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Understanding Fertility Attitudes and Outcomes Among Survivors of Adolescent and Young Adult Cancers in a Low-Resource Setting: A Registry-Based Computer-Assisted Telephone Interview Survey

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Purpose: To establish the extent of self-reported reproductive failure associated with cancer treatment, and attitudes toward fertility among adolescent and young adult (AYA) cancer survivors in Uganda.
Methods: A registry-based computer-assisted telephone interview survey was conducted in Uganda. The survey population were survivors of childhood, adolescent and early adulthood cancers diagnosed between 2007 and 2018. The survey explored fertility outcomes, experiences of oncofertility and fertility attitudes of AYA cancer survivors.
Results: Thirty-four (female = 14 and male = 20) interviews were completed. Survivors were 18–35 years of age. The median age at cancer diagnosis was 23.5 for females and 17.5 for males. Kaposi's sarcoma contributed to 44% of primary cancer diagnoses. All the survivors had received chemotherapy alone or in combination with other modalities and 79% of survivors had not received satisfactory information about future fertility before cancer treatment. Twenty one percent of males and 46% females met the criteria for infertility and 60% of these had met this criterion after their cancer diagnosis. Eighty two percent wanted to raise a biologically related child. Forty seven percent would be dissatisfied with their lives if they were unable to have a child or additional children.
Conclusion: AYA cancer survivors in this low-resource setting reported reproductive failure, despite a strong fertility desire. Information and counseling provided on therapy-related problems before cancer treatment was insufficient and reinforces the need to build capacity for oncofertility resources within the region.

Keywords: oncofertility, AYAs, survivorship, low-resource, Uganda, CATI

Background

While cancer cases are increasing globally,[1] knowledge of risk factors, advances in screening, and treatment have reduced cancer-related mortality, in low-resource settings.[2] The growing number of cancer survivors face lifelong effects from their disease and treatment.[3] The long term effects can be damaging for adolescent and young adult (AYA) cancer survivors, who experience these changes at a critical point during their development.[3] In

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particular, young cancer survivors are often faced with the reproductive failure associated with certain highly curative regimens of chemotherapy and radiation. These reproductive morbidities include, but are not limited to amenorrhea, premature menopause, and subfertility in women, and spermatogenic failure and infertility in men.[4–6] As a result, several major oncology and fertility societies have recommended that fertility preservation be discussed before starting cancer treatment.[7–9]

Despite the global campaign to increase access to fertility preservation for cancer patients, Uganda has lagged. The overall childhood cancer incidence in Kyadondo County, Uganda is 139 in one million children 0–19 years of age.[10] Although the country-specific long-term survival rates for most cancers within this age group are suboptimal,[11] the AYAs who survive these cancers have limited opportunities for fertility counseling and preservation. In addition, the lack of local expertise in gonadal tissue cryopreservation eliminates any fertility preservation options for prepubescent and teenage children in Uganda. While gamete and embryo freezing are available in Uganda, these services are provided in private facilities. Although access to these services by cancer patients is largely unknown, awareness and costs of gamete and embryo freezing can be prohibitive. Thus, because of a substantial awareness and knowledge gap regarding cancer-related reproductive failure, little or no fertility preservation is provided for cancer patients in Uganda.

Inadequate awareness and policies in Uganda on cancer-related reproductive failure stem from a lack of data about reproductive failure among cancer patients in Uganda. Although reproductive failure after cancer treatment in AYAs has been extensively described in high resource settings,[12–16] there are few anecdotal reports and no published data on these reproductive outcomes in Uganda. In addition, attitudes toward future fertility among survivors of AYA cancer in Uganda are unknown.

This study aimed to establish the extent of self-reported reproductive failure associated with cancer treatment among AYA cancer survivors in Uganda. In addition, we described the attitudes toward future fertility among survivors of AYA cancer.

Methods

Study design

This study utilized a Computer-Assisted Telephone Interview (CATI)-based cross-sectional survey. CATI is a robust reliable method of collecting community-level health-related data.[17–19] The purpose of the survey was to obtain population-level data about self-reported reproductive failure, fertility attitudes, and access to fertility preservation among survivors of AYA cancer. We abstracted data from the Kampala cancer registry (KCR) for AYAs diagnosed in a 11-year period that is, between 2007 and 2018.

Setting

The KCR was chosen to obtain the study population for the survey because it is the oldest, curated, and complete source of cancer incidence and outcome data in the region. Initiated in 1951, the KCR collects data on cancer incidence for the population of Kyadondo County, which includes the city of Kampala—the capital of Uganda—and a periurban area extending approximately 30 Km to the North.

Population

The survey population were survivors of adolescent, and young adult cancer diagnosed between 2007 and 2018. Participants eligible for the survey were at least 18 years of age, diagnosed with cancer between the ages of 0 and 25 years, alive at time of last contact, and with complete registry information.

Survey instruments

We designed the Understanding Reproductive Health among Survivors of Pediatric and Young-adult (URHSPY) cancer CATI questionnaire based on the Furthering Understanding of Cancer, Health, and Survivorship in Adult (FUCHSIA) Women's[19] questionnaire. The FUCHSIA questionnaire was the most suitable to answer the research questions. This questionnaire addressed salient elements of reproductive health among cancer survivors. The URHSPY cancer CATI questionnaire was developed from the FUCHSIA questionnaire by modification, deletion and addition of questions that were context sensitive and addressed study objectives. In addition, a version for male survivors was designed and made suitable to explore reproductive health among male cancer survivors. The URHSPY cancers CATI addressed (1) cancer history, (2) oncofertlity, (3) demographics, (4) menstrual health, (5) infertility history, (6) pregnancy history, and (7) lifestyle.

Infertility criteria was same as that used in FUCHSIA[19] survey and was as follows:

Females: Unprotected sex at least once a week with a male partner for 12 months or longer but did not get pregnant.

Males (modified from female definition): Unprotected sex at least once a week with a female partner for 12 months or longer but did not get her pregnant. Two versions of the questionnaire, English and Luganda dialect, were designed and pretested.

Data collection

The final version of the pretested URHSPY cancer questionnaire was programed into REDCap data capture software. All eligible participants were contacted by telephone. The interviewer read the questions directly off the interactive computer screen, waited for the respondent's corresponding verbal answer and entered the data into the REDCap survey instrument.

Ethics

The study was reviewed and approved by the Uganda Cancer Institute (UCI) and the University of Minnesota Institutional Review Boards.

Statistical methods

All survey data were entered in REDCap,[20] extracted, and analyzed in Microsoft Excel Version 16.6. Descriptive statistics were performed on the data to estimate various proportions and means of the survey responses. Further analysis to draw inferences from the responses in each survey section was conducted using chi-squared tests. A p-value of <0.05 was considered significant.

Table 1. Summary of Reasons for No Interview ($N=225$)

Reason	*Count*	*Proportion (%)*
Cannot be reached at the moment	91	40.44
Wrong number	65	28.89
Dead	49	21.78
Misdiagnosis	8	3.56
Repeated record	4	1.78
Double entry	4	1.78
Refused to take part	2	0.89
Age at diagnosis >25	1	0.44
Language barrier	1	0.44

Results

A total of 2321 entries existed in the registry for childhood, adolescent, and young adult cancer from the period of 2007–2018. Of these 259 were eligible. Attempts were made to contact all 259 potential participants but only 34 interviews were completed. The common reasons for no interview included phone numbers that could not be reached (40.44%), wrong number (28.89%), and dead participant (21.78%) (as summarized in Table 1).

Population characteristics

Fourteen female and 20 male participants completed the survey and were included in the analysis, as summarized in Table 2. Participants were 18–35 years of age, with a median age of 27 for females and 24.5 for males. The median age at cancer diagnosis was 23.5 for females and 17.5 for males, as summarized in Table 3. The common primary cancer diagnosis was Kaposi's sarcoma, affecting 15/34 (44%) of participants. Other cancer diagnoses included Hodgkin lymphoma, choriocarcinoma, and skin cancer. Almost all (27/34, 79%) received only chemotherapy, while five received additional surgery. One received additional radiation, and one an additional other treatment.

Oncofertility discussion

Only seven participants recalled discussing the impacts of cancer treatment on their fertility before or during the treatment, and none of these discussions resulted in a referral to a fertility specialist (as summarized in Table 4). A majority (27/34, 79%) disagreed or strongly disagreed that they received enough information about possible effects of cancer treatment on future fertility from a medical professional before cancer treatment. However, 15/34 participants noted that preparing to undergo treatment for cancer was too stressful at the time to consider how the treatment would affect their future fertility.

Fertility outcomes

Although only two participants had been told by a medical professional that they had a medical condition that could prevent pregnancy, 4/19 (21%) sexually active males and 6/13 (46%) sexually active females met the criteria for infertility. For 6 of these 10 participants, this period of time occurred after their cancer diagnosis (as summarized in Table 5). Of the participants who met the criteria for infertility, 6 out of 10 were actively trying to conceive. Five participants reported later visiting a doctor for fertility concerns, of whom two pursued fertility treatments. The average parity among women was two, whereas men were responsible for an average of 0.9 pregnancies. Nine female participants had given birth to at least one child at the time of the survey, with an average of 1.3 live births. Eight men had fathered a child, averaging 0.85 children. Of the 10 women who had been pregnant at least once, eight experienced their first

Table 2. Population Characteristics ($N=34$)

Female, n=*14;* n *(%)*		*Male,* n=*20;* n *(%)*	
Median age (years)	27	Median age (years)	24.5
Minimum age	20	Minimum age	18
Maximum age	35	Maximum age	33
Educational status		Educational status	
Less than primary school	2 (14)	Less than primary school	0 (0)
Primary-level graduate	2 (14)	Primary-level graduate	4 (20)
Lower secondary-level graduate	4 (29)	Lower secondary-level graduate	9 (45)
Higher secondary-level graduate	2 (14)	Higher secondary-level graduate	2 (10)
Technical or vocational school graduate	1 (7)	Technical or vocational school graduate	3 (15)
Graduate degree	3 (21)	Graduate degree	2 (10)
Employment		Employment	
Unemployed	6 (43)	Unemployed	7 (35)
Full time	5 (36)	Full time	8 (40)
Part time	3 (21)	Part time	5 (25)
Median annual income ($)	464.03	Median annual income ($)	1237.43
Marital status (*n*/*N*)		Marital status (*n*/*N*)	
Married	2 (14)	Married	2 (10)
Living with a partner	1 (7)	Living with a partner	5 (25)
In a committed relationship but not living together	3 (21)	In a committed relationship but not living together	0
Single	8 (57)	Single	12 (60)
Other	0	Other	1 (5)

Table 3. Cancer Treatment Characteristics ($N=34$)

Female, n = *14;* n *(%)*		*Male,* n = *20;* n *(%)*	
Median age at diagnosis (years)	23.5	Median age at diagnosis (years)	17.5
Minimum age	9	Minimum age	5
Maximum age	25	Maximum age	22
Primary cancer diagnosis		Primary cancer diagnosis	
Kaposi's sarcoma	8 (57)	Burkitt lymphoma, NOS	3 (15)
Choriocarcinoma, NOS	1 (7)	Hodgkin's lymphoma, NOS	2 (10)
Skin cancer	2 (14)	Kaposi's sarcoma	7 (35)
Colon cancer	1 (7)	Malignant lymphoma, NOS	1 (5)
Thyroid cancer	1 (7)	Chronic myeloid leukemia	3 (15)
Brain tumor	1 (7)	Spindle cell carcinoma	1 (5)
		Teratocarcinoma	1 (5)
		Nasopharyngeal carcinoma	1 (5)
		Fibrosarcoma	1 (5)
Treatment		Treatment	
Surgery[a]	2 (14)	Other treatment[a]	1 (5)
Radiation[a]	1 (7)	Surgery[a]	3 (15)
Chemotherapy alone	11 (79)	Chemotherapy alone	16 (80)

[a]Treatment in combination with chemotherapy.
NOS, not otherwise specified.

pregnancy before their cancer diagnosis. Four out of eight men who had gotten a woman pregnant at least once had done so before they were diagnosed with cancer.

Fertility attitudes

Males and females both desired a median of four children (as summarized in Table 6). A chi-square test revealed that predicted desired number of children differed by gender, with men more likely to predict that they would raise more children than they desired, $p=0.043$. Women expected to raise fewer children than they desired, with the most common reason being financial.

Overall, 19/34 (56%) participants indicated that raising a child who was biologically related to them was somewhat or

Table 4. Oncofertility discussion ($N=34$)

Female, n = *14;* n *(%)*		*Male,* n = *20;* n *(%)*	
Discussed effects of cancer treatment on fertility		Discussed effects of cancer treatment on fertility	
No	11 (79)	No	14 (70)
Yes	3 (21)	Yes	4 (20)
Do not remember	0	Do not remember	2 (10)
This discussion occurred ($n=3$)		This discussion occurred ($n=4$)	
Before treatment	3 (100)	Before treatment	3 (75)
During treatment	0	During treatment	1 (25)
Who initiated discussion ($n=3$)		Who initiated discussion ($n=4$)	
You	0	You	1 (25)
Oncologist	2 (67)	Oncologist	3 (75)
Another specialist(s) or doctor	1 (33)	Another specialist(s) or doctor	0
Fertility referral ($n=3$)		Fertility referral ($n=4$)	
No	3 (100)	No	4 (100)
Told to delay pregnancy after treatment ($n=13$)**		Told to delay pregnancy after treatment ($n=11$)**	
No	10 (77)	No	10 (91)
Yes	3 (23)	Yes	1 (9)
Received enough fertility information		Received enough fertility information	
Agree	3 (21)	Agree	1 (5)
Neither agree nor disagree	0 (0)	Neither agree nor disagree	3 (15)
Disagree	2 (14)	Disagree	3 (15)
Strongly disagree	9 (64)	Strongly disagree	13 (65)
Cancer too stressful to consider fertility		Cancer too stressful to consider fertility	
Strongly agree	4 (29)	Strongly agree	5 (25)
Agree	3 (21)	Agree	3 (15)
Neither agree nor disagree	6 (43)	Neither agree nor disagree	10 (50)
Disagree	1 (7)	Disagree	1 (5)
Strongly disagree	0	Strongly disagree	1 (5)

**Question eligible to those diagnosed above 15 years of age.

Table 5. Fertility Outcomes ($N=34$)

Female (n = *14*)		*Male* (n = *20*)	
Infertility diagnosis		Infertility diagnosis	
No	12 (86)	No	20 (100)
Yes	2 (14)		
Previous intercourse		Previous intercourse	
No	1 (7)	No	1 (5)
Yes	13 (93)	Yes	19 (95)
Infertility criteria		Infertility criteria	
No	8 (57)	No	16 (80)
Yes	6 (43)	Yes	4 (20)
Actively trying to conceive ($n=6$)		Actively trying to conceive ($n=4$)	
No	3 (50)	No	1 (25)
Yes	3 (50)	Yes	3 (75)
Visited fertility doctor		Visited fertility doctor	
No	11 (79)	No	18 (90)
Yes	3 (21)	Yes	2 (10)
Reason for visit ($n=3$)		Reason for visit ($n=2$)	
Regular sex >1 year and not able to get pregnant on your own	2 (67)	Regular sex >1 year and not able to get your partner pregnant	2 (100)
I could not ovulate or had irregular menses	1 (33)		
Type of fertility doctor ($n=3$)		Type of fertility doctor ($n=2$)	
Gynecologist	2 (67)	General practitioner	1 (50)
Fertility specialist	1 (33)	Another specialist(s) or doctor	1 (50)
Told respondent or partner had fertility issues ($n=3$)		Told respondent or partner had fertility issues ($n=2$)	
No	2 (67)	No	1 (50)
Yes	0	Yes	1 (50)
The exact reason was never determined	1 (33)	The exact reason was never determined	0
Pursued fertility treatments ($n=3$)		Pursued fertility treatments ($n=2$)	
No	1 (33)	No	2 (100)
Yes	2 (67)		
Live births		Live births	
0	5 (36)	0	12 (60)
1	3 (21)	1	4 (20)
2	4 (29)	2	1 (5)
3	1 (7)	3	1 (5)
4	1 (7)	4	2 (10)

very important when they were 18 years old, which increased to 28/34 (82%) at the time the survey was administered; however, the differences across all five Likert categories did not reach statistical significance. Twenty five of 34 (74%) participants reported that they would be disappointed if they found out they could not become pregnant (or impregnate a female partner) or become pregnant again. Most participants expressed comfort with assisted reproductive technology or adoption (23/34 and 21/34, respectively). Around 16/34 (47%) disagreed or strongly disagreed that they would be satisfied with their lives if they were unable to have children or additional children.

Discussion

There is a paucity of data on the reproductive outcomes of AYA cancer survivors in low-income settings. In addition, although a significant number of studies report on female childhood cancer survivors in high-income settings, a paucity of data exists for males of corresponding age groups. This cross-sectional survey used a CATI-based strategy to describe the burden of reproductive failure among survivors of adolescent and young adult cancer. In addition, the survey described their oncofertility experience and fertility attitudes.

Participants were young adult women and men, with median ages of 28 and 23.5 years, respectively. Median age at cancer diagnosis ranged between adolescent for males (17.5 years) and young adult for females (23.5 years). The majority of the survivors had been treated for Kaposi's sarcoma. This was likely epidemic Kaposi's sarcoma, which is a Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS)-associated soft tissue tumor.[21,22] Kaposi's sarcoma ccntributes to a significant burden of childhood cancer in areas of epidemic HIV spread.[21,22] A disproportionate burden of pediatric Kaposi's sarcoma in Uganda has been reported by others.[10,23] The relatively high proportion within these survivors compared with other cancers represents a concurrent burden of pediatric HIV and associated tumors within the sampled time frame.[10,23] Furthermore, a combination of highly active antiretroviral therapy and chemotherapy (Bleomycin–vincristine and paclitaxel regimens)[24,25] significantly contributes to high rates of

TABLE 6. FERTILITY ATTITUDES ($N=34$)

Female (n = *14*)		*Male* (n = *20*)	
Median desired children	4	Median desired children	4
Reproductive expectations		Reproductive expectations	
I will probably raise the number of children that I want	10 (71)	I will probably raise the number of children that I want	10 (50)
I will probably raise fewer children than I want	4 (29)	I will probably raise fewer children than I want	3 (15)
I will probably raise more children than I want	0	I will probably raise more children than I want	7 (35)
Importance of biological child at age 18		Importance of biological child at 18	
Very important	8 (57)	Very important	9 (45)
Somewhat important	1 (7)	Somewhat important	1 (5)
Neither important nor not important	2 (14)	Neither important nor not important	5 (25)
Somewhat not important	1 (7)	Somewhat not important	2 (10)
Very not important	2 (14)	Very not important	3 (15)
Current importance of biological child		Current importance of biological children	
Very important	11 (79)	Very important	13 (65)
Somewhat important	2 (14)	Somewhat important	2 (10)
Neither important nor not important	1 (7)	Neither important nor not important	3 (15)
Somewhat not important	0	Somewhat not important	1 (5)
Very not important	0	Very not important	1 (5)
Desire for a or another biological child		Desire for a or another biological child	
Strongly agree	12 (86)	Strongly agree	15 (75)
Agree	2 (14)	Agree	4 (20)
Strongly disagree	0	Strongly disagree	1 (5)
Disappointed if infertile		Disappointed if infertile	
Strongly agree	9 (64)	Strongly agree	9 (45)
Agree	4 (29)	Agree	3 (15)
Neither agree nor disagree	0	Neither agree nor disagree	3 (15)
Disagree	1 (7)	Disagree	5 (25)
Comfort with ART		Comfort with ART	
Strongly agree	3 (21)	Strongly agree	2 (10)
Agree	6 (43)	Agree	12 (60)
Neither agree nor disagree	2 (14)	Neither agree nor disagree	1 (5)
Disagree	2 (14)	Disagree	2 (10)
Strongly disagree	1 (7)	Strongly disagree	3 (15)
Comfort with adoption		Comfort with adoption	
Strongly agree	3 (21)	Strongly agree	4 (20)
Agree	5 (36)	Agree	9 (45)
Neither agree nor disagree	3 (21)	Neither agree nor disagree	2 (10)
Disagree	2 (14)	Disagree	0
Strongly disagree	1 (7)	Strongly disagree	5 (25)
Satisfaction if no more children		Satisfaction if no more children	
Strongly agree	2 (14)	Strongly agree	4 (20)
Agree	2 (14)	Agree	3 (15)
Neither agree nor disagree	4 (29)	Neither agree nor disagree	3 (15)
Disagree	2 (14)	Disagree	4 (20)
Strongly disagree	4 (29)	Strongly disagree	6 (30)

ART, assisted reproductive technologies.

Kaposi's sarcoma remission.[26] Indeed, survival rates in Ugandan children diagnosed within the sampled time frame were close to 70%.[10]

Data from this population are in line with what many have reported in other settings[15,16,27–30] that chemotherapy in AYAs is associated with subsequent subfertility. In this study, 18.8% of sexually active men and women met the criteria for infertility after their cancer diagnosis. This is higher than the background prevalence of primary (1.0%–2.5%) and secondary infertility (11.6%) within the sub-Saharan Africa region, as reported by Mascarenhas et al.[31] In addition, among those that experienced pregnancies, few (33.3%) had first or subsequent pregnancies after their cancer diagnosis. This infertility rate is lower from the overall 11.5% rate of infertility diagnosis among AYA survivors reported by Velez et al.[15] However, the proportion of infertility diagnosis in that population varied between cancer diagnoses and ranged from 8.9% for breast and colorectal cancer to 17.3% for Hodgkin's lymphoma.[15]

Nonetheless, the bleomycin–vincristine and paclitaxel regimens[24,25] used in Kaposi's sarcoma treatment in the region have a low risk of gonadotoxicity.[32] Therefore, it is paradoxical that this population of mainly Kaposi's sarcoma survivors had a higher infertility rate than the background for the setting.

Despite there being nearly no experience of reproductive counseling during their survivorship, AYAs of this population had a sustained desire to raise biological children. In addition, many were open to assisted reproductive technologies (ART) and expressed dissatisfaction with the possibility of never having a child. The motivation to attempt ART is against a background of prohibitive costs, estimated at $4500 per cycle, with the median annual income for the study population ranging from $464.03 (women) to $1237.43 (men)—all below the cost estimate. This is against a background national median income that is nearly twofold less, at $632 for men and $380 for women.[33] Similar desire for future fertility among AYA survivors has been reported in other settings.[12,30,34–36] Furthermore, lack of or insufficient fertility-related information and counseling has been reported in other settings,[30,37–40] and linked to significant psychosocial distress.[34]

There is clearly a major unmet need for oncofertility among AYA survivors in Uganda. Studies in developing countries have reported deficiencies in oncofertility processes for childhood and young adult survivors.[41] Some of the barriers at the organization level include lack of awareness, lack of early cancer detection, financial burden, lack of oncofertility providers, legal and cultural constraints, and lack of institutional support.[42,43] Global north–south collaborations, such as the Reproduction and cancer Oncofertility Professional Engagement Network, are vital in bridging this gap, through shared experiences, capacity building, and implementation strategies.[41,43,44]

Limitation

This study brings to light the challenges of conducting survivorship research in low-resource settings. Factors such as loss to follow-up, insufficient and inconsistent registry information, unreliability of telephone contacts, and poor survival from AYA cancers resulted in a low response rate for the survey. Although a CATI-based survey was ideal during the COVID-19 pandemic and for a low-resource setting, the deaths from the pandemic among survivors further limited the survey turn over. Lastly, lack of a reference group of AYAs without cancer limited the validity of the study findings.

Conclusion

AYA cancer survivors in Uganda experience infertility. In addition, they have desires for current and future fertility, despite having unmet needs of fertility-related counseling. Furthermore, this study informs reproductive counseling of AYAs with cancer in low-resource settings and reinforces the need for building capacity for oncofertility resources in the region. Consideration should be given to the socioeconomic context and the need for feasible and acceptable methods of fertility preservation. Future studies warrant a reference group and devised means of increasing survey response rate.

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Authors' Contributions

A.K.: conceptualization, methodology, validation, funding acquisition, project administration, investigation, formal analysis, and writing original article draft. J.N.J.: formal analysis, data curation, data visualization, and writing original article draft. D.Z.: methodology, validation, project administration, supervision, and article review. S.X.: methodology, validation, project administration, and article review. V.G.-L.: supervision, data curation, resources, article review, and editing. J.K.B.: methodology, validation, project administration, supervision, and article review. H.W.: methodology, validation, validation, funding acquisition project administration, supervision, and article review. R.G.: methodology, validation, validation, funding acquisition, project administration, supervision, and article review.

Author Disclosure Statement

No competing financial interests exist.

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