



Rome, 16th-18th October 2024

THE USE OF SOCIAL MEDIA FOR SHARING INFORMATION ABOUT PEDIATRIC PALLIATIVE CARE NEEDS: A SOCIAL MEDIA ANALYSIS

S. Germinario - V. Grassi - C. Radice – G. Volpetti - F. Pellegatta

PPC AND SOCIAL MEDIA



Annalisa Resiienza

Amministratore · 14 ottobre 2022 · 🌐



Buongiorno famiglia!! Domani 15 ottobre, è la giornata internazionale dedicata a tutti bimbi divenuti angeli in gravidanza o subito dopo la nascita. Vorremmo creare ,come tutti gli anni, un'onda di luce che salga fino a loro💗. Per questo vi chiediamo di pubblicare,dalle 19:00



"Social platforms are tools capable of facilitating mutual support, reducing embarrassment, and offering higher levels of information richness, humanity, and interactive dynamics typical of a real social network." (Asti, 2021)

OBJECTIVES

PRIMARY OBJECTIVE



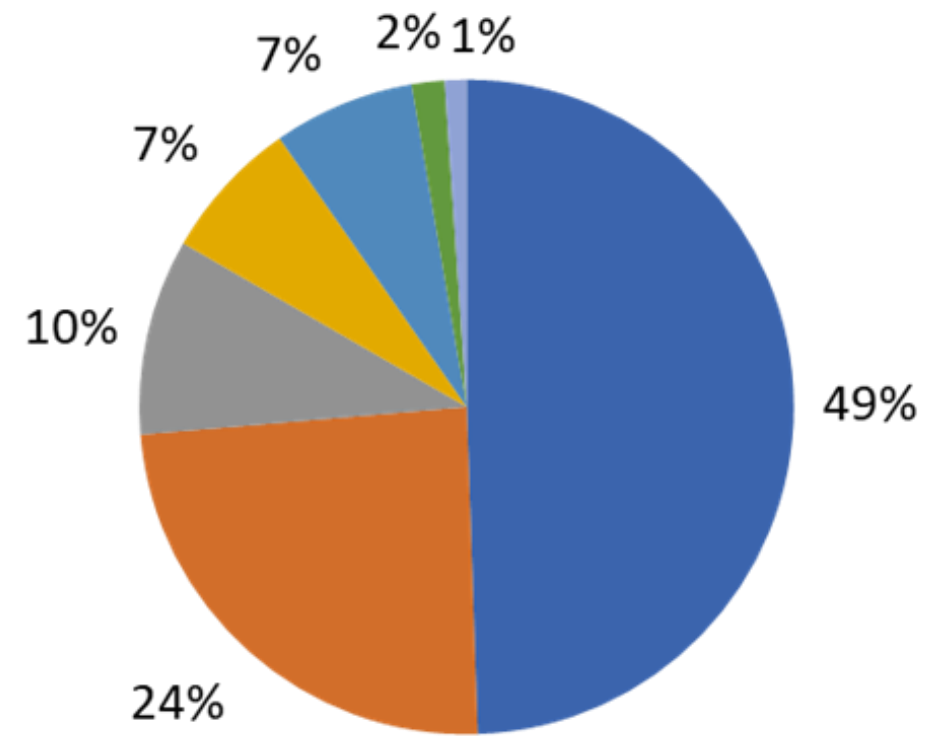
To observe how the topic of PPC is addressed among caregivers of children with chronic and even incurable conditions on social media

SECONDARY OBJECTIVE



To analyze the information contained in caregivers' writings to identify possible areas for improvement in communication management between healthcare professionals and families of children with chronic and even incurable conditions

NEEDS



- Clinical-assistential
- Psycho-communicative
- Socio-educational
- Spiritual-value needs
- Clinical-assistential/Psycho-communicative
- Clinical-assistential/Socio-educational
- Psycho-communicative/Spiritual-value needs

 20 ottobre 2022 · 🌐


Buonasera,avrei bisogno di un consiglio: a qualcuno i voi un altiepilettico(mia figlia prende Tegretol)da ipersensibilità'? Ogni 10 giorni ha temperatura a 37,piena di catarro ecc...vi e' capitato?grazie

👍 2 Commenti: 3

 26 ottobre 2022 · 🌐

Buonasera...oggi sante ha fatto la visita dalla fisio e dovremmo mettere la fatidiche doccette, voi come l avete fatta digerire ai vostri nanetti?

👍 3 Commenti: 12

 21 ottobre 2022 · 🌐

Ciao mamme, forse qualcuna di voi ha letto la mia storia, la mia bambina quasi 2 mesi fa è venuta a mancare dopo 13 gg di vita... volevo chiedervi se qualcuna di voi ha avuto la stessa esperienza e come ha affrontato e "superato" il lutto?

👍❤️👍 60 Commenti: 32

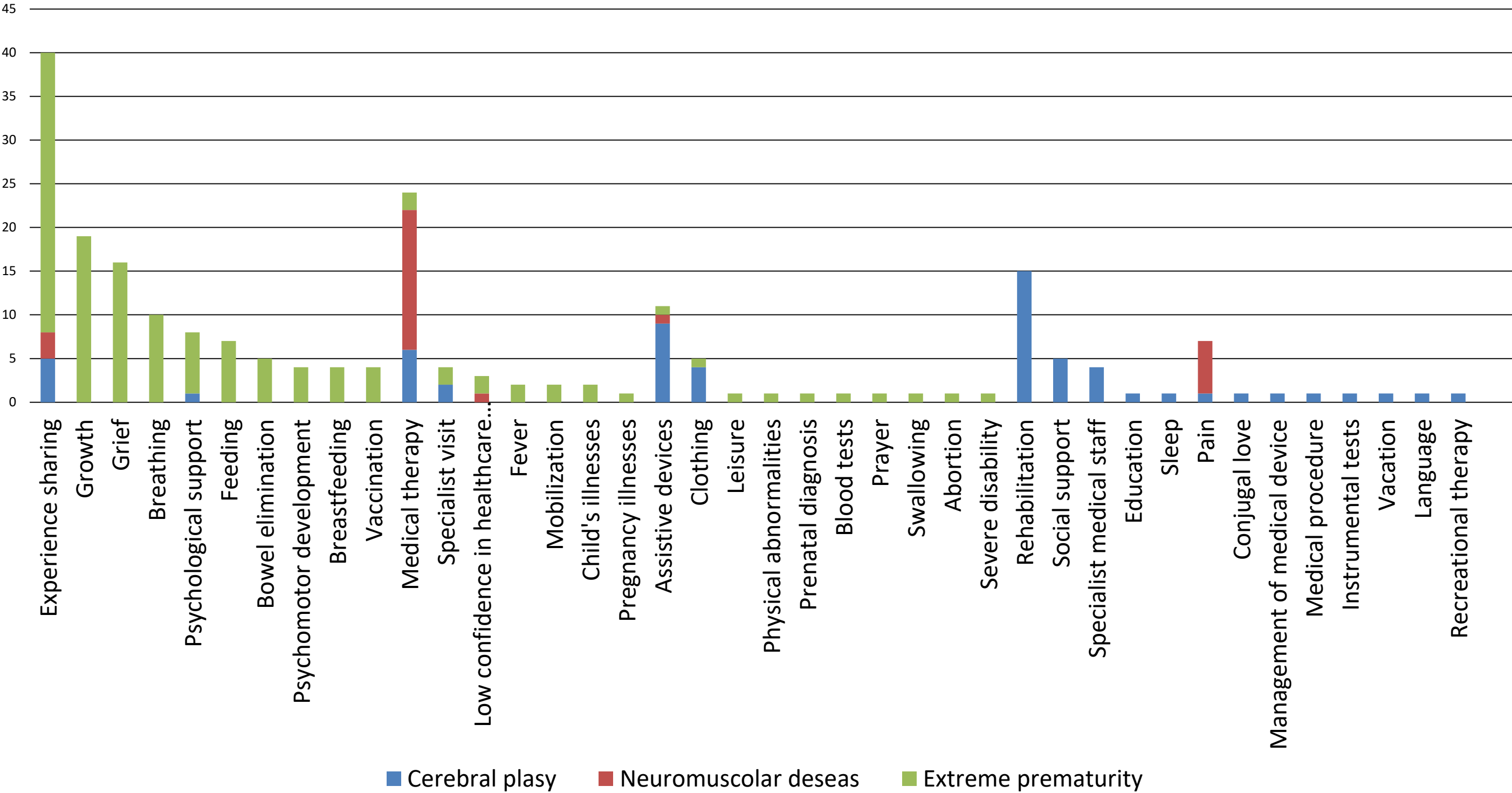
GENDER OF CAREGIVER

The collected data showed that the authors of the posts in all analyzed groups are predominantly female.

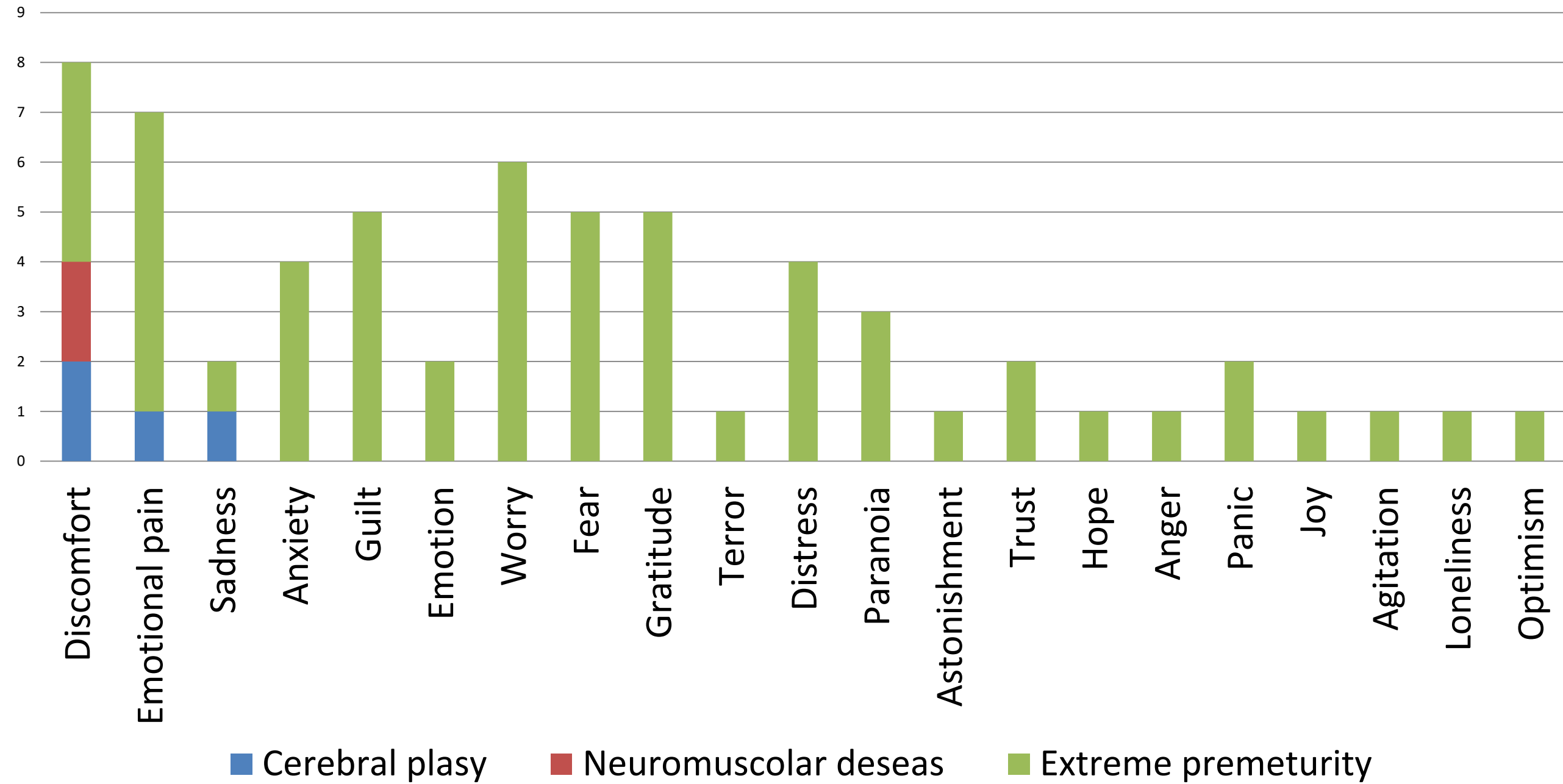


	Cerebral palsy N. 58 (31,2%)	Neuromuscular diseases N. 22 (11,8%)	Extreme prematurity N. 106 (57%)	Total N. 186 (100%)
Female	51 (32,3%)	4 (2,5%)	103 (65,2%)	158 (100%)
Male	4 (17,4%)	18 (78,3%)	1 (4,3 %)	23 (100%)
NA	3 (60%)	0 (0%)	2 (40%)	5 (100%)

TOPIC



FEELINGS



POSTING TIME



The authors post mainly on weekends, correlating this data to the need to compensate for clinical-assistential needs, which we hypothesize to be due to the reduction of services on holidays. Many patients use home services available only on weekdays, leaving evenings and weekends uncovered, where parents' questions go unanswered.



CONCLUSIONS

The topic of PPC is not explicitly mentioned

Families ask questions and receive answers from parents in the same conditions and not from specialized and trained healthcare professionals in PPC.

Tailored training

Individualized and personalized care based on specific needs, starting from the diagnosis.

Parents are often "forced" to turn to social media to ask questions

It is necessary to implement PPC healthcare services to ensure they are available 24/7 to support and sustain these families.