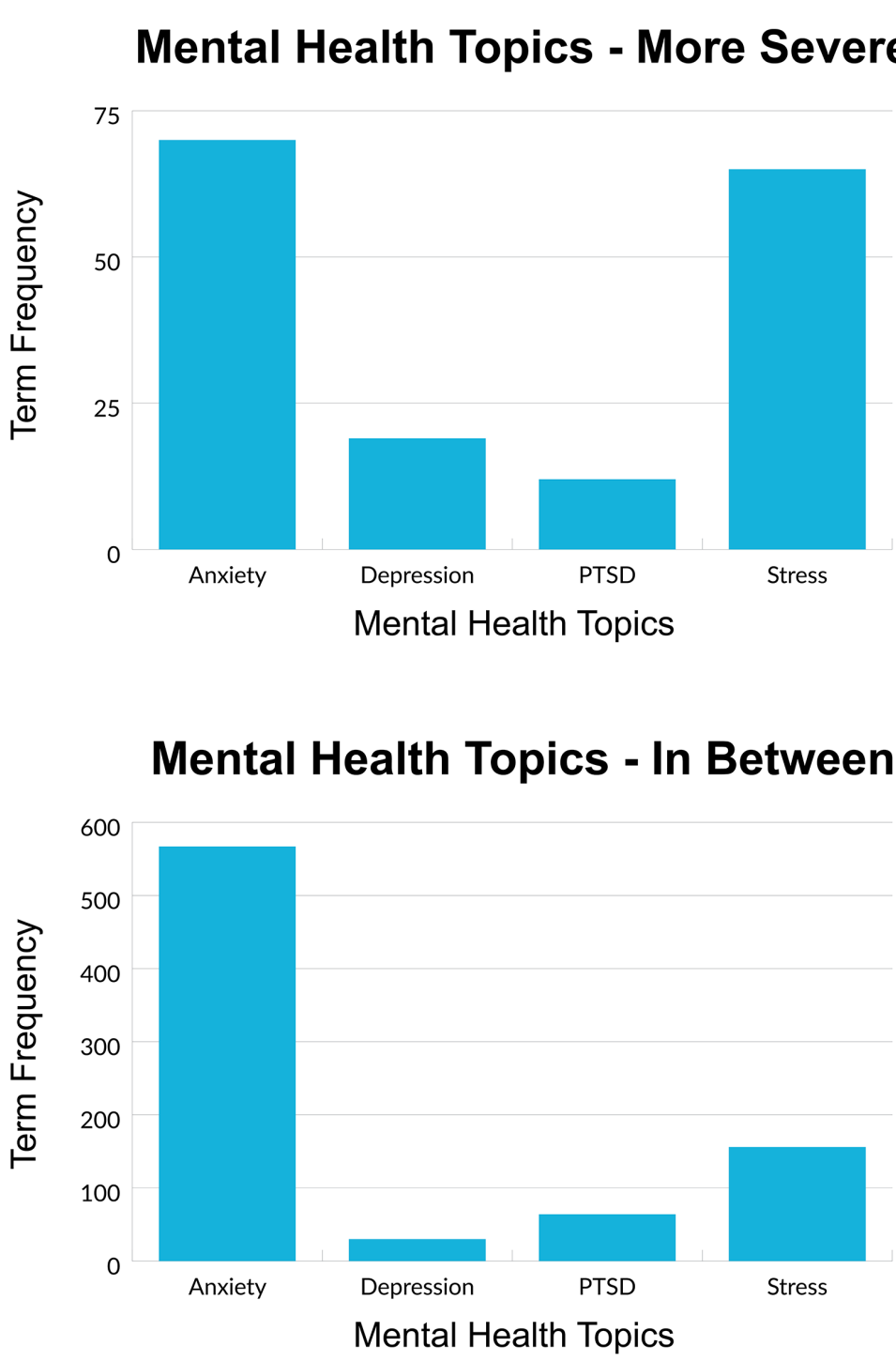Figure 3. Emotional Weights on Conversation by Subgroup

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

ABSTRACT

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

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Introduction:
Caregivers of individuals living with hypoxic-ischemic encephalopathy (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. A proprietary artificial intelligence (AI) analytics engine using natural language processing (NLP) was used to identify key MH and emotional wellness (EW) touchpoints along the HIE caregiver journey.

Materials and Methods:
AI using NLP was used to analyze conversations in 5 private Facebook groups representing the HIE community: Hope for HIE Support Parent Hub, New to HIE, The In Between in HIE, More Severe Outcomes, and Pregnancy after HIE, totaling more than 750,000 posts and comments from 2011 to 2021. A cluster-based approach was used to identify prevalent touchpoints in the caregiver journey and corresponding MH challenges.

Results:
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. The AI platform isolated statements with a high probability (>0.80) of discussing MH (~10% of all statements in the Early Stages of the caregiver journey). In Early Stages, 'anticipation', 'fear', and 'sadness' were the most prevalent terms. Within Early Stages, 'fear' and 'anticipation' remained high at birth, whereas 'trust´ grew in relative contribution. With neonatal intensive care unit and discharge experiences, 'trust' was the most prevalent affect in statements related to MH. 'Anxiety' and 'PTSD' (posttraumatic stress disorder) mentions were relatively high in the More Severe group (1% and 0.01% of 6148 total statements, respectively), whereas 'anxiety' was dominant in the In Between group (3% of 15,174 total statements). The AI platform also identified a series of recurring events during the Milestone Moments & Transitions of Care stage that present MH and EW challenges and opportunities for MH providers and peer support (Hospital/ER Visits, Diagnoses, Wait & See, and Management).

Conclusions:
The AI engine captured the perspectives and experiences shared online by caregivers in the HIE community. These analyses support the position that different touchpoints of the caregiver journey likely present with unique MH challenges (e.g., increased PTSD in Early Stages, increased stress in Middle Stages). The data underpinning this analysis can be explored further to gain additional clarity from this first assessment and prompt collaborative health initiatives to address the needs of this community.

METHODOLOGY
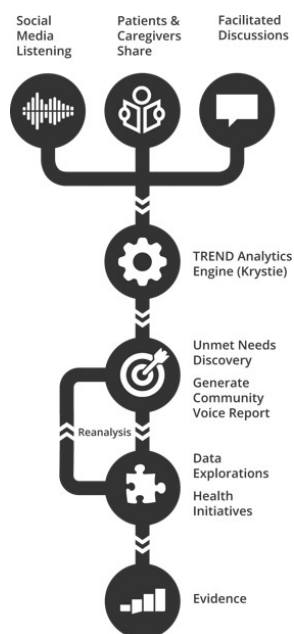
TREND Community harnesses machine learning and natural language processing techniques using Krystie^{TM}, our proprietary analytics engine, to capture the perspective and experiences shared online by people living with rare and chronic diseases. TREND received permission from site administrators to access deidentified data (i.e., no names were included in analyses). Data were analyzed using Krystie, as follows:

• Supervised learning and natural language processing techniques were used to identify disease burden and disease management concepts.
• Mentions of words and concepts (groups of highly related terms, e.g., the concept 'anxiety' includes counts of 'anxious', 'anxieties', and 'anxiousness') are tallied.

Obtaining real-world evidence is a process that extracts real-world insights that can be used toward many different objectives, including data exploration for peer-reviewed publications.

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This social media listening method is in line with the FDA Guidelines for Patient-Focused Drug Development.

DISCLOSURES & LIMITATIONS

Data obtained are limited to those with the means, interest, and ability to participate. Honest representation by participants of their diagnosis, illness, symptoms, and disease progression is an assumption. The analysis does not account for the context in which a term is mentioned; for example, the mention of a symptom might be in the context of its absence. The researchers who prepared this report are not doctors, are not providing medical advice, and are reporting only what was said in the online conversations.

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