Personalized Massive Open Online Course for Childhood Cancer Survivors: Behind the Scenes

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Abstract

Background Today, in France, it is estimated that 1 in 850 people aged between 20 and 45 years has been treated for childhood cancer, which equals 40,000 to 50,000 people. As late effects of the cancer and its treatment affect a large number of childhood cancer survivors (CCS) and only 30% of them benefit from an efficient long-term follow-up care for prevention, early detection, and treatment of late effects, health education of CCS represents a challenge of public health.

Objectives Massive open online courses (MOOCs) are a recent innovative addition to the online learning landscape. This entertaining and practical tool could easily allow a deployment at a national level and make reliable information available for all the CCS in the country, wherever they live.

Methods The MOOC team brings together a large range of specialists involved in the long-term follow-up care, but also associations of CCS, video producers, a communication consultant, a pedagogical designer, a cartoonist and a musician. We have designed three modules addressing transversal issues (lifestyle, importance of psychological support, risks of fertility problems) and eight modules covering organ-specific problems. Detailed data on childhood cancer treatments received were used to allocate the specific modules to each participant.

Results This paper presents the design of the MOOC entitled "Childhood Cancer, Living Well, After," and how its feasibility and its impact on CCS knowledge will be

Keywords
- survivors of childhood cancer
- health education
- information technology
- massive open online course

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measured. The MOOC about long-term follow-up after childhood cancer, divided into 11 modules, involved 130 participants in its process, and resulted in a 170-minute film. The feasibility study included 98 CCS (31 males vs. 67 females; $p < 0.0001$).

Conclusion Such personalized, free, and online courses with an online forum and a possible psychologist consultation based on unique characteristics and needs of each survivor population could improve adherence to long-term follow-up without alarming them unnecessarily.

Background and Significance

Childhood cancer is rare, as it represents only 1% of all cancers. In France, there are approximately 1,700 new cases of cancer per year in children under the age of 15 years.[1,2] Thanks to the improvement of the treatments, the overall survival rate of childhood cancer is now reaching 82%.[2,3] Today, it is estimated that one adult in 850 is a childhood cancer survivor (CCS), which equals 40,000 to 50,000 people.

Nevertheless, long-term health, quality of life, and survival of CCS are often altered by late effects related to the cancer and/or its treatments (radiotherapy, chemotherapy, surgery, etc.). Late effects include physical issues, such as second primary tumors, secondary leukemia, cardiovascular disease, infertility, growth impairment, and other manifestations, as well as educational, behavioral, and social problems.[4,5] Recently reported cumulative prevalence rates of chronic health problems in CCS were 95.5% (any) and 80.5% (disabling/life-threatening) by the age of 45 years.[6–10] In 2010 and 2016, a French study showed that in adulthood, 56% of patients treated for cancer in childhood reported experiencing at least one psychiatric disorder since cancer diagnosis, and agoraphobia and psychotic disorders were significantly more common than in the French population.[11,12] It is therefore recommended that CCS attend long-term follow-up care for prevention, early detection, and treatment of late effects.[13–18] Unfortunately, to date only 30% of CCS benefit from an efficient long-term follow-up. Several studies showed a lack of information for survivors and general practitioners (GP).[19–24] Also, the number of CCS responding to invitations to long-term follow-up ranges from 20 to 57% depending on the study, despite reminders.[23–26] Moreover, there is insufficient medical time to cover the needs of follow-up.

Objectives

In this paper, we present the massive open online course (MOOC)-based approach that we developed to provide young adult CCS with personalized information, aiming to empower them to organize their own follow-up and prevention practices with their GPs. We aimed to describe the construction of the MOOC entitled "Childhood Cancer, Living Well, After" and the preliminary results of participation in the feasibility study. The MOOC construction and dissemination are integrated in the national project START (Interventional Project on Long-Term Follow-Up Care: Virtual Help, Research and Transversality). Many actors, including professionals as well as former patients, have been invited to participate in the development of the MOOC.

Methods

The Massive Open Online Course Program

MOOCs are web-based courses accessible with internet connection open to a great number of participants during a specified period.[27] Traditionally, this entertaining and practical tool consists of a succession of online learning modules organized and structured around well-defined themes, accompanied by computerized resources such as links toward sites of interest, additional documents to download, an online forum (with the availability of a psychologist and medical doctors) and quizzes.

The MOOC team of this study brings together a large range of specialists involved in the long-term follow-up care after childhood cancer: pediatric oncologists and hematologists, endocrinologists, rheumatologists, ear-nose-throat doctors, cardiologists, pneumologists, dermatologists, ophthalmologists, radiotherapy oncologists, surgeons, gynecologists, radiologists, psychiatrists, psychologists, sociologists, sexologists, philosophers, nurses, physical medicine and rehabilitation doctors, occupational therapists, neuropsychologists, and adapted physical activity teachers. It also involves former patients' and parents' associations. Several professionals were also involved such as video producers, a communication consultant, a pedagogical designer, a cartoonist, and a musician. All contributors are listed on the home page of the MOOC. We have designed three modules addressing transversal issues (lifestyle, importance of psychological support, and risks that can lead to fertility problems) and eight modules covering organ-specific problems (►Table 1). The theme and content of the modules resulted from a preliminary work of drafting guidelines and patient information (Supplementary Material 1, available in the online version). The selection of the topics as well as the development of the modules themselves relied on a multidisciplinary expert team, involved in the definition of content, interviews, writing of the module, and reviewing and rewriting by working groups and then by groups of experts, each module being coordinated and supervised by a scientific referent in the topic.

The allocation of modules dedicated to a specific kind of sequelae follows an algorithm accounting for tumor sites and treatments received (surgery, chemotherapy, and radiotherapy) that was validated by the French National Long-Term Follow-Up

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Table 1 List of the modules of the massive open online course "Childhood Cancer, Living Well, After"

	Module	Title
Common modules	1	Taking care of yourself after cancer
	2	Well in your head, well in your skin
	3	Let's talk about fertility!
Personalized modules	4	Life after bone marrow transplant
	5	Heart and lung health
	6	Screening for other tumors
	7	Hormones and vitality
	8	Protect your hearing
	9	Strengthening bone structure and screening for eye problems
	10	Good kidney health
	11	Memory difficulties and other cognitive disorders

Committee of the SFCE according to the published guidelines (►Table 2).[17] This committee includes oncologists, radiotherapists, surgeons, psychologists, former patients, sociologists, and philosophers.

All the modules are made of videos on the basis of pedagogical scenarios validated by all professionals of the MOOC team and former patients' and parents' associations (**Supplementary Material 1**, available in the online version). They all combine a scientific dimension from interviews of specialists and a human dimension from the testimonies of patients' lived experience. Throughout the development of the MOOC, former patients were involved to ensure relevance and understandability.

We were particularly aware of the necessity that a large number of specialists and witnesses could speak on the video, and that the editing work maintain an appropriate rhythm by retaining only the best of each one and favoring short interventions. We have chosen the form of a sound film to make it accessible to the visually impaired patients.

Certain choices of realization had to be made for all the modules. Indeed, there were a lot of patient testimonies and the video producers had to make a choice as to which ones to keep to provide positive messages.

- The choice to rely on two complementary poles: the human dimension through the testimony of the lived experience, and the scientific dimension carried by the specialists.
- The number of specialists who spoke on video, the extensive choice of nearly 40 witnesses with a comprehensive diversity of origin, age, regions, and different experiences.
- The choice in the editing to maintain a dynamic rhythm by retaining only the best of each intervention and favoring short ones.
- The choice of witnesses from several regions.

Table 2 Algorithm for modules allocation of the massive open online course "Childhood Cancer, Living Well, After"

Treatment	MOOC modules
Nephrectomy	10
Pneumonectomy	5
Thyroidectomy	7
Corticoids ≥40 mg/m^2/day and ≥8 weeks in total (i.e., 2.24 g/m^2 in total)	9
Bleomycin (270 mg/m^2)	5
Alkylants (girl = any dose – Boy = if ≥3 g/m^2 cyclophosphamide and/or ≥36 g/m^2 ifosfamide or Busulfan (any dose) or combination of 2 alkylants)	7
Ifosfamide ≥36 g/m^2	7, 10
Busulfan (any dose)	5, 7, 9
CCNU (≥100 mg/m^2)	5
BCNU (≥100 mg/m^2)	5
Anthracyclines (any dose)	5
High dose methotrexate (≥5 g/m^2)	9, 11
Carboplatine (any dose)	10
Carboplatine ≥2.5 g/m^2 or carboplatine associate with cisplatine (any dose)	8, 10
Cisplatine (≥200 mg/m^2)	10
Cisplatine ≥400 mg/m^2 or cisplatine associate with carboplatine (any dose)	8, 10
Craniopharyngioma	7, 9, 11
Pituitary tumor	7, 11
Acute lymphoblastic leukemia	9
Optic tract tumor and retinoblastoma	9
Optic chiasma tumor	9 - 11
Osteosarcoma	9
Cerebral tumor	11
Renal tumor	10
Bone marrow allograft	4
Ocular proton therapy	6, 9
Cardiac irradiation (mediastinum and/or lungs and/or thoracic)	5, 6, 7
Cavum irradiation (unless protontherapy = no assignment of 8 and 11)	6, 7, 8, 9, 11
Cranial irradiation	6, 7, 8, 9, 11
Focal irradiation	6
Renal or abdominal irradiation	6, 7, 10
Total body irradiation	5, 6, 7, 8, 9, 10, 11
All Irradiations except exclusive limbs (thyroid = mediastinum or cranial or cervical or craniospinal or mantelet - pelvic - abdominal) (whatever the Gray dose)	7

Abbreviations: BCNU, bis-chloroethylnitrosourea (carmustine); CCNU, 1-(2-chloroethyl)-3-cyclohexyl-1-nitrosourea (lomustine); MOOC, massive open online course.
Note: Massive open online course modules: 4 = bone marrow allograft; 5 = cardiopulmonary; 6 = 2d cancer; 7 = hormones; 8 = hearing; 9 = bones and eyes; 10 = renal; 11 = cognitive.

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Fig. 1 Illustration of hearing in the module 8 "protect your hearing."

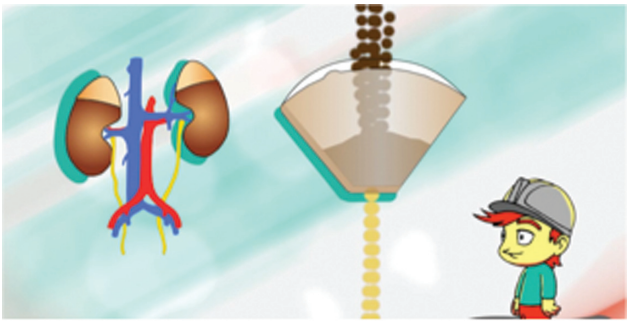

Fig. 2 Illustration of renal filtration in the module 10 "good kidney health."

The illustrations (►**Figs. 1** and **2**) and animations that energize the words supported by a soundtrack attract attention and underline the strong messages.

All professionals and associations of former patients and parents have seen and agreed with the modules in which they have participated.

The reflections on the pedagogical scenario started in March 2018. The proofreading, the shooting, the scene selection, and the editing that followed have lasted nearly 2 years. A total of 130 participants were involved in this process and it resulted in a 170-minute film. This film was divided into 11 modules, which were spread along 12 weeks for the first session of the MOOC.

Statistical Analysis

Data was analyzed with SAS software (SAS, version 9.2, SAS Institute Inc., Cary, North Carolina, United States).

Characteristics of participants and nonparticipants in the feasibility study were compared by using Chi-square test or Fisher's exact test for gender, diagnosis type and treatment received, and Student's *t*-test for age at diagnosis and age at the start of the MOOC. The threshold for statistical significance was set at $p < 0.05$.

Results

Course of the Massive Open Online Course

Former patients are invited to participate by a letter referring to an online teaser presenting the MOOC and giving a personal confidential access code to register on the MOOC website.[28] This personal confidential access code allows access only to the modules in accordance with the childhood cancer treatment received by the participant (algorithm in ►**Table 2**).

Once they have accepted to participate, they are asked to provide their GP's contact information so that they can access the same selection of modules as their patient.

One module is made available per week for 3 weeks and then the potential eight other modules, depending on the treatment received, are simultaneously released during the 4th week. All modules remain available during 12 weeks. The MOOC is implemented within the Claroline Connect platform at the University of Saint-Etienne[29] (►**Supplementary Material 2**, available in the online version).

Several pedagogical tools are used in complement. Quiz questions prepared by experts of the field are used to appreciate specific knowledge before and after a module. A satisfaction questionnaire is also given at the end of each module and at the end of the entire MOOC.

Participants are given access to a forum allowing them to interact with medical professionals and with other participants (presentation, questions, and experiences in the theme). A map of long-term consultation centers in France and links to various websites of interest are also provided (►**Supplementary Material 3**, available in the online version)[30].

Feasibility Study

The target population for the MOOC training program is composed of the young adults CCS who were diagnosed with a solid tumor or leukemia between 2000 and 2010, lived in mainland France, and were less than 15 years old at the time of diagnosis. They must be at least 18 years old at the time of their contact for the MOOC study and in remission for the 5 previous years. The eligible CCS are identified from the Childhood Cancer Observation Cohort (CCOP),[31] a cohort based on the French national registry of childhood cancer.[1]

In a first step, the MOOC was delivered in a feasibility study from March to May 2020. The purpose of this first study was to assess the feasibility and preliminary effects of an online educational program in the CCOP cohort, and, on the other hand, on their GP. As no literature about MOOCs and childhood cancer survival is currently available, the feasibility study is necessary to determine the different metrics to be measured, that is, participation rate, refusal rate, completion rate, satisfaction level, characteristics of participants and nonparticipants, and knowledge level before and after the MOOC.

We estimated that 25% of the global eligible population would be necessary for this purpose. Thus, 885 subjects were selected from the entire eligible population through cluster sampling according to the International Classification of Childhood Cancer group, third edition,[32] two age groups (18–25 years/26–34 years), and treatment center to obtain optimal representativeness of the initial population at the checkpoint of December 31, 2018.

Out of the 3,542 former patients aged 18 to 35 years who met the above eligibility criteria, 885 patients were thus selected for the feasibility study. Their vital status and their last contact information 5 years after their diagnosis were updated in

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August 2018, according to the CCOP procedures. For each eligible young adult, the initial referring onco-hematologists and radiotherapy oncologist were contacted for approval to contact their former patient for inclusion in the study.

The detailed data on treatments received during childhood available in the CCOP were computerized and used to allocate the specific modules to each participant in compliance with the algorithm (►Table 2). Doses of chemotherapy (alkylants, anthracyclines, etc.) have been considered, as well as surgery (nephrectomy, pneumonectomy, etc.), radiotherapy area (total body irradiation, cranial irradiation, etc.) and type of cancer (pituitary tumor, acute lymphoblastic leukemia, etc.) (►Table 2). For the feasibility study, additional control qualities of treatment consistency and correct allocation of the modules to each of the 885 selected patients were performed by the MOOC investigators together with those of the CCOP to enhance the computerized system for the impact study. Participants had thus access only to the modules adapted to their own tumor and the treatment they received.

Among the 885 eligible CCS, 574 were contacted and 170 were lost to follow-up (incorrect postal address). Around 17% of the eligible CCS participated in the MOOC ($n = 98$), with significantly more women than men participating ($p < 0.0001$; ►Table 3). Only three former patients refused to participate and 473 did not answer at all to the invitation letter.

Out of the 98 participants, 28 noted their GP's contact to allow them visualizing exactly the same modules as their patient, but despite a phone call from the project manager of the study, none of these GPs connected because of the simultaneous COVID-19 epidemic.

Legal Aspects

The free and accessible educational MOOC "Childhood Cancer, Living Well, After" is the intellectual property of the authors and no reuse is permitted without their agreement. The use of the contents is granted to the University of Saint-Etienne and the University of Angers.

For this preliminary feasibility study, a favorable opinion was obtained from the Ethics Committee of the University Hospital of Saint-Etienne on September 13, 2018 from the French Expertise Committee for Research, Studies, and Evaluations in the Field of Health (CEREES) on February 14, 2019 and from the French National Commission for Data Protection and Liberties (CNIL) on February 8, 2019.

Table 3 Characteristics of participants and nonparticipants in the massive open online course "childhood cancer, living well, after" of the feasibility study

	Total of contacted patients	Participants		Nonparticipants		*p*-Value
	($n = 574$)	*n*	% of contacted patients	*n*	% of contacted patients	
Total		98	17.1	476	82.9	
Gender						
Male	314	31	9.9	283	90.1	<0.0001
Female	260	67	25.8	193	74.2	
Diagnosis						
Leukemia	146	24	16.4	122	83.6	0.6
Lymphomas	132	25	18.9	107	81.1	
Central nervous system tumors	104	16	15.4	88	84.6	
Renal tumors	12	4	33.3	8	66.7	
Bone tumors	46	10	21.7	36	78.3	
Soft tissue sarcomas	43	6	14.0	37	86.0	
Others	91	13	14.3	78	85.7	
Treatment						
Chemotherapy	446	79	17.7	367	82.3	0.4
Radiotherapy	170	31	18.2	139	81.8	0.6
Allograft	29	3	10.3	26	89.7	0.4
Autograft	31	6	19.4	25	80.6	0.7
Surgery	285	52	18.2	233	81.8	0.5
Mean age at cancer diagnosis, years (± SD)		9.4 (± 3.9)		9.0 (± 3.8)		0.4
Mean age at the start of the MOOC, years (± SD)		24.3 (± 3.7)		23.8 (± 3.5)		0.2

Abbreviations: *n*, number; MOOC, massive open online course; SD, standard deviation.

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Discussion

Massive open online courses are a recent innovative addition to the online health-related learning landscape. MOOCs on health and medicine allow the general public to acquire, at their convenience, health education on niche topics. One potential area that can be targeted by health and medicine MOOCs is patient education and empowerment. As a result, patients would be able to engage in a meaningful discussion with medical professionals about the care they receive and other alternative treatments. They were preceded by interventions proposed on web applications. These applications, aimed at a better understanding of their disease and side effects, have helped to reduce stress symptoms. An example is iCancerHealth app in patients with gastrointestinal cancer.[33]

Put in perspective with the oncologist's and GP's lack of time to develop prevention and public health education for each cancer survivor, and the demand of former patients to be better informed about their long-term health risks, such personalized therapeutic education could be a good tool.[34,35] While most MOOCs about health are for health professionals, this one is intended for former patients, and their GPs are invited to watch the same modules as their patients. Other MOOCs offered this possibility with an excellent retention rate.[36] This is the first personalized MOOC developed for cancer survivors, and it had never been analyzed as a potential intervention to improve adherence to surveillance guidelines in survivors of childhood cancer.[37] Some internet-based tools are available for adult cancer survivors to promote long-term follow-up and to offer personalized recommendations.[38–40] Published data, although limited, suggest that such tools improve understanding of health risks, survivor, and GP satisfaction, and their adherence to long-term follow-up care. Some studies have shown that young survivors are interested in access to online education and social support.[41,42]

Among other sorts of patients suffering from chronic disease, MOOCs, including forums showed a positive impact on health condition, can increase adherence to treatments for example for adolescents and young adults with systemic lupus erythematosus (from 50 to 92% for patients who had access to the forum), and met the perceived needs of patients (for example for asthma).[43–46]

As eligible patients of this study are young adults aged 18 to 35 years, the use of an entertaining and practical modern tool like a MOOC seems more adapted than traditional tools such as paper guides, even if MOOCs can be used for older people.[47]

The strength of this study is to propose to each participant a tailor-made education including only what is useful for their long-term follow-up, avoiding some potentially stressful information concerning late-effects related to other cancer treatments than the ones received. Furthermore, the participation of many French national experts, as well as survivors, can guarantee a correct presentation of validated medical information, using for example an understandable vocabulary for the participants. We also propose during the MOOC a personalized psychological support by e-mail or telephone, according to the patient's choice, with a psychologist specialized in the long-term follow-up after childhood cancer.

One possible obstacle for this study might be to obtain an updated postal address for the eligible subjects, as today young adults move often, sometimes live with a divorced/married again parent whose name is different from theirs, or change addresses to study. Results of the feasibility study will be later published but the number of participants was higher than in other publications ($n = 98$)[43–45]. The participation of women was higher than men, as often found in such studies. Concerning GPs, none of them connected because of the simultaneous COVID-19 epidemic. They will be contacted again at a later date, but out of the COVID-19 context, and the results will be described in another paper.

The expected health impact of this MOOC study is to improve the quality of CCS long-term follow-up care thanks to a collaboration between experts and survivors, using a practical tool intended for survivors, leading to less inequity on the national territory and to increase knowledge about late effects of cancer and its treatment. This MOOC responds to a strong demand from former patients, and we will evaluate the degree of satisfaction of the participants.

A secondary study will aim to measure the impact of the MOOC on the knowledge level concerning the good practices of medical follow-up and lifestyle, and also on the quality of life of the patients. Another survey will be sent to the participants after the MOOC by the CCOP team including questions on lifestyle, health, medical follow-up, quality of life, and sexuality and will be later analyzed for the impact study. Analysis for the feasibility study is necessary to estimate the number of subjects to include in the impact study constructed on the cohort multiple randomized controlled trial design.[46,48]

Conclusion

This system of remote online training can easily allow a deployment at a national or international level (if there is a CCS registry) and make reliable information available for every CCS in the world, wherever they live if we were to offer English subtitles in the future.

Clinical Relevance Statement

Such personalized, free, and online courses with an online forum and a possible psychologist consultation based on the unique characteristics and needs of each survivor population, could improve adherence to long-term follow-up without alarming them unnecessarily.

Multiple Choice Questions

1. In our country, which percentage of childhood cancer survivors (CCS) is estimated to benefit from an efficient long-term follow-up care for prevention, early detection and treatment of late effects?
   a. 10% of CCS
   b. 30% of CCS
   c. 50% of CCS
   d. 70% of CCS

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Correct Answer: B is correct. In a French study published in 2017, only 30% of the asked GPs who follow a CCS declared implementing a particular follow-up of their patient after childhood cancer, the 70% others declared implementing no particular follow-up of their patient after childhood cancer.

2. How were the specific modules of the MOOC allocated to each participant?
   a. According to the treatment period of the childhood cancer
   b. According to the center where the childhood cancer had been treated
   c. According to the detailed data on childhood cancer treatments received
   d. According to the gender of the childhood cancer survivor

Correct Answer: C is correct. Only the cancer treatments received during childhood (surgery, chemotherapy, and radiotherapy) are relevant for allocating the specified modules of the MOOC. The gender of the patient, the period of the cancer diagnosis, and the center where the patient was treated are not useful.

Protection of Human and Animal Subjects

The study was performed in compliance with the World Medical Association Declaration of Helsinki on ethical principles for medical research involving human subjects, and was reviewed by the Ethics Committee of the University Hospital of Saint-Etienne on September 13, 2018, from the French Expertise Committee for Research, Studies, and Evaluations in the Field of Health (CEREES) on February 14, 2019 and from the French National Commission for Data Protection and Liberties on August 2, 2019.

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Conflict of Interest

None declared.

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