Development and Evaluation of an Integrated Digital Patient Platform During Oncology Treatment

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Abstract

Background: Patient platforms are seen as promising technologies in an integrated care approach to involve cancer patients in their own health care and to support them in managing their personal health information. However, few digital platforms have been codesigned with patients and caregivers. **Objective:** To develop, implement, and evaluate the feasibility and applicability of a digital oncology platform (DOP) for patients with cancer. **Method:** A mixed-method study was used, employing a survey, interviews, and logged data from caregivers and patients. The DOP was designed in cooperation with Information Technology (IT) staff, caregivers, and patients. **Results:** The DOP was actively used by half of the patients. These active patients were positive about the DOP. Caregivers acknowledged the added value but also indicate that additional workload was involved. Oncology nurse specialists are the users of the platform. General practitioners have indicated their interest in the platform. **Conclusion:** Thanks to the codesign process, the DOP could be tailored to the expectations of the end users. This study provides insight into which DOP functionalities the patients were interested in and includes further recommendations for implementation.

Keywords

cancer, codesign, eHealth, mobile health, oncology, patient platform

Introduction

The last decade has witnessed a rise in patient engagement (1). Patients desire to be involved in their care process, as they go online to self-diagnose symptoms, learn about their condition and treatment options when the diagnosis is known, and connect with people in similar situations to learn from their experiences and share their own (2). In fact, there has been a shift in the role of the patient from passive recipient to active consumer (2). Since several studies have indicated that patients who are actively involved exhibit better health, have improved care experiences, and incur lower health-care costs (3), patient engagement has rapidly become a key component of many oncology programs (4). As such, a variety of technologies have been developed to enhance patient engagement and to support, among other things, adherence to medication, behavioral changes, relationships, and patient-reported outcomes (5). One technology that can be used is a patient portal.

A patient portal is a secure web site for patients which offers access to a variety of functions, including secure messaging, protected health information (such as laboratory results and medication lists), appointment scheduling, programs for self-monitoring, and patient questionnaires (6). During cancer treatment, many patients welcome the opportunity to use engagement technologies, such as online tools and mobile apps, to track their symptoms and possible side effects (7). Patient platforms are thus seen as promising technologies in an integrated care approach to involving cancer patients in their own health care and in supporting them in managing their personal health information (8).

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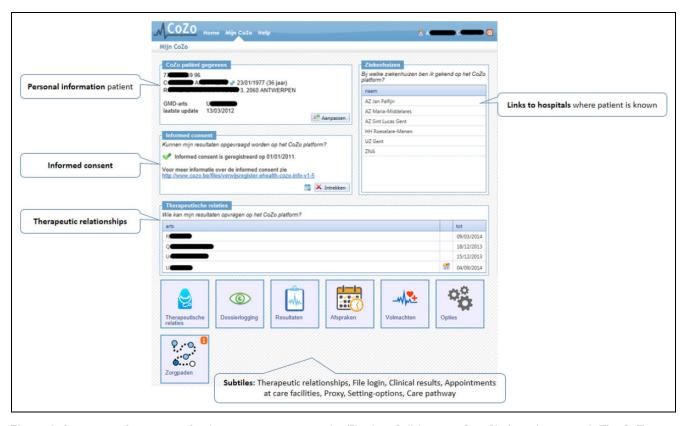


Figure I. Start screen for patients after logging on to www.cozo.be (Flanders Collaborative Care Platform Association). The CoZo start screen displayed for patients after logging with eID includes the following: the personal information of the patient, the hospitals where the patient has a medical record, the patient's therapeutic relationships, file logins, access to clinical results (such as X-ray images and laboratory results), overview and scheduling of appointments at care facilities, proxy access (eg, for children), options and setting, and the "care pathway" tile. From this page, the patient can click through to the different functions within the DOP. DOP indicates digital oncology platform.

Beyond that, the information gathered in the patient portal can be used by health care providers in clinical decision-making. On the institutional level, there is a need to integrate patientrelated information, in order to permit information exchange between the members of the multidisciplinary team and between various institutions (such as between different hospitals, or between a hospital and the primary care facility).

To date, the value of online interventions remains unclear (5,9). In addition, there are very few digital platforms for cancer patients that have been developed through codesign with patients and caregivers and that allow the integration of existing electronic care systems with 2-way communication with patients and their caregivers, as well as between caregivers (5). This study aimed to develop, implement, and evaluate a digital oncology platform (DOP) for patients with cancer.

Methods

In this article, we describe the development, implementation, and the evaluation of the DOP. First, the platform was developed in a number of steps. Second, the DOP was implemented for patients with metastatic kidney cancer who were receiving systemic treatment and for patients with a bone tumor or sarcoma being treated at the Oncology Center, Ghent University Hospital. Finally, the platform was evaluated by describing how patients and caregivers used and experienced it. We opted to integrate this oncological platform into the Flanders Collaborative Care Platform Association (CoZo; see Figure 1). The CoZo is part of Belgian eHealth architecture and aims to share health data with the aim of ensuring continuity of care. Over 40 Flemish hospitals, 30 psychiatric institutions, and several rehabilitation centers—as well as home nursing, extramural laboratories, and radiology practices-are directly connected to CoZo. Over 5000 physicians use CoZo each month, as it is connected to their own patient files. This makes CoZo the largest eHealth network in Belgium for the exchange of medical data. The main advantage of integrating DOP with CoZo is that it meets the high expectations for eHealth security and provides real-time integration into the electronic patient file at the hospital.

Development of the DOP

The literature was explored to determine the components needed for the DOP and patients' expectations of an

oncology platform. The PubMed electronic database was consulted with a combination of search terms, including guidelines or directs and cancer or oncology and eHealth or mHealth. Of 21 eligible articles, 7 relevant articles provided insight into the substantive and technical modalities of eHealth systems (10-16). To enhance the chance of successful implementation of the DOP, a "codesign" approach with intramural caregivers, technology developers, and end users was employed. This codesign process ensured that the execution of the project was optimally tailored to the needs of the target group (17,18). The stakeholders who participated in these meetings included physicians, nurses, nursing specialists, oncologists, head nurses, Information Technology (IT) staff, a project coordinator, and project staff. Appendix A shows the topics that were discussed at several monthly group meetings, on the basis of which priorities were determined. The stakeholders who participated in these meetings were physicians, nurses, nurse specialists, oncologists, head nurses, IT staff, a project coordinator, and project staff.

The decisions thus made were converted by IT staff into a prototype (see Figure 2) that was tested at different times by both IT staff and potential end users (health-care providers). Preliminary feedback on its layout, added value, and userfriendliness was requested from patients, their family, and health-care providers through individual interviews. Based on their comments, amendments were made to the DOP.

Implementation of the DOP

In April 2015, a group of care providers involved in the care of the patients (2 oncologists, 2 nursing consultants, 1 nursing specialist, and 1 psychologist) were individually trained in the use of DOP by an oncology nurse specialist, who was also the project coordinator. In early May 2015, the DOP was enrolled in 2 patient groups. IT support was available for caregivers and patients (eg, to assist patients who had problems logging in to the platform). The patients' general practitioners (GPs) were mailed a manual describing the DOP, with an additional statement that one of their patients was participating in the study.

Evaluation of the DOP

Study design. A mixed-method triangulation design (19) that combined qualitative and quantitative data obtained from patients and their caregivers was used in order to obtain different yet complementary data on the same topic.

Sample. Adult patients with metastatic renal cancer and patients with a bone tumor or sarcoma were included. Patients with any of the following criteria were excluded: (1) not having a computer with an Internet connection, (2) not being Belgian, (3) not Dutch-speaking, (4) suffering from a cognitive or psychological disorder (as assessed by the research team), and (5) unable to read or write (as judged by the research team).

Procedure. The project evaluation proceeded from May 2015 to December 2015. The DOP was presented to those patients who met the inclusion criteria by the physician or the nursing specialist. The participants were asked to test the DOP for 3 months.

Data collection. After 3 months, semistructured interviews were held with patients and their care providers to gain deeper insight into the user-friendliness and applicability of the DOP. Patients additionally received a validated survey after 3 months using the DOP. This survey, based on the questionnaire of Bakken et al, assessed the userfriendliness of the DOP and users' satisfaction with it (20). The original scales were translated into Dutch using the standard back-translation technique. A 14-item scale for user-friendliness was used ($\alpha = 0.809$ in our study sample). A sample user-friendliness question is: "I am more involved in my care using the digital patient report." We used 8 items for the satisfaction scale ($\alpha = 0.869$ in the current sample). One of the 8 questions for satisfaction is: "In general, I am satisfied with the digital oncology platform." The usability of the 8 different sections of the system was also asked (see Figures 1 and 2). Reponses were provided on a 5-point Likert scale, with anchors ranging from 1 (strongly disagree) to 5 (strongly agree), and for usability from 1 (not at all useful) to 5 (very useful). Previous research provides evidence of the high reliability and validity of evidence of perceptions of eHealth (21).

Similarly, system-related log data were tracked—namely, the number of logins to the system (by patients and caregivers), the number of times the various sections were consulted, the number of messages sent, and the number of completed diary entries. Demographic and clinical variables were also collected from patients.

Data analysis. Interviews were conducted with the end users by telephone and face-to-face and were recorded on tape. The findings were noted immediately after the interview, and the interviews were transcribed verbatim. Qualitative data were analyzed using thematic content analysis, which was carried out by 2 researchers experienced in qualitative research.

The sample and study variables underwent descriptive statistical analysis. Cronbach alpha reliability scores were calculated to test the internal consistency of the scales using SPSS software (version 25; IBM, Chicago, Illinois).

Ethical considerations. The study protocol was approved by the institutional review board (B670201524244), and all participants took part voluntarily. Written informed consent was obtained from all patients.

Results

A total of 29 patients were selected to evaluate the DOP. Three did not meet the inclusion criteria and 3 refused to

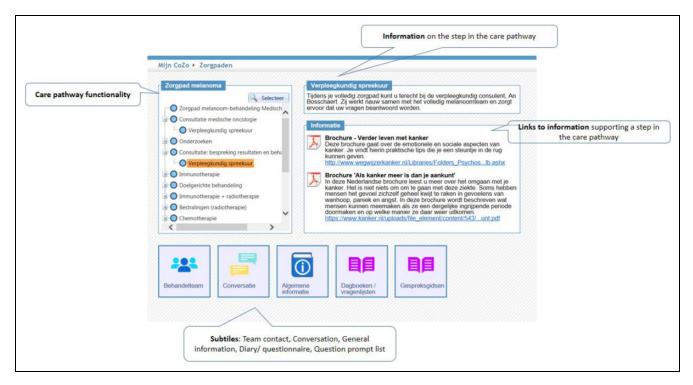


Figure 2. The digital oncology platform for patients, showing the individualized care path. The care path tile of the DOP contains a chart of the individualized care path (different steps can be chosen for each patient, which makes the pathway customized), reliable information about the cancer and its treatment, links to relevant web sites, contact details for the treatment team, secure conversations with the treatment team, self-registration of complaints and other problems in a diary, and other questionnaires. In addition to the modalities identified in the literature, the stakeholder group decided to integrate question prompt list. The nurse or doctor can individualize the care path for the patient in a user-friendly way. The care path linked to a specific type of cancer or treatment has been preprogrammed into the DOP. The health-care provider selects the respective care path and chooses the phases that apply to the patient. The patient can report his or her complaints in text. DOP indicates digital oncology platform.

participate (participation was too cumbersome or they saw no added value in the project). As such, 23 patients participated. Appendix B gives an overview of the demographic variables of the participating patients.

Experience of Active and Nonactive Patients With DOP

Thirteen patients were not active (logging in once or not at all) and 10 patients were active on DOP (logging in more than once). Table 1 shows the consultation and registration behavior of the active patients. The digital platform was most often used to register clinical complaints in the online diary.

The interviews demonstrated that the active patients were mainly positive about the possibility of consulting their medical results and recording their complaints. The latter tool was especially valuable because patients then felt that they had been "seen and heard" in the time between face-to-face consultations. None of the patients consulted the question prompt list. The information section was also rarely viewed. They generally found the system user-friendly and clear. The following elements for improvement were suggested by one or more patients: making DOP available as an app, so that

Table I.	Consultation	and	Registration	Behavior	of Patients
on DOP.					

	Mean (SD) ^a	Median	Range ^b
Number of times logged on DOP Number of times consulted	11.92 (25.3)	I	0.0-90.0
Information	0.75 (1.4)	0.0	0.0-6.0
Diary/questionnaire	14.92 (43.7)	0.5	0.0-199.0
Conversation	4.33 (8.1)	0.0	0.0-26.0
Question prompt list	0.00 (0.0)	0.0	0.0-0.0
Number of messages sent	2.13 (4.4)	0.0	0.0-211.0
Number of diary entries	15.42 (45.5)	0.0	0.0-15.0

Abbreviations: DOP, digital oncology platform; SD, standard deviation. ^aThe data were not normally distributed, but the mean and standard deviation are included in the table to simplify interpretation.

^bRange: minimum-maximum.

logging in with the eID could be avoided when registering complaints; being able to view complaints already registered; being able to consult a schematic overview (summary) of the registered complaints in order to have a personal diary; an integrated notebook in the DOP that could be used to pass on matters that should have been discussed during the consultation, such as requesting a prescription; and integrating

Variable	Mean (SD)ª	Median	Range ^b	Cronbach's α
User-friendliness	3.81 (0.8)	4.5	3.3-4.4	0.809
User satisfaction	4.09 (0.9)	4.0	3.1-4.8	0.869
Usability	()			
Överall	4.28 (0.2)	4.4	4.0-4.5	0.831
Information and web	4.10 (0.7)	4.0	3.0-5.0	
links	· · · ·			
Diary	4.40 (0.7)	4.5	3.0-5.0	
Questionnaire	4.00 (0.5)	4.0	3.0-5.0	
Conversation	4.50 (0.5)	4.5	4.0-5.0	
Question prompt list	3.80 (0.4)	4.0	3.0-4.0	
Overview	4.50 (0.9)	5.0	2.0-5.0	
appointments				
Team contact	4.60 (0.5)	5.0	4.0-5.0	
Results overview	4.30 (0.7)	4.0	3.0-5.0	

 Table 2. Descriptive Statistics and Cronbach's Alpha of the Measured Variables.

Abbreviation: SD, standard deviation.

^aThe data were not normally distributed, but the mean and standard deviation are included in the table to simplify interpretation.

^bRange: minimum-maximum.

entries from a private blog in the system, where things can be shared with family and friends.

Some of the inactive patients indicated that they had experienced difficulties logging on the CoZo platform and then did not try again. Other patients indicated that they did not feel the need for information. This had to do, among other things, with patients' coping mechanisms, experience, or lack of time. Patients who only came to the hospital in the follow-up phase after treatment to discuss checkup results were more interested in the functions such as the ability to consult appointments in the hospital and the results of the medical examinations on CoZo. Two patients also indicated that they had clinical complaints at the time of chemotherapy, but due to fatigue, they did not register their symptoms on the DOP platform.

The quantitative data on satisfaction, user-friendliness, and usability for the patients are shown in Table 2. The average score for satisfaction was 4.09 (minimum 3.1 and maximum 4.8 on a scale of 1-5). The average score for user-friendliness was 3.81 (minimum 3.3, maximum 4.4 on a scale of 1-5). The usability of the individual tiles (see Figure 1) showed that the question prompt list tile had the lowest score.

Experiences of Health-Care Providers in the Hospital

The consultation behavior (log data) of the care providers is shown in Table 3. The oncology nurse specialists consulted the DOP most frequently. The physicians and the psychologist consulted the DOP only to a limited extent.

Both physicians saw added value in providing reliable information to patients, the ability of patients to register

Table 3. Consultation Behavior of Care Providers on DOP.

Mean (SD) ^a	Median	Range ^a
2.5 (0.71)	2.50	2-3
36 (-)	-	-
105.5 (44.55)	105.50	74-137
9.60 (4.51)	12.00	2-13
I (-)	-	-
	2.5 (0.71) 136 (-) 105.5 (44.55) 9.60 (4.51)	2.5 (0.71) 2.50 136 (-) - 105.5 (44.55) 105.50 9.60 (4.51) 12.00

Abbreviations: DOP, digital oncology platform; SD, standard deviation. ^aRange: minimum-maximum.

^bNurse with expertise in the professional field and the content and structure of the digital oncology platform.

^cNurse responsible for the nursing consultation hour in which patients (and relatives) receive support from an oncology specialist on their disease process.

^dNurse at the department of medical oncology who follows patients during chemotherapy.

illness complaints, and the ability to exchange research results between care providers (eg, other hospitals and primary care). Both physicians indicated that medical results should be released to patients with caution. Regarding the registration of illness complaints and questions from patients, the physicians indicated that they were informed by the oncology nurse specialist if the illness complaints required attention.

The specialist oncology nurses saw added value in the DOP for both patients and health-care providers. They had insight into (much of) the patient's information through DOP and patients could be better monitored. One nurse indicated that working with DOP was additional to standard care and thus increased the workload. The other nurse had just started her consultations during the implementation of the DOP and it thus seemed to be more obvious to her that DOP be presented to her patients. The registration of illness complaints by patients was seen as an added value, but also as an additional burden within the limited hour available for the nursing consultation. They felt that patients might expect a reaction from them after sending a message or registering a complaint. Nevertheless, during training on the DOP prior to its implementation, the nurses indicated that they still lacked knowledge about the system. In particular, modifying the individualized care path for the patients was difficult. Nurses from the medical oncology department who monitor patients during their chemotherapy indicated that it helped them prepare for their telephone consultation with the patient. In this way, specific questions could be asked of the patient. The psychologist indicated that the system had not yet been rolled out sufficiently for her use, as the questions and patient registrations all seemed to be addressed to physicians or nurses. She also indicated that she would contact the patient by telephone more quickly, because she could then receive nonverbal information (eg, intonation). Care providers also mentioned additional functionalities that would improve the DOP: allowing video conferencing (providing face-to-face contact between patient and health-care provider at a distance), providing signals when abnormal values are registered by the patient, and offering (graphic) overviews when following parameters.

Consulting GPs. The majority of GPs (n = 13) consulted the CoZo digital platform regularly to access results of patients. However, none of the GPs consulted the registrations of patients in the DOP, but a majority (n = 12) expressed interest in being involved.

Discussion

The literature shows that patients desire online access to their medical records and insight into the progress of their health status (10-16). For example, patients are positive about having online access to their laboratory results, medication lists, and care process, as well as about sending messages to health-care providers (13). Some existing digital programs seem to be effective in these aspects (12). The common modalities in these digital programs include information about cancer, answers to frequently asked questions, and the ability to monitor symptoms. With regard to the technical modalities, attention should be paid to the user-friendliness and simplicity of the system, as well as its privacy, confidentiality, and compatibility with other systems (14). As such, the DOP meets all these basic user expectations, as was confirmed by our results.

The codesign of the program was an important asset in the development and further improvement of DOP. Research shows that the development and successful implementation of applications for telemonitoring in health care is difficult (22). One of the reasons for this is the lack of needs-driven development that is tailored to the specific needs of the sector and the target group. By means of codesign, where technology developers and health-care providers met, the DOP could be tailored to the end users. Patients and their families are still actively involved in the testing of new modules and applications in the DOP, and their reflections are being taking into account in its further development.

In this project, only 3 patients (<10%) did not desire to participate in the study, as they thought the project was too demanding or did not see the added value of this tool in their care process. Clearly there was a high level of willingness to participate. However, few patients consulted the DOP. Rozmovits and Ziebland have indicated that information needs differ and change over time for cancer patients (23). Cook et al also revealed a number of facilitators and barriers in adopting and using telehealth. For example, having a positive attitude and a perceived need were factors encouraging patients to adopt and engage with a service (24). Using the DOP could thus be connected to the phase and individual needs of the patient, which may explain why the DOP was not always consulted. However, it is important to provide the tool, as information-seeking behavior is a strategy that many people use as a means of coping with and reducing stress throughout their cancer experience (25). Cook et al also demonstrated that reassurance from the onset was paramount to continued engagement (24). As such, the role of the caregiver is of utmost importance in this process.

Several theories of technology acceptance suggest that high perceived usefulness and greater ease of use positively affect usage behavior (26,27). When technology is relevant to the job, there will be more perceived usefulness, which consequentially influences the intention to use the technology (27). All caregivers saw the added value of the DOP. However, the DOP needs some adjustments to improve usability, and a change in behavior among caregivers will be necessary to get the DOP established in practice and to actively promote its use in patients. It could be interesting to examine how the DOP can be integrated in the daily work of the health-care professionals. Support from management is needed, as the fit between organization, technology, and the user affects the factors related to user acceptance (28).

The DOP offers an opportunity for primary health workers to become better informed about the oncological care path that their patient follows in hospital. Hospitals play an important role in transitional care interventions and in coordinating chronic care with better outcomes for the patients, by taking a leading role in integrated care programs (29). In this way, the DOP optimized the exchange of data and the continuity of care across hospital walls.

Limitations

Although the patients were involved in evaluating the DOP, and although the tool was amended on the basis of their comments, patients were not involved in the project from the start. As such, we might have missed the perspectives of this important stakeholder group regarding the modalities needed in the DOP. Designing the DOP and including the perspectives of patients might have led to yield a tool with better uptake and overall utility.

This was a pilot study conducted in a single university hospital and was not intended to draw any conclusions about the effectiveness of the DOP, as the sample was too small for this. Research that attends to the implementation of the DOP in several hospitals would be necessary to verify the value added in terms of empowerment, patient participation, and improvement in quality of life. After all, being able to demonstrate that an eHealth application makes a substantial contribution to the intended healthcare objectives is an important condition for its effective implementation (30).

Conclusions

A prototype of a patient platform was developed by means of codesign with IT developers and caregivers. The DOP was actively used by half of the patients—and particularly by patients in the active treatment phase. For newly diagnosed patients with cancer, the DOP seems to add important value and can be an additional medium that guides patients through their treatment process. The study provided insight into which DOP functionalities interested the patients and includes patients' recommendations for implementation. Caregivers acknowledged the added value, but also indicated that an additional workload was involved. Oncology nurse specialists were the main users of the platform, while GPs indicated their interest in the platform. Additional modalities were requested by patients and caregivers and are to be included in the next version of the DOP.

Appendix

Content and Technical Modalities of the Digital Oncology Patient (DOP) Platform.

Appendix A. Content and Technical Modalities of the Digital Oncology Patient (DOP) Platform.

Content Modalities	Technical Modalities	
 Making reports, discharge letters, and research results available (with the possibility of foreclosure of certain data for the patient) Providing the individualized care path with access to information about diagnosis, treatment, and aftercare for the patients and other extramural care providers Working out online diaries/ scales where patients can register at home (including the registration of side effects due to treatment, psychosocial complaints, practical problems) adapted to the type of cancer and treatment Generating overviews/ summaries of an evolution of certain parameters over short/ long term Offering an overview of all planned appointments in the hospital in the future and from the past Sending messages for nonurgent questions Access rights for the various care providers of the multidisciplinary team 	 System performance Privacy and confidentiality Maintenance of the digital system Availability of (medical) data Integration into the electronic patient file Design and layout of the DOP 	

Appendix B. Demographics of the Patients.

	All Patients, $N = 23$	Active Patients, n = 10	Not Active Patients, n = 13
Gender			
Male/female	13/10	7/3	6/7
Mean age	47.1 (19-74;	44.3 (19-69;	49.2 (20-74;
(min-max; SD)	Ì7.8)	Ì6.5)	Ì9.0)
Living status	,	,	,
Living alone	2	0	2
Cohabit	21	10	11
Education			
High school	12	7	5
Further education	11	3	8
Type of cancer			
Bone cancer	16	6	10
Kidney cancer	7	4	3
Metastases			
No	10	5	8
Yes	13	5	5
Phase treatment			
Chemotherapy	6	3	3
Purpose treatment	10	6	4
Follow-up	7	I	6
Time of diagnosis			
<6 months	10	4	6
6 months to <1 year	2	I	I
l year to <5 years	7	2	5
>5 years	4	3	I
Estimate knowledge of			
PC/Internet			
Very good	8	5	3
Good	8	3	5
Average	2	I	I
Low	5	I	4
Average spend hours	15.7 (0-50;	18.4 (0-50;	13.6 (0-50;
on PC/week (min- max; SD)	13.9)	14.1)	14.0)

Abbreviation: SD, standard deviation; PC, computer.

Authors' Note

Dr Melissa De Regge and Mrs Elsie Decoene contributed equally to this work. K.E., E.D., and A.V.H. framed the research question. E.D. and A.V.H. collected the data. M.D.R. managed the database and carried out the statistical analysis. E.D., A.V.H., and M.D.R. wrote the manuscript. K.E. critically reviewed the article for important intellectual content. All authors approved the final version of submission.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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