



Beyond Words: Understanding Grit in Survivors of Stroke and Caregivers

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Abstract

Grit is defined as perseverance and long-term focus on goals. Grit may be helpful in surviving stroke for both survivors and caregivers. The purpose of this study was to investigate the level of grit among survivors of stroke and caregivers using health humanities to gain a deeper understanding of the lived experience of stroke survivors. A sample of convenience was used. Phase I (n = 22) utilized the Grit Scale survey. Phase II (n = 6) utilized phenomenological interviews. The Grit Scale survey data were analyzed with SPSS 25. Qualitative data were analyzed with the whole-parts-whole method of Giorgi, Dahlberg, Drew, and Nyström. Grit scores were high for both survivors of stroke (3.77 ± 0.50) and caregivers (3.89 ± 0.51). Themes emerging from the phenomenological interviews included: (a) gritty toughness, (b) challenges, (3) accomplishments, and (4) advice for health-care providers. Survivors of stroke and caregivers embodied high grit levels. Participants articulated the importance of long-term goals despite challenges. Understanding grit among survivors and caregivers may help clinicians develop best practices to better support these individuals.

Keywords

grit, survivor of stroke, caregivers

Introduction

Strokes affect 15 million individuals worldwide annually (1). Globally, stroke is the second leading cause of death and third leading cause of premature death and disability as measured by Disability-Adjusted Life Years (DALY) (2,3). One DALY represents 1 year of healthy life lost for an individual and is used on a global scale, indicating the influence and burden of disability and premature death on productivity within societies (2–5). These statistics illustrate the implications of stroke and subsequent impairments an individual may experience for the rest of their life. Further investigation is required to understand characteristics and behaviors of individuals who have not only survived a stroke but have been able to have better outcomes post-stroke and reintegrate into their communities. Successful reintegration into society requires tenacity to overcome newfound challenges. We hypothesize successful rehabilitation and surviving stroke requires grit and may play a role in decreasing disability.

Duckworth et al suggested grit is a personality trait shared by successful individuals and defines grit as “perseverance and passion for long-term goals” (6, p. 1087). Reed et al believe grit involves working strenuously toward challenges over time despite failure, adversity, and plateaus in progress (7). Based on these definitions, grit is essential to stroke survivorship and

the challenges faced during rehabilitation. Insight from caregivers may also shed light on grit levels required to navigate difficult health systems, maintain relationships, and provide support for survivors of stroke. Although there have been studies regarding grit and success in many fields, no studies have investigated grit among survivors and their caregivers. The purpose of this study was to investigate levels of grit in individuals who survived a stroke and their caregivers. Our research questions were:

1. What is the grit level of individuals who have survived a stroke with good outcomes?
2. What is the grit level of caregivers of individuals who have survived a stroke?
3. What is the lived experience of grit among survivors of stroke after reentry into the community?

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Methods

Mixed methods were used in this study to answer the research questions regarding grit among survivors of stroke and caregivers. A survey administered through Qualtrics included basic demographic information and the 12-item Grit Scale for phase I of this study (6,8). After completing the survey, survivors of stroke participated in an optional phenomenological interview for phase II of the study. These interviews provided researchers with deep, rich descriptions of grit among survivors of stroke. Participants ($n = 22$) in phase I included 9 males and 13 females. Additionally, survivors of stroke accounted for 14 participants, with 7 males and 7 females. The caregiver group ($n = 8$) was comprised of 2 males and 6 females. Six survivors agreed to phase II in-depth phenomenological interviews and were male ($n = 3$) and female ($n = 3$).

Phenomenological research is a qualitative research approach exploring lived experiences of participants by listening to personal stories to derive meaning from these experiences (9–11). Author van Manen defines phenomenology as “the study of the lifeworld or our everyday experiences and the meanings we construct from our experiences” (11, p. 33). Investigators bracket and set aside personal beliefs regarding the phenomenon studied. In this process, researchers and others begin to understand trends that develop from such experiences. Two main assumptions in phenomenological research are: (a) humans seek meaning in their lives and (b) multiple realities exist that are socially constructed (9–11). See Figure 1 for a diagram describing research methods used in this study. The institutional review board at Briar Cliff University approved this study (#0012-2017).

Participants

Participants were recruited from local and online stroke support groups as a convenience sample. Inclusion criteria for the study were that participants who (a) survived a stroke and returned home or be a caregiver of an individual who survived a stroke and (b) speak English. The phase I Grit Scale survey remained open between March 16, 2017, and November 15, 2017.

Instruments/Tools

The Grit Scale was designed to assess long-term success and perseverance in reaching goals and has Cronbach's α values ranging from 0.73 to 0.83, meaning the tool has good construct validity, measuring what it sets out to measure (8,12). It is a 12-item self-report measure of positive and negative aspects of reaching long-term goals. Statements on the Grit Scale are graded on a 5-point Likert scale. The higher the final grit score, the more perseverance and focus on goals a person demonstrates. Questions specifically target abilities to set, pursue, and focus on goals despite dealing with setbacks.

Procedures

Individuals who accepted the invitation to participate in this study were e-mailed a link to the Grit Scale and demographic survey through Qualtrics. Additionally, survivors completed an optional 45- to 60-minute interview about specific experiences of grit.

Screening of participants in phase II interviews by the principal investigator by telephone confirmed inclusion criteria were met. Participants received an informed consent document prior to the interview and chose an alias to maintain confidentiality. Interviews utilized processual consent described by Rosenblatt (13). By means of this process, intensity of interview questioning decreased when participants appeared distressed and were allowed time for silent reflection. Once conducted, interviews were transcribed by a research team member. A copy of the interview was e-mailed to the participant to verify content accuracy of the transcription. Any concerns of the participant were addressed by the primary investigator and corrected for final transcript analysis. This process of member checking transcripts provided researchers with an accurate transcript to analyze.

Data Analysis

Quantitative data were analyzed by SPSS 25 (14). Cronbach's α was used to determine the internal consistency of the Grit Scale for this study. Descriptive statistics were obtained, as well as mean grit scores. See Table 1 for details.

The analysis of interview transcripts used a descriptive approach involving a whole-parts-whole type of holistic examination of interview texts to reveal the constituents or themes and common description of the grit experience (9,15,16). Constituents or themes were shared with participants who responded by e-mail as to whether the constituents resonated well with their experience. This process served as the vertical analysis. A common description of grit among participants across interviews served as the horizontal analysis and was sent to all participants to ensure dependability and credibility.

Health humanities (HH) involve the use of literature and arts to explore human issues pertinent in health care and to reflect on the meaning of those experiences (17–33). An original piano composition was created by one member of the research team (B.Q.) representing the common description of grit among survivors of stroke. The piano composition embedded with the words of the common experience of surviving a stroke shared with participants and nonparticipants composed our resonance rounds. Nonparticipants were individuals who were survivors or caregivers who did not participate in the original study. The piano composition in this study served as a transcendent process allowing others to more deeply

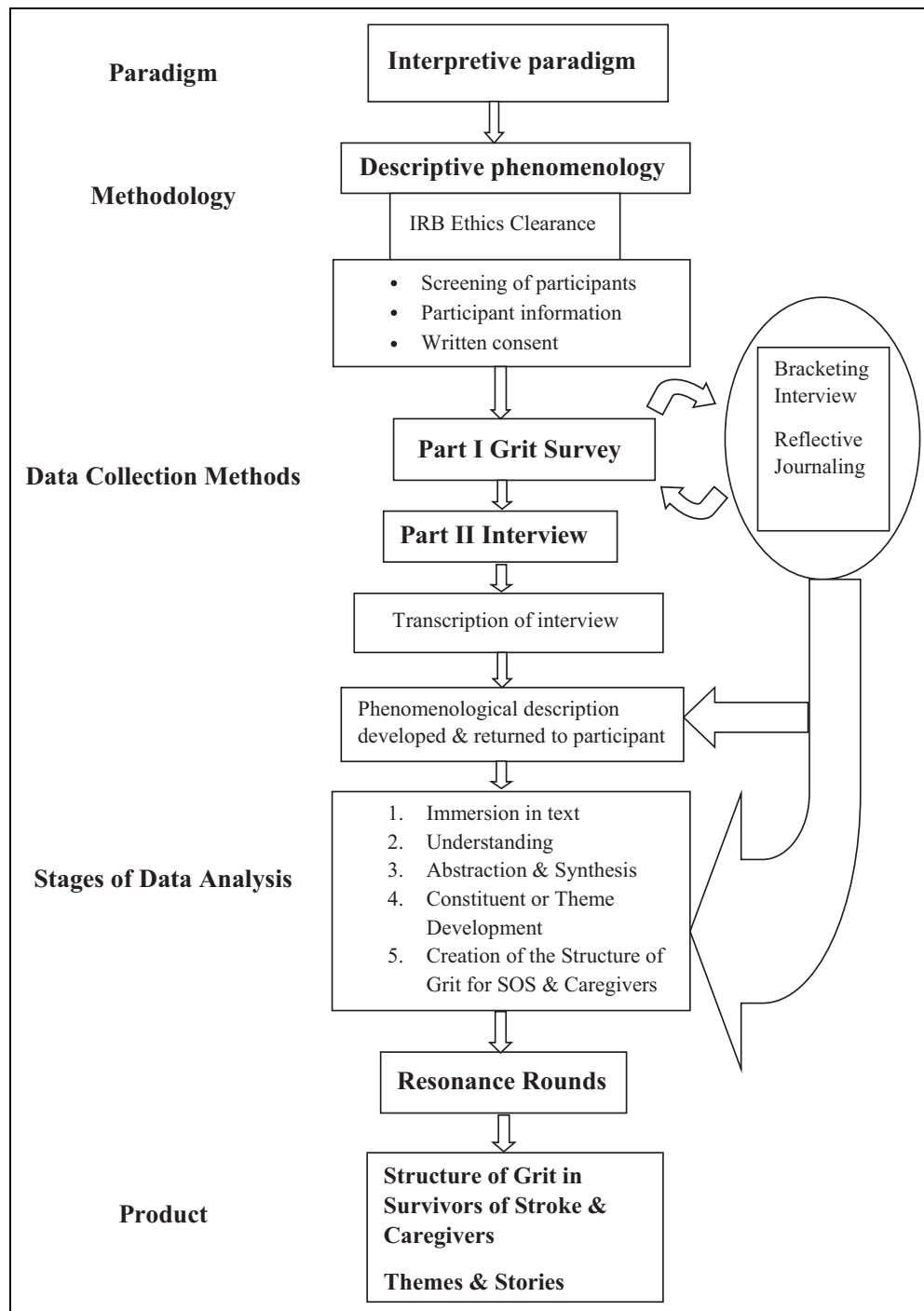


Figure 1. Research methods used, paradigm, methodology, data collection methods, stages of data analysis, and product.

understand lived experiences of stroke survivorship beyond words.

Methodological Rigor in Phenomenology

Methodological rigor is as important in phenomenological research as in other forms of research. The purpose of phenomenological research is to find meaning and understanding as opposed to causality and prediction (9–11).

McClelland suggests that phenomenological research answers questions about human experiences and provides fidelity to knowledge claims about that lived experience (34). The completed common description of grit and the piano composition shared with survivors and caregivers not a part of this study provided resonance rounds and a means to build credibility and trustworthiness in our findings for the common description of grit among survivors of stroke in both music and words.

Table 1. Results and Descriptive Characteristics of Participants in Phase I and II.

Phase I: Survey	
Number of participants	22
Stroke survivors	14
Caregivers	8
Sex	9 males; 13 females
Males (stroke survivors)	7
Males (caregivers)	2
Females (stroke survivors)	7
Females (caregivers)	6
Mean age (years)	53.91 ± 13.82
Stroke survivors	53.79 ± 14.25
Caregivers	54.13 ± 13.99
Mean age of stroke onset	47.93 ± 12.86
Mean grit score (all participants)	3.81/5.00 ± 0.49
Stroke survivors	3.77 ± 0.50
Caregivers	3.89 ± 0.51
Community settings	
Rural	73%
Suburban	13.5%
Urban	13.5%
Phase II: Interviews	
Number of participants	6
Stroke survivors (male)	3
Stroke survivors (women)	3
Mean age (years)	52.33 ± 14.45
Males	43.33 ± 20.21
Females	53.67 ± 9.02
Mean age of stroke onset (years)	47.67 ± 14.77
Mean grit score	3.90 ± 0.45

Results

Quantitative Results

Mean age was 53.79 ± 14.25 years for stroke survivors and 54.13 ± 13.99 years for caregivers. Cronbach's α for the Grit Scale in this study was 0.72 and indicated this scale had good internal consistency but was slightly lower than values reported in the literature (8,12). Perhaps the challenge of completing the questionnaire by survivors skewed the Cronbach's α . Mean grit scores for survivors (3.77 ± 0.50) and caregivers (3.89 ± 0.51) in phase I and survivors of stroke (3.90 ± 0.45) in phase II were all considered high values.

Qualitative Results

Saturation was reached at the sixth interview. Themes that emerged from phenomenological interviews describing the lived experiences of survivors and caregivers included: (a) gritty toughness, (b) challenges, (c) accomplishments, and (d) advice for health-care providers.

Participant OC described gritty toughness as not being afraid of failure. He states:

You have to realize that you are not a failure. You're only a failure if you don't get back up again. You are going to fail a

thousand upon millions of times but you can't look at failure this time as the end.

Challenges for survivorship were nicely articulated by Beatrice. She stated:

Oh, my God! I used to be this really smart, capable, independent person and now what is going on? But after I focused on what they told me to do in therapy and took one thing at a time, I began to make progress.

Accomplishments helped survivors reclaim life after stroke. Steve shared:

I need to be able to use my hands. I am not ready to sit in a chair for the rest of my life not doing anything . . . One of my biggest motivators was to stay focused. It's hard right now. I am in a difficult spot . . . I want to get back to life so I can reach my goal of being a kindergarten teacher. Teaching kindergarten is what I have always wanted to do and here I am!

Fred (survivor) and Wilma (caregiver) advised health-care providers:

You see some therapists that just did it as a job and you could really see the ones that really loved their job and loved what they did. Some therapists just went through the motions. Be personable.

Grace concurred and added:

It's not just your manual skills, it's your people skills too. Rehab is a hard time out of your life that you have to give away. If you go there and feel like you are making a friend, rehab can be pleasant.

Finally, the common description stated:

Surviving a stroke takes gritty toughness. Even though my body and mind are changed, I am still me! My stroke doesn't define me! After the initial shock of surviving a stroke, there are many challenges. I begin to wonder, "Who am I?" I reflect upon the meaning of my life now that I have to relearn many things. I must deal with my new mind and my new body. Nevertheless, I will reclaim my life! I still have accomplishments and goals to reach. There are new possibilities for me. I can inspire others and change the world. Don't let anyone tell you that you can't do things. Rehabilitation will be one of the most difficult things a survivor of stroke will ever have to go through. Rehab requires a team effort. It is a long road to recovery, but the team is here to support you. There will be days in which you may feel like you have failed, but you will find the courage to get back up and carry on. Having gone through this experience, I can offer advice to health-care providers. Love what you do! Remember I am more than my beautiful brain! Don't pity me. Let me take one thing at a time. Please be patient with me. Be personable, authentic, and fun. Surviving a stroke takes more than simply achieving goals or taking on new challenges. Surviving a stroke takes grit.

This common description of grit is highlighted in an original piano composition created by author B.Q. (<https://soundcloud.com/user-485179353/understanding-stroke-survivors/s-YeHpl>).

Resonance rounds from participants and nonparticipants in this study from around the world confirmed the common description and piano composition were a trustworthy and credible representation of the grit experience for survivors of stroke. See Table 2 for resonance round responses from participants and nonparticipants.

Discussion

Participants in this study had high levels of grit and were able to articulate strategies used to accomplish long-term goals when facing setbacks. Participants who chose to engage in both phase I and phase II of this study had higher grit scores than those who only participated in phase I. Perhaps individuals with grit tend to seek out meaningful experiences and engage in opportunities to advocate by sharing a personal narrative or story on challenges faced. Some participants may have chosen not to participate in phase II due to communication challenges.

Although the topic of grit among survivors of stroke has not been explored in the literature, several studies have investigated grit levels in various populations. Grit levels among physicians were studied by Reed et al (7). These physician caregivers were professional and not personal caregivers of individuals who specifically survived a stroke. Grit levels among professional caregivers such as physicians in the Reed et al study ranged from 3.26 to 3.31, with physicians working in rural or specialty areas having higher levels of grit (7). Personal caregivers in this study, however, had high grit scores (3.89 ± 0.51). High grit scores of personal caregivers in this study may indicate an ability to undertake new life roles and responsibilities in supporting survivors of stroke.

Survivors of stroke described the mental focus faced when recovering function after a stroke. They learned new strategies and developed mental toughness or grit as the survivors focused on functional goals. Stroke recovery is often a long-term process. The average length of stay in an inpatient rehabilitation facility after a severe stroke, as categorized by the Centers for Medicare and Medicaid, is 22.2 days followed by outpatient rehab (35). Physical and mental rigors of rehabilitation present a challenge participants described as boot camp. A participant of phase II of this study expressed rehabilitation following a stroke as *the most difficult thing a survivor will ever have to do*. Studies by Duckworth et al have explored grit in high-achieving populations such as Ivy League Undergraduates, West Point Cadets, and National Spelling Bee finalists. Grit scores among these groups ranged from 3.41 to 3.78 (6,8,9). It appears that survivors of stroke in this study were high-achieving individuals based on their grit scores ranging from 3.77 to 3.90.

Table 2. Resonance Rounds: Grit Descriptions.

Participants

Well done with everything! The piece is just beautiful! Great job to you for this. (Iowa, Fred and Wilma, October 24, 2017)

I think the draft is spot on and the piano piece is so soothing.

Pretty and calm. I liked it. Thanks for your hard work and for your students. (Minnesota, TW, caregiver and pastor, October 24, 2017)

It's absolutely perfect! While I was reading and then listening to the piano piece, all I could picture was the survivors' smiles, interactions, and laughter from stroke camp. They are tough, have persevered, and are full of grit! They have survived and realized that life doesn't have to end after stroke. The possibilities are endless! Enough said! This is a wonderful combination between the description and music! (Iowa, JA, family caregiver, October 24, 2017)

Nonparticipants

I think that the description regarding a stroke that you provided is excellent and that it takes grit through patience and time to rebuild the body. The body may not be as it was before, but with the help of those experienced in rehabilitation of stroke patients, to me, grit now becomes a reality. The music provides a soothing warmth by adding an element that helps calm my brain. (Minnesota, RN, caregiver, October 25, 2017)

My father suffered several strokes until he died from respiratory complications. At all times his essence remained, although he was not communicative and was completely dependent, but in his gaze was always Him. I think as a family we achieve synergy with the rehabilitation team and in fact we make sure that the professionals really "love what they do." About the melody, it feels so emotional... I pick up on those feelings of love I have for my father and the beauty of the team that worked with him. (Honduras, MDRE, audiologist and family caregiver, October 24, 2017)

Absolutely beautiful! (Iowa, support group coordinator, October 24, 2017)

Oh! I love this! I think the piano is beautifully played, but I read the test of the statement as soaring, assertive and uplifting. The piano music says something more mellow, more restrained, at least to my untrained ear... I love the statement itself. I think it is spot on! (Minnesota, PT, October 24, 2017)

I really like it! I read the description first and then listened. Hearing the music is what I was hearing subconsciously as I read the description. Unfortunately, I don't get to work as closely with stroke patients during the rehab process (30 minutes follow-up usually). But I think this will be a powerful piece regardless! I am excited to hear how it all turns out! (Iowa, physician, October 27, 2017)

Oh! This is so beautiful!! The words are so powerful and so true. They reflect everything I have heard from my fighters over the past 20 years. What a beautiful musical composition to go with this! I LOVE, LOVE, LOVE IT!!! Thank you for sharing with me!!! (Iowa, PT, October 30, 2017)

The words are powerful and positive. The music suggests a hopefulness that inspires despite the tension of a possible catastrophe within the body. Thank you. (Japan, caregiver, October 30, 2017)

Well, this is a very interesting project. The music and words together create a deep union regarding the meaning of surviving a stroke. It describes the important connection to others for success and new meaning in life after a stroke. (Vienna, Austria, physiotherapist, October 30, 2017)

Our hypothesis that improved function with stroke rehabilitation can be a challenging task that requires grit. Individuals who possess high levels of grit are capable of overcoming barriers during the rehabilitation process. To that effect, changes in grit levels may occur in survivors who have learned how to be gritty during the rehabilitation process. If grit is learned, further investigation into methods of teaching grit may be beneficial in providing insight into aiding survivors of stroke to achieve successful rehabilitation and societal reintegration. Some suggest the greater amount of time spent engaged in working toward meaningful, well-defined goals such as participating in rehabilitation may teach grit (8,36–38). Grit among wheelchair basketball players correlated with hours of sport engagement (38). These concepts are important aspects utilized by physical therapists in designing rehabilitation programs.

Returning quality of life to survivors of stroke and caregivers is a long-term process. Not only limited by physical, mental, and emotional challenges, a stroke may also impose barriers to social health. For example, caregivers assume new responsibilities and life roles during the stroke recovery process. The mean grit scores of caregivers (3.89 ± 0.51) in phase I of this study were comparable to specialty care physicians (3.31 ± 0.34), as reported by Reed et al (7). It may be inferred that both groups possess growth mind-sets to learn new things to support the care of others.

Our investigation of grit levels among survivors of stroke and caregivers has provided insight into challenges faced during stroke survivorship and community reintegration. The Grit Scale provided a means for quantitative comparisons among survivors, caregivers, and high-achieving subgroups. Collectively, our findings and those of Duckworth (6,8,36) support a possible relationship between grit levels and achievement of long-term goals. Results of this study support the proposal in the context of stroke survivorship. As a complement to quantitative findings, a phenomenological component was included in this study providing a qualitative means of understanding grit and stroke survivorship.

Using HH through music allowed survivors of stroke and caregivers to unveil beliefs about grit experiences in this research project. Merleau-Ponty suggests, true communication occurs not only when we become conscious to an experience but take on a willingness to become the experience (39). “To be an experience is to hold inner communication with the world, the body and other people, to be with them instead of being beside them” (39, p. 111). Including a common description enmeshed in the piano composition allowed the essence of grit experiences of survivors to emerge helping others see things differently. As Macann states, “In learning how to see, we learn how to be, how to be something other than what we were when we remained blind to the new way of seeing” (40, p. 170). In sharing the final common description, participants and nonparticipants, pianist, speaker, and listener connected deeply to lived experiences shared by the survivors of stroke.

Strengths and Limitations

Strengths of this mixed-method study included the Grit Scale due to its strong psychometrics and multiple populations assessed in previous studies. The sample size for the survey in phase I ($n = 22$) and for interviews for phase II ($n = 6$) is adequate for a phenomenological study. The researchers achieved saturation after the sixth interview, which provided a rich description of grit among survivors of stroke interviewed. The primary researcher who interviewed participants was experienced in phenomenological interview skills. Finally, the primary researcher who interviewed the participants was not involved in the identification and analysis of themes in order to limit bias of results.

Some limitations exist in this study. The researchers acknowledge the results of this study do not apply to every survivor or caregiver. Finally, the Grit Scale worded in the present tense asked participants to reflect on a challenging time. Perhaps participants did not accurately recall exact feelings of surviving a stroke several months after the stroke. The resonance rounds conducted in this study were used to mitigate this problem.

Future Study Recommendations

Future researchers may want to investigate grit levels among survivors of stroke who had adaptive versus nonadaptive experiences to determine if grit is predictive of successful participation in life roles after surviving a stroke.

Conclusions

Everyday lived experiences of participants in this study indicated that survivors of stroke and caregivers embodied high levels of grit based on survey and interview results. All participants were able to articulate how they remained focused on long-term goals despite facing difficult challenges. Opportunities for peer mentorship may assist survivors and caregivers with positive coping strategies in order to reach goals. Gaining a better understanding of grit may shed light on support systems needed for survivors of stroke to reenter life and thrive.

Authors' Note

Susan G. Klappa contributed to concept development, design, supervision, data collection/processing, analysis, literature search, and writing or critical review. Brian Quach is creator of original piano composition and contributed to design, data collection/processing, analysis, literature search, and writing or critical review. Jordan Steele contributed to design, data collection/processing, analysis, literature search, and writing or critical review. Chelsea Harper contributed to design, data collection/processing, analysis, literature search, and writing or critical review. The IRB at Briar Cliff University approved the protocol for this study.


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