



Cancer Screening and Treatment Delays During the COVID-19 Pandemic and the Role of Health Literacy in Care Re-engagement: Findings from an NCI-Designated Comprehensive Cancer Center sample

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Abstract

The COVID-19 pandemic has led to numerous delays in cancer-related care and cancer-specific screening, but the extent is not fully understood. For those that experience a delay or disruption in care, health related self-management is required to re-engage in care pathways and the role of health literacy in this pathway has not been explored. The purpose of this analysis is to (1) report the frequency of self-reported delays in cancer treatment and preventative screening services at an academic, NCI-designated center during the COVID-19 pandemic and (2) investigate cancer-related care and screening delays among those with adequate and limited health literacy. A cross-sectional survey was administered from an NCI-designated Cancer Center with a rural catchment area during November 2020 through March 2021. A total of 1,533 participants completed the survey, and nearly 19 percent of participants were categorized as having limited health literacy. Twenty percent of those with a cancer diagnosis reported a delay in cancer-related care; and 23–30% of the sample reported a delay in cancer screening. In general, the proportions of delays among those with adequate and limited health literacy were similar with the exception of colorectal cancer screening. There was also a notable difference in the ability to re-engage in cervical cancer screening among those with adequate and limited health literacy. Thus, there is a role for those engaged in cancer-related education and outreach to offer additional navigation resources for those at risk to cancer-related care and screening disruptions. Future study is warranted to investigate the role of health literacy on cancer care engagement.

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Introduction

On January 30th, 2020 the World Health Organization (WHO) declared the rapidly spreading novel coronavirus (2019-nCoV) an international public health emergency and subsequently characterized coronavirus disease 2019 (COVID-19) a pandemic on March 11th, 2020 [1]. Hospitals became overwhelmed with inpatients, staffing was limited, surgeries were postponed, and routine cancer screenings were paused (e.g. mammograms, pap smears, and colonoscopies). At the height of the pandemic in April 2020, cancer screenings for breast and colorectal cancer decreased by 85% and 75%, respectively [2]. Similarly, outpatient evaluation and management visits decreased by 70% for new patients and 60% for established patients [2]. Prolonged time to treatment initiation (TTI) among cancer patients, which includes both delays in diagnosis as well as delays in treatment after diagnosis, is associated with worse health outcomes among patients with solid tumor malignancies [3]. Specifically

in the UK context it is estimated there is an increase in 281–344 projected deaths for those with breast cancer; an increase of 1445–1563 projected deaths for those with colorectal cancer; and an increase in 1235–1372 projected deaths for those with lung cancer [3].

Researchers have projected that such delays in diagnosis and treatment may increase mortality from breast and colorectal cancer by as much as 9.6% and 16.6%, respectively, after 5 years [4]. Modeling efforts project that delayed or interrupted screening associated with the COVID-19 pandemic is associated with a 0.52% increase in cumulative breast cancer deaths [5]. Younger age, residence in a neighborhood with greater area deprivation, lack of health insurance, need for an interpreter, and longer travel time were all associated with a lower likelihood of returning to screening following closures due to COVID-19 [6].

COVID-19 also impacted those diagnosed with cancer who were undergoing active treatment, symptom management, oncologic emergencies, and surveillance in the inpatient and outpatient settings [7–9]. Standard of care practices were altered to minimize contact with the healthcare system, minimize the need for blood products, and mitigate hospital admissions due to emergency department and inpatient bed capacity. London and colleagues [9] demonstrated a decrease in cancer-related patient encounters during the early wave of lockdown, but the extent of these interruptions and the impact on patient outcomes has not been well described.

There has been growing evidence that health literacy (HL), or the ability to obtain, appraise, and act on health-related information, is an important predictor of effective self-management and prevention of chronic medical conditions, ranging from COPD [10] and diabetes [11] to cancer care [12]. Effective self-management has been associated with increased patient engagement and improved health outcomes [13]. Patient-centered, precision medicine should include tailor-fit communication [14] as those with lower HL have higher information needs [15] and are less likely to seek additional information independently [16]. Patients with limited HL are also less likely to undergo breast [17], cervical [18], and colorectal cancer screenings [19] as well as receive prescribed chemotherapy for colorectal cancer [20]. However, to our knowledge, there have been no studies to date investigating the degree to which HL may impact delays in cancer care and prevention during the ongoing COVID-19 pandemic. With the ever-increasing demands on health care systems, patients are required to take a more active role in their health, which may further underscore the importance of targeting HL to improve/prevent delays in cancer care and prevention.

Given the ongoing prevalence of COVID-19 cases, undulating pattern of new variants arising, and constant changes to hospital workflow, there is a need to further understand how COVID-19 has impacted cancer treatment and

preventative services and to elucidate contributing factors, such as health literacy. The purpose of this analysis is to (1) report the frequency of self-reported delays in cancer treatment (i.e. routine appointments, laboratory tests, chemotherapy, radiation-therapy, cancer-related surgery, physical or occupational therapy) and preventative screening services (e.g. screening mammograms, pap smears, and colonoscopies) at an academic, NCI-designated center during the COVID-19 pandemic and (2) investigate cancer-related care and screening delays among those with adequate and limited health literacy. We hypothesized that those with limited health HL would be more likely to experience delays in both cancer treatment and screening.

Methods

Questionnaire Development

In 2019, our NCI-designated Comprehensive Cancer Center joined a collaborative with 17 other cancer centers across the United States to assess cancer screening, prevention, and treatment along with behaviors and social determinants of health in order to better understand and address the health-related impacts of COVID-19. Each institution selected its own study population based on the shared aforementioned goals. The study questionnaire (Appendix 1) included a core set of measures common to all 17 cancer centers along with institution-specific items that addressed potential exposure to COVID-19, the impact of COVID-19 on household income, employment, emotional wellbeing, and health-related behaviors (e.g. nutrition, physical activity, tobacco use), access to medical care including access to technology and telehealth, COVID-19 vaccine intent and hesitancy, and self-reported health literacy. The study questionnaire also collected information on demographics, comorbidities, prior cancer diagnoses, and cancer related care including cancer screening, prevention, and/or active treatment.

The validated 3-item HL questionnaire [21] was included in the survey as follows:

1. How often do you have problems learning about your medical condition because of difficulty understanding written information?
2. How often do you have someone help you read hospital materials?
3. How confident are you filling out medical forms by yourself?

Each question was answered on a Likert-type scale ranging from 1 to 5 with higher scores representing lower health literacy. Patients who had a total score of ≥ 7 were classified

as having low HL, whereas patients with a total score of ≤ 6 were classified as having adequate HL [21, 22].

Participants and Study Context

Participants included in this single-center analysis were recruited through two established protocols, Partners in Discovers for Total Cancer Care (PID) and our NCI-designated Comprehensive Cancer Center Catchment Area Needs Assessment. PID (IRB-HSR#18,445) is a registry protocol in which patients consent to allow investigators to recontact patients to let them know about other research studies. Respondents to our institution's Catchment Area Need Assessment who consented to being recontacted about future research opportunities were enrolled in a contact database protocol (IRB-SBS#3993). The catchment area of the Comprehensive Cancer Center includes one-third rural residents reaching 87 counties throughout central, northern, southside, and southwestern Virginia. Many patients drive multiple hours to reach the Cancer Center. All potential participants over age 18 were invited to complete the study questionnaire. Questionnaires completed between November 2020 – March 2021 were included. The questionnaire was available in two forms- electronic and hard copy.

An invitation letter and questionnaire was sent to potential participants within the two cohorts listed above with an email address on file with a link to an electronic survey administered via REDCap. Individuals without an email address or whose email failed to send were mailed a study invitation letter in the mail with a link to access the study electronically. Participants who preferred a hardcopy were mailed the questionnaire with a pre-addressed return label and stamp. Each potential participant received a maximum of three study invitation correspondences and had four weeks to complete the study questionnaire. Overall, 3655 emails and 1240 questionnaires were sent via email and mail respectively. Overall, 1682 participants completed the survey (response rate 34.4%) but only 1533 had responses complete enough to be included. Participants who completed the questionnaire received a \$10 gift card that was sent to them either electronically or in the mail following completion of the survey.

Data Collection

Demographic data collected included age, gender, race, ethnicity, highest level of education, health insurance status (binary yes/no), and cancer diagnoses, if applicable.

The primary outcomes of this study were to report the number of delays in cancer treatment (among patients with a prior cancer diagnosis) and cancer screening and to determine if HL status was associated with delays in such cancer care. Outcomes related to cancer treatment included delays

in surgery, chemotherapy, radiation therapy, physical or occupational therapy, routine appointments or blood tests. Outcomes related to cancer screening included delays in screening mammograms, pap smears, and colonoscopies. Among the patients whose screening tests were delayed, the number of patients who had them rescheduled or already completed, and those whose appointments had not yet been rescheduled were tabulated.

Statistical Analysis

A cross-sectional analysis of patients seen at our NCI-designated cancer center who met inclusion criteria was performed between those with limited and adequate HL scores. Patient demographics along with primary outcomes were analyzed and summarized. Numerical data (age) was summarized using mean and standard deviation while categorical data was summarized using count and percentage. Statistical significance was determined using Student T-test and Chi-square test using SPSS version 28. Normality for the continuous variables was assessed using a Komogorov-Smirnov test to assess the distribution. For all statistical analyses, a p -value of 0.05 or less was considered significant.

This study was approved by the University of Virginia Institutional Review Board (UVA IRB #22,747).

Results

A total of 1,533 participants completed the survey with complete responses: 287 with limited HL (18.7%) and 1,246 with adequate HL (81.3%). Patient demographics are shown in Table 1. There were statistically significant differences in the demographic variables sex, ethnicity, highest level of education, and health insurance status between the limited and adequate HL groups. The majority of participants were female (70.1%), white (90.5%), non-Hispanic (96.9%), had health insurance (98.4%), and completed *at least* a Bachelor's degree as their highest level of education (59.9%).

Among 1,225 (79.9%) participants with cancer diagnoses, breast cancer was most common (468, 38.2%). There were 243 cancer patients (19.8%) who reported having to cancel or reschedule at least one cancer-related medical care (Table 2) between March 2020 (beginning of COVID-19 restrictions) – March 2021 (end of study period). This included having to cancel or reschedule routine appointments (197, 1.1%), screening tests (86, 7.0%), blood tests (74, 6.1%), surgery (25, 2.0%), chemotherapy (14, 1.1%), and radiation therapy (10, 0.8%). Limited HL was not significantly associated with having to cancel or reschedule any of the aforementioned cancer-related medical care (Table 2).

Regarding cancer prevention, postponement of screening mammograms, pap smears, and colonoscopies were

Table 1 Participant Demographics

	Limited HL (N=287)	Adequate HL (N=1,246)	All Participants (N=1,533)	P-value
Age, mean (SD)	60.7 (16.5)	60.6 (15.1)	60.7 (15.4)	0.943
Gender, n (%)				
Male	109 (39.5%)	335 (27.3%)	444 (29.6%)	<0.001
Female	163 (59.1%)	889 (72.6%)	1052(70.1%)	
Prefer not to answer	4 (1.4%)	1 (0.08%)	5 (0.33%)	
Race, n (%)				
Caucasian	236 (86.1%)	1111 (91.5%)	1347 (90.5%)	0.053
African American	24 (8.8%)	63 (5.2%)	87 (5.8%)	
American Indian or Alaskan Native	0 (0%)	3 (0.25%)	3 (0.20%)	
Asian	4 (1.5%)	12 (0.99%)	16 (1.1%)	
Arab	0 (0%)	1 (0.08%)	1 (0.07%)	
Other ^a	2 (0.73%)	11 (0.91%)	13 (0.87%)	
Prefer not to answer	8 (2.9%)	13 (1.1%)	21 (1.4%)	
Ethnicity, n (%)				
Hispanic	6 (2.2%)	25 (2.1%)	31 (2.1%)	0.017
Non-Hispanic	258 (95.2%)	1176 (97.3%)	1434 (96.9%)	
Prefer not to answer	7 (2.6%)	8 (0.66%)	15 (1.0%)	
Highest Level of Education, n (%)				
Less than high school	8 (2.9%)	1 (0.08%)	9 (0.61%)	<0.001
Some high school, no diploma	16 (5.9%)	13 (1.1%)	29 (2.0%)	
General education development (GED)	12 (4.4%)	15 (1.2%)	27 (1.8%)	
High school graduate	47 (17.2%)	99 (8.2%)	146 (9.8%)	
Some college but no degree	63 (23.1%)	179 (14.7%)	242 (16.3%)	
Associate degree—occupational/vocational	21 (7.7%)	57 (4.7%)	78 (5.2%)	
Associate degree—academic program	13 (4.8%)	53 (4.4%)	66 (4.4%)	
Bachelor's degree (e.g., BA, AB, BS)	63 (23.1%)	348 (28.7%)	411 (27.6%)	
Master's degree (e.g., MA, MS, MEng, Med, MSW)	24 (8.8%)	298 (24.5%)	322 (21.7%)	
Professional school degree (e.g., MD, DDS, DVM, JD)	3 (1.1%)	69 (5.7%)	72 (4.8%)	
Doctorate degree (e.g., PhD, EdD)	3 (1.1%)	82 (6.8%)	85 (5.7%)	
Health Insurance, n (%)				
Yes	263 (96.7%)	1195 (98.8%)	1458 (98.4%)	0.010
No	9 (3.3%)	14 (1.2%)	23 (1.6%)	

^aDefined as any race not represented in the discrete categories or more than one racial group identified

reported by 130 (23.0%), 62 (24.3%), and 61 (30.0%) participants, respectively. Limited HL was significantly associated with delays in colonoscopies ($p = 0.012$) with a higher proportion of the sample that experienced delays in the limited HL group, but HL was not associated with delays for mammograms ($p = 0.246$) or pap smears ($p = 0.707$). Among patients with delays in screening mammograms, pap smears, and colonoscopies, 109/130 (83.8%), 29/62 (46.8%), and 37/61 (60.7%) participants, respectively, reported still not having their screening test scheduled at the time of completing the survey. For those who needed to reschedule their pap smear, 57% in the adequate HL group were able to reschedule, while only

33% in the limited HL group rescheduled their delayed pap smear (Table 3).

Discussion

Our study demonstrated numerous delays in cancer treatment and prevention among this sample of cancer survivors, cancer patients, and cancer community stakeholders. Among cancer patients, nearly 20 percent of participants had an appointment that was cancelled or rescheduled, including 2 percent of participants experiencing postponement or rescheduling of a cancer-related surgery. This

Table 2 Delays in Cancer Treatment among Cancer Patients

	Limited HL (N=210)	Adequate HL (N=1,015)	All Participants (N=1225)	P-value
Cancer Type, n (%)^a				
Bladder Cancer	4 (1.9%)	14 (1.3%)	18 (1.5%)	0.702
Bone Cancer	3 (1.4%)	14 (1.3%)	17 (1.4%)	0.909
Breast Cancer	46 (21.9%)	422 (41.6%)	468 (38.2%)	<0.001
Cervical Cancer	3 (1.4%)	11 (1.1%)	14 (1.1%)	0.794
Colon Cancer	14 (6.7%)	38 (3.7%)	52 (4.2%)	0.123
Endometrial Cancer	6 (2.8%)	57 (5.6%)	63 (5.1%)	0.056
Head & Neck Cancer	14 (6.7%)	30 (3.0%)	44 (3.6%)	0.024
Leukemia/ Blood Cancer	16 (7.6%)	91 (9.0%)	107 (8.7%)	0.300
Liver Cancer	8 (3.8%)	18 (1.8%)	26 (2.1%)	0.112
Lung Cancer	30 (14.2%)	80 (7.9%)	110 (9.0%)	0.017
Hodgkin's Lymphoma	5 (2.3%)	8 (0.8%)	13 (1.1%)	0.067
Non-Hodgkin's Lymphoma	20 (9.5%)	75 (7.4%)	95 (7.8%)	0.548
Melanoma	25 (11.9%)	115 (11.3%)	140 (11.4%)	0.783
Oral Cancer	2 (1.0%)	6 (0.6%)	8 (0.7%)	0.648
Ovarian Cancer	11 (5.2%)	50 (4.9%)	61 (4.9%)	0.888
Pancreatic Cancer	2 (1.0%)	11 (1.1%)	13 (1.1%)	0.757
Pharyngeal (throat) Cancer	0 (0%)	10 (1.0%)	10 (0.8%)	0.128
Prostate Cancer	17 (8.1%)	55 (5.4%)	72 (5.9%)	0.276
Rectal Cancer	7 (3.3%)	11 (1.1%)	18 (1.5%)	0.027
Renal (kidney) Cancer	3 (1.4%)	30 (3.0%)	33 (2.7%)	0.152
Non-melanoma Skin Cancer	21 (10.0%)	106 (10.4%)	127 (10.4%)	0.510
Stomach Cancer	2 (1.0%)	10 (1.0%)	12 (1.0%)	0.855
Other Cancer	28 (13.3%)	89 (8.7%)	117 (9.6%)	0.133
Number of cancer patients scheduled for any cancer-related medical care that had to be cancelled or rescheduled during the COVID-19 restrictions, n (%)	37 (17.6%)	206 (20.3%)	243 (19.8%)	0.171
<i>What did you have to cancel or reschedule?^b</i>				
<i>Routine appointment^c</i>	30 (14.2%)	167 (16.4%)	197 (16.1%)	0.309
<i>Screening test (i.e. mammogram, pap smear, colonoscopy)</i>	14 (6.7%)	72 (7.1%)	86 (7.0%)	0.424
<i>Blood test</i>	9 (4.3%)	65 (6.4%)	74 (6.1%)	0.370
<i>Surgery</i>	6 (2.8%)	19 (1.9%)	25 (2.0%)	0.236
<i>Chemotherapy</i>	4 (1.9%)	10 (1.0%)	14 (1.1%)	0.134
<i>Radiation therapy</i>	1 (0.4%)	9 (0.9%)	10 (0.8%)	0.634
<i>Physical or Occupational therapy</i>	3 (1.4%)	9 (0.9%)	12 (1.0%)	0.369

^a A participant may have had more than one cancer diagnosis

^b A participant with a prior cancer diagnosis may have had more than one cancer related treatment cancelled or rescheduled

^c Routine appointment is defined as a standard follow-up visit for interim surveillance (not problem-focused or acute in nature)

Percentages are calculated among the health literacy group to be able to draw comparisons between health literacy group

question did not include inquiry into delays of appointments and procedures not yet scheduled, so likely represents an underreporting of this phenomenon. Additionally, it does not take into account other protocols or guidelines that were changed during this time in anticipation of mitigation of risk and resource allocation (i.e., visitor restrictions, parameters for supportive care admission, etc.). HL

was not associated with interruptions in care for people with an active cancer diagnosis.

This study highlights delays encountered among those requiring appointments and procedures for cancer screening with 23–30 percent of the sample experiencing delays and cancellations with mammograms, pap smears, and colonoscopies that were already scheduled. Again, this delay

Table 3 Delays in Cancer Prevention^a

	Limited HL	Adequate HL	All Participants	<i>P</i> -value
Mammogram, <i>n</i> (%)	<i>N</i> = 84	<i>N</i> = 480	<i>N</i> = 564	
Do not know/ not sure	2 (2.4%)	3 (0.63%)	5 (0.89%)	0.246
No, not delayed	61 (72.6%)	368 (76.7%)	429 (76.1%)	
Yes, delayed	21 (25.0%)	109 (22.7%)	130 (23.0%)	
Rescheduled or already completed	7 (33.3%)	14 (12.8%)	21 (16.2%)	0.724
Not yet rescheduled	14 (66.7%)	95 (87.2%)	109 (83.8%)	
Pap smear, <i>n</i> (%)	<i>N</i> = 34	<i>N</i> = 221	<i>N</i> = 255	
Do not know/ not sure	0 (0%)	4 (1.8%)	4 (1.6%)	0.707
No, not delayed	25 (73.5%)	164 (74.2%)	189 (74.1%)	
Yes, delayed	9 (26.5%)	53 (24.0%)	62 (24.3%)	
Rescheduled or already completed	3 (33.3%)	30 (56.6%)	33 (53.2%)	0.196
Not yet rescheduled	6 (66.7%)	23 (43.4%)	29 (46.8%)	
Colonoscopy, <i>n</i> (%)	<i>N</i> = 39	<i>N</i> = 164	<i>N</i> = 203	
Do not know/ not sure	3 (7.7%)	1 (0.61%)	4 (2.0%)	0.012
No, not delayed	23 (59.0%)	115 (70.1%)	138 (68.0%)	
Yes, delayed	13 (33.3%)	48 (29.3%)	61 (30.0%)	
Rescheduled or already completed	5 (38.5%)	19 (39.6%)	24 (39.3%)	0.941
Not yet rescheduled	8 (61.5%)	29 (60.4%)	37 (60.7%)	

^a Among participants who were planning on having a cancer prevention screening between March 1st, 2020 and December 31st, 2020

Percentages are calculated among the bolded total per screening modality per health literacy group

likely represents an underreporting of the phenomenon if the screening procedures were not already scheduled or the window to schedule happened to occur in March through June 2020. HL was associated with delays/cancellation of appointments for colonoscopy screening with a greater proportion of those in the limited health literacy group experiencing a delay or cancellation.

A finding that warrants attention is that only 33 percent of those who had a delay in pap smear were able to reschedule in the limited HL group compared to 57 percent of women with adequate HL ($p=0.012$). Previous research suggests that there is a relationship between HL and cancer screening measures generally [12, 23] and these stressors were heightened during the COVID-19 pandemic. It is paramount to incorporate additional outreach, education, and alternatives including self-collected cervical screening [24] to those at greater risk for screening-related delays, including those with limited health literacy, during times of COVID-19 related strains to the system.

Overall, 19% of participants in this study had limited health literacy, which coincides with other United States-based national assessments [25]. This sample was overwhelmingly white, non-Hispanic, insured, college-educated, and female. Therefore, the relationship between health literacy and interruptions in care and delays to re-engage in care may not be as apparent due to the lack of sample diversity. Additionally, while close to 80 percent

of the sample had a cancer diagnosis, the remainder were other stakeholders of the Cancer Center. This sample, in general, represents a group actively engaged in care already and less likely to experience delays in cancer screening or disruption in cancer services compared to the general US population not under the care of a comprehensive team. There are also limitations in the temporal association of the survey administration in relation to the COVID-19 pandemic. At the time the survey was administered, more stringent lockdowns were lifted and elective procedures and surgeries were occurring. However during this Omicron wave, hospital resources related to capacity and nurse staffing were in general, strained. Additionally, early administration of the COVID-19 vaccine occurred during this window, which may have had an influence on perceptions related to the ability to engage in care. Specific elements related to cancer stage and phase of treatment were not collected among those with a diagnosis, and these factors can also elucidate patterns in delays of care. Finally, a cross-sectional survey has limitations in determining delays and disruptions in episodic care services. This work is meant to be hypothesis-generating for future study that targets specific screening delays among particular types of cancer survivors at various phases of treatment and survivorship to specifically elicit how health literacy, clinical, and sociodemographic factors contribute to care re-engagement.

Implications for Cancer Education Programs

There are numerous implications for cancer education programs tailored to individual health literacy. First, previous research has demonstrated that routine assessment of health literacy for every person treated with cancer including cancer survivors is feasible and can be integrated within the electronic medical record [22]. Based on this routine non-stigmatizing assessment, cancer education and information related to screening and general cancer care can be tailored in a variety of formats including visual and video formats [22]. Further, cancer education programs that are integrated within cancer centers can use this information to re-engage persons who may have had a lapse in general screening procedures. This type of care model also has implications for general treatment of cancer patients and interruptions related to the ongoing pandemic. Those with limited health literacy may prefer care re-engagement through the telephone speaking with a care navigator or cancer education liaison as opposed to written materials. Routine assessment of health literacy is an important first step in integration with cancer education programs.

Conclusion

The COVID-19 pandemic highlighted numerous disruptions and delays in cancer care services and screenings that can result in more aggressive stage at diagnosis and less optimal treatment care pathways [9]. Disruptions in care patterns as a result of strains to the healthcare system require active health-related self-management strategies to re-engage in care. Health literacy can impede the re-engagement process due to difficulty in navigating self-management tasks within a complex health system. The role that health literacy plays in mediating the relationship between delays in cancer care and cancer screening due to pandemic strain and re-engagement in care is not yet known and requires future study focused on longitudinal assessments within a more diverse sample among both patients undergoing active cancer therapy and those not associated with an NCI-designated Cancer Center. There is also a role for those engaged in cancer-related education and outreach to offer additional navigation resources for those at risk to cancer-related care and screening disruptions.

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Data Availability Metadata is available upon request to the authors.

Declarations

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