

Power to the patients: a framework for a peer-led AYA virtual support group

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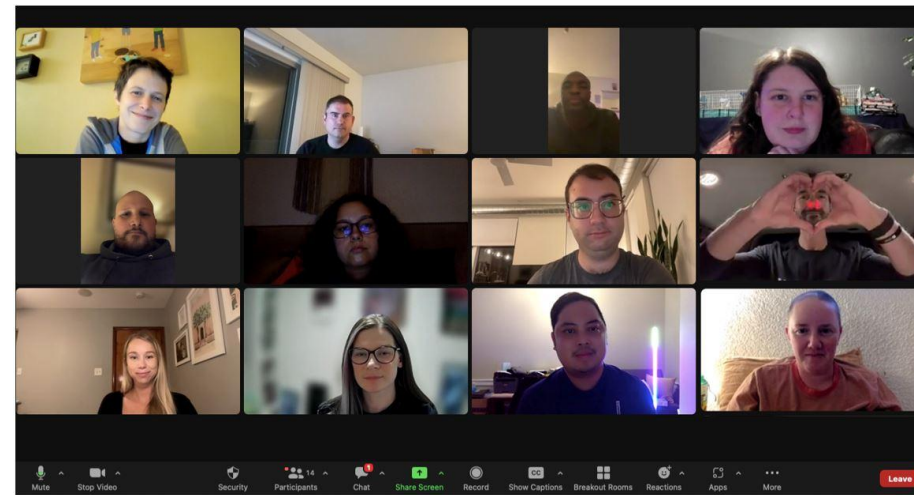
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Background

- **Adolescent and young adult (AYA) patients (age 15-39) constitute 14.3% of new brain tumor diagnoses annually³.**
- While navigating cognitive and physical challenges from their tumor and treatment, these patients are at a critical point in personal development. During the AYA years, patients are also exploring identities and relationships, establishing social independence, pursuing education, developing careers, and planning and supporting their families.
- Due to these contemporaneous challenges in personal development, these patients face unique, and often, unmet psychosocial needs. As a result, AYA brain cancer patients often experience a sense of **deep social isolation, depression, and lack of connection to peers⁴.**
- Existing support groups have limited relevance to AYA brain cancer patients, e.g. young patients but different cancers, or older adults with brain cancer but different everyday challenges. In other contexts, peer support is effective at improving the psychosocial experience of people living with cancer^{5,6}.
- This work here demonstrates that a **peer-led support group can effectively provide social support to AYA patients with brain cancer.**

Methods

- Three AYA neuro-oncology patients (median age 32) volunteered to facilitate the support group. Volunteers were trained in peer support and group facilitation by a cancer educator, with consultation from a psychologist.
- A multidisciplinary steering committee was formed, including a nurse practitioner, cancer patient educator, communications specialist, two neuro-oncology physicians, and the peer facilitators. This group met monthly by video meeting to discuss group facilitation challenges and to optimize support group efficacy.
- Promotion was done by flyers in the UCSF neuro-oncology clinic, and on the UCSF and ABTA websites. Email reminder was sent prior to each session.
- Registration was ongoing and required, and asked questions about patient demographics and personal objectives.
- The support group was run virtually through a commercially-available video meeting program, once monthly, for 1.5 hours. Participants were able to log on via personal device (computer or mobile phone).
- Format of meeting was typically open format but some meetings had preset topics of discussion focus. Rules for mutual support and emotional “safety” were presented at the beginning of each meeting.
- Feedback and satisfaction surveys were distributed at 7 and 16 months, respectively, from group start. Feedback also sought in informal discussions.
- Some participants used a video chat app to connect between meetings.
- Data was collected from May 2022 to October 2023.



Results

Figure 1: Demographics of patients who registered for YABS (Young Adult Brain Tumor Support Group) (n = 102)

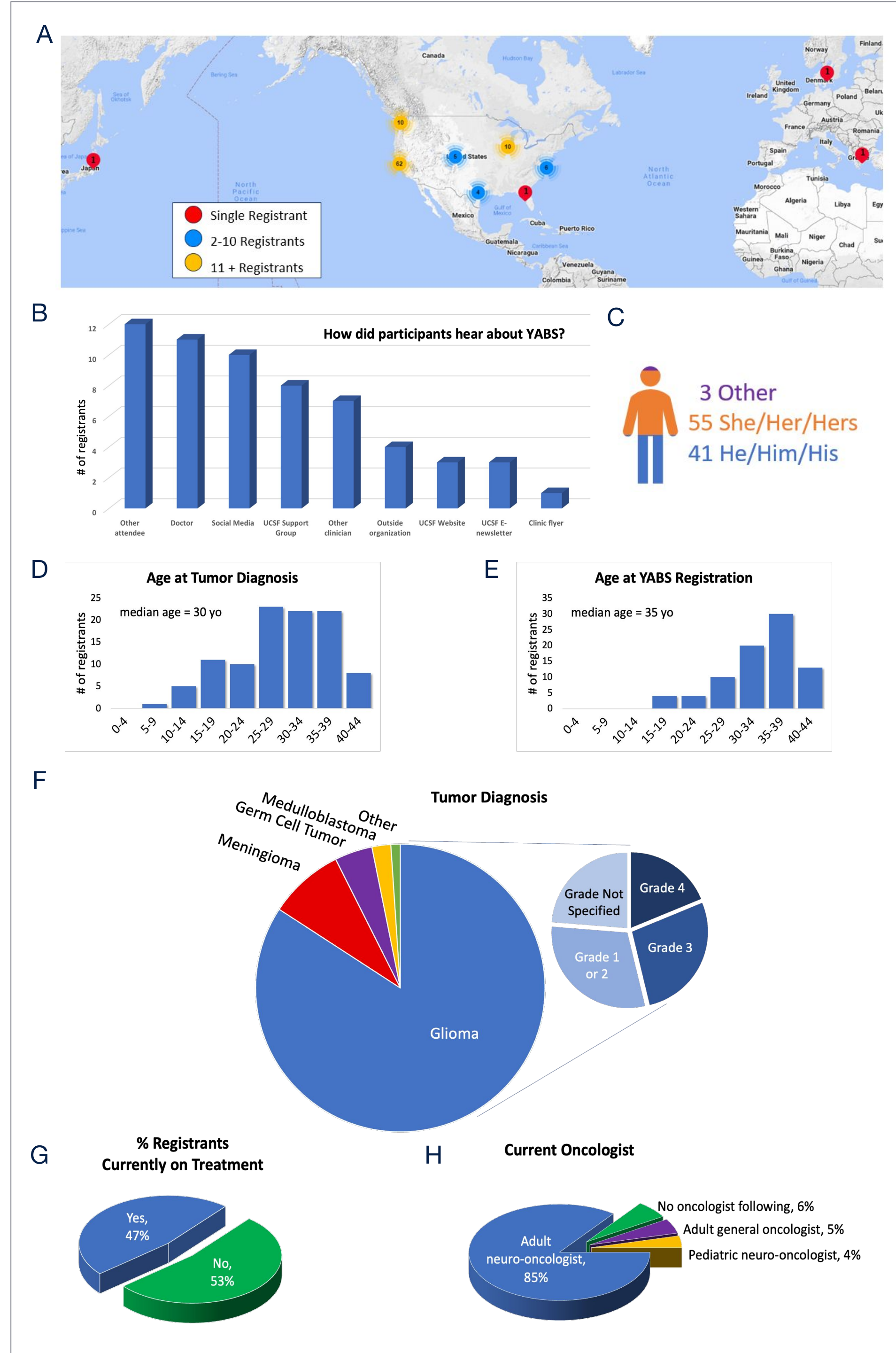


Figure 1. A. Geographic distribution of registrants B. Method by which registrants learned about YABS C. Self-identified pronouns of registrants D. Age at diagnosis of brain tumor E. Age at registration for YABS F. Tumor diagnosis G.

H. Current Oncologist.

Results

- **Of 102 registrants, 53 (52%) attended one or more YABS meetings.**
- **Data here included analysis from 17 meetings.**
- **Each meeting included a median of 15 participants, range 4-22.**
- **Peer facilitators each spent ~6 hrs/mon preparing and facilitating YABS**
- **Participants preferred combination of open and topic-driven discussions.**

Figure 2: Relative interest of YABS registrants (n= 22) in topics discussed with peer-led support group versus with medical provider. Topics were sorted by weighted ranking of importance, then compared.

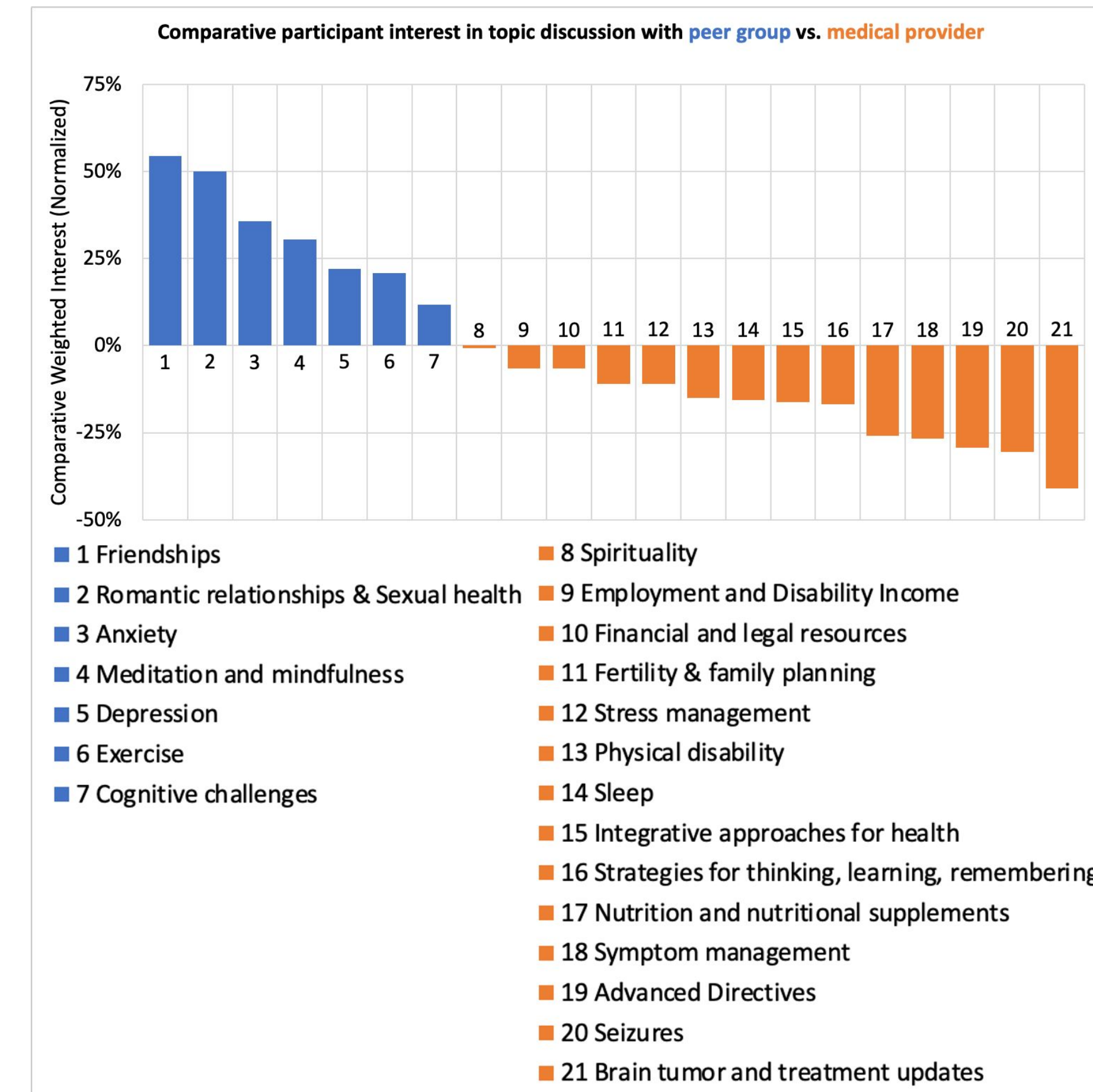
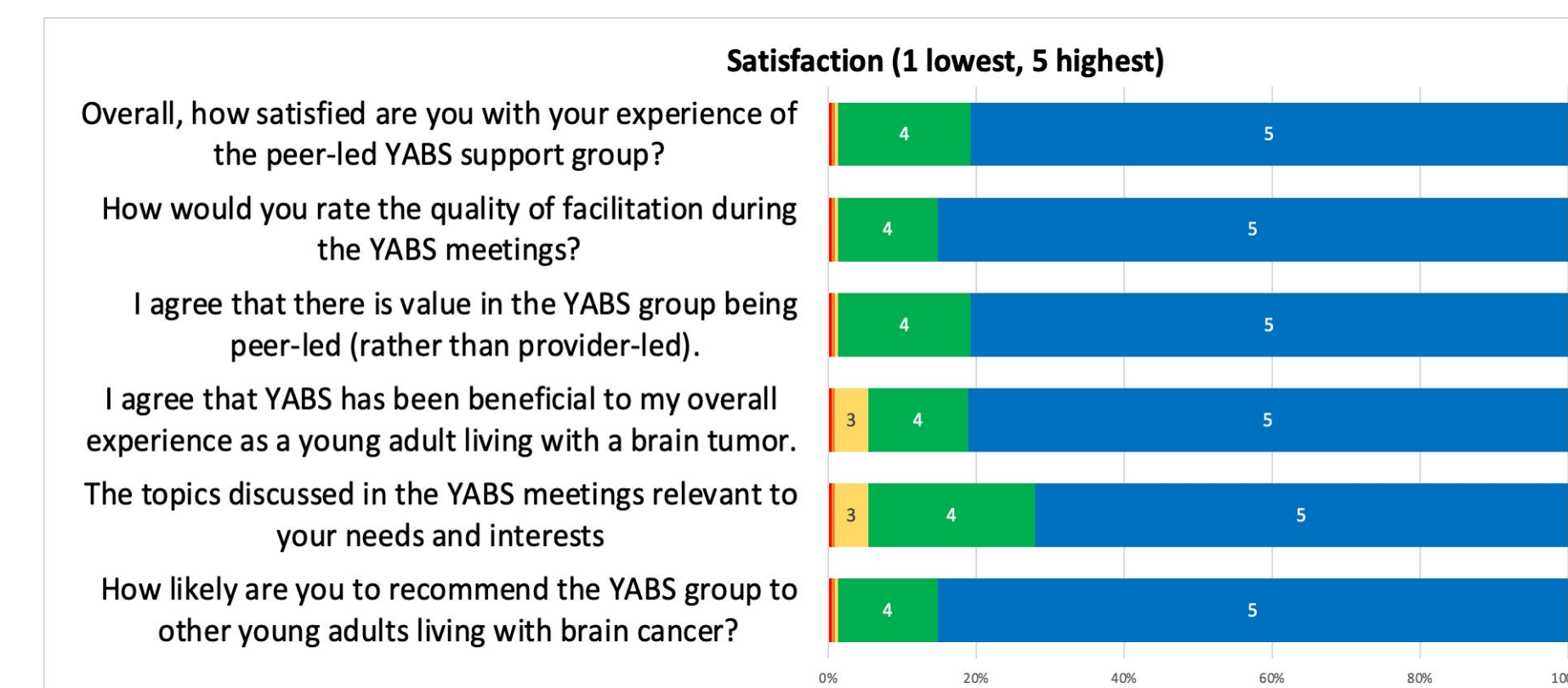


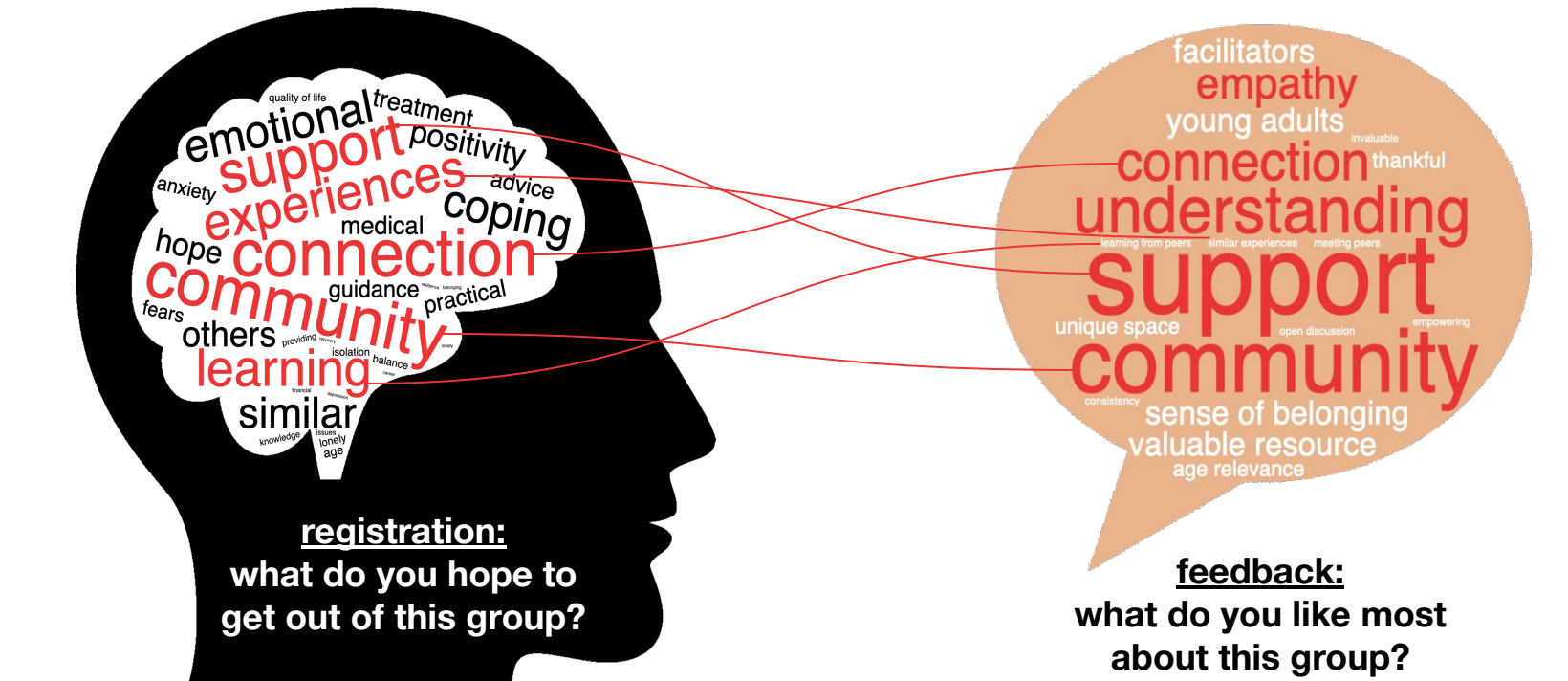
Figure 3: Satisfaction survey data, completed by YABS participants (n= 22)



Results

- **Qualitative feedback highlighted community and social support from similarly-aged peers facing similar challenges amongst the most valuable aspects.**
- Quotations from feedback surveys:
 - “Age of participants allows discussion relevant to my concerns.”
 - “It is unbelievably appreciated and makes such a difference for me personally.”
 - “I think it is an invaluable resource for an often-overlooked patient population.”

Figure 4: Participant goals for YABS prior to attendance versus benefits identified after attendance



Qualitative registration & survey data sentiment weighted by frequency of occurrence using OpenAI ChatGPT software⁷, then reviewed by study authors for accuracy. Larger words = more frequently expressed sentiments. Red = Top 5 sentiments.

Discussion

- **Peer-led virtual support groups provide social support for AYA brain tumor patients, with a high level of satisfaction.**
- AYA brain tumor patients have different information and support needs from peers versus providers.
- Preference for peer-led groups suggest that provider-created groups may also benefit from incorporation of a peer/patient co-lead.
- Remote format expands access to patients in distant locations, but may be limited by participant access to a “smart” device and the internet.
- Success of a peer-led brain tumor support group may rely on:
 - 1) developing a pool of multiple (3-4) patient peers who are able and willing to facilitate the group on a regular basis
 - 2) professional training of peer facilitators
 - 3) a steering committee including peer facilitators and medical professionals to meet regularly and optimize support group efficacy
- Given the resources, patients can effectively empower themselves to build their social support system.

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References

- 3 Ostrom et al., 2019
- 4 Park & Rosenstein, 2015
- 5 Ziegler et al., 2022
- 6 Matsui et al., 2020
- 7 <https://chat.openai.com>

Acknowledgements

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