



# Patient- and caregiver-reported factors associated with school absenteeism in children with chronic kidney disease

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## Abstract

**Background** Children with chronic kidney disease (CKD) are at risk for neurocognitive deficits while simultaneously being at risk for chronic school absenteeism ( $\geq 18$  school days per school year). Chronic school absenteeism compounds the negative impacts of CKD on academic achievement. In this study, we examined patient- and caregiver-reported factors associated with school absenteeism in children with non-dialysis- or transplant-dependent CKD in order to help identify which factors could be modifiable and ultimately improve school attendance.

**Methods** We utilized a combination of chart review and questionnaires distributed in person to patients and caregivers at a pediatric nephrology clinic between November 2018 and August 2019 to gather data. We used descriptive statistics to illustrate clinical characteristics of the children included in the study, caregiver characteristics, and examined reported reasons for missing school.

**Results** Twenty-one percent of participants (10/48) missed 18 full days of school or more, categorizing them as chronically absent. The top three reasons for missing school were doctor appointments, feeling sick, and being bullied. More specific sequelae of CKD were not highly reported as reasons for missing school.

**Conclusions** Chronic absenteeism is a highly reported phenomenon among children with pediatric CKD. Given that missing school for doctor appointments was a top reason for absenteeism, this data suggests alternative appointment hours and virtual appointments may reduce chronic school absenteeism in children, and by extension improve their health, behavioral, and academic outcomes.

**Keywords** Chronic kidney disease · School · Absenteeism · Academic achievement · Chronic illness

## Introduction

Chronic school absenteeism is defined as missing 10% or more of school days per school year ( $\geq 18$  school days) [1]. Using this definition of absenteeism, data from the US National Health and Nutrition Examination Survey (NHANES) demonstrates that 2.7% of children are chronically absent from school based on self-reported survey data [2, 3]. Children who are chronically absent from school

are at risk for lower academic achievement and behavioral, social, and health sequelae [4]. One subset of students who are particularly at risk for school absenteeism and its resultant negative outcomes are children with chronic illness. Previous research demonstrates the heightened risk of absenteeism in children with asthma, diabetes mellitus, sickle cell disease, and other chronic illness populations [1, 4–11]. Unfortunately, limited research exists on school absenteeism in children with chronic kidney disease (CKD), particularly patient- and family-reported data. School-age children, independent of whether they have a chronic disease, report illness as the most common reason for missed school days [4]. Additionally, children with chronic illness may not be receiving the additional school support they often require [12]. A diagnosis of CKD requires children to navigate frequent clinic visits, laboratory tests, medications, and, depending on etiology, may require bladder catheterization or immunosuppressive medications. Children with mild-to-moderate

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CKD are at risk for neurocognitive deficits, with glomerular filtration rate (GFR) being a significant predictor for overall academic achievement [13]. Thus, school absenteeism is one important factor which, if modified, could mitigate against the known impacts of CKD on achievement. Prior research, using data from the NIH-funded Chronic Kidney Disease in Children (CKiD) multicenter cohort study, demonstrates that the relative risk of chronic school absenteeism among children with CKD is 6.2 times that of the NHANES population [2]. Factors previously associated with school absenteeism include female sex, lower maternal education, glomerular etiology of CKD, enuresis or bladder catheterization, greater medication burden, and acute illness [2]. We used a survey of children with mild-to-moderate CKD and their caregivers to examine patient- and caregiver-reported factors associated with school absenteeism in order to help identify modifiable risk factors to optimize school attendance.

## Methods

We obtained Institutional Review Board approval at Oregon Health and Science University prior to study implementation. We conducted a non-anonymous, cross-sectional descriptive study of child and caregiver perceived factors influencing school absenteeism among children with CKD stages 1 through 4. Children with a diagnosis of CKD who were  $\geq 6$  years of age and  $< 19$  years of age were eligible for inclusion, as this study was evaluating school-age children. Children who were dialysis or transplant dependent, homeschooled, currently undergoing oncology treatment, or did not speak English were excluded. Intellectual disability was not used as an exclusion criterion since the goal was to capture all children with CKD attending school.

We utilized a combination of chart review and paper questionnaires distributed in person at a pediatric nephrology clinic between November 2018 and August 2019 to gather data. There are no known validated questionnaires to examine reasons for absenteeism among children with chronic illness; therefore, this questionnaire was created by our study team based on prior research and data from other chronic disease populations. We distributed two different versions of the questionnaire, one for children and the other for caregivers. The child and caregiver surveys contained the same questions, but were directed at the proper recipient (Supplementary Material 2 and 3). Children only completed the survey if they were 10 years of age or older and intellectually able to complete the study. Thus, for participants 10–18 years old, we collected separate surveys from both the children and their caregivers. The survey was designed to assess a broad range of medical, social, and school-related factors, given that little is known on this topic. Child and caregiver questionnaires were collected to determine if

discrepancies in patient reported outcomes existed between the two groups. We collected the following variables via chart review: age of child in years, sex, etiology of CKD (glomerular vs. non-glomerular), stage of CKD, presence of hypertension, and medication burden. The survey assessed self-reported number of full and partial missed school days in the last year, perceived child health status, utilization of additional school accommodation (known as an individualized education plan (IEP) or 504 plan), diagnosis of anxiety or depression, whether the child takes medications at school, caregiver age, caregiver relationship to the child, caregiver education level, and family income. Some of these factors are known to be associated with absenteeism in other populations, and others were exploratory potential patient-reported factors leading to absenteeism. All of these variables were based on child or caregiver report. Additionally, we collected information on factors impacting school attendance and attitudes towards school through Likert scale questions.

We used descriptive statistics (frequency, percentage) to characterize clinical characteristics of the children included in the study, caregiver characteristics, and examined reported reasons for missing school. We examined caregiver responses for non-Likert scale questions since more caregivers were eligible to fill out the survey than children, and child and caregiver data was congruent in these areas. For the Likert scale questions, however, we examined both child and caregiver responses, as we felt there could be variation between child and caregiver perceptions. Because this was a preliminary survey study with a small sample size, we approached analyses as hypothesis-generating rather than hypothesis-testing, so only descriptive statistics are reported. Analyses were conducted using SAS version 9.4 software (Copyright © 2016 SAS Institute Inc., Cary, NC). Given that this is a pilot study to identify patient-reported factors associated with absenteeism, we focused on reporting results that could be modifiable and helpful to clinicians caring for these children.

## Results

The analysis included 48 children with mild-to-moderate CKD, with a mean age of 13 years (range 7–18 years; Table 1). All 48 caregivers completed questionnaires, while 10 of the 48 children were younger than 10 years old and thus 38 total children completed questionnaires. The participants were 69% male (33/48). Based on caregiver response, the majority of children (90%,  $n = 43$ ) had non-glomerular causes of CKD, 83% ( $n = 40$ ) had CKD stage 2 or 3 at the time of survey distribution, and 31% ( $n = 15$ ) had a diagnosis of hypertension (Table 1). Medication burden varied substantially among participants: 17% ( $n = 8$ ) of children

**Table 1** CKD clinical characteristics, collected via chart review

Characteristic	<i>n</i> <i>N</i> =48	Percent
Child age		
7–9 y	10	21
10–14 y	17	35
15–18 y	21	44
Child sex		
Male	33	69
Female	15	31
Etiology of CKD		
Glomerular	5	10
Non-glomerular	43	90
Stage of CKD		
I	4	8
II	24	50
III	16	33
IV	3	6
Hypertension		
No	33	69
Yes	15	31
Number of medications		
0	8	17
1–4	18	38
5–9	15	31
≥ 10	7	15

took 0 medications, 38% ( $n=18$ ) took 1–4 medications, 31% ( $n=15$ ) took 5–9 medications, and 15% ( $n=7$ ) took 10 or more medications (Table 1). A minority of caregivers reported that their child had been diagnosed with anxiety (17%,  $n=8$ ) or depression (13%,  $n=6$ ; Table 2). Most children (71%, 27/38) and caregivers (67%, 32/48) reported the child to be in “good” health, while 29% (11/38) of children and 29% (14/48) of caregivers reported the child to be in “fair” health, and 0% (0/38) of children and 4% (2/48) of caregivers reported the child to be in “poor” health (Table 2). Caregivers who filled out the survey were on average 42.6 years old (range 26–70 years), 67% ( $n=32$ ) had an education level of “some college” or less, 56% ( $n=27$ ) had a household income of \$60,000 or less, and 73% ( $n=35$ ) were the child’s biological mother (Table 3).

Based on caregiver report, 21% (10/48) of participants missed 18 full days of school or more, categorizing them as chronically absent. The median number of missed full days was 10 (range 1–91), while the median number of missed partial days was 4 (range 0–50) (Fig. 1a and b). Just over one third of caregivers (35%,  $n=17$ ) reported that the child had an IEP, while 25% ( $n=12$ ) reported that the child had a 504 plan (Table 2). Over 65% of children and over 70% of caregivers reported that the child enjoys

**Table 2** Child characteristics, collected via survey report

Characteristic <sup>a</sup>	<i>n</i> <i>N</i> =48	Percent
Depression		
Yes	6	13
No	41	85
Don’t know	1	2
Anxiety		
Yes	8	17
No	36	75
Don’t know	4	8
Takes medications at school		
Yes	6	13
No	42	88
Individualized Education Plan (IEP)		
Yes	17	35
No	30	63
Not reported	1	2
504 plan		
Yes	12	25
No	35	73
Not reported	1	2
Child’s health status		
Good	32	67
Fair	14	29
Poor	2	4
Child’s health status (per child report) <sup>b</sup>		
Good	27	71
Fair	11	29
Poor	0	0

<sup>a</sup>All characteristics are caregiver-reported unless otherwise indicated

<sup>b</sup> $N=38$  for child-reported health status

school, has friends at school, and does well in school (Table 4). Based on Likert scale questions examining reasons for missing school, the top three reasons were doctor appointments, feeling sick, and being bullied (Table 5). Among caregivers, 69% ( $n=33$ ) reported doctor appointments were a factor, 60% ( $n=29$ ) reported feeling sick was a factor, and 19% ( $n=9$ ) reported bullying was a factor in school absenteeism (Table 5). Among children, 79% ( $n=30$ ) reported doctor appointments were a factor, 63% ( $n=24$ ) reported feeling sick was a factor, and 16% ( $n=6$ ) reported bullying was a factor (Table 5). Fewer children (11%,  $n=4$ ) and caregivers (17%,  $n=8$ ) reported that the child missed school due to being in the ER/hospital, while 13% ( $n=5$ ) of children and 10% ( $n=5$ ) of caregivers reported that the child missed school due to school anxiety (Table 5). The following did not seem to be significant factors impacting school attendance: swelling, high blood pressure, bladder issues, taking medications at school, and

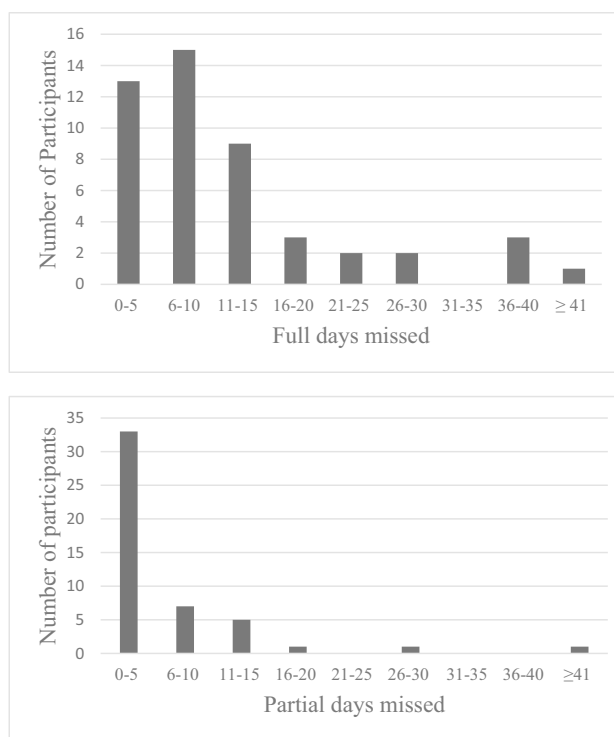
**Table 3** Caregiver and household characteristics, collected via survey report

Characteristic	<i>n</i> <i>N</i> =48	Percent
<b>Caregiver age</b>		
26–36 y	8	17
37–47 y	24	50
48–70 y	10	21
Not reported	6	13
<b>Education level</b>		
Some high school	4	8
High school graduate	13	27
Some college	15	31
College graduate	11	23
Advanced degree	2	4
Not reported	3	6
<b>Annual household income</b>		
Less than \$20,000	7	15
\$20,000–40,000	11	23
\$40,000–60,000	9	19
\$60,000–100,000	6	13
> \$100,000	12	25
Not reported	3	6
<b>Relationship with child</b>		
Mother (biological)	35	73
Father (biological)	7	15
Mother (adoptive)	1	2
Father (adoptive)	1	2
Other	1	2
Not reported	3	6
<b>Number of adults in home</b>		
1	8	17
2	26	54
≥3	11	23
Not reported	3	6
<b>Number of children in home</b>		
0	1	2
1–2	23	48
≥3	19	40
Not reported	5	10

having health problems they perceived the school could not handle (Table 5).

### Discussion

Children with CKD in this study were chronically absent from school 21% of the time, based on a definition of missing 18 or more full school days per year. This is a substantial proportion of children and does not take into account



**Fig. 1** a, b Caregiver-reported full and partial days missed

**Table 4** Child and caregiver reported perceptions about school

Attitude towards school <sup>a</sup>	<i>n</i> (%) — caregiver <i>N</i> =48	<i>n</i> (%) — child <i>N</i> =38
<b>Enjoys school</b>		
Agree	36 (75)	26 (68)
Neutral	8 (17)	8 (21)
Disagree	4 (8)	3 (8)
Not reported	0 (0)	1 (3)
<b>Has friends at school</b>		
Agree	42 (88)	35 (92)
Neutral	3 (6)	1 (3)
Disagree	2 (4)	1 (3)
Not reported	1 (2)	1 (3)
<b>Does well at school</b>		
Agree	38 (79)	32 (84)
Neutral	5 (10)	5 (13)
Disagree	5 (10)	0 (0)
Not reported	0 (0)	1 (3)

<sup>a</sup>Participants responded on the survey as “strongly agree,” “some-what agree,” “neutral,” “somewhat disagree,” or “strongly disagree.” Response categories were combined for strongly/somewhat agree and strongly/somewhat disagree to assist interpretation

partial days missed, which adds significant extra time lost in the classroom. These results are consistent with results using the CKiD cohort, which demonstrated 17.3% of

**Table 5** Child and caregiver reported reasons for school absences

Reasons for missing school <sup>a</sup>	n (%) — caregiver N=48	n (%) — child N=38
<b>Felt sick</b>		
Agree	29 (60)	24 (63)
Neutral	9 (19)	2 (5)
Disagree	10 (21)	12 (32)
Not reported	0 (0)	0 (0)
<b>Swelling</b>		
Agree	1 (2)	2 (5)
Neutral	6 (13)	3 (8)
Disagree	39 (81)	32 (84)
Not reported	2 (4)	1 (3)
<b>High blood pressure</b>		
Agree	4 (8)	3 (8)
Neutral	8 (17)	3 (8)
Disagree	35 (73)	32 (84)
Not reported	1 (2)	0 (0)
<b>Had doctor appointment</b>		
Agree	33 (69)	30 (79)
Neutral	9 (19)	2 (5)
Disagree	6 (13)	5 (13)
Not reported	0 (0)	1 (3)
<b>In ER/hospital</b>		
Agree	8 (17)	4 (11)
Neutral	6 (13)	5 (13)
Disagree	34 (71)	28 (74)
Not reported	0 (0)	1 (3)
<b>Bladder issues at school</b>		
Agree	3 (6)	2 (5)
Neutral	6 (13)	2 (5)
Disagree	38 (79)	34 (89)
Not reported	1 (2)	0 (0)
<b>Take medications at school</b>		
Agree	4 (8)	3 (8)
Neutral	4 (8)	2 (5)
Disagree	40 (83)	32 (84)
Not reported	0 (0)	1 (3)
<b>Health problems the school cannot handle</b>		
Agree	3 (6)	2 (5)
Neutral	7 (15)	1 (3)
Disagree	38 (79)	33 (87)
Not reported	0 (0)	2 (5)
<b>School anxiety</b>		
Agree	5 (10)	5 (13)
Neutral	9 (19)	4 (11)
Disagree	34 (71)	29 (76)
Not reported	0 (0)	0 (0)
<b>Have been bullied</b>		
Agree	9 (19)	6 (16)
Neutral	7 (15)	3 (8)
Disagree	32 (67)	29 (76)
Not reported	0 (0)	0 (0)

<sup>a</sup>Participants responded on the survey as strongly agree, somewhat agree, neutral, somewhat disagree, or strongly disagree. Response categories were combined for strongly/somewhat agree and strongly/somewhat disagree to assist interpretation

children with CKD were chronically absent [2]. Although our study found a slightly higher percentage of chronic school absenteeism, our sample is too small to determine if this is a significant difference. The US NHANES survey collected self-reported data on school absenteeism up until 2008, and results from 2005 to 2008 demonstrated that 2.7% of children missed 18 or more full school days per year [2, 3]. Although there is unfortunately no NHANES data on this topic collected after 2008, the self-reported rate of chronically absent children in our study far exceeds the rate from NHANES.

The most agreed upon reason for missing school was doctor appointments. These results consequently make a strong case for expanding clinic availability to include evening and weekend appointment options. Furthermore, this study was conducted before the SARS-CoV-2 pandemic, at which time virtual visits were not yet a routine part of most nephrology practices. Since the pandemic began, clinics have adapted to include more video visits, and the results from this study reinforce the importance of keeping those appointment options as a long-term part of medical care. Many patients travel hours to attend pediatric nephrology clinic appointments, and by offering video visits when appropriate, patients may miss fewer school days due to travel. Additionally, the results stress the importance of continuing to offer outreach clinics, so that when patients do need an in-person appointment, they may be able to do so closer to home. Children with mild-to-moderate CKD are at risk for poorer neurocognitive outcomes, and children who are chronically absent from school are also at risk for poorer academic, behavioral, and health sequelae [4, 13]. The multiplicative nature of these two problems makes it crucial to actively implement preventative measures to reduce school absences in children with CKD. Clinic policy and appointment availability are a modifiable area in which to start.

Sequelae of CKD, such as edema, hypertension, bladder issues, and medication burden, were not highly reported as reasons for missing school in our population. “Feeling sick” in general was highly reported, but this does not necessarily point to CKD-specific sickness. Feeling sick was included in the survey as illness/perceived illness is the most common reason for missing school in the general school-age population, as well as other studies of children with chronic health conditions [4, 14]. Caregivers of children with CKD may perceive their children as more vulnerable given their chronic disease. This perception may make these children more likely to stay home when feeling ill in comparison to their peers without chronic disease. Additionally, this perception of vulnerability may have rightfully worsened during the pandemic, which we would hypothesize caused more school absences during this time.

Bullying was the third most agreed upon reason for missing school (reported by 16% of children and 19% of

caregivers). Previous research has established that children with chronic diseases are more likely to be victims of bullying than their peers without chronic disease [15]. The vast majority of such research does not examine children with CKD, however. One study which surveyed adolescents with CKD across 15 centers demonstrated that CKD patients had a lower rate of being bullied at school compared to the national prevalence [16]. In the CDC's 2019 Youth Risk Behavior Survey, 19.5% of high school students reported being bullied on school property [17]. Our study specifically asked whether children missed school due to bullying, not whether they had been bullied at all. Additionally, it included children younger than high school. Thus, it is not possible to discern the overall rate of bullying among survey participants from this data. Further studies examining the rate and impact of bullying across the age spectrum of children with CKD would be useful. A multitude of factors contribute to children with CKD being targets of bullying. For example, social and physical quality of life is known to be impacted by short stature, which could make them feel socially isolated and more likely to be victimized [18]. Though relatively few families in our study reported that the child missed school due to bladder problems or taking medications at school, these differences—which may be visible to peers—could also make this subset of children especially at risk of being bullied. Finally, missing significant amounts of school can lead to a spiral of further social isolation and victimization.

Children with chronic health conditions often do not receive the appropriate school supports that would help to optimize school attendance and success. IEP and 504 plans represent the most common school supports and combined were utilized by about 60% of the study population. This is in stark contrast to the percentage of school children overall receiving special services, which was reported to be 15% by the Department of Education in 2020–2021 [19]. Although it is a positive sign that over half of children with CKD in this study use some form of school accommodation, such utilization likely is not enough to help reduce absenteeism, given that CKD qualifies most of them for additional supports. Studies suggest that positive education practices targeted at improving student wellbeing and addressing mental health, as opposed to focusing solely on traditional academic goals, can help lower absenteeism in children with chronic illness [20]. More intensive approaches to improving school engagement are one potential future strategy to improve attendance in children with CKD. Appropriate school supports also impact how children feel about taking medications at school [21]. Research has shown that a child's ability to take medications during the school day is impacted by side effects, peer and staff attitudes, and whether medications are scheduled or as needed [21]. There are high levels of non-adherence among children taking medications, and

educational interventions alone have not been successful in improving adherence, further illustrating the multitude of factors influencing a child's ability to take medications at school [22]. It is reassuring that this study population did not report "taking medications at school" as a common reason for school absence. This may reflect the relatively high percentage receiving accommodations through IEP or 504 plans, school staff who are appropriately familiar with management of the child's illness, or medication regimens that have been optimized for minimal disruption at school.

In diabetes mellitus, as well as other chronic conditions, it has been reported that school nursing support, autonomy for children to perform their own medical care, and teachers' understanding of disease are limited and lead to dissatisfaction and potentially more missed school days [10, 23]. Patients with sickle cell disease note that school personnel frequently lack information on the disease and its management in the school setting, despite the patients themselves being knowledgeable about disease management and ways in which they can attain classroom success [24]. Among children with cystic fibrosis, self-efficacy correlates with academic achievement and positive attitudes towards school, which highlights the importance of fostering children's autonomy in their medical care in the school setting [25]. High school students with asthma who felt encouraged by school nurses to get treatment or perform self-treatment were more likely to stay in class, once again echoing the importance of school nursing support and autonomous disease management [8]. A small percentage of our study population reported "health problems that the school cannot handle" as a reason for school absences. However, if a child does not attend due to other symptoms (swelling, blood pressure, other illness symptoms), this may be indirectly reflective of such a reason, since the child or caregiver may be worried about how the school will handle these symptoms. The impact of school nursing support, teacher support, and communication regarding health needs with the school for children with CKD should be further explored.

Our study was limited by a small sample size at a single center, thus restricting its generalizability to the general pediatric CKD population. Additionally, the results may have been impacted by the setting of survey distribution. Surveys were distributed in clinic, which may have caused some children and caregivers to overestimate the number of missed school days due to doctor appointments since many were missing school at the time the survey was administered. Furthermore, the study was conducted prior to the pandemic, and rates of school absenteeism for those with chronic illness have likely been substantially impacted by the pandemic. However, the significance of this problem even before the pandemic highlights the need for addressing this issue. Future research should include a larger sample size of children with CKD across multiple

centers. There is a substantial amount of research in other pediatric chronic disease populations that addresses school absenteeism and its associated factors, while a knowledge gap exists among patients with CKD [1, 4–11]. Therefore, further studies not only need to examine more children with CKD, but should also evaluate these patients alongside children with other chronic diseases in order to compare their experiences. Finally, future research should evaluate the impact of the pandemic on school attendance. This should include whether virtual school and virtual medical appointment options helped children with CKD or whether fear of COVID-19 increased absenteeism in this population.

Overall, this study suggests that alternative appointment hours and virtual appointments may reduce chronic school absenteeism in children with CKD and may by extension improve their academic outcomes. It also identifies common patient-reported factors as reasons for missing school, for example feeling sick and being bullied, and highlights the need for providers to ask about these factors in clinic. A patient-centered approach to care calls upon clinicians to obtain and act upon patient-reported outcome metrics, as they can illustrate patient priorities and in certain instances are even sensitive to clinical status. Thus, clinicians should be identifying and actively intervening against patient-reported risk factors for school absenteeism when they are identified, as they would do in the context of abnormal laboratory values or physical exam findings. Given the relationship between school absenteeism and long-term outcomes, this study elucidates the importance of building systems in clinic that work in conjunction with schools to support the academic success of children with chronic illness.

**Supplementary Information** The online version contains supplementary material available at <https://doi.org/10.1007/s00467-022-05780-2>.

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**Author contribution** Kelsey Richardson and Sarah Craven contributed to the study conception and design. Material preparation, data collection, and analysis were performed by Barbara Brumbach and Sarah Craven. The first draft of the manuscript was written by Sarah Craven, and all the authors contributed to the final manuscript. All the authors have read and approved the final manuscript.

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**Data availability** The datasets generated and analyzed for this current study are available from the corresponding author on reasonable request.

## Declarations

**Ethics approval** This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Institutional Review Board of Oregon Health and Science University.

**Consent to participate** Informed consent was obtained from legal guardians and assent was obtained from minor participants as per institutional guidelines.

**Competing interests** The authors declare no competing interests.

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