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Seizure detection watch improves quality of life for adolescents and their families☆

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ABSTRACT

This article reports the findings from a pilot study conducted to explore the impact of using a wearable seizure detection device on quality of life for 10 adolescents with epilepsy and their parents. Quality of life in Epilepsy for Adolescent (QOLIE AD-48) and the Parent Response to Child Illness (PRCI) Scale were compared at study onset and 6 months after using the SmartWatch seizure detection device. At the conclusion of the study, a qualitative interview explored the adolescent's and parent's experiences with using the device. In this sample, the wearable seizure detection device was well accepted as a means to increase seizure safety for both adolescents and their caregivers. In addition, adolescents and parents felt more secure with the adolescent increasing independent activities when wearing the watch. Barriers to use included technical difficulties, such as false alarms, and the burden of adding another aspect to their epilepsy care. While these data cannot be generalized to all populations, findings suggest that further research with wearable seizure detection devices is warranted. Considering current sudden unexplained death from epilepsy (SUDEP) prevention guidelines that encourage seizure monitoring, especially during sleep, the wearable seizure detection device may provide adequate seizure monitoring without the negative consequences to the adolescent's developing autonomy.

1. Introduction

Epilepsy is one of the most common neurological problems in adolescence. Over 3 million people have an active diagnosis of epilepsy in the United States, roughly 470,000 of those are children under the age of 17 [1]. Poor quality of life (QOL) and poor health outcomes have been documented in adolescents living with epilepsy [2–5]. Quality of life in adolescents with epilepsy (AWE) is defined by varying domains including psychological, social, and school performance. The nature of epilepsy, including the unpredictability and effects of seizures and medications, coexistent mood problems, and anxiety about seizure safety contributes to poor QOL for AWE and their families. In addition, the factors contributing to poor QOL also have a direct impact on the adolescent's achievement of normal developmental milestones. Additional research is needed to look more specifically at drivers of QOL in AWE, along with specific interventions to improve these outcomes. In this study, we evaluated the impact of the SmartWatch detection and notification system (www.smart-monitor.com) on QOL for AWE and family. To date, the implications of a seizure detection device and notification of parent/caregiver on QOL has not been evaluated. Seizure detection devices and notification systems have the potential to impact QOL for AWE by helping to normalize adolescent development.

2. Background

Adolescence is a developmental phase characterized by changes to physical maturity, emotional development, and other life changing measures. During this rapid change in development, adolescents may experience concerns related to sexuality, mood changes, substance use, peer relationships, career choices, and participation in behaviors that either promote or impinge upon their health [6]. When a chronic illness, such as epilepsy, overlaps with the healthcare needs of an otherwise normally developing adolescent, concerns pertaining to management of their condition becomes challenging. Concerns such as medication compliance, lifestyle adjustments, and other social situations become anxiety provoking for AWE and may interfere with normal developmental milestones, such as achieving independence. The rapid changes associated with adolescent development, in association with the complex management of epilepsy, often results in compromised QOL for the AWE.

The transitional years between childhood and adulthood are a particularly vulnerable period for AWE creating specialized healthcare

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needs [7]. Adolescents with epilepsy who had frequent seizures, and lower levels of knowledge about their epilepsy, were found to have higher rates of depression, social anxiety, and lower levels of self-esteem [8]. Health outcomes for AWE can have a life-long impact. Increases in unemployment, binge drinking, unplanned pregnancy, and a decrease in high school graduations rates have been documented in young adults with current or past history of epilepsy [9]. The importance of further research that contributes to a deeper understanding of the factors that impact on AWE health outcomes has been reported [10,11].

For some adolescents, the diagnosis of epilepsy is not just a chronic medical diagnosis, but also a social label associated with behavioral, psychological, and emotional outcomes that affect the entire family [8]. Epilepsy is a long-term condition that requires restrictions, adjustments, and constraining lifestyle demands [12]. Living with a chronic condition, such as epilepsy, creates substantial daily challenges and persistent stress that may result in social and emotional complications [8]. Adolescents with epilepsy are burdened with the task of learning how to cope with their diagnosis and manage their illness, in addition to integrating their self-image, social role, peer-related concerns, and educational achievements. Researchers studied the challenges that AWE face in their daily lives and found that, despite knowing the risks, some AWE purposely compromise their own well-being (such as not being compliant with their medication) because it provided them with a sense of empowerment over their condition [12]. Findings such as these support the need for further research into the challenges that AWE face in their daily lives which may impact on their QOL and their families' QOL.

3. Methods

This was a pilot study, using mixed method design, to investigate the impact of using the SmartWatch seizure detection device on QOL for AWE and their family. SmartWatch is a noninvasive wristwatch that uses a 3D accelerometer to detect motion and pattern recognition software to analyze and identify motion that is seizure-like. Using Bluetooth technology, the SmartWatch communicates with the user's smartphone. Caregivers are also alerted when seizure-like activity is detected and vocalizations are recorded during the event. Users can record nondetected seizures (i.e., partial seizures that do not involve shaking motion) by pressing a button on the SmartWatch. In addition, false alarms can be canceled by pressing a button on the watch. Data such as time, location, duration, motion severity, and frequency are recorded and logged into a cloud-based web server [13]. The device has been evaluated for accuracy in adult and pediatric patients for detecting generalized tonic–clonic seizures (GTCSs) with further refinement of the detection system still needed [14,15]. The study was approved by the University Institutional Review Board.

3.1. Participants

Ten adolescents, ages 14–20, and one parent/guardian, were recruited from a specialized clinic for AWE associated with a major University Health System in Central Virginia. All participants signed written consent to participate in the study. Adolescents who had a history of GTCSs, with an average of 1 GTCS every 3 months over the past 12 months, or 4 in one year, and were currently on an antiepileptic medication, were eligible for the study. Adolescents who had moderate to severe cognitive impairments, moderate to severe behavioral issues, who had a known pregnancy, or a history of psychogenic nonepileptic spells, were not eligible for the study to prevent confounding factors.

3.2. Procedures

Study duration was 6 months and involved 3 study visits. Recorded from the adolescent's medical record during the initial visit were: (1) GTCSs frequency over past year, (2) age at diagnosis, (3) seizure type and frequency of other seizures, (4) etiology of epilepsy, (5) current antiepileptic drug (AED) treatment. At subsequent visits, GTCSs and other seizure frequency and change to AED treatment were recorded.

3.2.1. Psychosocial measures

At entry and study end, adolescent participants were administered the Quality of life in Epilepsy for Adolescent (QOLIE AD-48). The QOLIE-AD-48 is a 48-item scale measuring eight subscales: epilepsy impact (12 items), memory/concentration (10), attitudes towards epilepsy (4), physical functioning (5), stigma (6), social support (5), school behavior (4), health perceptions (3), with higher total summary score (0 = minimum, 100 = maximum score) indicating better HRQOL. The scale was tested for reliability and validity in AWE ages 11–17 years [16]. Mean scores for AWE who had no current seizures were 77.3 (12.6 standard deviation [SD]), low-severity seizures were 70.3 (16.6 SD), and high severity seizures were 62.7 (16.5 SD).

The corresponding family member was administered the Parent Response to Child Illness (PRCI) Scale at entry and 6-month study end. The PRCI is a 35 item, Likert scale (strongly disagree = 1, disagree = 2, not sure = 3, agree = 4, strongly agree = 5), measuring five subscales: Child Support, Family Life/Leisure, Condition Management, Child Autonomy, and Child Discipline. The Child Support factor is an eight-item subscale that measures parental emotional support to the child relative to the health condition. The 10-item Family Life/leisure subscale reflects family participation in leisure activities, a higher scale indicating greater family participation. A higher score on the five-item Condition Management subscale indicates greater parental confidence in their ability to manage their child's health condition. The Child Autonomy subscale is a six-item subscale reflecting parental encouragement of their child's independence, a higher score indicating more encouragement. Finally, the Child Discipline subscale contains six-items that indicate parental confidence in their ability to manage their child's behavior, a higher score indicating more confidence. The PRCI was tested for reliability and validity in parents of children 4–14 years-old who had epilepsy more than 5 years [17]. Average scores were as follows: CS = 4.37 (0.24 SD), FL = 4.27 (0.13 SD), CM = 4.04 (0.17 SD), CA = 3.11 (0.6 SD), and CD = 3.6 (0.48 SD).

3.2.2. Qualitative questions

At completion of the study, the AWE and the family member were interviewed using a semistructured, phone interview to further explore their experiences using the watch. Qualitative interview question guide included: (1) What has been your experience using SmartWatch? (2) Has it changed how you feel about your (your child's) epilepsy? (3) Do you think life has changed in any way since you (your child) has been using SmartWatch? (4) Were there any barriers to using the device? (5) Would you use this device in the future?

3.3. Data analysis

3.3.1. Quantitative data analysis

The QOLIE AD-48 quantitative survey data were analyzed by calculating each participant's mean baseline scores and mean end scores. Mean total scores were calculated by adding the relative weight of each of the eight subscales. The PRCI data were calculated by summing each item in the subscale and dividing by the number of items to obtain a mean score, ranging from 1.0 to 5.0, there is no total score. The effect size was calculated using Cohen's d [18] for the paired t-test difference of the mean scores, in order to determine the extent of the difference between the beginning and end scores. A Cohen's d effect size of 0.2 is considered a small effect, a medium effect is 0.5, a large effect is 0.8, and a very large effect is 1.3.

3.3.2. Qualitative data analysis

All qualitative interviews were recorded using TapeACall, a secure, recording service for the iPhone (https://www.tapeacall.com). A

research assistant transcribed audio files, and both audio and transcribed text were stored on a secure site. Segments of transcribed text data were organized into categories in table format. The research team discussed the categories, and using an iterative process as described by Sandalowski [19], compared the categories to the larger context of AWE QOL resulting in one overarching theme for both the Parents and AWE titled *Watch Performance*; and additional themes for both the Parents (*This is the Answer, Source of Freedom, and Bargaining*) and AWE (*Comfort, Normalize, and Barriers to Use*).

4. Results

4.1. Demographics

The study sample consisted of 10 male and female adolescents with a mean age of 17.5 years (ages ranging from 14 to 20 years); and onset of epilepsy at mean age of 11.9 years (ages ranging from 7 to 15 years). One parent or caregiver for each AWE also participated in the study. See Table 1 for additional demographic data.

4.2. Psychological measures

The average QOLIE-AD-48 for this study population was 45.17 (9.2 SD) at baseline and 48.69 (12.3 SD) at study end (see Table 2). While the overall scores did show an increase in QOL, statistical significance could not be determined due to small sample size. However, Cohen's d for the QOLIE-48 baseline and end total t-scores was 0.34 (−0.97, 0.31 95% CI), indicating a medium effect size on improving QOL. In addition, our study population had a mean QOLIE AD-48 score equivalent to the severe seizure group in the primary instrument testing study [16]. As defined in that study, severe seizure activity included GTCSs of greater than 1 over the past 12 months, and/or high frequency (>20 in past 12 months) of partial, absence, or myoclonic seizures. In our study sample, the average number of GTCSs at study onset was 4.7 (4.24 SD) per year and 4 of the 10 experienced frequent other seizure activity (18.6 [56.73 SD]) per year which would classify them as severe seizure activity according to the primary study definition. At study end, our sample average GTCS activity was decreased to 2.2 (3.61 SD) and only 3 of the 10 participants were experiencing frequent other seizure activity, 30.1 (90.69 SD). However, this still classified this sample in the severe seizure activity definition.

The PRCI parent mean end scores for the subscales of Child Support and Condition Management were lower than baselines scores indicating that parents felt less able to provide emotional support to their child and to manage their child's health condition at study end [17] (see Table 2). The mean end subscale scores for Family Life/Leisure and Child Autonomy were higher than baseline scores, indicating that families felt less negative impact from the child's condition on the family's activity and that parents were more likely to encourage autonomy in their child and to worry less and have a better mood associated with their child's health condition at the end of the study. There was no difference between baseline and end scores for the Child Discipline subscale.

Similar to the findings in the primary study (3.11 [0.6 SD]), the lowest scores in our sample were in the Child Autonomy subscale at baseline (2.6 [0.76 SD]) and end (3.04 [0.76 SD]). While the Child Autonomy scores did increase at the end of our study, these low scores indicate caregivers having less encouragement for their child's autonomy overall. Most interesting was that Cohen's d for the Child Autonomy subscales calculated at 0.75 (−0.07, 1.52 95% confidence interval [CI]), indicating a large effect size (see Table 2). This strongly supports the benefit of using a seizure detection device for parents of transition-age youth with epilepsy and for the AWE as well. Cohen's d statistic for the Child Support and Child Discipline subscales showed no effect change. The Family Life/Leisure (0.23 [−0.48, 0.92 95% CI]) and Condition Management (0.27 [−0.45, 0.96 95% CI]) Cohen's d scores indicated a small effect size.

Table 1
Demographic characteristics.

Gender	70% female (n, 7), 30% male (n, 3)
Age (yr)	17.5 ± 2.22; range, 14–20
Age at onset	11.9 years ± 2.96; range, 7–15
Epilepsy type	40% CLRE (n, 4), 60% IGE (n, 6)
GTCSs baseline (#/yr)	4.7 ± 4.24; range, 0–12
GTCSs end (#/yr)	2.2 ± 3.61; range, 0–12
Other seizures[a]	
baseline (#/yr)	18.6 ± 56.73; range, 0–180
end (#/yr)	30.1 ± 90.69; range, 0–288

GTCSs, generalized tonic–clonic seizures.
CLRE, cryptogenic localization-related epilepsy.
IGE, idiopathic generalized epilepsy.
[a] Simple partial, complex partial, myoclonic, and absence seizures.

4.3. Qualitative findings

4.3.1. Watch performance

Caregivers and adolescents encountered multiple issues with the watch performance. This became frustrating and annoying for them and caused many of the adolescents to stop using the watch on a continual basis. Adolescents and caregivers reported that it was difficult to adjust the sensitivity of the watch and it would be triggered when the adolescent actively moved their arm, for example in physical education class or when clapping. The increased sensitivity caused multiple false alarms that notified the family member who was connected to the system. The system had a reset button that allowed the adolescent to send a false alarm text to notify the family member. However, the false alarms often caused confusion and apprehension for the families.

> "*… my husband was just ignoring them, because … we were making sure it was working and we weren't sure what was going to happen to her. One day she was actually with me … and my husband was trying to reach her and couldn't. He said, "all I could hear was her talking, and a lot of noise, but I couldn't tell whether it was her or somebody else." So, he called me on my phone and said, "I'm going to get…" I said, she's with me and she's fine.*"

In addition to false alarms, caregivers reported concerns with the watch 'not picking up' seizure activity. Caregivers reported receiving multiple texts notifying them of disconnections. The watch had to be in proximity to the phone for it to work. This was difficult for the adolescent during certain activities when they could not keep the phone on their body, such as during physical education. They were able to adjust the settings, such as the sensitivity, but then, in some cases, the watch did not trigger when the adolescent was actually having a seizure. As one parent remarked, "*… her younger brother did a better job than the SmartWatch. In early December, all the kids camped out in the younger brother's room … and the watch did not alert us, but the youngest one did.*" One parent noted that the watch had a long response time when notifying her of her daughter's seizure. "*… it sent me a message probably 3 or 4 minutes after I'd already known.*" The inconsistency of accuracy in the watch's seizure detection caused adolescents to not want to use the watch. "*The fact that it didn't detect the seizures when she had them … that just kind of blew the air right out of the bubble. … 'Why am I wearing this if it doesn't work?'*

Adolescents reported additional problems with the watch and phone, beyond connection issues. Many adolescents described difficulty attaching the watch to the charger, "*… it doesn't stay on the charger well … it's a magnet, it falls off.*" Another adolescent described the battery percentage dropping quickly, "*… it'd be on 70 and then it'd be on 30.*" Most of the adolescents complained about having to carry two phones, one that was connected to the watch and their personal phone. They hoped that a new system would allow them to connect the watch

Table 2
Psychosocial measures.

Measure	n	Mean Baseline score	Mean End score	Cohen's d (95% CI)
QOLIE-AD-48	10	45.17 [9.2 SD]	48.69 [12.3 SD]	0.34 (−0.97, 0.31)
Parent Response to Child Illness (PRCI) Scale	8			
	Child Support	4.41 [0.49 SD]	4.38 [0.42 SD]	0.05 (−0.65, 0.74)
	Family life/Leisure	3.78 [0.73 SD]	3.88 [0.57 SD]	0.23 (−0.48, 0.92)
	Condition Management	4.63 [0.22 SD]	4.5 [0.31 SD]	0.27 (−0.45, 0.96)
	Child Autonomy	2.6 [0.76]	3.04 [0.76]	0.75 (−0.07, 1.52)
	Child Discipline	3.75 [0.67]	3.75 [0.58]	0 (−0.69, 0.69)

with their personal phone. However, one parent noted wanting two separate systems so that the watch alerts would not "*… get mixed up into my personal texts and emails.*" One final issue that adolescents and families mentioned was that the watch was not waterproof. Because it was not waterproof, the adolescents had to remove the watch while bathing, swimming, or during certain activities, such as art class. Often, the adolescents would forget to put the watch back on

> "*Yeah, it was really hard for me to remember putting it on. … I'll go take a shower, or something, and leave it in the bathroom; or leave it somewhere, like on the counter after doing dishes and stuff, so it doesn't get wet or ruined.*"

4.3.2. Parental theme: this is the answer

Despite the limitations in using the watch, caregivers were optimistic about what the watch could do for them. Having the watch provided much needed peace of mind and a sense of safety and security. As one parent explained:

> "*I feel a whole lot more comfortable with the watch. Because there is no way to predict when she is going to have a seizure or prepare for it. With the watch, we will get a call and go over and check on her and make sure she is Okay.*"

Caregivers described living with the 'fear factor' when having a child who has epilepsy. The unpredictability of seizures and the constant worry contributed to parental stress. The watch was viewed as *a* 'source of comfort.' In the parent's own words:

> "*In the beginning, when I found the study, it was like oh my god I think I found the answer! Because, I went down and found her seizing one morning and I had no clue … we had no clue how many she had before then… There were numerous times in the hospital where they were getting ready to intubate her because her oxygen had dropped so low. So that was the fear … it wasn't just the seizures, it was the effects of the seizures as well. So, when I found out I was like oh my god this is the answer, this is the answer!*"

Many caregivers were also conscious of the difficulties that their adolescent faced in learning to manage their epilepsy. Caregivers acknowledge that the watch provided a 'level of security' during a time when the adolescent might not be as compliant and therefore more at risk for seizures. Overall, the watch was seen as a way of providing safety during the time of transition as the adolescent with epilepsy adapted to more independence.

> "*And then, just because the drugs are working, we sometimes stop taking them because we think everything is fine, or we miss one here and there because everything is fine. It's harder to convince yourself that you need something … So, I think keeping them safe is a huge thing, which I think this [seizure watch] just gives a level of security.*"

4.3.3. Parental theme: source of freedom

The watch was also a way to keep in touch with their child and to monitor them while not being directly with them. "*So, just the peace of mind that it gave us… cause she's a teenage girl — she wants her privacy. Obviously, she doesn't want to sleep in her mom and dad's room.*" Caregivers reported feeling more comfortable allowing the adolescent to engage in normal adolescent activities, such as "band trips" and "sleep overs." While parents were aware of the developmentally appropriate need for increased independence with their adolescent, they were hesitant to support activities leading towards independence due to the increased risk of harm from the epilepsy.

In the words of one parent:

> "*… to me it's a source of freedom … for my mind. And that was the biggest thing, and that's the hardest thing, I think, for these adolescents to understand. They don't see the seizures, they don't remember the seizures, they don't know what it's like to be on the outside… It becomes all-consuming and it's very difficult, it's very hard … I physically know where you're at and I can now let you out of my sight because something will tell me where you're at. And that is comforting.*"

4.3.4. Parental theme: bargaining

After using the watch for some time, caregivers and adolescents were more aware of the overall benefits and limitations of using the watch. As one caregiver described "*… the benefits outweigh the difficulties. It is worth it for the peace of mind.*" However, an inadvertent limitation of wearing the watch, was that it brought attention to the adolescent's epilepsy. People recognized that it did not look like an average watch and asked what the watch was and why the adolescent was wearing it. "*… [it is] kinda gaudy and everybody is asking her questions about it and she doesn't like talking about it anymore.*" Caregivers reported that disclosure of their epilepsy was difficult for the adolescent. "*… because in the beginning she wanted to keep it really quiet. She's a teenager, you don't want to share your business, you don't want to look different, you don't want to be different, you don't want to tell people your different.*" As the watch alerted others to the fact that they had epilepsy, the adolescent was less willing to wear the watch. Despite these limitations, caregivers recognized the watch as a means to independence for their adolescent, opening possibilities that might otherwise have not been possible. Caregivers described a process of *bargaining* with the adolescent, so they would wear the watch more consistently. One parent described the process:

> "*Okay, so it's been a positive thing I think especially for me. She got into it, I think, primarily because we were having trouble with kind of trust and allowing her to be a normal teenager, and me not be overprotective. We came to an agreement on when it was necessary to actually use the watch, because we won't say that she's nearly as excited as I have been. It's not a 24-7, she has it on all the time … But, we've come to an agreement, when you are out of sight, out of my control, you have to wear this.*"

4.3.5. Adolescent theme: comfort

Adolescents appreciated that the watch provided increased *safety and security*. As one adolescent stated: "*I feel safe enough to go to school without being scared. …if I go to the bathroom, and I have a seizure, somebody will actually get the notice that I'm actually having a seizure.*"

Another adolescent explained: "*I try to wear it as often as I can… I don't feel like it is a burden, I feel like it's just helping me out and keeping me safe.*" At the same time, adolescents admitted that they wore the watch to appease their caregivers' fears: "*It made me feel better knowing that they weren't stressed out over it and I wouldn't have to camp out in their bedroom.*" In one instance, a female adolescent reported that the watch provided security beyond warning her caregivers about potential seizure activity.

> "*Just a few months before I got the watch … it was just an incident where I was in danger and I needed somebody. It wasn't seizure danger, but it was kinda like stranger danger, and my mom saw that as a comfort kinda thing. And to me, I wanted to do it for her. I was like this could be good for me too if it works … but yeah, I would say it was mainly her that wanted it.*"

However, despite the additional circumstances in which the watch provided security, the adolescent remarked that she wore the watch primarily to appease her mother.

4.3.6. Adolescent theme: normalize

The adolescents were able to recognize that wearing the watch also benefited them, as their parents were more likely to relax their restrictions on activities. Using the watch provided the adolescents with a much-needed opportunity to experience developmentally appropriate independence from their families; essentially 'normalizing' their life.

> "*I really like it, … my mom was a real hoverer before we got the watch and it made her feel a lot better, and so it was a lot easier to go out with my friends and it made her feel a lot better when I went out with my friends with my watch on.*"

Another adolescent described: "*I went and stayed overnight with an old friend which I wasn't allowed to do back when my epilepsy started.*" Finally, the following statement summarizes the effect of the watch on the adolescent's lifestyle: "*It really helped me. I felt more independent. I didn't have to be surrounded by mom and my grandma and everybody else. I could do more things by myself.*"

Adolescents commented that the watch did draw attention from others: "*Yeah they asked me is that like a Fitbit?*" However, adolescents were able to use the watch as a way to *disclose* their epilepsy diagnosis with their friends and associates. As one adolescent explained: "*A few friends know about why I wear the watch. Some of my classmates … know the fact that I have epilepsy.*" Additionally, one adolescent female used the watch as a source of unity with friends around her epilepsy safety: "*I'm really close with my friends, so I told them all about it and we talked about how to use the watch. And we made up a name called the "seize team.*"

4.3.7. Adolescent theme: barriers to use

Despite recognizing the advantages of using the watch, adolescents described feelings of additional *burden* about their epilepsy care when using the watch. In the words of one adolescent: "*… when I first had epilepsy, I was like 'I can't believe I have it. I can't believe I have to take all of these pills.' And then I got the watch. It was just another thing to do.*" Another adolescent reported:

> "*And then it became extremely stressful to me because I was like, well I agreed to do this… This was part of the assignment, like I'm trying really hard here, but I would lose it and it became extremely stressful and kind of just a big burden.*"

Adolescents also reported negative comments about the comfort and usability of the watch. In addition to having to remove the watch to prevent it from getting wet, they described times when the watch interfered with their normal daily activities. For example: "*I wasn't wearing it hardly at all during the day because I would have to take it off when I'm in class … because … then I couldn't write.*" Another adolescent aptly stated:

> "*It did not really help me any at all … I just wasn't used to wearing a watch, and then it was uncomfortable. But, I gave it a try because everybody kept telling me to and then it just got really annoying.*"

Adolescents also reported skepticism about the usefulness and accuracy of the seizure

> detection watch. "*When I've had a seizure, I have never like [shaken] my arm that much to where it would go off…*" One adolescent went so far as to state that he no longer needed the watch as he was not currently experiencing any seizures. "*I tried a couple of time but … I didn't think I needed it, I stopped having seizures.*" Another commented that the watch was not for them. "*… it wasn't what it was cracked out to be, for us at least. But I still wanted it to work … like I still tried.*" Overall, adolescents did try to use the watch but mostly for their caregiver's sake. "*I mean, my grandmother was interested in it, and everybody thought it would be a good idea, and I just thought I'd give it a try.*" However, the multiple barriers encountered made it difficult to use the watch long-term.

5. Discussion

Findings from this research reflect the experiences of the 10 adolescent-caregiver dyads who participated in this pilot study. While these results cannot be generalized to the larger population due to the descriptive/qualitative nature of the data and the small sample size, the findings do support future studies that explore the effectiveness of using a wearable seizure detection device for AWE. The moderate effect size for the QOLIE-48 QOL and the large effect size for the Child Autonomy subscale of the PRCI, as well as the qualitative data, support that a wearable seizure detection device has strong implications in increasing QOL for AWE and their families. Overall, the wearable seizure detection device was well received despite the technical difficulties. Smart Monitor continues to develop new models of the watch that improves on the technical issues [20,21].

5.1. Safety and sudden unexplained death from epilepsy (SUDEP)

One of the most important functions of the seizure detection device was to provide an additional level of safety and supervision for the AWE. Both the parents and AWE reported concerns with safety and fear in living with the risk of unpredictable seizures. The seizure detection device was seen as a way to mitigate the anxiety and provide some much-needed security and comfort around these fears for both parents and AWE. A major benefit of the seizure watch design is the effectiveness of seizure detection during sleep. Generalized tonic–clonic seizures activity during sleep is associated with increased risk for SUDEP in people with epilepsy. Current guidelines recommend nocturnal seizure supervision to lower SUDEP risk [22]. Previously, nocturnal seizure monitoring has involved using an auditory listening device or having another person sleep in the same room. However, as expressed by the AWE in our study, this supervision is not generally well-received by AWE as it impinges on their sense of autonomy. In our study, the seizure detection watch allowed for effective nocturnal seizure monitoring with less encroachment on the AWE's privacy which has been associated with other methods of seizure monitoring.

5.2. Implications for fostering autonomy

The parents and adolescents in this study were willing to incorporate an additional burden to their daily epilepsy care, as they were hopeful that it would decrease vigilance over seizure monitoring and allow the adolescent increased autonomy. The adolescents in this study

were experiencing high seizure frequency and parental heightened vigilance over seizure activity is understandable. Other research also supports that increased concern and monitoring of adolescents with higher frequency of seizures lead to poorer QOL for families [23]. As indicated in this study, a wearable seizure detection device has positive future implications in improving QOL for AWE and their families, particularly those who are experiencing severe seizure activity.

The caregivers in our study were low in their encouragement to support their adolescent's autonomy but the SmartWatch had a positive effect on improving parent's ability to support their child's autonomy. The caregivers in this study had overall higher scores in Condition Management and Child Discipline, indicating that they felt confident in supporting their child and managing their child's epilepsy. This study sample was recruited from an epilepsy clinic designed specifically to care for the educational, emotional, and medical needs of AWE and their families. Therefore, it is understandable that the parents in our sample would have increased confidence in their ability to manage their child's epilepsy, as they are receiving specialized education and support to do so. However, as found in other studies [24,25], parents of children who have epilepsy encounter prolonged psychological trauma and anxiety. When parents witness their child experiencing a seizure, they may feel loss of control and have frightening thoughts of their child experiencing brain damage and even death. A primary coping method for anxious parents is overprotectiveness, which would lead to decreased encouragement of their child's autonomy.

However, persistent vigilance can be overburdening for both the parent and the child. Desperation, guilt, and exasperation are common feelings in parents of children [26]. Rapport between parents and AWE can diminish as the child grows angry or withdrawn due to parental involvement, and the parent feels they have lost both behavioral and psychological control [25]. Overtime, coping skills decompensate, and the family's mental health may decline. Parents and adolescents in our study commented about the stress and anxiety associated with parental supervision during a time when most adolescents are naturally developing more independence. In this study, the seizure detection watch provided a way to mitigate these negative interactions and foster improved relationships between the adolescent and parent. While multiple factors play a role in improving QOL, seizure detection devices can potentially improve the relationship between AWE and their caregivers by easing parental anxiety and increasing autonomy for the child.

5.3. Managing disclosure and stigma

In this study, AWE and their parents expressed concerns that wearing the SmartWatch would lead to an involuntary disclosure of their epilepsy. The adolescents in this study all had a diagnosis of GTCSs and reported having at least one GTCS in public. Due to the unpredictability of the seizures, adolescents often had limited control in how and when they disclosed their epilepsy. Disclosure of epilepsy is a concern for AWE and their caregivers due to fear of stigma associated with the disease. Stigma may be experienced as discrimination by others resulting in lack of social acceptability and inferiority or felt personal feelings of shame and embarrassment [27]. Fear of stigma often results in concealing their epilepsy diagnosis as an attempt to be normal. In adolescence, acceptance within their social group is an important developmental task and involves recognition of desirable group traits, such as being “normal” [12]. Anything that brought attention to the fact that the adolescent was different or disclosed their epilepsy diagnosis was frustrating to them, and the watch was perceived as another source of disclosure.

In addition, parents of children with epilepsy want to protect their child from societal stereotypes and stigma associated with epilepsy [28]. This is understandable as AWE who suffered from stigma due to their epilepsy, had decreased QOL and increased rates of depression, anxiety, somatic symptoms, and reduced self-esteem [8]. It is not surprising therefore, that the AWE and their parents would be concerned about any outward indicator that might trigger attention towards the epilepsy. However, the freedom from worry surpassed the threat of disclosure, and parents encouraged wearing the watch. The AWE were also more receptive to wearing the watch knowing the positive outcomes of increased independence. Therefore, the parent and child underwent a process of negotiating and bargaining that encouraged the continued use of the watch, despite the added burden, technical difficulties, and perceived fear of disclosure associated with wearing the watch. This process of bargaining may be reflected by the lower end scores in the PRCI Child Support and Condition Management subscales. The experiences of the AWE and caregivers in this study recommend future research that explores how to best support AWE in using a wearable seizure detection device while mitigating the negative aspects associated with its use.

5.4. Future studies

The findings from this pilot study support future investigations in using seizure detection devices to improve QOL for AWE and their families. The large effect size for increasing parental autonomy in the AWE supports the need for a larger, random controlled trial to further investigate the benefits of a wearable seizure detection device. Future studies that target autonomy in self-management, while incorporating a seizure detection device, may have strong implications towards improving QOL for AWE and their families.

6. Conclusion

This is the first pilot study of the impact on QOL for AWE and their caregivers using the SmartWatch detection and notification system. Measures of overall QOL showed a trend towards improvement for AWE, as did increased encouragement for autonomy in the parent, during the study period. The data suggest that while there are some limitations using the SmartWatch, AWE and their caregivers were receptive to using the seizure detection device. Findings from this study support that seizure detection devices have the potential to improve QOL for AWE and their families by decreasing anxiety about seizure safety and normalizing the typical adolescent developmental task of gaining independence from their families. Further studies using wearable seizure detection devices are warranted to improve the usability and effectiveness of the device.

Declaration of Competing Interest

The authors certify that they have NO affiliations with or involvement in any organization or entity with any financial interest in the subject matter or materials discussed in this manuscript.

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