

Seizure response dogs: Evaluation of a formal training program

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ABSTRACT

Evidence supporting seizure-related behaviors in dogs is emerging. The methods of seizure response dog (SRD) training programs are unstudied. A standardized survey was retrospectively applied to graduates of a large SRD program. Subjective changes in quality of life (QOL) parameters were explored. Data were captured on animal characteristics, training methods, response and alerting behaviors, effects on seizure frequency, and accuracy of epilepsy diagnosis. Twenty-two patients (88%) participated (median age = 34, range = 12–66, 73% female). Most had childhood-onset epilepsy (87%) that was refractory with averages of 36 seizures/month and 4.8 medications failed. All had neurologist-confirmed epilepsy, most being symptomatic partial (64%). SRD behaviors were reliable, including emergency response system activation in 27%. All reported SRD-related QOL improvements (major 82%, moderate 18%) across multiple parameters. Spontaneous alerting behavior developed in 59%. That SRD programs may select genuine epilepsy patients, instill valuable assistance skills, and generate meaningful QOL improvements supports further seizure dog research.

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1. Introduction

Evidence supporting seizure-related behaviors in dog companions of humans with epilepsy is emerging [1–4]. Although spontaneous development of behaviors is common in dogs living with children and adults with epilepsy [1,5,6], the training of such skills is less studied. Seizure response dog (SRD) behaviors follow clinical seizure onset and may include assistance skills. SRD training organizations are increasing, but their methods and outcomes are unstudied. Placement of SRDs with individuals having nonepileptic seizures has raised concerns regarding diagnostic accuracy [7,8].

Despite available therapies, up to 30% of persons with epilepsy (some 20 million people worldwide) have intractable seizures [9]. The bulk of epilepsy morbidity stems from widespread limitations placed on all aspects of independent living and quality of life (QOL) [10,11], important targets of innovative epilepsy management strategies. We completed a qualitative, retrospective review of a large SRD training program, hypothesizing that valuable assistance skills and enhanced QOL were being provided to *bona fide* patients with epilepsy.

2. Methods

2.1. SRD training program

The Lions Club Foundation Dog Guides (LCFDG, www.dogguides.com) has >25 years of experience, training >1200 assistance animals for people with disabilities. A seizure assistance dog program was initiated in 2001. All program

procedures were reviewed through interviews with trainers and executive management, including recruitment and selection, confirmation of epilepsy diagnosis, financial costs, and stages of training and follow-up. Accuracy of information provided was validated through subsequent interviews with program graduates.

Consistent with previous definitions [1,4], an SRD demonstrates specific behaviors after the clinical onset of seizure activity. Animals demonstrating premonitory behavior prior to individual or observer awareness of impending seizure are seizure alert dogs (SADs). As response behaviors were the intention of the LCFDGD seizure dog program, animals here are subsequently referred to as SRDs.

2.2. Patient selection and evaluation

All LCFDGD seizure dog program graduates (2001–2006) were approached for enrollment. Following initial contact by LCFDGD personnel to confirm willingness to provide personal information, telephone contact was made and informed consent was obtained. For individuals with intellectual impairment, parental or primary caregiver informed consent was obtained in addition to individual consent/assent. Research ethics board approval was obtained.

A comprehensive, standardized survey was developed and administered by the same investigator via personal interview (Table 1). Demographic variables included age (pediatric <18 years); education (<high school/high school/postsecondary/professional); employment (student/part-time/full-time/unemployed/retired); living environment (number of people, urban/rural, home/apartment); and marital status (single/married/divorced/separated). Seizure terminology and epilepsy classifications were in accordance with International League Against Epilepsy (ILAE) definitions [12]. Data were captured from patients, family members, neurologists, and program staff on patient medical history, animal details, training methods, SRD behaviors and effectiveness, spontaneous alerting ability, and effects on seizure frequency and QOL. Details of response and alerting behavior variables are published elsewhere [1]. The survey encompassed both open- and close-ended questions. Likert-scaled scoring of all qualitative variables was performed: (1) very poor, (2) somewhat poor, (3) neutral, (4) somewhat favourable, (5) very favourable. Each variable was hence semiquantitated, allowing mean scores to be calculated for each variable (maximum score of 5).

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Table 1
SRD Program Graduate Survey^a

| Category | Data collected |
|--------------------------|--|
| Demographics | Age, DOB, gender, education, home type and location, environment, marital status |
| Epilepsy/medical history | Age at onset, years with epilepsy Seizure: types, frequency, duration, semiology Medical treatment: AEDs (current, previous) Alternative treatments: vagus nerve stimulation, ketogenic diet, surgery, other Past medical history, family history of epilepsy Neurologist diagnosing/managing epilepsy |
| Seizure dog program | Where did you first hear about seizure dogs? Did you ever receive unsolicited contact from a seizure dog operation? How would you rate your overall experience with the LFCFG SRD training program: How would you rate each of the following components of the LCFC program: Initial contact and selection, on-site training, home visits, long-term follow-up, staff professionalism and qualifications |
| Response behavior | Specific trained behavior(s) At which point does the dog first demonstrate its behavior? How often is a seizure missed? Any explanations? How long does the response behavior continue? Has the response behavior(s) changed? Any other UNTRAINED behaviors? Behavior checklist: whining, pacing, growling, barking, staring, licking, wagging tail, etc. Does your animal appear anxious during a seizure? Any aggressive behavior or harm? Change in seizures since SRD (frequency, severity, duration)? |
| Alerting behavior | Anticipation behavior observed? Describe behaviors. Differences from response behaviors. Time to develop, number of seizures observed. Accuracy? Missed events? Anticipation time. Did this change over time? Reliability. Do you rely on alerting to manage your seizures? How? |
| Quality of life | Overall quality of life change since SRD? QOL variables: Mood or feelings of depression Feelings of anxiety Interpersonal relationships—family and friends Interpersonal relationships—strangers Work/education Self-confidence Independence Safety and security Other ways owning an SRD has affected your life? Treated differently by others with your SRD? Challenges your SRD added to your life? Trouble accessing public places with your SRD? Would you recommend an SRD to someone with epilepsy? |

^a All program participants and their immediate family members and caregivers were asked a standardized series of both open- and close-ended questions via personal interview.

Participants were requested to provide retrospective estimates of changes in QOL parameters between the present and the period immediately prior to SRD pairing. As summarized in Table 1, QOL parameters were extrapolated from validated measures of QOL in epilepsy [13], including issues of interpersonal relationships, work/education, independence, self-confidence, safety and security, and psychiatric comorbidities.

Group comparisons employed Fisher's exact test using SPSS 13.0.

3. Results

3.1. SRD program patient selection

Comprehensive written applications included:

1. SRD application: Personal demographics, living environments, occupation/school, family/supports, lifestyle/physical activity, seizure/epilepsy history, medical history, physical abilities/limitations, desired SRD skills and expectations.
2. Character references [2].
3. Employer/educator/landlord: Approvals to accommodate training and placement.
4. Home assessment: Surveys home, neighborhood, working/school environments, and lifestyle factors (e.g., modes of transportation).

5. Neurologist evaluation: Consented epilepsy history from treating neurologist (diagnosis, seizure types/semiology, treatments, disabilities, capacities). (A history of pseudoseizures was specifically sought and constituted an absolute exclusion to program enrollment.)

A minimum developmental age of 12 years was required to ensure adequate maturity for SRD training and ownership. Minimum seizure frequency was ≥ 1 seizure/month for 6 months. SRDs were offered to successful applicants from across Canada without cost. Following basic education in assistance animal ownership and training, individuals entered a 4-week training period, living in on-site dormitories with a family member. Training for 10–14 hours per day, 6 days per week, ensued with classes of six individuals and two trainers. Pairing with an individual SRD was achieved within 2–3 days. Once paired, the SRD and individual remained in constant contact 24 hours a day. Animal behaviors were modeled on individual patient seizure semiology. This was initiated by training staff with seizures occurring during on-site training, but continued with the assistance of the family following discharge home. Although the actual number of seizures required to achieve successful response behavior was not documented, patients reported an average interval of 2 weeks and none longer than 1 month.

3.2. Patient population

Twenty-two of 25 patients participated (88%) and their data are summarized in Table 2. All subsequently reported proportions do not include the three patients who were lost to follow-up (all >2 years from graduation). Median age was 34 years (range: 12–66) and 73% were female. The pediatric subgroup included four patients (18%, 3 female). Adults tended to be unmarried (14/18, 78%) despite a median age of 38, and 22% lived alone. Adults were often unemployed (13/18, 72%), with only 2 (11%) holding full-time jobs. Education varied from less than high school in 4 (22%), to high school diploma in 8 (44%), to postsecondary or higher in 6 (33%). All adolescents were full-time students in normal classrooms and living at home. Most adults lived in houses (10/18, 56%); the remainder lived in apartments and usually in rural environments (73%). The majority had lived with a dog at some point in the past (17/22, 77%).

All participants had neurologist-confirmed epilepsy diagnoses. Seizure onset occurred at a median of 7 years (range: 0.2–63), and before age 21 in 19 of 22 (86%). Median duration of epilepsy

was 22 years (range: 5–63). Eleven (50%) participants had symptomatic etiologies, including malformations of brain development (3), bacterial meningitis (2), mesial temporal lobe sclerosis (2), benign neoplasms (2), and hemorrhagic stroke (1). Of the remaining 11, most (9) had idiopathic (otherwise neurologically normal) complex partial, secondarily generalized epilepsy; with others including cryptogenic (neurologically abnormal without specific diagnosis) etiologies (1) and idiopathic primary generalized epilepsy (1) were uncommon. Seizures were refractory, with means of 36 seizures/month (range: 1–140) and 4.8 anticonvulsant medications failed (range: 2–12). Median seizure duration was 2.7 minutes (range: 0.5–140), and status epilepticus had occurred at least once in 3 of 22 participants (14%). At least one additional nonpharmacological treatment (surgery, vagal nerve stimulation, or ketogenic diet) had been attempted in 16 of 22 participants (73%).

Awareness of the LCFCDG program usually occurred through mass media (TV/Internet, 11/22, 50%); physician referral was rare (1, 5%). None had received unsolicited contact from an SRD organization. The overall experience with the SRD program was rated very highly with a mean score of 4.8. Favourable evaluations extended across all elements including contact and selection (5.0), on-site training (4.6), staff professionalism/qualifications (5.0), home visitations (5.0), and long-term follow-up (4.9). Two criticisms were reported by three or more participants: (1) Overlap of training period with other service animal programs was inefficient, and (2) program intensity (hours per day) was tiring.

Table 2
Patient demographics

| Patient | Age/ gender | Age at seizure onset (years) | Duration of epilepsy (years) | Epilepsy type ^a | Monthly seizure frequency | Total no. of meds |
|---------|----------------|---------------------------------------|------------------------------------|-------------------------------|---------------------------------|-------------------------|
| 1 | 17/F | 0.25 | 17 | Idio CP/ SG | 12 | 8 |
| 2 | 72/M | 63 | 9 | Idio CP/ SG | 2 | 3 |
| 3 | 22/F | 7 | 15 | Idio CP/ SG | 140 | 11 |
| 4 | 31/M | 21 | 10 | Sympto CP/SG | 16 | 5 |
| 5 | 43/F | 3 | 40 | Crypto CP/SG | 2 | 6 |
| 6 | 27/F | 12 | 15 | Idio CP/ SG | 4 | 1 |
| 7 | 17/F | 7 | 10 | Sympto CP/SG | 4 | 7 |
| 8 | 23/M | 0 | 23 | Sympto CP/SG | 30 | 3 |
| 9 | 33/F | 0 | 33 | Idio CP/ SG | 30 | 1 |
| 10 | 15/M | 3 | 12 | Sympto CP/SG | 90 | 7 |
| 11 | 28/F | 3 | 25 | Sympto CP/SG | 14 | 12 |
| 12 | 37/F | 17 | 20 | Idio CP/ SG | 8 | 4 |
| 13 | 62/F | 13 | 49 | Idio CP/ SG | 1 | 4 |
| 14 | 52/F | 14 | 38 | Sympto CP/SG | 2 | 7 |
| 15 | 54/F | 30 | 24 | Sympto SP | 28 | 3 |
| 16 | 66/M | 3 | 63 | Sympto CP/SG | 2 | 2 |
| 17 | 12/F | 1.5 | 10.5 | Idio CP/ SG | 1 | 3 |
| 18 | 42/M | 12 | 30 | Idio CP/ SG | 20 | 5 |
| 19 | 35/F | 5 | 30 | Sympto CP/SG | 115 | 3 |
| 20 | 28/F | 7 | 20 | Sympto CP/SG | 100 | 2 |
| 21 | 45/F | 19 | 26 | Sympto CP/SG | 60 | 3 |
| 22 | 39/F | 34 | 5 | Idio PG | 100 | 6 |

^a Idio, idiopathic; Crypto, cryptogenic; Sympto, symptomatic; SP, simple partial; CP, complex partial; SG, secondarily generalized; PG, primary generalized.

3.3. SRD training program: assistance animals

Animals were selected from a long-standing institutional breeding program engineered toward favourable assistance work characteristics while minimizing recessive disease traits in accordance with established guidelines. Puppies were placed in foster homes from 8 weeks for socialization and basic skills training. After returning to LCFCDG at 12–14 months, animals underwent behavioral analysis and training to determine suitability for seizure assistance work. The standardized selection criteria used to select animals included disposition, control, distraction, responsiveness to human command, initiative, chase instinct, attention/sensitivity to handler, prolonged concentration, confidence, tolerance of animals and children, energy/hyperactivity, attitude adaptability, dominance/self-interest, crate/kennel livability, and complete veterinary evaluation. During the study period, 32 animals were evaluated to achieve the 22 SRDs trained, for a “placement rate” of 69%.

Suitable animals entered 2–3 months of obedience training during which preliminary assistance skills were instilled through an operant conditioning method. Animals with SRD potential then received response training, including specific barks on command, fetching of assistive devices (e.g., telephone), and activation of emergency response systems. Multiple animals were trained to assist specific individuals based on event semiology and desired response behaviors, facilitating immediate pairing with individuals entering the program.

3.4. Seizure response dogs

SRDs were placed at a median age of 1.5 years. At the time of study, all dogs were living and at a median age of 4.8 years (range: 2–8). Labrador retrievers were most common (17/22, 77%) including black (11), yellow (3), and chocolate (3), in addition to standard poodle (2), border terrier (1), toy poodle (1), and cocker spaniel (1). Animal genders were evenly distributed (55% female) and most dogs were large (mean weight: 28 kg).

3.5. Seizure response behaviors

SRD behaviors were reported as reliable, beginning within seconds of clinical seizure onset in all cases. Several described delays in behaviors in certain circumstances including nocturnal events (3) and excessively noisy places (2). Five individuals described imperfect reliability including missed single events (3) and <50% sensitivity for “mild,” partial events (2). No false-positive responses were reported. Behaviors terminated on a return to normal or the arrival of assistance. Behaviors always included trained responses, though additional behaviors developed in some (7/22, 32%). The most common behavior was barking/whining (21/22, 95%) that was distinct from the animal’s normal vocalizations. Licking behavior (11/22, 50%) and close physical attachment (7/22, 32%) were common. Although potential signs of event-related animal anxiety (whimpering, anxious pacing, tail between the legs) were described (9/22, 41%), no adverse events or harm occurred.

Successful, reliable activation of emergency notification devices was reported in all SRDs trained to perform this skill (6/22, 27%), with no missed or false activations reported. One animal would bring the cordless phone, another would roll its companion (with a history of aspiration pneumonia) on the side, and a third would turn off the electrical wheelchair (several accidents had occurred during seizures).

3.6. Seizure alerting behavior

Spontaneous development of seizure alerting behavior was described by 13 patients (59%). Onset was often within 4 weeks (46%), the remainder evolving over months. Anticipation behaviors were varied and distinct from response behaviors. Intense staring was most common (6/13, 46%) but never reported as response behavior. Other alerting behaviors included close attachment (5), sniffing (3), barking/whimpering (3), jumping (3), and licking (2). Five (38%) alerting animals physically prevented their owners from leaving the house prior to seizures. Anticipation was reported to occur an average of 31 minutes (range: 0.5–180) prior to clinical seizure onset. The anticipation interval increased over time in 6 of 13 participants (42%). Anticipation behaviors were reported as reliable in both character and timing, and most reported no missed events (11/13, 85%). Alerting abilities directly influenced 8 (62%) patients’ management of their epilepsy, including notification of family/caregivers, assumption of safe positions/locations, and, in one case, taking abortive anticonvulsant medication.

3.7. Seizure frequency

When asked if SRD placement had affected seizure frequency or severity, 10 of 22 (45%) individuals responded affirmatively. Improvements included decreased frequency (6), intensity/severity (5), and duration (3). None could attribute this benefit to another change in management. Improved seizure parameters were more commonly reported by those with alerting animals (69% vs 11%, $P = 0.02$).

3.8. Quality of life

All patients reported improved overall QOL with their SRD (major 82%, moderate 18%; mean score = 4.82). Benefits were distributed across multiple QOL parameters (Fig. 1), summarized here with direct patient quotations.

A. Interpersonal relationships (family/friends). Beneficial differences in social and interpersonal interactions were reported in 16 of 22 participants (73%) with a mean score of 4.14. “The dog has become part of family and has benefited us all.” “My

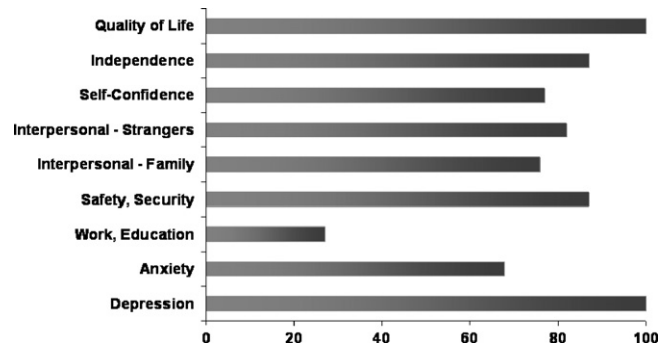


Fig. 1. Subjective changes in quality of life with SRD. With QOL parameters listed on the y axis, the proportions (%) of participants reporting increased QOL (either improved, scaled score = 4, or much improved, scaled score = 5) for each since receiving their SRD are illustrated.

SRD has improved my relationship and communication with my partner who always worried about me.” “My family shares the confidence and security I do with my SRD and worry about me less.”

B. Interpersonal relationships (strangers). Most (18/22, 82%) described positive differences in treatment by others. Sixteen (73%) described direct social benefits with the SRD facilitating new interpersonal relationships. “My dog acts like a magnet and people want to meet us.” “It is a great icebreaker to meet new people.” “She attracts people in such a positive way; it is so much easier to make friends.”

C. Self-confidence. Improvements in self-confidence were reported in 17 of 22 participants (77%) with a mean score of 4.48. “My SRD allows me to trust more in myself and I am less afraid to leave my apartment.” “I have great pride in my SRD and the confidence they give me has allowed more freedom in what I feel I can do.” “He brought me out of my shell.”

D. Work/education. Career-related benefits were reported in only 6 of 22 participants (27%) though a mean score of 3.73 suggested benefit. “I am more accepted at my school and have been transformed from an outcast last year to being named the queen of the prom!”

E. Safety/security. Improved feelings of security were reported by 19 of 22 participants (87%). “I am no longer afraid of going out and being taken advantage of.” “He is my security blanket.” “I didn’t have any quality of life before my SRD. I was locked up in my apartment for more than 2 years, too afraid and embarrassed to interact with other people, but I have overcome this thanks to her.”

F. Mood/depression. Improvements in mood were reported by all (mean score = 4.18). “I didn’t care about life before my SRD, I just went through the motions. But he was like a light turning on and that they cared for me while I had the responsibility to care for her changed my life.” “I am a much happier person and no longer take medication for depression.” “My SRD gives me a reason to get out of bed in the morning.”

G. Anxiety. Symptoms were subjectively improved in 15 of 22 participants (68%) with a mean score of 4.18. “The dog helps reduce my agoraphobia and boosts my confidence.” “I was always nervous but I hardly ever worry since getting my SRD.” “Since I got my SRD, other people feel less anxious around me and seem to understand my condition better.”

H. Independence. Enhanced independence was commonly reported (19 of 22, 87%). “I used to rely on others to help me but now I go anywhere with my SRD and feel safe and confident.” “I was always told not to go out alone because I had many accidents with my wheelchair but now my SRD helps me and I don’t hesitate to go anywhere.” “My SRD has empow-

ered me; I am motivated to do more and feel like I can do anything.” “Having an SRD has changed people’s perception of me. It has legitimized my condition, helped people understand epilepsy, and reduced the stigma suffered by most people.”

Prior to their enrollment in the SRD program, most (19/22, 86%) described their attitudes towards dogs as “favourable” though responses of “neutral” and “unfavourable” were also recorded. Most (17/22, 77%) had lived with a dog previously, and 63% (14/22) were already living with another dog though none reported conflict between animals. Many described having to make “substantial lifestyle changes” to accommodate their SRD (63%) and estimated mean additional costs of \$90.00/month (range: \$25–250).

Negative SRD effects on QOL were uncommon. Twelve (55%) described occasional difficulty entering public facilities with their SRDs. These were usually overcome with education and official licensing though two required legal intervention. Additional challenges of SRD ownership included financial and time considerations (2) and veterinary expenses (1), though all still rated their QOL as much improved. All participants strongly recommended an SRD to others with epilepsy.

4. Discussion

We report the first formal evaluation of an SRD training program. Though preliminary, subjective, uncontrolled, and retrospective, our data suggest that significant benefits may be conferred to individuals with refractory epilepsy. The scope and magnitude of potential effects on QOL merit further study.

Recent reports have raised the issue of diagnostic accuracy in seizure dog use [7,8], calling into question the validity of seizure dogs in general because of their use by individuals with nonepileptic seizures. However, as summarized elsewhere [14], the weight of this evidence is small compared with other studies of seizure dogs and does not supersede the substantial potential benefits to be gained. A substantial selection bias is also acknowledged as these individuals sought out their own enrollment in the training program. The current study provides preliminary evidence that SRD training programs can employ valid means to ensure diagnostic accuracy. As previous studies have suggested [15], neurologist-validated epilepsy diagnoses do not exclude the possibility of individuals with nonepileptic seizures being included. Rigorous diagnostic methods should be required of all SRD organizations, and prospective studies with increased participation of neurologists and epileptologists will improve selection methods.

Prominent among reported QOL benefits were effects on interpersonal relationships with strangers. Stigmatization of persons with epilepsy is underestimated and socially devastating and remains a major barrier to societal integration [16–18]. A novel study demonstrated that children with neurological disabilities received greater social attention and interaction from strangers when accompanied by an assistance animal [19]. Although our study did not directly evaluate the issue of stigma, the results suggest such simple but powerful benefits may be extended to people with epilepsy via an SRD. Additional epilepsy QOL issues possibly improved with SRD include decreased self-esteem and self-control [20], activities of daily living, and perceived self-efficacy [21].

Both anxiety disorders [22,23] and depression [24] commonly complicate QOL in chronic epilepsy, although most respondents here reported decreases in both with their SRD. This finding is consistent with evidence that depression accompanying chronic medical illness is reduced by animal companionship [25,26]. This raises the question of whether the SRD benefits we report relate to seizure assistance abilities or just animal companionship. That most people here had owned other dogs previously would suggest

otherwise, but prospective, case-control studies are required to accurately assign the QOL benefits to SRD specifically. The largest study of seizure-related behaviors in dogs [1] reported similar differences in QOL scores between families with and without dogs (particularly seizure-sensitive animals).

Comorbid conditions in epilepsy were recently identified as a research benchmark and target of new therapeutic approaches by the NINDS. Examples like depression and anxiety are well described and current treatment options exist. However, these treatments usually target only a single problem, involve complicated medical therapies with potential side effects, and may be incompletely effective. In contrast, the results described here suggest that SRDs may provide a more comprehensive therapeutic intervention, potentially encompassing a more complete spectrum of epilepsy QOL comorbidity with a single intervention.

This preliminary, retrospective study carries significant limitations. Substantial reporting bias is inherent in the required retrospective approach as some patients may confer unfounded benefits on the animal that has become an important part of their life. This report examined only a single SRD program, and although their methods appear validated, it would be premature to extend the same credit to other organizations. Potential limitations of this and other SRD training programs are unstudied. Instead, those treating individuals interested in obtaining an SRD should be willing to assist them in a critical evaluation of the program issues identified here.

Future directions for seizure dog research include prospective, case-control studies using standardized outcome measures to better define QOL benefits. Validating and exploring anticipation abilities will require larger efforts but are of great therapeutic and scientific interest.

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