

HHS Public Access

SSM Ment Health. Author manuscript; available in PMC 2022 March 04.

Published in final edited form as:

Author manuscript

SSM Ment Health. 2021 December; 1: . doi:10.1016/j.ssmmh.2021.100037.

Children's appraisals of threat in pediatric cancer*

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Abstract

Purpose: Although many children with cancer cope well with challenges, some experience distress that results in poor adjustment. Children's perceptions of threat may be one explanation for heterogeneity in outcomes, but relatively little is known about what children find threatening. This study aimed to describe the threats that children report.

Method: Youth (4–18 years old) newly diagnosed with cancer and their primary/parent caregivers (PC) participated in a multi-method study. Appraisals of threat were assessed via self-report and a narrative technique at two weeks post-diagnosis. PCs reported children's anxiety and depressive symptoms three months post-diagnosis and children reported their quality of life (QOL) six months post-diagnosis.

Results: Youth reported various types of threatening events (e.g., receiving the cancer diagnosis, fear or pain of procedures) across multiple domains (e.g., threat to self, physical threat, threat of loss). Adolescents tended to report threat to life (e.g., the seriousness of the diagnosis itself) whereas younger children reported other threats (e.g., procedural pain). Children with high perceived *threat to self* had higher subsequent anxiety symptoms and lower QOL compared to those with low appraisals of threat to self. There was also a significant mean difference between high and low appraisals of *threat of loss* in child reported QOL.

Conclusions: Youths' reported threats, as well as how threat appraisals related to adjustment outcomes in distinct ways, underscores the developmental nature of how youth interpret medically stressful events and the utility of developmentally sensitive assessment. Understanding perceived threat could ultimately inform efforts to foster positive long-term adaptation for youth with cancer.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Pediatric cancer; Coping skills and adjustment; Mental health; Quality of life

1. Introduction

It was estimated that in 2021 nearly 16,000 children ages zero to 19 would be diagnosed with cancer in the United States (Siegel et al., 2021). According to the National Cancer Institute, whereas in 1975 approximately 58–68% of children diagnosed with cancer before age 20 years survived at least 5 years, by 2016 that number had risen to about 85%. As of 2018, there were approximately 438,000 survivors of childhood cancer in the United States (National Cancer Institute, 2021). Owing to advances in treatment of pediatric malignancies, this marked increase in survival has shifted the focus of psychosocial research to fostering both short and long-term quality of life (QOL).

Despite the decrease in mortality and morbidity associated with pediatric cancer, diagnosis and treatment continue to be extremely stressful experiences for children. Not only will an estimated 1,780 children die of the disease in 2021 (Siegel et al., 2021), but treatment entails taxing and painful procedures, distressing side-effects, separation from family and friends, and lifestyle restrictions. Research has established that at least a subset of children (20–30%) have difficulty adapting and suffer poor mental health outcomes, either concurrent with their diagnosis and treatment or later; outcomes include, for example, elevated child anxiety and depressive symptoms and poorer QOL (Compas et al., 2014; Smith et al., 2013).

As researchers consider sources of heterogeneity in pediatric cancer outcomes, some have conceptualized cancer as an early experience of threat that contributes to psychological and neurodevelopmental consequences (Marusak et al., 2018). This aligns with theoretical and empirical work emphasizing that the objective medical aspects of pediatric cancer (e.g., illness severity, treatment intensity) may be weaker and/or less consistent predictors of later socioemotional adjustment, including post-traumatic stress symptoms (PTSS), than subjective *perceptions* of things like threat and treatment intensity (e.g., see Kazak et al., 1996).

Most research to date has focused on relations between children's perceived threat and their PTSS, but its association with other important mental health outcomes (e.g., anxiety, depression, and quality of life) has yet to be established. In addition, nearly all studies have focused on the extent to which children feel *their life* is threatened and have not yet addressed other potentially-salient threats to the well-being of children with cancer. The threat to the child's life is likely to be especially salient to adults, but that may not be the case with children, particularly younger children who may not yet have the cognitive capacity to conceive of long-term consequences such as death. For example, when Stuber and colleagues asked children to identify a "worst moment" in treatment, older children were more likely to identify a life threat whereas younger children were more likely to identify a life threat whereas younger children with cancer are asked what they find threatening or stressful in more open-ended ways, for example in qualitative studies, they tend to report a myriad of events and conditions. Across ages, the themes of threat that

emerge do not necessarily include fear of death; most often, foci include being fragile (e.g., different from before, sick, or lonely/abandoned) (e.g., Arruda-Colli et al., 2015; Darcy et al., 2014a; Darcy et al., 2014b). Therefore, although threat of death is clearly of profound significance, there is also a need for studies exploring threats that children identify as salient for themselves and are therefore, likely to confer risk for poor adjustment.

Finally, what the child perceives as threatening has yet to be explicated. In other words, it is not clear what the underlying worry is regarding the threatening event/circumstance. Only one study has, to our knowledge, addressed potential underlying dimensions of threat in pediatric cancer. Fearnow-Kenney and Kliewer (Fearnow-Kenney & Kliewer, 2000) asked 40 children to identify a threatening medical-related event; their open-ended question resulted in the following categories: marrow aspiration, getting bad news, spinal tap, waiting in the clinic, marrow transplant, radiation, chemotherapy, staying in the hospital, surgery, and being stuck with a needle. Children then rated how threatening the event was in a series of items reflecting four dimensions of the source of worry: threat to the self (negative self-evaluation, rejection, and negative judgment from others), threat to others (harm and criticism), threat of loss (of control/autonomy, activities, and desired material items), and threat of physical harm (including, but not limited to, death). Children ranged in age from 8 to 19, with 68% of the youth being adolescents ages 13-19 years old. Children's point on the cancer trajectory varied: 22.5% were newly diagnosed, 40% were on treatment, and 37.5% were off treatment; 15% of the children had relapsed. Higher parent-reported child internalizing symptoms were associated with greater child-reported threat to self, but not to other types of threat. Results were intriguing, particularly in identifying dimensions of threat, but also limited by the concurrent design, sole focus on adolescents, and inclusion of children at various stages of treatment.

The current longitudinal, multi-reporter, and multi-method study extends previous research by soliciting children's self-report of what they find threatening during the treatment trajectory and assessing the underlying dimensions of the threat. We utilized the threat measure employed by Fearnow-Kenney and Kliewer (Fearnow-Kenney & Kliewer, 2000) and extended it to children across a broader age range. In addition, we piloted a second way of assessing threat appraisals. Specifically, we utilized a narrative story stem technique that has the potential to provide insight into the meaning children derive from their illness experiences (Fiese & Spagnola, 2005). Such techniques capitalize on children's natural interest in storytelling (Bretherton et al., 1990) and can be tailored to represent potentiallythreatening illness-related events (Winter et al., 2011). Finally, we examined internalizing symptomatology (anxiety and depressive symptoms) and child cancer quality of life (QOL) as outcomes.

The main aim was to describe the threatening events that pediatric cancer patients endorse. This included: (1) cataloging the types and frequencies of threat that are reported, and (2) examining if children at different ages reported life/physical-threat vs. other types of threat. In addition to the main aim there were two exploratory aims. First, we examined if threat intensity was associated with key markers of adjustment and whether associations differed by dimension of threat. We tentatively hypothesized that children with higher intensity of threat measured near diagnosis would evidence more anxiety and depressive symptoms at

three months post-diagnosis and worse quality of life at six months post-diagnosis. Second, we explored a different way of measuring threat – a story stem technique – by examining whether children high in self-reported threat would also introduce more threat themes in their narratives. Demographic and illness-related descriptors were examined for potential inclusion and covariates.

2. Method

2.1. Participants

Participants were drawn from a longitudinal study of 51 children diagnosed with cancer and their primary/parent caregivers (PCs). Two participants were deemed ineligible after enrollment when their tumors turned out to be non-cancerous. Of the remaining 49 enrolled children, 17 (34.7%) were diagnosed with acute lymphoblastic leukemia, six (12.2%) acute myeloid leukemia, eight (16.3%) with Hodgkin's and non-Hodgkin's lymphoma, and 18 (36.7%) with solid tumor. At enrollment, children were between the ages of 4 and 17 (M= 10.59 years, SD = 4.12 years; 39% female and 61% male). Caregiver-reported child race was 69.4% Caucasian, 18.4% Black or African American, and 6.1% mixed race; 6.1% did not report race. Six percent of families reported that they were of Hispanic/Latino ethnicity. Seventy-nine percent of primary caregivers (PCs) were biological mothers, 17% biological fathers, and 4% grandmothers. The majority (67%) of PCs reported being married and living with a spouse while 17.4% were single and never married, 4.3% married and separated, 6.5% divorced and single, and 4.3% divorced and living with a partner.

2.2. Procedure

Participants were recruited at pediatric oncology and hematology units at two sites (55% from New York and 45% from Virginia) at which local IRB approval was obtained. Both sites serve as the Level 1 pediatric trauma center and top referral hospital for seriously ill or injured children in their respective regions. The study consisted of four assessment points: at or close to diagnosis, two weeks after diagnosis, 3 months after diagnosis, and 6 months after diagnosis. Researchers met with families in the child's hospital room or a meeting room in the oncology clinic; there they obtained informed consent and assent and administered questionnaires, interviews, and activities separately to children and PCs. Families were compensated in cash or gift card for their time at each visit.

2.3. Measures

2.3.1. Child perceived threat (2 weeks post-diagnosis)—We measured child appraisals of threat in two ways. First, youth ages 7 and up self-reported how threatening they perceived an event to be via the 36-item Threat Appraisal Questionnaire (TAQ) (Fearnow-Kenney & Kliewer, 2000; Sheets et al., 1996). They described a recent medical-related stressful event, then rated on a four-point scale how concerned/worried/threatened they felt about various outcomes across four categories of threat: (1) *threat to self* (e.g., "Someone you care about thought you had done something bad"); (2) *threat to others* (e.g., "Someone you care about would be hurt"); (3) *threat of loss/restriction* ("You might not get to do something you wanted to do"); and (4) *threat of physical harm* to self ("You might be in pain or feel sick"). Internal consistencies, indexed by Cronbach's α, were 0.87, 0.79,

0.83, and 0.71, respectively. Each subscale was grouped into high and low perceived threat such that children were classified as endorsing low or high threat.

Second, child appraisals of threat in the context of challenging cancer events were assessed using narrative story stem techniques tailored to child age: a story stem completion task for younger children ages 4–12 and a parallel semi-structured interview for adolescents. The protocol for the story stem completion task (Winter et al., 2011) which as adapted for the cancer context, has roots in the MacArthur Story-Stem Battery (Bretherton et al., 1990) and work by the narrative consortium (Fiese et al., 1999). Children were presented with a series of four story stems accompanied by storyboards and props. The experimenter introduced four family events (dinnertime, family vacation, special celebration, and bedtime) each followed by an illness-related mild threat; children's responses to the illness-related challenges were used for this study. More specifically, children were told that the target doll (1) has an illness like you, (2) starts feeling sick, (3) has to go to the hospital, and (4) the family realizes they forgot the child's medicine; then children were asked to show and/or tell what happens next. For adolescents, the same story stems were presented via an interview format. On average, youth spent 21 min completing the stories/interviews (SD = 10.18). All story stems were video recorded for coding purposes. Coders met weekly throughout coding to reach consensus on any discrepancies and to prevent coder drift. Two trained coders independently rated the story stems; coder 1 coded 100% of the story stems and coder 2 coded 67% of the same story stems as coder 1 to establish inter-rater reliability. The threat rating scale consisted of a three-point observer rating of how much additional threat the child introduced beyond the relatively mild/ambiguous threat inherent in each story stem: none, some, and high. Mean inter-rater reliability for the four stories was $\alpha = 0.73$. Ratings were averaged across the four stories to yield an overall score, upon which participants were placed into one of two groups: none to very little threat (M threat <1) and moderate to significant threat $(M \ 1)$.

2.3.2. Child anxiety and depression (3 months post-diagnosis)—PCs completed the Child Depression Inventory (CDI) (Kovacs, 2011) and the Multidimensional Anxiety Scale for Children, 2nd Edition (MASC) (March 2013; March et al., 1997). The parent report CDI is a 17-item questionnaire used to assess child depressive symptoms. PCs selected the statement (e.g., "My Child ... looks sad ... not at all/some of the time/often/ most of the time") that best described their child in the past two weeks. The MASC is a 50-item questionnaire used to assess anxiety symptoms in youth from ages 8–19. PCs rated each statement ("My Child feels tense or uptight") based on a 4-point Likert-type scale of 0 (Never) to 3 (Often) on how true the statement was for their child. Items assessing physical symptoms were not included in the MASC total score, as somatic complaints may be directly attributable to the medical condition or procedural pains (March et al., 1997). In pediatric cancer samples, the CDI and MASC have demonstrated good reliability and validity (Chao et al., 2003; Yallop et al., 2013). In this study, reliability was adequate for both the CDI ($\alpha = 0.78$) and MASC ($\alpha = 0.86$).

2.3.3. Child quality of life (QOL; 6 months post-diagnosis)—Children ages five and older reported their QOL over the last month via an age-appropriate form of

the PedsQL 3.0 Cancer Module. Using a 5-point Likert scale (*neve*r to *almost always*), participants rated how often they had problems on 27 items in eight domains: pain and hurt, nausea, procedural anxiety, treatment anxiety, worry, cognitive problems, perceived physical appearance, and communication (Varni et al., 2002). For this study, a total QOL score was calculated using a mean of all items, with higher scores indicative of higher quality of life ($\alpha = 0.92$).

2.3.4. Potential covariates—PCs self-reported child, family, and their own demographics at the first visit. At the time of the final study visit, researchers extracted diagnosis, stage, and treatment data from medical records to complete the Intensity of Treatment Rating Scale (ITR-3.0) (Kazak et al., 2012). Per ITR-3.0 instructions, children were classified into one of four levels of intensity: least intensive, moderately intensive, very intensive, and most intensive. We asked an experienced pediatric oncologist to rate a subset of ITRs; rater agreement was 100%. There were two patients for whom researchers were not readily certain about intensity rating; for those, initial ratings were assigned and then the ratings were verified for accuracy by contacting the medical team that developed the ITR-3.0.

2.4. Data analysis

All analyses were conducted using SPSS version 25 and alpha was set to 0.05. Given different age minimums for child report measures, there was missing data which was data handled via listwise deletion. Thus, sample sizes for different analyses varied. As part of Aim 1, a two-tailed *t*-test was used to examine whether threat type (life threat vs. other threats) differed by age. To test the first exploratory aim, a series of ANCOVAs were used to test the hypothesis that children in the high appraisal of threat group would display higher levels of maladjustment (e.g., more anxiety and depressive symptoms, worse QOL) than those in the low threat group. To test the second exploratory aim - whether higher self-reported threat would be associated with themes of threat in child narratives – a series of one-tailed t-tests were conducted.

3. Results

The types of threatening events that youth reported are presented in Table 1. Two threat types were categorized as threat to life/physical integrity: diagnosis (n = 13) and ineffective treatment (n = 1). Children who reported life threat were aged 13–17 years (Mage = 14.57) while other categories of threat were more commonly reported by younger children (ages 7–16 years; Mage = 10.06), t(28) p < .001. Descriptive statistics for each subscale = -5.09, of the TAQ, as well as threat measured via narrative story stem completion, are presented in Table 2.

Based on preliminary analyses, child age and sex were included as covariates in ANCOVAs. Youth who had high appraisals of *threat to self* subsequently reported higher anxiety and lower QOL compared to those with low appraisals of threat to self (see Table 3). However, the mean difference in anxiety symptoms was not statistically significant at p < .05. There was a significant mean difference between high and low appraisals of *threat of loss* in child

reported QOL. There were no statistically significant mean differences between groups in appraisals of *threat to others* or *threat of physical harm*.

Children and adolescents who depicted higher threat in their stories also reported more threat to self [t(19) = -2.75, p = .005], threat to others [t(19) = -1.75, p = .048], threat of loss [t(19) = -2.35, p = .02], and threat of physical harm [t(19) = -1.65, p = .058].

4. Discussion

Threat is inherent in cancer diagnosis (Kupst et al., 2016) and has been identified as a potential explanatory mechanism for heterogeneity in child mental health and QOL outcomes. In this study, open-ended questions and narrative techniques were leveraged to describe which aspects of cancer diagnosis and treatment children found threatening at various ages and to explore whether threat intensity was associated with later child adjustment.

As shown in Table 1, children reported a myriad of threats, highlighting the diversity in what children find threatening during diagnosis and early in treatment. In general, these findings correspond to categories reported in previous research, such as "worst moments" groupings reported by children that Stuber and colleagues: procedures/pain, diagnosis/life threat, and hospitalization/isolation (Stuber et al., 1996). Although we did not ask specifically whether children feared for their lives, we reasoned that two of the categories we found were likely to reflect fear of cancer as a life threat: diagnosis and treatment ineffectiveness. Adolescents were more likely to report life threat than younger children, who tended to report other types of threat. These results may be viewed as exploratory given the small sample size but highlight the need for developmentally sensitive assessment of threat experienced by children diagnosed with pediatric cancer.

Children's appraisals of threat at two weeks following the pediatric cancer diagnosis were associated with children's adjustment three and six months later in distinct ways. First, youth with high perceived *threat to self* (as in, threat of rejection, judgment) had more symptoms of anxiety - but not depression - and lower QOL compared to those with low perceived threat to self. These results are generally consistent with Fearnow-Kenney and Kliewer's findings that a sense of *threat to self* is associated with greater levels of parent-reported psychological difficulties (Fearnow-Kenney & Kliewer, 2000), but add specificity in that threat appraisals were more associated with anxiety than with depressive symptoms. This is not surprising given the propensity of threat (and associated fear) lead to elevated anxiety. However, it should be noted that although we measured anxiety several months after we measured threat, we did not control for earlier anxiety and thus cannot rule out that children who tended to be more anxious perceive events as more threatening. Future research would benefit from baseline measures of mental health symptoms.

There were no significant differences in adjustment across levels of *threat to others* or *threat of physical harm*. It may be that appraisals of threat to others may not be as relevant for the medical/cancer context as it may be in other settings (e.g., peer or parent-child relationships) [see 11]. Similarly, it may be that the *threat of physical harm*, like other forms

of distress, may be heightened in the immediate period following the cancer diagnosis and diminish over time (Kupst et al., 2016), such that its deleterious effects also diminish. It may also be that the association depends on other contextual characteristics not examined in the present study. Finally, youth that had higher appraisals of *threat of loss/restriction* reported lower cancer-related QOL six months later. These associations, if replicated, would suggest that youth who feel threatened by the loss of specific aspects of their daily activities and associated identity (e.g., control, autonomy, activities, or opportunities) may have more long-term difficulties adjusting to their diagnosis and returning to their daily lives and activities.

In addition to examining children's threat via questionnaire, we also piloted a story-stem method with this population. Although based on an especially small sample from who we had story stem responses, the results were encouraging for the method in that there was overlap with self-reported threat. Children in the high threat groups for *threat to self* and others as well as *threat of loss/restriction* also introduced more threat into their narrative responses. The same was true for *threat of physical harm* but it was not statistically significant.

This study's findings should be considered in light of a number of limitations. First, the sample was small and limited our power to detect anything but large effects; it also limits the generalizability of our results. Families were recruited at the time of diagnosis and those who enrolled were willing to consent to participate in a six-month longitudinal study, possibly resulting in a selection bias. Similarly, we had missing data and it is possible that those children who did not complete the TAQ and/or story stems are also those who felt the highest threat and/or felt the most depressed or anxious. Finally, the participants largely identified as Caucasian and from two-parent households, further limiting generalizability.

5. Conclusions

Despite limitations, results suggest avenues of future research. First, the open-ended beginning of the TAQ allowed youth to self-identify threatening situations, providing a more detailed exploration of the types of situations children find threatening in a cancer context. The broad range of youth self-reported events – and the post-hoc findings regarding age differences – underscore the developmental nature of how youth interpret medically stressful and traumatic events (Kazak et al., 2006) and the utility of developmentally sensitive assessment (Holmbeck & Devine, 2009). In addition, including multiple dimensions of threat - threat to self, others, physical health, and loss of activities – revealed that it was the *threat to self* and *loss/restriction* that were associated with later child adjustment. While findings are certainly preliminary, if replicated this pediatric patient-centered approach could contribute information for treatment.

Second, narrative techniques, while time consuming to code, allow active child participation from children as young as four years old. Such techniques are likely to feel less burdensome than traditional question-and-answer formats (Yoshikawa et al., 2008) and indeed we noted that this method allowed us to spend time with children – typically in their hospital rooms – and help alleviate boredom. Thus, it is worthwhile to explore how narrative methods, such

as story-stem techniques, can be further employed with children with cancer. Qualitative studies have shown that even young children want to feel active in responding to questions about their own cancer experience (Darcy et al., 2014b) and this may be one way of achieving patient-reported outcomes with children. Future research with a sample large enough to fully explore the reliability and validity of a story-stem assessment technique is warranted.

Finally, stressors and needs change across the cancer diagnosis, treatment, and survivorship periods (Compas et al., 2014). Thus, longitudinal studies with larger samples are essential to understanding children's experiences and what puts them at risk for poorer adjustment. Developmentally-sensitive studies designed to examine children's and adolescents' threat appraisals, concurrent and later mental health symptoms, and QOL across the various periods of cancer treatment and survivorship could ultimately be informative for targeted prevention and intervention.

Funding

This work was supported by the Eunice Kennedy Shriver National Institute of Child Health & Human Development [grant number R00HD070953] and the National Center for Advancing Translational Sciences [CTSA award number UL1TR000058] and the Wynne Center for Family Research.

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Types of threat reported by children on the TAQ.

Threat Type	n	Example
Diagnosis	15	"I got pneumonia then went to the hospital for a procedure and got transferred and was diagnosed." (age 15)
Procedure Pain or Fear	7	"When the nurse poked me for my port." (age 7)
Physical Side Effects	2	"I had a headache and stomachache due to chemo." (age 9)
Restrictions	3	"When I can't do things I used to like dancing." (age 13)
Staying in Hospital	4	"I had to stay here overnight for a while." (age 7)
Going to the Clinic	4	"Having to go to the doctors a lot makes me feel like I'm going through too much." (age 10)
Treatment Ineffective	1	"I found out that the chemo wasn't working." (age 15)

Table 1

Table 2

Descriptive statistics for threat.

Variable	M (SD)	N	Min-Max Value
Threat to Self (TAQ)	1.37 (0.47)	29	1.00-3.00
Threat to Others (TAQ)	1.89 (0.59)	28	1.00-3.38
Threat of Loss/Restrictions (TAQ)	2.07 (0.62)	28	1.00-3.50
Threat of Physical Harm (TAQ)	2.18 (0.81)	29	1.00-4.00

	Threat to Se	If				Threat to Oth	lers				Threat of L	0SS			
Dependent Variable	High threat M (SD)	Low threat M (SD)	F	d	partial ŋ²	High threat M (SD)	Low threat M (SD)	F	d	partial η ²	High threat M (SD)	Low threat M (SD)	F	d	partial η ²
Anxiety symptoms	53.62 (17.30)	39.29 (12.94)	4.08	0.06	0.15	51.57 (17.86)	40.53 (13.42)	1.56	0.22	0.06	53.00 (11.57)	41.54 (19.15)	2.26	0.15	0.10
Depressive symptoms	14.46 (6.60)	10.08 (5.28)	1.93	0.18	0.08	13.79 (6.64)	10.83 (5.52)	0.23	0.64	0.01	15.60 (4.67)	12.43 (6.60)	2.53	0.13	0.12
Quality of Life	60.95 (16.25)	79.43 (14.74)	5.99	0.02	0.21	64.03 (17.09)	77.24 (16/21)	1.41	0.25	0.06	58.21 (14.75)	78.47 (15.01)	7.69	0.01 **	0.29
			Threat	of Physical L	Harm										
Dependent Vari	able		High th	reat M (SD)		Low threat M	[(SD)			${F}$		þ			partial η^2
Anxiety symptor	ns		46.59 (1	5.57)		46.59 (15.57)				2.10		0.16			0.08
Depressive symf	toms		13.45 (4	(66		11.44 (6.87)				0.13		0.73			0.005
Quality of Life			66.48 (1	9.74)		73.90 (16.06)				0.10		0.76			0.004
* indicates a signif	cant difference	, <i>p</i> <.05,													
** indicates a signi	ficant differenc	e, <i>p</i> < .01.													

SSM Ment Health. Author manuscript; available in PMC 2022 March 04.

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Table 3