

Exploring the Use of Neurofeedback by Cancer Survivors: Results of Interviews with Neurofeedback Providers and Clients

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ABSTRACT

Objective: Cancer survivors may experience persistent physical and psychological symptoms following completion of cancer treatment. Neurofeedback is a noninvasive form of brain training reported to help with symptoms including pain, fatigue, depression, anxiety, insomnia, and cognitive decline; however, there is a lack of research exploring its use with cancer survivors. The objective of this study was to describe the experiences of neurofeedback and its impact on the lives of posttreatment cancer survivors as perceived by neurofeedback providers and cancer survivor clients. **Methods:** This qualitative descriptive study employed semi-structured interviews and thematic analysis of interview transcripts. A convenience sample of twelve neurofeedback providers and five cancer survivor clients participated in this

study. **Results:** Thematic analysis revealed seven overarching themes as follows: (1) paying it forward; (2) transforming lives; (3) regaining control; (4) brain healing itself; (5) comforting experience, (6) accessibility, and (7) failure to respond. The first five themes related to benefits of neurofeedback, and the final two related to challenges of using neurofeedback with cancer survivors. **Conclusions:** Results support the use of neurofeedback to improve quality of life for cancer survivors; however, more research is needed to determine which neurofeedback systems and protocols are most effective for this population with persistent symptoms.

Key words: Biofeedback, cancer, cognitive function, fatigue, neurofeedback, qualitative research

Introduction

Cancer survivors are more likely to use complementary and alternative medicine therapies than individuals who

have never had cancer, often to manage persistent symptoms including pain, anxiety, depression, and insomnia.^[1]

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Interest is growing in using mind-body therapies to manage symptoms and improve quality of life and well-being in cancer survivors.^[2,3]

Whereas biofeedback is the use of electronic monitoring of a bodily function such as blood pressure or muscle tension to train an individual to acquire voluntary control of that function, neurofeedback is a mind-body technique that incorporates real-time biofeedback of electroencephalography (EEG) activity to train individuals in self-regulation and potentially meditation.^[4] Basically, the electrical activity of the brain or EEG is recorded by placing electrodes on the scalp. These brain waves are categorized by their amplitudes and frequencies which are associated with various states of relaxation and arousal.^[5] Then, the neurofeedback provider and/or the computer software provide audio or video feedback to the client in response to desirable or undesirable brain wave patterns which teaches self-regulation of brain function.

Self-regulation is related to neuroplasticity, the capacity of the brain to develop new neural pathways in response to experience and changes in the environment, and neural efficiency, which refers to a decrease in the amount of energy/resources dedicated to performing a given task.^[6] Neurofeedback is reported to improve pain and fatigue of fibromyalgia,^[7,8] depression and fatigue in multiple sclerosis,^[9] posttraumatic stress disorder (PTSD) symptoms,^[10] stress and anxiety,^[11,12] and to improve athletic performance.^[13] Many conditions reported to improve with neurofeedback also improve with regular meditation.^[4] Both techniques enhance concentration and emotional regulation; however, neurofeedback is driven by computer software, making it easier and potentially faster to manifest in clinical changes.

There are many types of neurofeedback approaches, systems, and protocols. In traditional targeted neurofeedback approaches, the provider selects a specific brainwave target based on the presenting symptoms; quantitative electroencephalogram (QEEG) driven approaches seek EEG normalization; whereas nonspecific approaches such as NeuroOptimal are generalized neuroregulation approaches that can be applied to nonclinical populations to promote optimal mental fitness.^[14] In general, neurofeedback sessions last between 20–50 min, and the number of sessions required to manage symptoms ranges from 10 to 40 or more depending on the issues and their severity.^[15] The cost for a neurofeedback session ranges from \$25 to \$200, with most practitioners charging between \$50 and \$100.

Few studies have examined neurofeedback to manage symptoms in cancer survivors. Results of an integrative review suggest neurofeedback for management of cancer pain.^[16] A systematic review provides preliminary evidence of use neurofeedback to manage fatigue and cognitive

impairment.^[14] One study in this review demonstrated the feasibility of neurofeedback in a sample of breast cancer survivors who showed significant improvements in cognition, fatigue, psychological symptoms, and sleep.^[17] A randomized controlled trial (RCT) of neurofeedback conducted in the U. S. demonstrated improvement in chemotherapy-induced peripheral neuropathy symptoms.^[18] However, a Dutch RCT of QEEG-based neurofeedback training protocols found no significant effect on neurocognitive functioning compared to placebo neurofeedback in pediatric brain tumor survivors.^[19] Thus, there is a need to determine which neurofeedback systems and protocols are safe and most effective for different populations of cancer survivors with persistent symptoms.

We previously conducted a cross-sectional survey of neurofeedback providers to explore the use of neurofeedback by cancer survivors.^[15] Results revealed some cancer survivors are using neurofeedback to reduce or eliminate persistent symptoms such as fatigue, cognitive impairment, sleep problems, stress, anxiety, depression, and pain, with few but transient side-effects including fatigue and headache. We now aim to explore these results from a qualitative perspective. Thus, the objective of this study was to describe the experiences of neurofeedback and its impact on the lives of posttreatment cancer survivors as perceived by neurofeedback providers and cancer survivor clients.

Methods

Design and participants

This exploratory study utilized a qualitative descriptive design.^[20] A convenience sample of neurofeedback providers who had cancer survivors as clients were recruited from a purposeful sample of neurofeedback providers who had participated in our previous survey study. Participants were approached to complete a semi-structured interview and to forward recruitment materials to clients who were cancer survivors. This was determined to be the most feasible way to identify cancer survivors who had used neurofeedback. Potential participants were contacted by the research assistant who provided information and obtained consent. All individuals willing to be interviewed were included in the sample. Although data redundancy was noted, we were unable to recruit additional participants to confirm data saturation was reached, as noted in the limitations section.

As this is a preliminary exploratory study and it was unknown to what extent cancer survivors were participating in neurofeedback, it was deemed most feasible to approach neurofeedback providers to describe their experiences with cancer survivors. In addition, we asked them to pass along our contact information to any clients who were cancer survivors so that we could describe their experiences first

hand. Unfortunately, this approach resulted in few cancer survivor participants. Although it is possible that the neurofeedback providers' perceptions were biased, it should be noted that for most, neurofeedback was only one aspect of their clinical practice.

Ethical approval

Ethical approval was received from the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board. Informed written consent was obtained from all participants prior to their enrollment in this study.

Data collection and analysis

Consenting participants completed a 30–60 min interview conducted and transcribed by the primary author. The semi-structured interviews were guided by a semi-structured interview guide outlining similar questions and potential prompts for the neurofeedback providers and the cancer survivors [Table 1]. The second author reviewed all aspects of data analysis guided by the phases of thematic analysis described by Braun and Clarke.^[21] Data coding was conducted independently by two researchers. Similar codes were combined to create subthemes using emerging, process, and theoretical coding, and subthemes were grouped and regrouped to generate analytic themes. Data mapped to each theme were interpreted as benefits or challenges. A detailed audit trail was kept throughout data collection and analysis to promote dependability and confirmability. Emerging themes were discussed to create the final set of themes. The credibility of findings was supported by peer debriefing with the third author, who validated whether themes were supported by raw data.

Results

The sample consisted of twelve neurofeedback providers and five clients who were cancer survivors interviewed in 2015 or 2016. The majority was female, North American and had experience with Neuroptimal neurofeedback [Table 2]. Neurofeedback providers were mainly psychologists, with a mean age of 57 years, and average 6 years' experience with neurofeedback. Cancer survivor participants were mainly breast cancer survivors with a mean age of 53 years. Although the number of years after cancer diagnosis was not collected from the cancer survivor participants, it was clear they had struggled with their symptoms for years before trying neurofeedback. Seven overarching themes emerged describing provider and client experiences with neurofeedback for cancer survivors [Table 3].

Theme 1: Paying it forward

Many neurofeedback providers in our study described having past personal experiences with neurofeedback. Some were cancer survivors themselves whereas others were recovering from other clinical conditions such as a traumatic brain injury and had such positive experiences for managing their own symptoms they felt strongly compelled to become neurofeedback trainers to help others.

"I am a survivor, that's how I fell into it. I had an incredible experience with it. I suffered from really awful cognitive issues... Chemo brain. Just couldn't remember... I'd leave the dog in the car. I couldn't even write the 'at' symbol when I was writing my E-mail address. There would just be blocks there. I couldn't function... and also depression and anxiety were surfacing out of nowhere, and I wasn't

Table 1: Semi-structured interview guide

Neurofeedback providers	Cancer survivors
Tell me about how you became involved with neurofeedback therapy	Tell me about how you became aware of neurofeedback therapy
Tell me about the neurofeedback training you provide e.g., system/s or protocols used; how to decide which one to use; when to stop or switch to another system/protocol	Tell me about the type/s of neurofeedback training you experienced
Tell me about the reasons cancer survivors are seeking neurofeedback therapy? Prompts: symptoms, quality of life, roles and activities	Tell me about why you decided to do neurofeedback training Prompts: symptoms, quality of life, roles and activities
Tell me about your experience of providing neurofeedback to cancer survivors	Tell me about your experience during neurofeedback training
Describe the impact of neurofeedback on long-term symptoms such as fatigue, cognitive impairment, depression, anxiety etc., in your cancer survivor clients	Describe the impact of neurofeedback on your long-term symptoms such as fatigue, cognitive impairment, depression, anxiety etc.
Describe your perception of the impact of neurofeedback training on quality of life in your cancer survivor clients	Describe the impact of neurofeedback training on your quality of life
Describe any side effects of neurofeedback experienced by cancer survivors or other clients with long-term symptoms? How are these managed?	Describe any side effects of neurofeedback you experienced during or after your sessions. How did the neurofeedback provider manage these?
Describe the average course of therapy i.e., how many sessions; how this varies between clients; length of time before symptom relief is experienced; whether booster sessions are required to maintain symptom control	Describe the course of your therapy i.e., how many sessions did receive; when did you begin to experience symptom relief; if you received any additional booster sessions?
What recommendations do you have for cancer survivors regarding neurofeedback?	What recommendations do you have for other cancer survivors regarding neurofeedback?

Table 2: Interview participant demographics

Variable	Neurofeedback providers (n=12)
Country	
Canada	6
U.S.	4
U.K.	1
Australia	1
Type of neurofeedback	
Neuroptimal	8
QEEG-based	2
Alpha/Theta protocol	1
Neurogen HPN	1
Age	
Years (range)	57 (37-70)
Gender	
Female	10
Male	2
Primary occupation	
Psychologist/Psychiatrist	5
Neurofeedback provider	3
Family physician	1
Occupational therapist	1
Dietician	1
Engineer	1
Clinical experience	
Years (range)	21 (4-40)
Variable	Cancer survivors (n=5)
Country	
Canada	2
U.S.	3
Type of neurofeedback	
Neuroptimal	4
QEEG-based	1
Age	
Years (range)	53 (42-70)
Gender	
Female	5
Cancer type	
Breast	4
Head and neck	1

able to sleep, and all those things just melted away and got better with neurofeedback.”(P1).

Some participants were physicians or psychologists who decided to incorporate neurofeedback into their practices, whereas others shifted into new career paths to help others through neurofeedback.

“My lifelong sleep problems... when I got to perimenopause... became horrible, and I tried many medications, many alternatives... acupuncture... nothing helped. A colleague suggested neurofeedback and I started doing sessions. My sleep improved quite quickly... I noticed after several sessions that my lifelong anxiety dreams were going away, and at that point I realized I needed to bring it into my practice. I’ve been a psychotherapist for 11 years and this has really taken over my practice... I still love doing

psychotherapy, but neurofeedback is such a useful tool to help people.”(P8).

“I have no idea when the cognitive issues actually cleared. I was just fascinated with it, and I stopped doing the work I was doing because it felt like the most important question in my life at that point was, am I just the outlier for whom this is good therapy, or could this help other people with these issues?”(P9).

Theme 2: Transforming lives

Client participants described their experiences with neurofeedback as life-changing.

“The military introduced me to this, helping me with everything that went on in Afghanistan, at the same time it’s helping me with cancer. I’ve come a long way... you wouldn’t believe the difference with me sitting here now, it’s night and day.”(C2).

“My emotional stability and memory are a lot better... before I was getting really overwhelmed with two or three thoughts in my head, and I would get frustrated and forget, but now its just occasionally. My quality of life is definitely better.”(C3).

“With neurofeedback, there was a clear change. In 10 sessions, the depression was gone, and I was my cheerful self again. Over the next few months, I wasn’t seeing the cognitive symptoms anymore.”(C4).

“I’m feeling different now... I now wake up before the alarm feeling ready to go.”(C4).

Provider participants also described the remarkable changes they or others noted in cancer survivors.

“I haven’t seen a cancer survivor who hasn’t seen improvement in their symptoms. I’ve seen a couple of people whose faces were so different at the end of the first session, that if I had taken a photograph at the beginning and the end, anyone could have seen the difference, it was that striking. It was just a lifting of a flat affect and a brightness of the eyes.”(P5).

“When they try neurofeedback, they’re just amazed, so impressed, and they notice improvements in their memory even though they weren’t referred for chemofog.” (P7).

“I found that protocol extremely helpful for cancer survivors. They felt much brighter, more vital, much more energy, felt rested and relaxed, and so less disturbed.”(P9).

“I’ve worked with people who have undergone chemotherapy... I can tell you that people have said not only does their brain fog clear but they feel their cognitive function is even better than before.”(P10).

“She was lifted up after the first neurofeedback session, and her acupuncturist called me and asked “what is this that she’s doing?” He witnessed this huge shift in her.”(P1).

Theme 3: Regaining control

Participants described neurofeedback as something empowering cancer survivors could do for themselves to manage symptoms and regain control of their lives.

Table 3: Perceived benefits and challenges of neurofeedback for cancer survivors

Themes	Subthemes	Perceived by
Perceived benefits		
Paying it forward	Compelled to help others	Neurofeedback providers
	Incorporating neurofeedback into practice	Neurofeedback providers
	Career shifts	Neurofeedback providers
Transforming lives	Life changing experience	Cancer survivor clients
	Seeing the difference	Neurofeedback providers
Regaining control	Feeling empowered	Both
	In control again	Both
Brain healing itself	Healing process	Neurofeedback providers
	Brain knows what to do	Neurofeedback providers
Comforting experience	Calming, comforting and relaxing	Cancer survivor clients
Perceived challenges		
Accessibility	Costs	Both
	Should be standard care	Cancer survivor clients
	Lack of awareness	Both
Failure to respond	Nonresponders	Both
	Interference mechanisms	Both

“During my sessions, I wrote a note that said ‘feeling parts of me are coming back’ and I also wrote something about feeling empowered, that I was hopeful... as a physician it was very debilitating.”(C3).

“My diagnosis turned everything upside down... I felt like I was fighting for my life, so I was seeking out something on my own terms for healing... I look back on neurofeedback as an important ingredient of the overall wellness level I’ve reached... it was something I was resourcing with my own will like I’m doing this, I’m choosing this treatment.”(C5).

“I’m in control again. My mental clarity is almost back to normal, I think it’s clearer.”(C3).

Theme 4: Brain healing itself

Neurofeedback was seen by participants as a therapy that allowed the brain to heal itself.

“The fact that it allows your brain to fix itself, is really something unique. Everybody’s central nervous system is different, some people need two sessions, some need 10, and your brain takes out of it what it needs... You’re not trying to fix anything, just providing information to let it fix itself... like an invitation for the brain to change.”(P2).

“The brain will do it in the way that is right for that person... it’s going to do this process in the way that’s right for you... then we get to discover what that is.”(P8).

Theme 5: Comforting experience

Client participants described neurofeedback as relaxing, calming, or comforting.

“I liked going in and sitting in the chair and getting hooked up. It felt like adult swaddling...it made me feel confident I was doing something that was going to help me. It was a place for me to stop freaking out. It was traumatic what I went through, so being in her cozy office, sitting in this comfortable chair, all hooked up, my only job was to let go and let the thing work...that relaxed me... it was just like a little vacation from what my brain was doing otherwise.”(C5).

“I feel really calm after treatments... I want to go straight home and have a quiet time because then I really get the benefit.”(C3).

“Things were changing for me... I was able to relax more, after being so tight all the time. It relaxes you, whatever it does for cancer patients, for me, it makes you relax, it comforts you.”(C2).

Theme 6: Accessibility

Many participants commented on the cost of the neurofeedback sessions and barriers to access, and the wish that it could be available and affordable for anyone who could benefit from the therapy.

“It’s all privately paid... this is the biggest difficulty, even though it works, they always have to cover it themselves.”(P9).

“I wish it were more easily accessible for people, and more affordable because it helps traumatized brains... think about all the people who could use that. I wish it would be more part of healthcare.”(C5).

“I really recommend it... because patients are suffering from chemo brain... and it should be part of standard care, right at the hospital, and I’m glad I learned about it.”(C3).

Another aspect of accessibility is lack of knowledge among health-care professionals and patients that neurofeedback is an option for management of symptoms in cancer survivors.

“It’s not well known, and unfortunately I don’t think cancer survivors are aware of how much it could help them and improve their quality of life.”(C1).

“It works. The challenge is to convince oncologists and physicians that it’s safe.”(P2).

“It’s so good with chemo brain. It’s upsetting to me I can’t attract more people.”(P8).

“The potential is so great, why aren’t more people aware of it? Neurofeedback is more accepted in other countries... here people are more used to taking drugs... I don’t think we’re as ahead as many other countries.”(P10).

Theme 7: Failure to respond

Participants noted that particular types of neurofeedback

do not work or work as well for everyone, but another type might be helpful.

“Some people respond very quickly, some by the end of 20 sessions, so I’m curious whether the two people who didn’t respond were just slow responders, and if 30 sessions would have improved them?”(P5).

“I tried directed neurofeedback which involves diagnosing what’s wrong with the brain and developing individual protocols. I would get little hints of improvement, and then I could never reproduce them again... then I found somebody who used Zengar and in three sessions my sleep was returning to normal.”(C4).

As well, some participants suggested mechanisms that may interfere with neurofeedback.

“People who are young and healthy tend to respond more quickly and robustly than people who are frail or older.”(P12).

“I feel like survivors’ systems are so dysregulated it takes coming in weekly if not twice a week, to balance things out again... a lot of times I get people, who are already on antidepressants, and all these different drugs, and I think that can inhibit the changes... things don’t shift as quickly as somebody that hasn’t had all the trauma and isn’t on medication... that’s not to say that people can’t still improve.”(P1).

“Where I have clients stop training, is when they are embedded in the medical system, and their GP/specialist does not understand and works against the process, often increasing medication when it should be reduced. These clients will stop coming.” (P12).

Discussion

This qualitative study provides new insights into the experiences of neurofeedback providers and clients with cancer. Most published neurofeedback studies use quantitative or case study approaches which may include anecdotal evidence. Our study is among the first to explore experiences of neurofeedback providers and clients using a qualitative research design and the first to explore experiences with cancer survivors.

Five of seven emerging themes in our study related to benefits of neurofeedback. Our client participants described neurofeedback as a comforting experience, related to the relaxing effects of the therapy. This is not surprising as results of neurofeedback are often described in the literature as being similar to those derived from meditation, as both are mind-body therapies with a calming effect.^[4] Many neurofeedback providers in the community have another primary occupation and use neurofeedback within their practices when appropriate. Many practitioners in our study who described paying it forward had experienced their

own personal healing experiences with neurofeedback or witnessed dramatic changes in family members, for issues such as cancer and traumatic brain injury that influenced them to add neurofeedback services within their clinical practices. These results are similar to those described by participants in a grounded theory study who described taking the “leap” into neurofeedback because results were so compelling they couldn’t walk away.^[22] Participants in both studies recognized neurofeedback doesn’t fix the brain but prompts learning of self-regulation, and the brain healing itself. This ability is due to the principle of neuroplasticity, which is the ability of the nervous system to respond to stimuli (such as neurofeedback) and reorganize its structure, function, and connections.^[23] This principle also underlies the sustained effects of neurofeedback,^[24] which is an advantage of neurofeedback therapy over medication therapies which may need to be continued over a patient’s lifetime, whereas neurofeedback can usually be discontinued after 20–40 sessions.

Although practitioners may note changes in clients following neurofeedback sessions, it is important to understand whether these changes are positively impacting their daily lives and functioning. Although participants described the positive effect of neurofeedback on their symptoms, it was the impact on quality of life that came through strongest in their narratives. Both providers and clients in our study described results with cancer survivors as transforming lives. Similarly, participants who completed interviews following neurofeedback treatments for anxiety reported “an exponential improvement,” and ability to “start doing things without fear of something happening.”^[25] Both providers and clients in our study credited neurofeedback with helping cancer survivors in regaining control of their lives, and in managing their symptoms. Similarly, in the anxiety study, one participant noted that following neurofeedback she rarely has panic attacks, and when she does she is better able to control them.^[25] Following biofeedback and neurofeedback training, elite athletes also described feeling more “in control” when competing.^[26]

Two themes emerged related to challenges of using neurofeedback with cancer survivors. Neurofeedback inefficacy or failure to respond has been documented with a variety of neurofeedback protocols and populations.^[27] With targeted neurofeedback protocols, treatment inefficacy may lie in need to adapt protocols to individuals; however, with generalized approaches, other confounders such as concurrent medication use must be considered.^[14] Research suggests nutrition, allergies, toxins, and infections could affect neurofeedback outcomes, as well as client factors such as motivation, culture, and family system.^[22] Our

participants reported aging, diet, inflammation, and medication use may slow or reduce an individual's response to neurofeedback. Research is needed to confirm these observations, which are particularly relevant to cancer survivors.

Our participants suggested accessibility to neurofeedback is limited by lack of awareness and pushback from health-care providers. Although neurofeedback is used globally, it has not been widely accepted by the traditional medical community or general public largely due to lack of rigorous scientific research demonstrating effectiveness.^[28] The medical field is seen to support a culture in which patients expect to receive medication to fix their problems, or actively discouraging patients from trying complementary therapies.^[22] Neurofeedback can be expensive and is covered by few insurance companies,^[5,28] and may not be affordable for cancer survivors experiencing financial hardship due to out-of-pocket expenses or loss of salary.^[29] Most neurofeedback providers are psychologists and research has tended to focus on mental health applications; thus more research is needed with cancer survivors.

Strengths and limitations

We employed several strategies to establish the dependability and credibility of our research findings including clear descriptions of research design and methods, focused data immersion activities including transcription accuracy, and independent coding procedures. Analytic rigor was also strengthened by including the voice of participants through verbatim quotes, and triangulation of data with the research literature.

As themes were drawn mainly from neurofeedback provider's point of view, the practitioner role may be overemphasized and the importance of client factors underemphasized. Another limitation is that the vast majority of neurofeedback providers (83%) and all cancer survivor participants in this study were female. Thus, the female perspective is overemphasized. Future qualitative studies with cancer survivors including males might provide better insight into their experiences with neurofeedback and expand on themes highlighted in this study.

Individual participants may have had particularly positive feelings toward neurofeedback which motivated them to participate; however, for the most part, participants provided balanced perspectives of the benefits and challenges. As data consisted of subjective experiences, there was potential for recall bias or failure to disclose, however, participants' tone and responses reflected a genuine willingness to share both their positive and negative experiences.

Although measures were taken to reduce bias and increase credibility, qualitative research involves data gathering and analysis performed and interpreted by the

researcher; thus, there is a risk of researcher bias. Strategies employed to establish confirmability included a detailed audit trail, peer debriefing, and care to ensure findings emerged directly from the data.

Implications for practice and research

Although neurofeedback therapy is well established in clinical practice in the fields of psychology and psychiatry, there are few studies reporting on its use in cancer survivors. Although there is little direct evidence generated with cancer survivors, there is evidence from studies with other patient populations experiencing similar debilitating symptoms.^[14,24,30-32] Thus, clinicians in oncology and primary care settings should be aware of this therapy and its potential to help cancer survivors with persistent symptoms that are not successfully managed by conventional therapies. Academic and clinical researchers must engage in rigorous trials to establish efficacy and support the establishment of best-practice recommendations for the use of neurofeedback with cancer survivors.

Conclusion

Although individuals may experience neurofeedback differently, participants in our small sample shared similar experiences of symptom reduction and healing. Interview results are encouraging and support use of neurofeedback to improve quality of life for cancer survivors experiencing long-term symptoms; however, more research is needed to determine which neurofeedback systems and protocols are most effective for this population. Challenges could be addressed through research seeking to further understand underlying mechanisms.

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Conflicts of interest

There are no conflicts of interest.

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