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# FROM SURVIVING TO THRIVING WITH A BRAIN TUMOR: A MODEL FOR AN EMPOWERED AND ENGAGED PEER VOLUNTEER SUPPORT COMMUNITY

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## Background

People with brain tumors often experience feelings of isolation, identity loss, and existential distress<sup>1</sup>. Peer-to-peer support can have a positive impact in these areas<sup>2,3</sup>. Providing peer support, however, can be emotionally demanding and presents unique challenges for neuro-oncology patient volunteers (PVs), with little guidance available to address these issues<sup>4</sup>. Herein we describe an innovative program that supports volunteers and provides a framework for implementing peer-to-peer volunteer programs within a clinical neuro-oncology practice.

## Methods

**Recruitment:** 1+ yrs post diagnosis of a primary brain tumor and interested in supporting others. Self- or physician-referred.

**Volunteer Training:** 2-hr training, signed forms. Training emphasized: 1) the importance of confidentiality; 2) how to offer support and individual perspectives without administering medical advice or strong medical recommendations; and 3) self-care and ability to recognize situations that require referring to the program's staff.

**Volunteer Role:** To have an in-depth supportive phone call with a matched peer requesting support.

**Ongoing Volunteer Support:** A weekly virtual "Thrivers' Group" was created to offer PVs support, additional training, and opportunities for practice.

**Feedback Survey:** PVs were surveyed in 2022 and 2023 on their experience in the program.

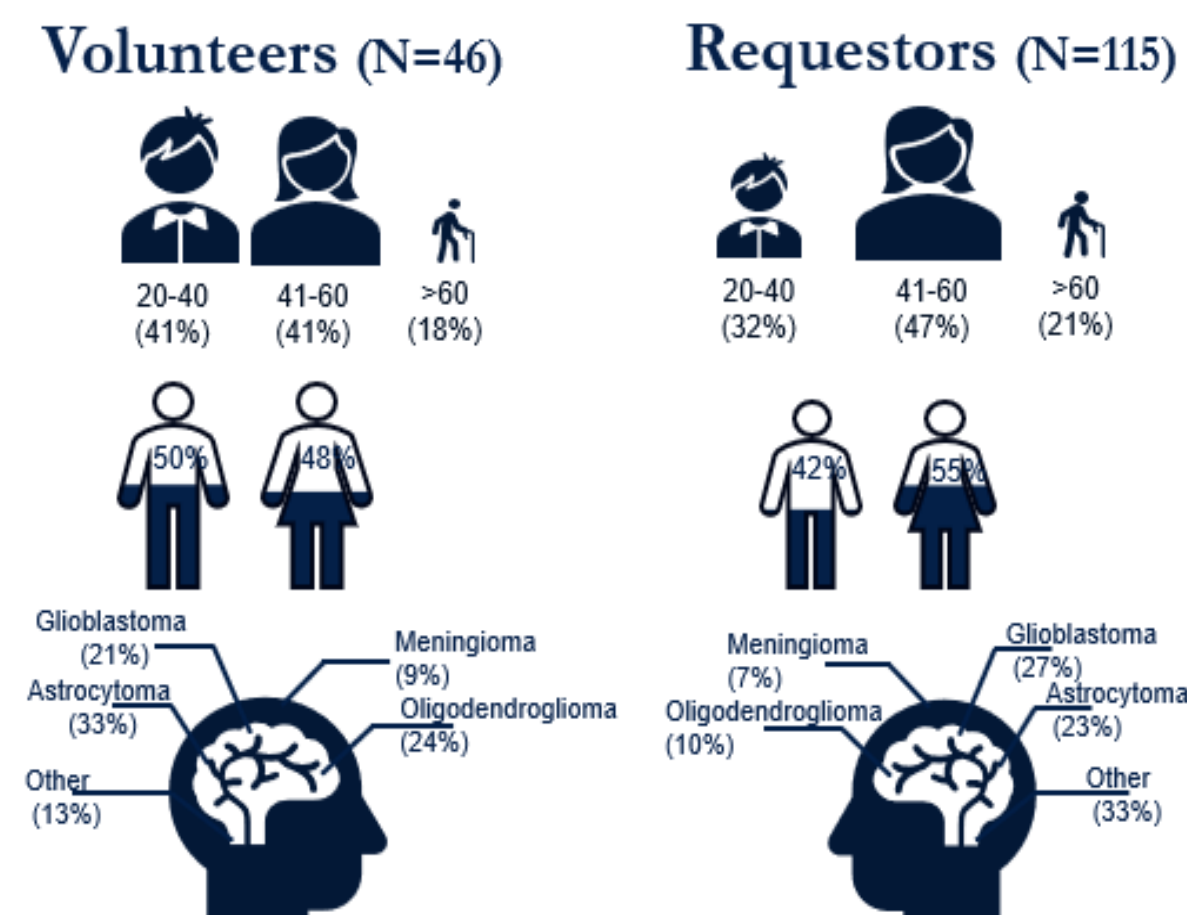
## Results

**Volunteers:** Between August 2020 and December 2023, 60 brain tumor patients were identified, 48 were trained across six cohorts. 46 completed paperwork and advanced to volunteer status.

**Requestors:** 115 brain tumor patients requested peer-support. The most common topics of interest to discuss with peer volunteers were 'Emotional Impact' (68.6%), 'Survivorship and Quality of Life' (40.5%), and 'Side effects and long-term effects of treatment' (37.1%).

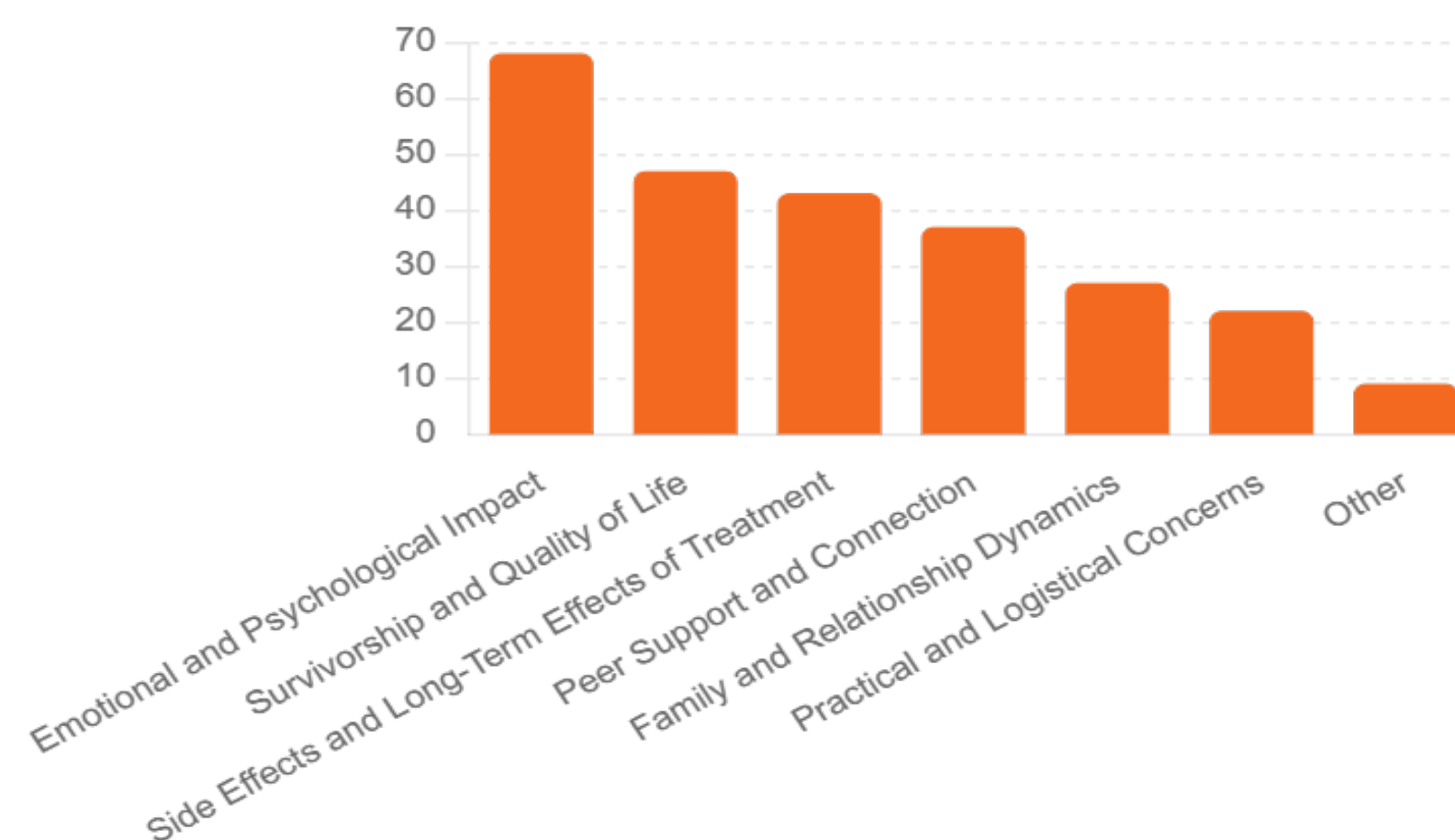
**Peer Matches:** 132 matches were made for an average of 3 matches per volunteer. Some requestors were matched with more than one volunteer.

**Engagement:** 175 weekly Thrivers' meetings were conducted, with an average of 12 volunteers in attendance per session. 70% of all volunteers attended 12 or more meetings per year.

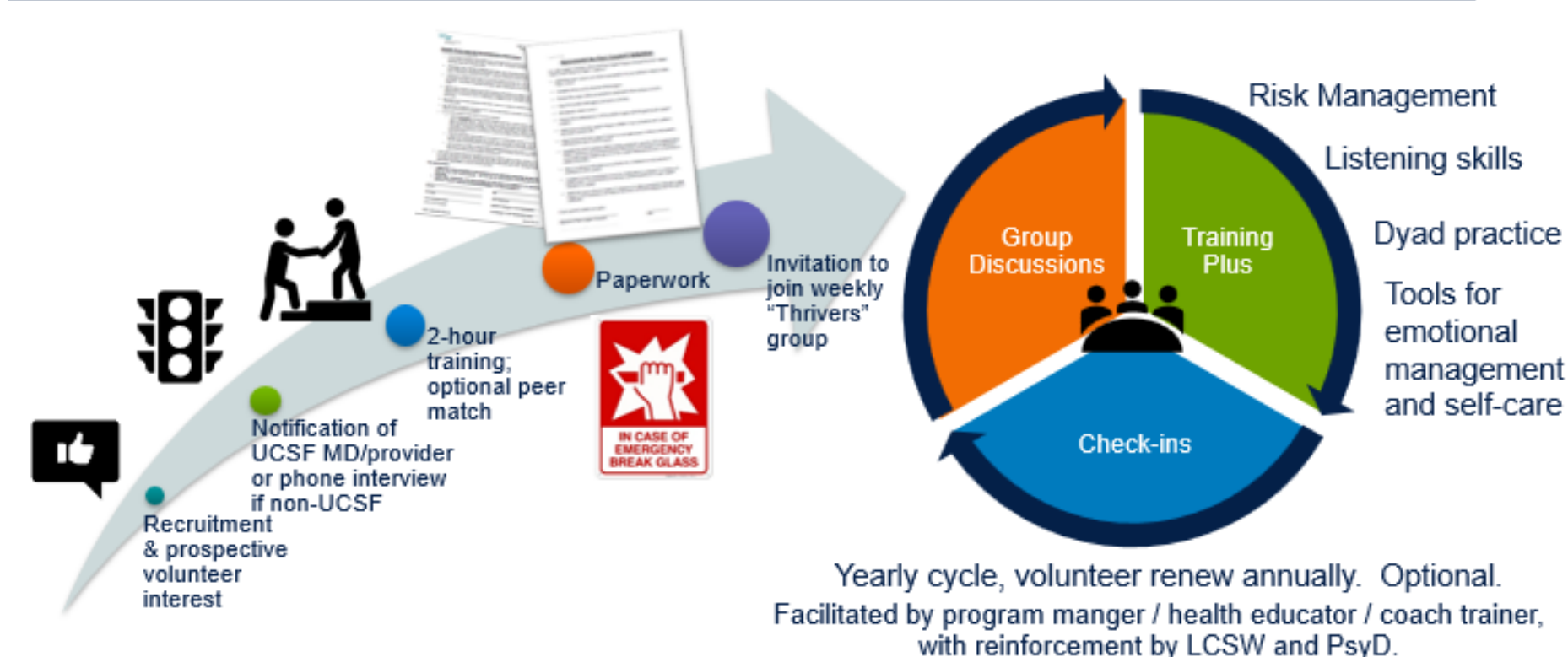


## Breakdown of Concerns by Category

In response to the PR question, "What would you like to discuss with a peer?" Each concern entry can fall into multiple categories, reflecting the multifaceted nature of living with a brain tumor diagnosis.



## Development of a Thrivers' Group



## Quotes from Patient Volunteers

Almost all of us speak with counselors, but it's so nice to be able to speak with someone who suffers as well; there's a unity that's difficult to describe.

The ability to express myself and to hear others do the same are both very important. Learning from others is key. I'm also passionate about trying to help others so this is great for me and I'm learning a ton on how to better do so.

Being in community with others who truly understand all the ways that brain cancer changes and shapes our perspectives is invaluable. Having an opportunity to share with each other how we've weathered the multitude of challenges we face, to hear what helped others, and to transform the 'crappy hand' we've been dealt into something good - to support and encourage others in their seasons of difficulty - is life-changing.

## Results (cont.)

**Feedback:** Of those who responded to the online survey 96% (n=29) reported to be extremely satisfied with the program, while only 4%(n=1) reported to be somewhat satisfied with the program. Additionally, PVs highlighted benefits such as mutual support, impactful contributions, and personal growth and empowerment. Of note, volunteers who reported to feel adequately resourced to engage in peer-support conversations frequently attended Thrivers' meeting sessions (>12 sessions per year). Based on further review of the PV's feedback, additional topics were integrated into training, including responding to medical emergencies (e.g. seizures), as well as the creation of a structured format for volunteers to share their own best practices for supporting peers and for living well.

## Lessons Learned and Recommendations for a Successful Peer-to-Peer Program

**Help PVs with boundaries to prevent burnout:** we emphasized the scope of the program as a single supportive phone call. Additional calls are completely optional and at the discretion of both the PV and PR. PVs can decline match requests and still remain in the program.

**Plan for recurrence and EOL:** we allowed PVs to put their volunteer status on hold but remain in the Thrivers community for ongoing support and connection. We created a ritual to honor regular Thriver members who pass.

**Give PV's the reins** to come up with discussion topics and share their best practices with one another. Consider a non-clinician as a facilitator to help PVs feel empowered and comfortable sharing.

**Offer PVs fast-track access to peer support for themselves** by creating an opt-in shared volunteer contact list.

## Conclusion

The UCSF Neuro-Oncology Peer Support Program has demonstrated strong feasibility, engagement, and preliminary benefits in reducing isolation and restoring purpose. This unique 3-year pilot suggests that ongoing group support and training is a plausible and effective way to enhance a peer-to-peer volunteer program and expand supportive services.

## References

1. Randazzo & Peters, 2016
2. Zieger et al., 2022
3. Jablonschkin et al., 2022
4. Ozier & Cashman, 2016

## Acknowledgements

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