

Batten disease and parents: marital quality, support, and communication

Elizabeth J. Cozart, MD¹; Erika F. Augustine, MD, MS²; Jonathan W. Mink, MD, PhD²;
Alyssa R. Thatcher, MS²; Heather R. Adams, PhD²

¹University of Vermont Medical Center; ²University of Rochester Medical Center

Corresponding author: Heather Adams, PhD, University of Rochester Medical Center, Box 631 (Child Neurology), 601 Elmwood Avenue, Rochester, NY 14642, e-mail: heather_adams@urmc.rochester.edu, tel: 585.275.9330

ABSTRACT

Background: The neuronal ceroid lipofuscinoses, collectively known as Batten disease, are rare pediatric neurodegenerative disorders resulting in blindness, progressive motor impairment, dementia, and premature death. This study identified services and support accessed by parents of children with Batten disease and assessed parental marital quality.

Methods: Parents completed a survey to identify services their affected children received, and their own uses of social support, information, and online resources. We used the Dyadic Adjustment Scale to evaluate parental marital quality.

Results: 29 parents of 23 Batten-affected children completed the survey. 18 children (78%) received receiving in-home nursing or paraprofessional care. Over 90% of parents used the internet and social media to learn or talk about Batten disease; their preferred learning method was from other parents of children with Batten disease. Batten parent marital quality was significantly lower than that reported in studies of the general population or parents of children with chronic, but non-neurodegenerative, disease.

Conclusions: Parents expressed an interest in and preference for parent-to-parent communication for support and information about Batten disease. Further work is needed to understand factors associated with the significantly lower marital quality among Batten parents.

Keywords: Genetics and genetic disorders; critically ill children; family functioning

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BACKGROUND

The neuronal ceroid lipofuscinoses (NCLs) are rare, neurodegenerative, predominantly autosomal-recessively inherited lysosomal storage disorders with varying genetic etiologies; disease-causing mutations in over 10 different genes have been described to date [1]. Collectively referred to as Batten disease, the NCLs are the most prevalent neurodegenerative diseases of childhood [2]. Common clinical features include seizures, behavioral impairments, and progressive decline in vision, cognition, and motor function, followed by premature death. Phenotypic classifications for Batten disease are in part based upon age at symptom onset, including during the first year of life (infantile); the second or third year of life (late-infantile), or between approximately 4-7 years old (juvenile). Life expectancy varies and is typically shorter for the earlier-onset forms; the average lifespan for children with classic infantile Batten disease is two to nine years, while those with juvenile Batten disease typically survive into their third decade of life.

Like other chronic pediatric illnesses, Batten disease impacts families. Compared to caregivers of children with non-neurodegenerative, chronic medical conditions, caregivers of children with Batten disease have greater levels of depression and anxiety [3, 4]. Greater behavioral problems in children with Batten disease are associated with lower parental quality of life [5].

Several factors may be associated with the mental health and coping abilities of parents caring for chronically ill or disabled children, including the available social support and family relationship quality [6-14]. Parents have reported that support from close family members, particularly a spouse, was the most important factor in their ability to cope with a child's disability or chronic illness [9, 11, 15]. Higher marital satisfaction was associated with decreased parenting stress and/or fewer depressive symptoms [10, 16, 17]. Parents also receive support from parents of other affected children [15, 18, 19]. Use of the internet for information sharing and social support may be another means to support coping strategies for parents of children with rare diseases [20].

Batten disease is a life-limiting condition requiring intensive, time-consuming, and financially burdensome care [21-23]. Difficulties in providing care may play a role in the increased parental depression and anxiety seen in Batten parents. Increased caregiving time has been associated with decreased maternal mental health in mothers of children with cerebral palsy [24], but this has not been studied in Batten disease. Among families affected by Batten disease, little is known about the available caregiving services, whether parents consider the services helpful, or if such caregiving services improve marital satisfaction [22, 23].

We studied how parents cope with their child's illness, with three aims: 1) to identify and describe the types and

extent of caregiving services parents use to care for their affected child; 2) to determine the types of social support and information resources used by parents; and 3) to assess parental marital quality. We hypothesized that marital satisfaction would be positively associated with more hours of child caregiving services.

METHODS

Participants: Eligible participants were parents/primary caregivers of children and adults with any form of Batten disease. Prospective participants were recruited from the University of Rochester Batten Center (URBC) research contact registry, and at the 2014 Batten Disease Support and Research Association (BDSRA) family support conference (Columbus, Ohio, USA, July 24th – July 27th, 2014). At the BDSRA conference recruitment occurred by providing information about the study at a URBC-staffed table that parents were free to visit at any time to learn about research activities of our group. Separately, a study packet with an invitation to participate in the study, two copies of all study materials (one for each parent), and postage-paid return envelopes were mailed to 55 eligible families in the URBC registry, all of whom had a confirmed genetic diagnosis for their affected child. A follow-up call to each household confirmed receipt of the packet and enabled parents to ask any questions about the study. All research activities were approved by the University of Rochester's Research Subjects Review Board (RSRB#00052901). All participants completed a written informed consent process.

MEASURES

Impact of Batten Disease: We developed a questionnaire, "Impact of Batten Disease: Questionnaire for the primary caregivers of a child with Batten disease" (Appendix 1). This 54-item questionnaire assessed the types of services and support that parents accessed for their affected child. The questionnaire was developed with input from the URBC research team and with reference to a study of Batten families in the United Kingdom [22]; no Batten-specific questionnaires exist in the literature. All participants were asked to complete this questionnaire. Parents with more than one affected child completed it for the oldest affected individual in the household, to capture the broadest possible range of services over the disease course. The questionnaire asked about the child's participation in school, therapeutic activities (e.g., physical and occupational therapy), direct caregiving services (e.g., hospice, home nursing), and the average weekly hours for each. Parents also rated the perceived helpfulness of each activity or service (1 = "not helpful at all," 2 = "slightly helpful," 3 = "helpful," 4 = "very helpful"), and the payment method, if applicable. To understand any difficulties with access, we asked about services that had been applied for but not received. The questionnaire also included items regarding parents' social support network, their preferred method and source of information for learning about Batten disease, and participation in Batten-related research, support organizations, and fundraising. We also obtained demographic data about respondents and their affected children.

Dyadic Adjustment Scale: Among participants sharing a household with a spouse or partner, we assessed marital quality with the Dyadic Adjustment Scale (DAS), a 32-item self-report instrument [25]. The DAS is a widely used rela-

tionship satisfaction inventory that has been used in parents of children with chronic conditions [7, 16, 17, 26, 27]. Item responses are summed to create a total score (range: 0 – 151); lower scores indicate greater marital distress [25]. The DAS has good clinimetric properties with high internal consistency [28]. In parents of children with chronically ill children, the DAS score is predictive of marital distress [29].

Statistical Analyses: Descriptive statistics were performed for demographic variables of parents and Batten-affected individuals. We also calculated the number of children (per parent report) participating in school and therapeutic services, and receiving caregiving services, and the number of parents endorsing the various support and information-seeking activities. In evaluating caregiving service hours, we focused upon services that provided direct caregiving to the child, and in which the parent was presumed to be relieved of primary caretaking activities (e.g., in-home nursing, daycare). We performed a Pearson correlation to evaluate the bivariate relationship between the total hours of these caregiving services and DAS score. A Student's *t*-test was used to compare the DAS scores of parents who did versus did not endorse regular contact with other parents as a form of social support.

RESULTS

Sample characteristics: Participants were 29 parents (22 mothers, 7 fathers) of 23 individuals with Batten disease. Twenty-six participants were married (in six couples, both individuals participated), two were unmarried and single, and one was in a long-term relationship. Participants' average age was 49.6 years (standard deviation (SD) = 8.5, range = 31-64 years). Most participants (N = 27) responded through the research contact registry; two were recruited at the BDSRA conference. All participants were Caucasian.

All of the male participants were employed; 59% (13/22) of the female participants were employed. Of the nine unemployed females, eight were not working to provide care for their affected child. Forty-one percent (12/29) of participants said the mother was primarily responsible for parenting the Batten-affected individual; the remainder said that both the mother and father were equally responsible for parenting the affected individual.

Participants also reported their affected family member's diagnosis, current age, and age of symptom onset. Though diagnosis was self-reported when completing the survey, the genetic diagnosis was confirmed in our databases for the 27 respondents who were recruited through our research contact registry. To preserve privacy for families whose children are affected by these rare diseases, we did not report demographic characteristics among the diagnostic subgroups where fewer than 5 unique families participated. Among all affected children (N = 23), the average age was 18.1 years old (SD = 5.8; range = 7-28 years), and average age of symptom onset was 5.2 years (SD = 2.0; range = 1-9 years). The broad range for symptom onset reflects the diversity of the sample. Several affected individuals had infantile (N = 1), late infantile (N = 3), or variant late infantile (N = 2) Batten disease. The majority of children had been diagnosed with juvenile-onset Batten disease (n = 17/23; Mean age = 19.7 years, SD = 3.7, range = 13-26). Five families had two children with juvenile Batten disease, but as instructed, only the oldest affected child was the focus of the questionnaire.

Services / Care for Child with Batten Disease: On average, parents reported that their child participated in $M = 43.3$ total hours per week ($SD = 17.5$; range = 8-87) across a variety of activities and services which included attendance at school, participation in therapeutic services, and professional, para-, or non-professional caregiving (Figure 1). Of the 23 persons with Batten disease: 11 attended school, 13 received in-home nursing, and five had paraprofessional caregivers. One individual attended daycare and one received hospice care. All 11 children who attended school had special education placements, although some ($N = 4$) also participated in regular-education classes or activities. All parents whose affected child received in-home nursing ($N = 13$) ranked it as “very helpful” (4 out of 4 on scale). Of the 10 parents whose child received physical therapy, nine ranked it as “helpful” or “very helpful.” Of the six parents whose child received occupational therapy, four ranked it as “helpful” and two as “slightly helpful.”

Parents also reported their current method of payment for caregiving or therapeutic services and the services they applied for, but were ineligible to receive. Table 1 shows payment methods used for in-home nursing and paraprofessional in-home care. Some families used more than one payment method. Eight parents also reported applying for but failing to receive benefits through Supplemental Security Income, Social Security Disability Insurance, or a state program; ineligibility was based on family income. Four parents reported failing to receive insurance coverage for physical therapy or occupational therapy; coverage was reportedly denied due to lack of improvement after therapy.

Table 1. Payment methods for home nursing or paid caregivers

Payment Method	Number of Families	
	Nursing	Paid caregiver
Out of pocket	0	1
Health insurance	2	0
Medicaid	4	0
Medicaid Waiver	6	2
State program/waiver	4	2

Information and Support: The four most common sources from which parents sought information about Batten disease were: a specialist, such as a neurologist or pediatric neurologist ($N = 11$), internet websites ($N = 11$), the BDSRA ($N = 6$), and other parents of children with Batten disease ($n = 4$). Other less frequent sources of information included research journals, a primary care provider, family or friends, and the URBC. Ninety three percent (27/29) of parents said that they used websites or social media to learn about or discuss Batten disease; of these, 11 reported daily use and 11 others reported weekly ($N = 3$) or least monthly use ($N = 8$). An additional 5 parents engaged online (websites or social media) with Batten content less than one time per month. The most frequently endorsed method was learning from other parents of children with Batten disease (Figure 2). Parents also indicated interest in learning more about a variety of topics, including information on Batten research progress ($N = 20$), symptom management ($N = 19$), obtaining health care services ($N = 17$), caregiver support ($N = 15$), and financial/legal matters ($N = 11$).

Aside from specific use of the internet or social media to learn about Batten disease, approximately 76% (22/29) of parents reported they were in regular contact (at least monthly) with other Batten-affected families, and most used more than one form of contact: phone ($N = 18$), website ($N = 18$) email ($N = 14$), in person ($N = 13$), and mail ($N = 4$).

Dyadic Adjustment Scale: The DAS questionnaire was completed by 86% (25/29) respondents. The mean DAS score in this study was 101.2 ($SD = 21.0$, range = 40-128). Previous studies have used a DAS score ≤ 97 as an indicator of marital distress [7, 16, 25, 30], as this score falls one standard deviation below the mean score of 114.8 in Spanier’s original study [25]. In the present investigation, 28% (7/25) of participants had a DAS score ≤ 97 , suggesting marital distress; in the general population, 16-20% of respondents are expected to have DAS scores indicative of marital distress [30]. We also evaluated whether the mean DAS score in the current sample was lower than in Spanier’s reference sample; a one sample t test showed this difference was significant: $t(24) = -3.23$, $p < 0.01$, 95% confidence interval (95%CI) [92.58, 109.90]. The mean DAS score in the present sample was also significantly lower than that found in a study evaluating marital quality among parents of chronically ill children, where the DAS score was quite similar to Spanier et al.’s reported Mean DAS score = 114.5: $t(24) = -3.16$, $p < 0.01$, 95%CI [92.58, 109.90] [29]. Among children receiving any professional, paraprofessional, or nonprofessional caregiving services, we evaluated the association between the total weekly caregiving hours and the parents’ DAS score. This association was not significant ($r = .12$, $p = 0.61$; $n = 19$).

DISCUSSION

Most parents received daily caregiving services for their child, made possible for most by Medicaid, Medicaid waivers, and state programs. In-home nursing was perceived as being “very helpful” for all families receiving this service. Children attending school always received special education services, illustrating increased needs for these individuals as well. It is also possible that some caregiving services were provided during the school day, such as nursing or personal aid care. Despite special education and/or caregiving services for most children, over 50% of parents wanted to learn more about obtaining health care services and caregiver support. This suggests that even with the extensive services already provided, more support was still needed. Additionally, in some cases, insurance coverage for therapeutic services such as occupational or physical therapy was denied because of lack of improvement, not unexpected given that all forms of Batten disease are degenerative. It would be informative to study whether affected individuals nonetheless receive therapeutic benefit from such services, in the form of symptomatic relief, maintenance of function, or enhanced quality of life.

Marital quality was assessed via the DAS, which revealed 28% of parents had scores indicating marital distress as defined by Spanier et al, and a significantly lower mean DAS score than the general population. A past study of marital distress among parents of children with chronic illnesses such as cystic fibrosis, muscular dystrophy, and diabetes found that marital quality was comparable to that reported in Spanier et al. [25, 29]. However, a more recent study of cystic fibrosis with a similar DAS distress cutoff score found 25% of parents to have marital distress [31].

We also examined whether marital quality was associated with those particular services (e.g., daycare, nursing etc.) for the affected child that might have alleviated parents' caregiving burden. Recent studies have investigated the effects of caregiver time burden on parents' mental health and marital satisfaction by examining required caregiver time and respite care benefits [24, 27]. For instance, among parents of children with autism spectrum disorders, receiving more hours of respite care was associated with decreases in daily stress and increased marital quality. However, our study found no association between marital quality and caregiving services for the affected child. Our study may not have found an association because we did not account for associated factors such as the affected child's health characteristics. This study included children and young adults with several types of Batten disease, at various ages, and with various degrees of disability and behavioral difficulties. The affected individuals with greater health needs may be receiving more services; the potential positive impact of the services on caregiver marital quality may have been off-set by the increased health needs of the affected individual. Furthermore, some parents had more than one affected child, but we surveyed the caregiving hours for only one child per family. It is reasonable to hypothesize that families with more than one affected child might require more services and experience a greater burden of caregiving.

We also surveyed parents of children with Batten disease, regarding informational support. Parents reported on preferred methods for learning about Batten disease; among all the options, contact with other families was the most preferred learning method. Prior studies of children with special health care needs have reported that parents communicate with one another to gain advice on caregiving, medical decisions, accessing resources, and for emotional support [15, 18, 32]. Formats for parent communication include parent-to-parent education programs, support groups, and social media. Studies of parent-to-parent programs describe "parent as expert" models, where a more experienced parent is paired with a less experienced one. Parents have reported these programs help them cope with stress, decrease feelings of loneliness, and made them feel more positive [19, 33]. Such programs also helped parents to combat day-to-day problems and provided anticipatory guidance. The BDSRA offers 'parent mentoring' as an informal support program, pairing newly diagnosed families and those with longer experience with the diagnosis, although not formally studied.

Because Batten disease is rare, it may be difficult for parents to meet face-to-face on a regular basis. In the present study, over 90% of parents in our study had used the internet (e.g., websites, social media, email, other online forums) to learn about Batten disease and/or to connect with other affected families more generally, with many endorsing daily use. Like the parent-to-parent programs described above, studies have shown that parents of children with rare diseases use the internet for both problem solving and psychological coping [20, 32]. In a study of internet-based parent support groups for children with special health needs, 98% of parents received "problem-focused support" and 90% received "emotional support" [15]. Social media platforms such as Facebook have also been used by parents of children with chronic disease for emotional support, advocacy, fundraising, and information sharing [34-36], and including by the BDSRA. However, internet use may not always yield positive emotional results. In an ethnographic study

of parents of children with genetic disorders, some parents "talked about the anxiety caused by online resources that contained contradictory advice, failed to answer questions, painted a dire portrait of their child's future, or made them feel as though they had to keep looking to find the missing piece or link to information that would help their child" (p. 22); [32]. The proportion of internet/social media use devoted to emotional support vs. information gathering was not differentiated in our study and future studies could investigate this more directly. Future research could also be helpful in distinguishing between helpful and non-helpful emotional support.

It is interesting that parents preferred to learn from each other rather than from clinicians or researchers. There are relatively few clinicians with Batten disease expertise, and parents may have limited access to expert clinicians to address unique and challenging symptoms [21]. Parents may also prefer support from other parents because of the emotional challenges of having a child with a neurodegenerative and terminal condition. Future research could investigate whether Batten parents desire parent-to-parent support and communication more than parents of children with other diseases, and could explore whether this preference is due to informational vs. emotional challenges, and/or challenges in accessing expert care.

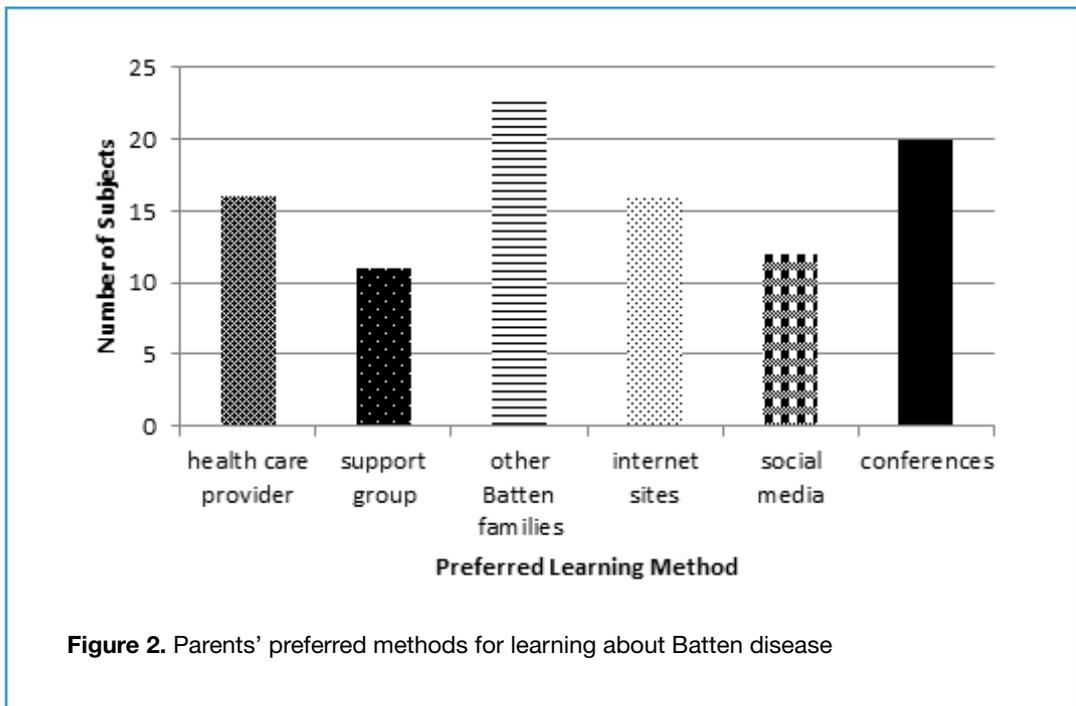
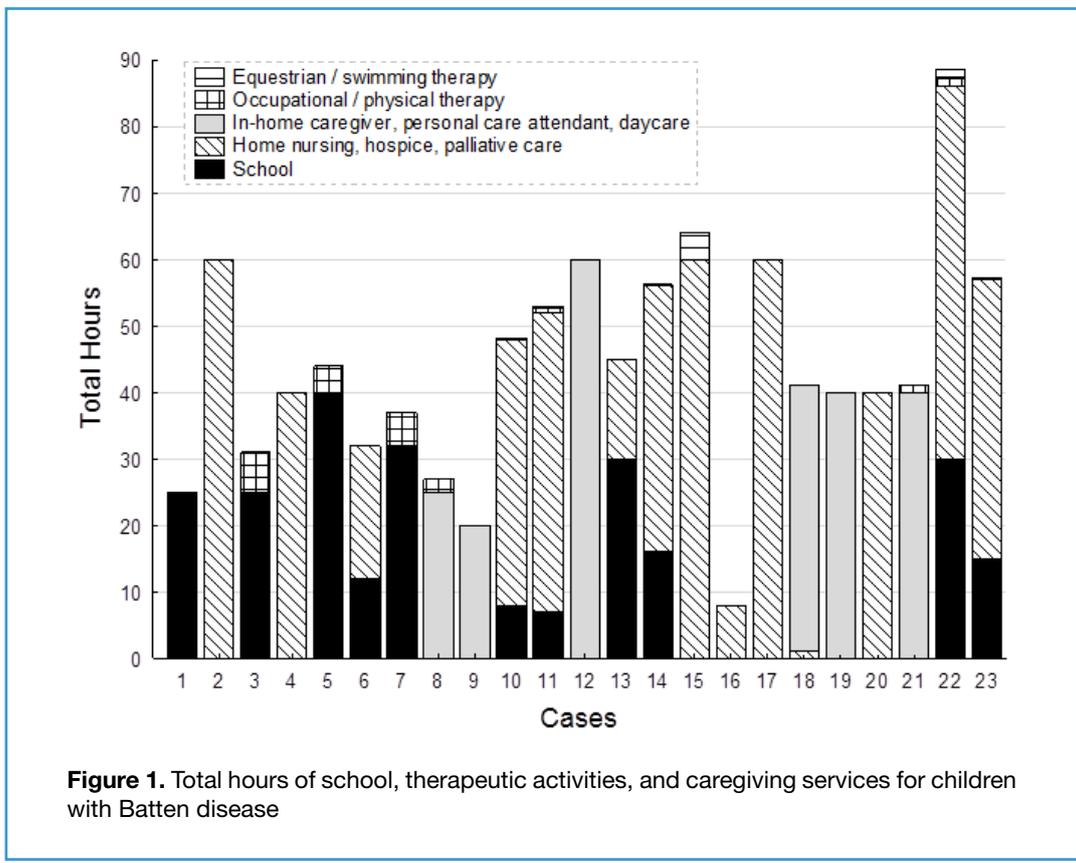
There are some limitations of our study; all participants were recruited from the URBC disease research contact registry or at the BDSRA conference, potentially creating selection bias in the sample. Though we had genetic confirmation for most affected children, the diagnosis was based upon self-report for the parents who participated at the BDSRA meeting. We also selectively focused on the oldest Batten-affected child in a family, but those with more than one affected child, or a different duration of experience with the disease may have different experiences with the support and information they sought, their marital quality, and the types or levels of services needed for their affected children. Additionally we recognize non-participation bias may have affected the results; participants may have had relatively less burden of care related to their Batten affected child, affording them more time to participate in the study.

CONCLUSIONS

The results of this study indicate that Batten parents use the internet and social media frequently to learn and talk about Batten disease, and they prefer to learn from each other as opposed to learning from clinicians or other resources. Future research could clarify how parents use the internet and social media, and determine whether parent-to-parent learning is aimed at emotional and/or informational support. We also found that marital quality may be reduced in Batten parents. These findings warrant further efforts to understand the nature of marital distress in parents of children with Batten disease and how to enhance marital quality.

Abbreviations:

BDSRA	Batten Disease Support and Research Association
DAS	Dyadic Adjustment Scale
NCLs	Neuronal ceroid lipofuscinoses
URBC	University of Rochester Batten Center



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Declarations

HRA and JWM are members of the BDSRA Medical Advisory Board. The authors declare that they have no competing interests.

Author contributions

All authors contributed to the research presented here. EC conceived of the study, implemented the research, and had primary responsibility for interpreting results and preparing and revising the

manuscript. EFA contributed to the study design, analytic plan, and interpretation of results. JWM provided research advisement, and interpretation of results. ERT assisted with study recruitment. HRA provided research advisement, conducted statistical analysis, and contributed to interpretation of results. All authors contributed to manuscript preparation and approved the final manuscript.

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