


Stopping to Listen: Using Qualitative Methods to Inform a Web-Based Platform for Adults With Neurofibromatosis

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Abstract

Introduction: Psychosocial care for people with neurofibromatosis (NF) is challenging to access. Therefore, we sought to develop a self-guided web-based treatment platform for people with NF based on the live video relaxation response resiliency program for NF (3RP-NF). Here we report on qualitative interviews with adult patients who participated in the 3RP-NF to: (a) understand participant perceptions of the 3RP-NF program and (b) gather feedback for a self-guided web-based treatment platform (i.e., *NF-Web*). **Methods:** We conducted individual semistructured interviews ($N = 23$; videoconferencing). We utilized both the Framework method and a hybrid deductive and inductive approach to analyze qualitative data. **Results:** We examined findings within the following themes for both 3RP-NF and *NF-Web*: (a) general attitudes, (b) barriers and facilitators, and (c) program-specific factors. Participants endorsed positive attitudes towards the 3RP-NF and *NF-Web* and described unique barriers and facilitators to each and provided suggestions regarding technology, NF-specific needs, and ways to promote social support virtually. **Conclusions:** This study highlights the importance of gathering participant feedback when designing novel, illness-specific interventions. In future studies, we aim to provide people with NF effective and efficient access to psychosocial support that matches their needs and life context. Results are informing *NF-Web* development.

Keywords

neurofibromatosis, quality of life, stress management, mind-body, web-based, resiliency

Introduction

The neurofibromatosis (NF; including NF1, NF2, and schwannomatosis) is a group of neurogenetic conditions characterized by tumors in the nervous system and skin (1). NF1 occurs in about 1 in 3000 births (96% of NF cases), NF2 occurs in about 1 in 25,000 births (3% of all cases), and schwannomatosis is rarer with estimated prevalence of 1 in 40,000 (2). NF can cause significant morbidity including disfiguring cutaneous tumors, hearing loss, poor gait, and chronic pain (3). NF disorders are life-long and the only treatments available are medical interventions that help manage symptoms (e.g., surgery, chemotherapy) (1).

Individuals with NF experience a number of ongoing stressors, including frequent medical visits, concern for malignant tumors, and possibility of having children with NF (3). Compared with the general population, individuals with NF experience heightened emotional distress (4). They are at risk for lower quality of life (QoL) (5), self-esteem, social skills (6), as well as more depression (3),

stress (7), anxiety (3), learning disabilities (6), and pain (5). Given these elevated rates and the lack of tailored psychosocial treatments available, we developed live video psychosocial programs to enhance psychosocial functioning among adults with relaxation response resiliency program for NF (3RP-NF) (8), adolescents with NF (RY-NF) (9) and adults with NF2 who are deaf (d3RP-NF2) (10). In three individual single-blinded randomized controlled trials, participation in these programs was associated with improved QoL (physical

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health, psychological, social, and environmental), pain, and psychosocial functioning in comparison to population-specific attention placebo health education controls (7,9,10). Efficacy trials for adults (11) (not d3RP-NF) and adolescents (12) are currently ongoing.

Although these programs helped to enhance outcomes, we observed several barriers that interfered with the 3RP-NF adult trials (e.g., time-zone differences, conflicting occupational/familial obligations, internet limitations, vision and hearing difficulties, and NF-specific appearance concerns) (13). Specific to the live video platform, appearance on-screen and real-time interaction with other participants can be a significant barrier for people with NF who have social interaction concerns or who avoid these situations all together. Further, in terms of human resource live video interventions require trained psychologist providers with experience working with people with NF to deliver the intervention. To overcome these barriers and increase access to care, we sought to develop a website-based (i.e., web-based) platform for asynchronous program delivery. Prior literature indicates that web-based interventions can enhance accessibility for hard-to-reach populations (e.g., rare conditions) and reduce interpersonal discomfort given the anonymity they provide (14). Although these platforms are still under investigation, they have been effective for reducing psychological distress for individuals coping with diabetes and cancer (15). These resources also can save time and travel costs (16) for patients with rare illnesses where specialty providers are limited. Adapting the existing program to a web-based platform may provide the needed convenience, cost-effectiveness, accessibility, and scalability, all while retaining the core evidence-based mind-body and resiliency skills. However, a patient-centered approach to understanding population-specific needs, barriers, and preferences is needed to inform the development of a web-based program.

We conducted semistructured qualitative interviews with completers from the existing adult live video program (3RP-NF; completion at 1-year assessment follow-up) to inform the development of the future web-based platform (NF-Web). Qualitative methods are effective for refining interventions and capturing the unique experiences of understudied and overlooked populations (17). Here, we report on results from qualitative interviews that aimed to: (a) understand participant perceptions of the 3RP-NF program and (b) gather feedback on the development of a self-guided web-based treatment platform (i.e., *NF-Web*) based on 3RP-NF.

Methods

Participants and Setting

We emailed all participants who completed the 3RP-NF program (11) (>1-year completion) to gather interest in participating in a follow-up study. We interviewed participants from the 3RP-NF because we were interested in getting

feedback on both our existing program and the web-based adaptation of the same program simultaneously. This aided our research question regarding attitudes and adaptation because participants would have familiarity with the existing structure and materials of the group and have a point of comparison. Practically speaking, interviewing previous participants also allowed us to save time not explaining the structure of the program during the interviews given the participants familiarity.

Interested participants contacted the study coordinator by phone. Those who met inclusion criteria provided verbal and written informed consent. Inclusion criteria for the 3RP-NF study were (a) 18 years or older, (b) English-speaking, and (c) previous participation in the 3RP-NF live video trial. Inclusion criteria for our live video program included: (a) 18 or older, (b) NF diagnosis, (c) English speaking and literacy at sixth-grade reading level, (d) difficulties coping with NF and stress, (e) score >6 on the Perceived Stress Scale (18), (f) no changes in psychiatric or psychosocial treatment in the past 3 months, (g) medical illnesses not expected to worsen during the course of the 8-week study. For participants to enroll in this study, they needed to demonstrate (a) completion of the active 3RP-NF at one year and (b) willingness to comply with study procedures (11).

Interview Procedure

We conducted individual semistructured interviews through secure Vido© software (same platform as 3RP-NF). Our semistructured interview guide included two domains: (a) participant experiences with 3RP-NF and (b) their feedback on NF-Web development. The first two authors conducted the interviews, of which the first author (EGL) was the clinician for several of the participants during the live video trial. To address the potential for interviewer influence and on participant feedback, interviewers encouraged participants to give honest feedback, elaborate, and/or expand on their responses based on recommendations from previous qualitative researchers (19). Our Institutional Review Board (IRB) approved all study procedures.

Relaxation Resiliency Response Program for NF (3RP-NF)

We have reported details about the 3RP-NF program previously (8,11). To summarize, the 3RP-NF program teaches resiliency skills for NF-related stress within four broad treatment areas: (a) relaxation response exercises (e.g., deep breathing, guided imagery), (b) stress awareness skills (e.g., symptom awareness, stress warning signals), (c) coping strategies (e.g., adaptive thinking, social support), and (d) healthy lifestyle behaviors (e.g., sleep, diet/nutrition, physical activity). Our treatment targets included general QoL (physical, psychological, social, and relational), as well as anxiety, depression, pain, and resiliency. We delivered 3RP-NF

virtually to groups of people with NF (5–8 per group) through secure live videoconferencing (8 weeks). We collected baseline, posttest, 6 months, and one-year follow-up data (secure research data collection software; i.e., REDCap) (20). We conceptualized NF-Web to have a similar framework (e.g., content, treatment targets) to the 3RP-NF program with adaptations based on participant feedback from interviews.

Data Analysis

We used a hybrid deductive and inductive approach— informed by the Framework Method to ensure rigor—to analyze interview data (21,22). First, we transcribed interview recordings verbatim and edited them for accuracy. All transcripts were de-identified, uploaded, and stored on a secure, encrypted computer on NVivo 10 (23). We created an initial codebook to align with the main study aims (i.e., experiences with 3RP, feedback on NF-Web). Two coders assessed the usability of the designed codebook by practice coding one transcript. To optimize coding consistency and usability, we refined the codebook with coder discussions and feedback. Since interview questions were similar across various aspects of the interview, coders were trained to look for specific codes and place them in context (i.e., the subsection of the interview to which the participants were responding at any given time during the interview) to help specify which themes data applied to and were subsequently coded. Both coders double-coded 30% of interviews ($n = 7$) and met 4 times to discuss coding strategy and reconcile any disagreements. With coders trained and in agreement, the remaining interviews ($n = 16$) were single coded evenly between the two coders (i.e., 8 each).

For data analysis, coders started with deductive a priori categories and added new codes flexibly and inductively as they and discussed the initial transcripts and refined the codebook. We created matrix queries to summarize and interpret the data. Our hybrid analytic approach used deductive and inductive methods to inform general themes of (a) attitudes toward programs, (b) barriers and facilitators, and (c) program-specific factors or considerations for 3RP-NF and NF-Web programs. Using thematic analysis, we extracted findings within these themes related to improvements and adaptations of both programs. Once qualitative analyses were complete, study staff met to resolve inconsistencies.

Results

Participants

Of the 37 participants contacted, 2 declined, and 12 were unreachable by study staff after initial contact. Our final sample consisted of 23 participants: 16 participants with NF1 (69.56%), 4 with NF2 (17.39%), and 3 with schwannomatosis (13.04%), which is in line with population prevalence. Participants were mostly female ($n = 16$; 78.26%),

Table 1. Sample Demographics.

Demographics information for participants (N = 23)	
Gender	N (%)
Female	18 (78.26%)
Male	5 (21.74%)
NF type	
NF1	16 (69.56%)
NF2	4 (17.39%)
Schwannomatosis	3 (13.04%)
Ethnicity	
Hispanic or Latino/Latina	1 (4.35%)
Race	
White	20 (86.96%)
Asian	1 (4.35%)
More than one race	1 (4.35%)
Choose not to answer	1 (4.35%)
Marital status	
Single, never married	8 (61.5%)
Married	2 (15.4%)
Separated/divorced	2 (15.4%)
Education	
12 years or less	3 (13.04%)
16 years or less	16 (69.56%)
More than 16 years	4 (17.39%)

white ($n = 20$; 86.96%), and well educated (>15 years of formal education; $n = 20$, 86.86%). Table 1 displays sample demographics.

3RP-NF Themes

Theme 1: Attitudes Towards 3RP-NF Program. This theme includes general attitudes towards the 3RP-NF program, such as the format, delivery, modality, and materials. Overall, participants endorsed positive attitudes towards the 3RP-NF. Positive aspects included the 3RP-NF mind–body materials, 8-week timeframe, learning pace, session content, and group sizes. Participants noted that the group format was effective for reinforcing resiliency skills through weekly homework assignment reviews and in-session discussions with other group members. Participants had positive attitudes towards the specific skills taught (e.g., diaphragmatic breathing, relaxation, adaptive thinking), and enjoyed having a live teacher and electronic and printable versions of the program manual. A few participants expressed mixed attitudes toward the 3RP-NF—citing “occasional inconvenience” of weekly sessions (i.e., scheduling). However, most participants easily incorporated weekly groups into their schedule Table 2.

Participant attitudes towards the live video modality were positive. Participants found it enjoyable and beneficial to connect with others “face-to-face” compared to other formats (e.g., chatrooms, social media posts). A few participants mentioned mixed attitudes towards the virtual format, suggesting this might be resolved with more instructions

Table 2. Primary Qualitative Data From Semistructured Interviews: Relaxation Response Resiliency Program for Neurofibromatosis (3RP-NF) (N = 23).

Program	Theme	Sample of participant quotes
3RP-NF	Theme 1: Attitudes towards 3RP-NF Program	<ul style="list-style-type: none"> • “I liked that it was a small group. Everyone had a chance to talk a little bit, but you weren’t relying on one person to talk all the time.” • “... I think coming, like the 8 weeks ... it was a good time frame to learn the skills. It wasn’t rushed or anything ... I liked the timeframe.” • “Honestly, I think I liked the fact that it was live and that it was actual people because it kept you accountable and I would feel guilty if I didn’t go on. Where if I was having a bad day and would go to do it on my own, I might not do it.” • “I thought it was ok I think I probably spent the least amount of time doing the audio, I tend to, probably because of my hearing issues, I tend to like, read something and reading it as much as I can.”
	Theme 2: Barriers and facilitators experienced in 3RP-NF program	<ul style="list-style-type: none"> • “I was just saying that they [the group sessions] were hard to fit into my schedule also because I have just had so much going on with work and it was just hard for me to just be home, at my desk at a certain time for an hour.” • “I always wanted to share; it was me being shy. This was the first time I ever did something like that so I was like kind of like ok do I talk? Do I not talk? It was my shyness getting in the way.” • “I mean sometimes I felt, like the good thing about the homework for me was that we kind of had to submit it. That held you accountable to actually doing it and so I think that’s a good thing to do in a, in a setting like that because it’s easy enough to not do it and sit there and act like you did it you know”
	Theme 3: Evaluation of 3RP-NF program	<ul style="list-style-type: none"> • “... The breathing techniques, which for some reason I heard before but never really fully understand. I mean for me, I think to take a grasp I need to read it, talk about it, read it, talk about it and umm it helped and I, I mean every day to this day I use breathing, you know, techniques that I learned, which help me get grounded if I’m having a problem.” • “Because that made a huge difference, being able to look at other people and hear their experiences of what it’s done to them was very helpful so some way that that needs to be incorporated in there so that again you’re not isolated and alone in doing all this”

and troubleshooting methods. Although attitudes were mostly neutral towards audio recordings, participants tended to stop listening to self-guided skill recordings a few weeks into the program, usually because of a perceived lack of utility, and/or individualizing their own practice. Notably, participants with NF2 mentioned difficulties hearing in session audio and recordings, however, participants mentioned making their own modifications to effectively participate (e.g., reading the manual ahead of time, using technology assistance) which seemed to produce neutral attitudes from these participants towards the audio from the videos as well as the audio recordings.

Theme 2: Barriers and Facilitators Experienced in 3RP-NF Program. This theme includes barriers and facilitators to the 3RP-NF program (e.g., attendance, engagement, and motivation). Participants reported they were unlikely to read the manual outside of the session and occasionally had difficulties completing assignments, using audio files, and attending sessions because of “changes in work schedules” or “other life demands.” Participants shared that practicing skills in session with a trained clinician and other people with NF

and in-session feedback on homework practice helped facilitate participation. Group dynamics and support were also mentioned as the main reason for participating and seen as major facilitators of their participation. A majority of participants expressed appreciation for meeting others with NF because it made them feel “less alone.”

A few participants reported that they felt “unmotivated,” which prevented them from fully engaging in the program and home practice. Others described “forgetfulness” (e.g., weekly sessions, turning in homework) as a barrier to engagement. Some participants endorsed difficulties discussing emotions or “opening up” (i.e., sharing thoughts and feelings) in a group setting. Personal reminders (e.g., phone reminders, calendar) and staff emails helped facilitate participation. Participants stated group size was conducive for support and discussion. Additionally, participating with others with NF helped them feel more accountable, engaged, and facilitated homework completion Table 3.

Theme 3: Evaluation of 3RP-NF Program. This theme includes participants’ perceptions about the 3RP-NF program, such as program benefits, skills acquired, and reasons for

Table 3. Primary Qualitative Data From Semistructured Interviews: Neurofibromatosis (NF)-Web (N = 23).

Program	Theme	Sample of participant quotes
NF-Web	Theme 1: Attitudes towards NF-Web	<ul style="list-style-type: none"> • “I think it would be less stressful for people having to like ... rush home from work. They can do it on their own time ... kind of like online college if you do it at your own pace ... and I think that would be helpful especially for people who work long hours like I work 9 h a day most days.” • “... I think that having that flexibility, of going your own pace, especially for anyone who does have appearance concerns, you know it just, it might feel a little more intimate to them and they might share more.”
	Theme 2: Barriers and Facilitators to Participating in NF-Web	<ul style="list-style-type: none"> • “I like the idea of the workbook, visual program to back it up, the fact that you can leave and jump back in at any time.” • “If you could play it over and over again, you know repeat it, I think that’s helpful” • “Allowing them to be self-paced would be more helpful to some people. Like people who are more crunched on time commitments, so like people just need more time to like listen to [the session].”
	Theme 3: Suggestions for NF-Web Adaptations	<ul style="list-style-type: none"> • “I know you can’t make them that short but between 5–10 min would be convenient.” • “Um maybe like a dashboard or like public forum where they get to choose if they wanna do it and they get to talk about what they did that week, that day ...” • “... sometimes you have a video option an audio option of the video and a transcript option and I find that you know depending on my day I would turn to different media for the information, so you know sometimes you want to read it and sometimes you want to hear it and some people are really visual, so they want to watch the video.”

participating. Participants noted that they wanted to participate in the program to “manage stress” and “meet other people with NF.” Participants evaluated the mind-body and coping skills as helping manage their stress and valuable for coping with NF. Participants said the program helped them to manage negative thoughts and moods and learn how to think more adaptively. A few participants perceived improvements in cognitive (e.g., attention, concentration) and physical (e.g., reducing pain) functioning.

All participants reported that breathing exercises and mindfulness meditation were valuable skills and helpful for managing NF-specific stressors and associated emotions. Participants endorsed that they used specific skills such as SMART goals, gratitude, and MINIs (i.e., brief relaxation skills) daily (11). Participants reported the benefits of learning a variety of skills for different situations and experiences.

NF-Web Themes

Theme 1: Attitudes Towards NF-Web. Participants shared their general attitudes towards the proposed NF-Web program, with the majority endorsing positive attitudes towards NF-Web. Participants had particularly positive attitudes towards the virtual format, stating it may help increase accessibility for people “hard to reach” (i.e., people managing scheduling challenges, learning and sensory differences [e.g., deafness], and appearance concerns). Participants said that the website’s self-directed format would be “valuable” and they could navigate materials on their own time in one

centrally located place. Participants were receptive and willing to participate in the proposed program, if available.

Theme 2: Barriers and Facilitators to Participating in NF-Web. Participants described perceived barriers and facilitators to participating in NF-Web. A few participants were concerned that they may not be “tech savvy” enough for this format. Others said that accountability and/or limited motivation (e.g., procrastinating, forgetting, focusing/distraction) may prevent engagement. With regard to facilitators, participants said that NF-Web would help overcome barriers of accessibility (e.g., ease of using a web-platform), scheduling (e.g., participating for 8 weeks), and learning differences (e.g., preferences for different modalities [visual, audio]). Participants stated that the structure and format of NF-Web (e.g., self-paced, multimodal, weekly sessions) would serve as a facilitator and promote engagement. They said this format would likely increase their utilization of session materials (e.g., pausing and re-watching sessions) and help make them take “responsibility” of their psychosocial care, manage stressors, and enhance mood. They pointed out that it may be especially useful for those who may not participate in 3RP-NF programs because of self-consciousness, depression, anxiety, and/or appearance concerns.

Theme 3: Suggestions for NF-Web Adaptations. Participants provided suggestions for NF-Web, such as ways to effectively: present program materials, provide social support, make the program accessible, and make NF-specific

adaptations. They suggested using high quality audio-video technology (similar to an online course curriculum). They suggested that video tutorials, printable handouts and materials, and a frequently asked questions page would help enhance participation. Participants reported that it is *necessary* to ensure accountability and comprehension with this online format (e.g., reminders, tutorials, and novel teaching methods). They also said that it is important to include a social component (e.g., discussion boards, forums).

Participants suggested designing the website and materials to accommodate learning and sensory differences common in NF (e.g., captioning for videos, shorter video lengths, written materials and audio-only materials). Participants also suggested combining modalities (e.g., having text inside of video) and providing summary sheets to increase engagement for those with these differences. Participants said that it would be valuable to include a “personal touch” in the web-based platform—specifically suggesting ways to interact with others with NF and feeling that the website was developed by a “real person” who understood NF and was accessible as needed.

Discussion

The 3RP-NF virtual group program helped to enhance psychosocial outcomes for individuals with NF (7,9,10). However, many individuals endorsed barriers that interfered with participation and engagement (e.g., scheduling, sensory difficulties, appearance concerns) (13). The 3RP-NF program also required trained psychologists with NF expertise. Here, we utilized individual qualitative interview to understand participants’ experiences with virtual 3RP-NF and gather feedback on the development of NF-Web. Participants discussed general attitudes, barriers and facilitators, and specific factors relevant to both 3RP and NF-Web programs.

Overall, participants endorsed positive attitudes toward the live video 3RP-NF program as well as the materials and format of it. Participants cited session skills, structure, and modality as facilitative aspects of the program. They also mentioned that their interactions with others who have NF were helpful for their participation. With regard to NF-Web, participants provided positive feedback about the potential program. They understood the rationale for web adaptation and valued the self-paced format. They said that having session materials in one convenient place and potential accessibility modifications for people with NF who have learning and sensory differences may help increase participation. Participants provided valuable suggestions for NF-Web platform, such as keeping videos short and including embedded text with them. Participants noted that quizzes, summary sheets, and interactive social components (e.g., discussion board) would help enhance accountability and engagement. Participants were willing to participate in NF-Web if offered, especially if they were unable to participate in the live video 3RP-NF. Our findings highlight the importance of adapting and designing psychosocial interventions for specific patient populations with patient-centered feedback. By

including this feedback throughout intervention development, we hope to enhance the feasibility, efficacy, and accessibility of a psychosocial program for people with NF.

Clinical Implications and Future Directions

Study results have important clinical implications. First, this study effectively captured participants’ attitudes, preferences, and feedback for virtual evidence-based mind-body interventions for people with NF. Qualitative interviews helped inform our prior 3RP-NF (5) study and it helped make the program more accessible and patient centered. We have used these findings to inform the development of NF-Web and a subsequent open pilot study. Currently, we are piloting NF-Web and have already captured some participants who were unable to participate in the 3RP-NF program. We plan to conduct qualitative interviews with these NF-Web participants after this initial phase to understand participants’ experiences and further refine the program. Given the feasibility of this format, we plan to utilize mixed-methods designs to adapt NF-Web for specific subgroups.

Strengths and Limitations

Our study had several strengths. First, we conducted individual in-depth semistructured interviews to best capture participants’ experiences. Second, we utilized a flexible analytic strategy (hybrid deductive–inductive approach), which helped to collect key information while also allowing room for themes to emerge (21,22). Although we did not discover inductive themes as part of our data analysis, a strength of this flexible approach is that it allowed for novel information in the context of existing a priori research questions to occur. Third, we took a patient-centered approach to digital intervention development, which has the potential to enhance usability and applicability to specific medical populations.

With regard to limitations, there was a lack of socio-demographic diversity (majority white, well-educated women). The sample of participants who participated in our study was similar to our studies implementing NF-specific psychosocial interventions in terms of demographic characteristics (7–11,13). In our current trials, we aim to recruit more diverse samples across illness types to assist in developing these tailored and adapted web-based programs. Next, participants had similarities in program perceptions (i.e., all enjoyed the 3RP-NF program and were motivated to participate), which may have been related to the sampling bias (interviewed those who participated in 3RP-NF). Finally, it was difficult to assess diagnostic differences despite the literature on a variety of experiences of those with NF1, NF2, or schwannomatosis.

Conclusions

Participants in the live video 3RP-NF reported positive attitudes towards both the 3RP-NF and proposed NF-Web

program. Both programs overcome unique barriers and complement each other. The live video 3RP-NF provides support from participants and group leader in addition to skills, but requires commitment to a specific day and time for 8 weeks, and a trained clinician. NF-Web can provide cost-effective access to the same skills when participants want it without the need of a trained clinician, but lacks in the person support and may have challenges with engagement. Using this information we will iteratively optimize NF-Web, determine its effectiveness when compared to the live video 3RP-NF, and explore patient characteristics that predict response to each treatment modality. Our long-term goal is to provide people with NF with effective and efficient psychosocial support that matches their needs and life context.

Declaration of Conflicting Interests

The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: Vranceanu reported receiving funding from the Department of Defense and the National Institutes of Health and serving on the scientific advisory board for the Calm application outside of the submitted work. Lester reported receiving funding for his salary from the above-mentioned funding sources. No other conflicts of interest were reported.

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Ethical Approval

All procedures in this study were conducted in accordance with Massachusetts General Hospital Institutional Review Board (#2019P002950) approved protocols.

Informed Consent

Written informed consent was obtained from the patients for their anonymized information to be published in this article.

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Supplemental Material

Supplemental material for this article is available online.

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