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CureCancer Platform Facilitates Patients' Self-Data Recording, Treatment Adherence and "Distancing Interventions". A Feasibility and Satisfaction Study.

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Keywords:

Cancer; Digital Tool; Patient Driven; Patient-Reported Outcomes; Telemedicine

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Abbreviations:

HCP: Healthcare Professional, GDP: Gross Domestic Product, HeSMO: Hellenic Society of Medical Oncology

1. Summary

1.1. Aim: To assess CureCancer's feasibility and patients' and Oncologists' satisfaction. CureCancer is a patient-centric/driven platform, which enables patients to self-create their profile, report symptoms, and communicate with physicians.

1.2. Methods: Patients from 9 Centers were asked to register at CureCancer, upload their data and complete a questionnaire on demographics, disease and treatment characteristics, and their satisfaction.

1.3. Results: 159 patients were enrolled and 144 (90.6%) registered. 114 of 144 (79.1%), 63 males and 51 females, median age 54.5 years, completed the questionnaire. 64 patients were University and 35 were high School graduates. 46 patients had metastatic disease, 87 were on active treatment and 51 received supportive care. All patients also visited non-oncology Healthcare Professionals (HCPs). Nineteen patients changed work status and 49 had children below 24 years.

Registration was "much/very much" easy for 98 (86.0 %) patients. File uploading was "much/very much" easy for 47 (41.2%) patients. Over 80% of patients and physicians preferred the digital way. 99 patients and all HCPs will recommend CureCancer to others. Easy data access, improved communication, feeling safe, clinicsofoncology.com treatment adherence, interventions from distance, particularly during covid-19 pandemic and saving time and money, were highly commented by patients and oncologists.

1.4. Conclusion: CureCancer was feasible, and patients and oncologists were satisfied. File uploading changed to become more user friendly. Integration of CureCancer in the routine practice is expected to improve cancer care and reduce cancer costs. Patients' self-reporting, with CureCancer, can increase the accuracy of clinical trial results and map social/work/economic issues following cancer diagnosis to assist health care policy.

2. Introduction

Globally 43.8 million people live with cancer. A 60% increase of cancer cases is estimated by 2040, with 29.4 million patients per year requiring therapy [1, 2]. The increasing burden of new cancer cases and cancer survivors and the development of novel therapies have made cancer clinical practice more complex, and with increased care costs. Cancer care cost in the European Union, in 2017, was €141.8 billion, reaching the 1.07% of gross domestic product (GDP). In the USA (2017), cancer economic burden was 342.2 billion, (1.8% of GDP). Optimization of cancer management, using digital innovation, is urgently needed [3, 4]. A digital health care solution for effective supportive care and communica-

tion should have the following features:

(1) A well-informed patient, having a direct access to his medical files, sharing them with cancer care team.

(2) An accurate symptoms' record, in real world and real-time, to share with the caring physicians and facilitate early management. Early initiation of supportive care during disease has been shown to reduce cancer costs by up to 33% [2, 5, 6]. Furthermore, embedding the patient perspective, using PROs is considered a hallmark of quality clinical care and research [7-9]. (3) The potential to provide a live communication between patients and HCPs and facilitate patient's assessment, monitoring and management from "Tele" (meaning of or across a distance in Greek). Telemedicine is particularly useful during pandemics and when patients live outside the Cancer Center and travelling is not easy due to individuals' being unwell, work or family/children care and other problems [10, 11]. (4) The availability of the accurate patient files to (a) complement clinical trials and assist treatment decision making and (b) to advise the health care policy and economic modelers.

During the routine dental-oral oncology clinical practice, Dimitra Galiti faced the difficulties in having access to patients' medical history, which limited our ability to provide adequate supportive patient care. CureCancer was, then, inspired. CureCancer, https:// curecancer.eu//, is a patient-centered and patient-driven, which enables patients to self-create their medical profile, record their symptoms, and share files and symptoms with their physicians. It is in the unique property of each patient. Patients can communicate with their HCPs with a video call to receive early, safe, and effective supportive care, at low cost. CureCancer has been assessed by the Ministry of Research and Innovation and is included in the "Elevate Greece" list of Innovative Start Ups of the Ministry of Research and Innovation https://elevategreece.gov.gr/.

In the present study, we aimed to assess the feasibility of Cure Cancer and the satisfaction of patients', and oncologists. The oncologists were members of the Hellenic Society of Medical Oncology, https://www.hesmo.gr/en/. HeSMO is the National Society of Certified and Qualified Medical Oncologists of Greece.

3. Patients and Methods

3.1. Patients

Eligibility criteria

Patients were included in the study if they were: (1) 18 years of age or older, (2) diagnosed with cancer at least one month earlier, when they were well-embarked on a treatment plan, (3) were on active cancer treatment and thereafter, (4) had over one-year prognosis, (5) self-reported internet knowledgeable, (6) could understand the Greek language to read and understand the forms and questionnaire and (7) agreed to sign the information and consent forms. Patients were excluded if they lacked the capacity to give informed consent due to psychopathology, cognitive dysfunction, learning difficulties and other problems.

3.3 Ethical approval

The study was approved by the Committee of Research and Ethics of all participating Cancer Centers. Eligible patients were invited to participate in the study and signed an information letter and a consent form. An electronic consent was also available online.

3.3. Methods

A multicenter, non-randomized prospective cohort study was performed. Collaboration between the Hellenic Society of Medical Oncology-HeSMO, www.hesmo.gr and the CureCancer, www. curecancer.eu, was signed in September 2019. HeSMO invited their members to the study. Oncologists from 9 Cancer Centers responded and accepted to participate. Eligible consecutive patients were invited by their oncologist and signed the information letter and the consent form. Patients were educated about their benefits when using CureCancer and were given written instructions for accessing the platform. According to the signed agreement, after the completion of the study, the data were sent to both HeSMO and Dimitra Galiti, anonymously and in aggregates.

3.4. Questionnaires

Registered patients completed the Questionnaires 1, 2 and 3. Questionnaire 1 included questions on patient demographics. Questionnaire 2 included disease characteristics. Questionnaire 3 included questions of "no or a little" and "much or very much" and "Yes or No" related to the platform's feasibility and their satisfaction. It also included open questions for patients to describe why they preferred the digital innovation and suggest improvements for the platform.

Oncologists completed Questionnaire 4. It included questions of "no or a little" and "much or very much" and "Yes or No" related to their communication with their patients and other colleagues, and their clinical practice. It also included open questions to describe why they preferred the digital innovation and suggest improvements for the platform.

3.5. Primary Endpoints

Feasibility assessment

A priori criteria for the feasibility of patients were (a) a rate of \geq 70% of patients, who registered of those who signed to participate, and (b) a rate of \geq 70% of the registered patients, who completed the questionnaire.

Satisfaction assessment

Satisfaction and preferences were extracted from patients' and physicians' responses.

3.6. Secondary Endpoints

Cancer patients' profile and potential socioeconomic problems, following cancer diagnosis, were important to further assess the usefulness of the platform.

3.7. Data Analysis

Patients' demographics, disease characteristics, therapies, social

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profile, the feasibility, and satisfaction outcomes were primarily analyzed using descriptive statistics. For categorical variables absolute and relative frequencies were provided, while continuous variables were described by N, mean and standard deviation or median and range. Any possible association was investigated using Chi-square and T test. Open-ended patients' and oncologists' feedback and satisfaction questions were examined qualitatively. Statistical Analysis was conducted in Stata 15.1 [12].

4. Results

4.1. Patients

Patient, disease, and therapy characteristics: 159 patients, between January to December 2020, were enrolled and 144 of those (90.56%) registered at the platform. One hundred and fourteen of all 144 registered patients (79.16%) completed the questionnaire (Table 1). Sixty-four patients were University graduates, followed by High School ones. Breast and lung cancers were most common. Eighty-seven (76.3%) patients were on active cancer therapy, 46 (40.4%) had metastatic disease, and 51 (59.6%) reported receiving supportive cancer care, including antiemetic medications, medications for pain relief, and other.

During the study period, all patients reported visiting at least one non-oncology specialist as well. Forty-seven patients visited 2-9 different non-oncology specialists (Table 1). The total number of HCPs from different specialties was 208, (mean number per patient=1.82). The mean number of HCPs was higher, though not significantly, among patients under active treatment compared to no current therapy group, 1.92 versus 1.51 (P=0.18). The total number of visits of each patient to each HCP was not recorded.

Previous Cancer therapies: Eighty-one of the 114 patients (71.05%) reported having received previous cancer therapies, surgery (n=62), chemotherapy (n=44), radiotherapy (n=5), hormonal therapy (n=5) and targeted therapy (n=1) (Table 1). Furthermore, 27 patients also recalled receiving supportive care including anti-depressants, pain medications, feeding support and medications for bone metastases. Fifty patients had received more than one types of therapy.

Social profile and working status: Nineteen (26.39%) of 72 patients changed their work status following cancer, 16 (14%) lived alone and 49 (43%) had children younger than 24 years of age. Nine (7.9%) patients were members of Patients' Associations (Table 2).

Patients' responses: Of the 114 patients, 98 (86.0%) reported their registration and use of the platform being "very to very much" easy. Forty-eight (41.2%) patients reported file uploading as "very to very much easy". Ninety (78.9%) patients preferred the digital way and 99 (86.8%) will introduce it to others (Table 3).

Patients' comments: 54 patients completed this part of the questionnaire. They highlighted the easy data access, well organized data, increased communication with HCPs, feeling safe, treatment adherence and interventions from distance, particularly during the covid-19 pandemic, reduced visits to physicians, saving time and money. (Table 4). Twelve patients asked for a user-friendlier environment, 6 had nothing to change, 2 asked to receive newsletters, one requested for a mobile application, and another complained of the many questions. One patient "believes" that the platform should be particularly useful for the people, who live in areas remote from the Cancer Centers, and that all HCPs should collaborate. He also suggested the platform to be widely publicized to HCPs, because they are most responsible for the proper promotion and effective use and function of the platform.

Table 1: Patient, Disease, Treatment Characteristics, Other HCPs needed, n=114

Parameter		N	%
Gender			
	Male	63	55.3
	Female	51	44.7
Age	Range (n)	23-87 (104)	
	Median	54.5	
Educational status		·	·
	University	64	56.1
	High School	35	30.7
	Junior & Elementary School	15	13.2
Cancer type		· ·	·
	Breast	23	20.2
	Lung	16	14
	Head/Neck/Oral	12	10.5
	Colorectal	10	8.8
	Pancreatic	9	7.9
	Other cancers*	16	14
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	Other, not identified types	23	20.2
	Multiple cancers	5	4.4
Patients with metastatic disease		46	40.4
No current therapy		27	23.7
Patients under active cancer therapy			
	Chemotherapy	48	42.1
	Immunotherapy	9	7.9
	Targeted therapy	4	3.5
	Radiotherapy	4	3.5
	Combined therapies	13	11.4
	Hormonal treatment	9	7.9
Supportive Care**			
	No current supportive care	63	55.3
	Any Supporitive care	51	44.7
	Antiemetics	22	19.3
	Pain relief	16	14
	Psychological support	15	13.2
	Bone Targeting Agents	13	11.4
	Feeding support	10	8.8
Visiting other HCPs**			
	At Least 1 other HCP	144	100
	Cardiologist	44	38.6
	Dentist and/or Stomatologist	40	35
	Dietician	19	16.7
	Psychologist/Neurologist	18	15.7
	Endocrinologist	11	9.6
	Other HCPs	51	44.7
	More than 1 HCPs(2-8)	47	41.2

*other cancers: Sarcomas (n=4), Hepatic (n=3), Gastric (n=3), Leukemia (n=2), Multiple Myeloma (n=2), Skin (n=2).

** categories are not mutually exclusive.

Table 2: Social and working status, n= 114	4	
Working prior to cancer diagnosis	Ν	%
	74	69
Same job continued after diagnosis n=72	Ν	%
Yes	53	59.6
No	19	40.4
Reason for the change/stop working		
My contract was not renewed	7	36.9
I changed work due to my therapy	2	10.5
I retired	6	31.6
Not Applicable	4	21
Living		
with spouse	88	77.2
In relation	10	8.8
Alone	16	14
Having children under 24		
Yes	49	43
No	65	57
Member of cancer patient Associations		
Yes	9	7.9
No	105	92.1

	No / A little	Much / Very much
	N (%)	N (%)
1 Was your registration and CureCancer use easy?	16 (14.0)	98 (86.0)
2 Was it easy to upload your files?	67 (58.8)	47 (41.2)
	YES	NO
	N (%)	N (%)
3 Do you prefer the digital way?	90 (78.9)	24 (21.1)
4 Will you recommend CureCancer use to others?	99 (86.8)	15 (13.2)

Table 3: Patients experience and responses, closed questions, N=114

4.2. Physicians

Eighteen oncologists responded. Most oncologists reported that CureCancer improved their communication with patients and colleagues and minimized their patients' risk of infection, reducing unnecessary visits to hospital. All oncologists will continue inviting their patients to use CureCancer (Table 5).

Most oncologists preferred the digital innovation for having fast, easy, and safe access to well organized data, reducing paperwork, and space for files/hard copies. Direct, communication, anytime, from anywhere, easy information access, early reporting of symptoms and timely management, and reduced patient burden were the most important benefits reported. Oncologists suggested a user-friendlier digital environment/access of the platform, the potential/possibility to collect their patients' data in aggregates and receiving a message when a patient uploaded a new file or symptom, or an alert sign (Table 6).

Table 4: Open Questions-Patients comments on their preferences*, n=54

why do you prefer the digital way and in what way it was useful to you	N (%)
Visits with doctors, Communication	26 (48.1)
Reduced visits	
Saved money	
Saved time	
Minimized risk for contacting covid-19	
Direct, fast, effective response	
I uploaded photos/reports and informed my doctor	
Doctor was better informed for my condition	
All my doctors could communicate each other and myself	
Communicating my experience with others	
Data/medical history access	54 (92.2)
From anywhere	
Easy, I do not carry with me my hard copy examinations	
Did not miss data, direct information	
Facilitated my treatment adherence	
Avoid volume of hard copies	
Data well organized at any time	
With a click I can see my medications	
No need to count days/time for my medications	
Well organized treatment plan	
What did you like best	
Communication	22 (40.7)
The direct communication between patients and physicians	
The communication and collaboration of different doctors, at any minute	
Feeling secure, I can communicate with my doctor	
I Communicated with other patients	
Uploading my photos and reports and direct doctor's response	
Digital way	54 (92.2)
Well organized data and examinations	
Organized treatment plan	
Easy access to me and to all my doctors	
Self-reporting my condition and symptoms	
Make me feel safe	
Easy to use	
Reduce inconvenience visits travels	
*Categories are not mutually exclusive	

	No / A little	Much / Very much
	N (%)	N (%)
1 Did CureCancer use improve communication with your patients?	5 (27.8)	13 (72.2)
2 Did CureCancer use improve your clinical practice?	5 (27.8)	13 (72.2)
3 Did CureCancer use improve your communication with other colleagues?	6 (33.3)	12 (66.7)
4 Did CureCancer reduce your clinical burden?	11 (61.1)	7 (38.9)
5 Did CureCancer reduce your patients' urgent calls and visits	10 (55.5)	8 (44.4)
6 With CureCancer did you provide advice to your patients without meeting them at the Hospital?, n=16	10 (62.5)	6 (37.5)
7 Did you feel that you minimized your patients' infection risk, reducing physical visits?, n=16	7 (43.8)	9 (56.2)
	YES	NO
	N (%)	N (%)
8 Do you prefer the patient- driven digital way?	15 (83.3)	3 (16.7)
9 Will you continue inviting your patients to use CureCancer?	18 (100)	-

 Table 6: Physicians open questions, comments*, n=18

Reason for preference of the digital innovation, n=12 response	
Easy, fast, safe access, easy to handle, more accurate data, n=12	
organized data, direct communication, n=12	
reduced beaurocracy, n=1	
reduced filing space, n=1	
CureCancer's most important benefit to patients and physicians, n=14 response	
Direct, safe communication, anytime from anywhere, n=12	
patient has an organized file, with easy access of information by a multidisciplinary team of physicians, n=1	
Direct report of toxicity, sense of safety for the patients and better management, n=2	
Reduced patent burden, n=1	
Changes needed to improve CureCancer's use, n=4 response	
Easier, more friendly digital environment and access/visiting of the platform, n=3	
Offer of the potential to access the data in aggregates for statistics, n=1	
Physicians would like to be informed when a patient has uploaded a new data, n=1	
Physicians would like to be informed for an alert sign oy urgent symptom, n=1	
*categories are not mutually exclusive	

5. Discussion

5.1. Platform's Feasibility and Patients' Satisfaction

CureCancer was feasible, as it was highlighted from the increased participation of patients (> 80%) who offered us a wealth of patient-driven information. Importantly, patients highlighted the sense of safety, treatment adherence, reduced hospital visits and infection risk, saving time and money and their good communication with oncologists. Treatment adherence τ o oral anticancer agents and supportive care services can highly benefit with telemedicine particularly during the COVID-19 pandemic, while patient – doctor communication is an important factor in cancer care [10, 11, 13, 14]. Receiving newsletters and request for a mobile application were considered positive comments. Importantly, one patient highlighted that Medical Oncologists are responsible for clinicsofoncology.com

the promotion and effective use of CureCancer.

5.2. Physicians' Satisfaction

Oncologists were satisfied and commented on the improved communication with patients and colleagues, enhancing their clinical practice. Cross-sectoral video consultations to enhance continuity of cancer care received positive comments by oncologists, general practitioners, and patients in another study [15].

Discussing the patient-reported profile, cancer status and socioeconomic details

As cancer diagnosis and therapy affect different physical, socioeconomic and occupational domains of life, the above information was thought necessary to assess the overall profile of cancer patients - users, in this preliminary phase of CureCancer function. Age and level of education: Our patients were about one decade younger than the global median age of 66 years of cancer patients. A younger median age was also reported by other digital health solutions [16-19]. A median age of 63 years, aligned with the global median cancer rage, was reported in a web-based study, when, however, patients completed the survey, at the hospital, receiving assistance, when needed [6, 14]. Most participants, in the present study, were University and High School graduates, indicating an association between younger age and digital solutions. A higher education level was also related to higher acceptability of the digital solutions by other investigators [16-19]. Furthermore, in our study, the percentage of the University graduates was reduced at the completion of the study, compared to the one assessed 5 months after the initiation of the study (56% versus 61%), while the High School graduates were increased (30.75 % vs 23%) indicating a push to internet literacy due to the urgent need for digital solutions because of social distancing, related to the COVID-19 pandemic [20].

Cancer types, status and treatments, supportive care, and care by non-oncology HCPs: Breast and lung cancers were most common cancer types, while the lack of prostate cancer reporting was interesting and could be related to the younger age of our cohort [1]. CureCancer was feasible for patients under active treatment and/ or advanced cancer. Almost half of our patients (44.7%) received supportive care. With appropriate supportive care, patients under active treatment successfully participated in another digital health solution [15]. Although disease, users, and treatment characteristics, reported in the present study, were relatively aligned with those in the literature, the level of agreement between disease and treatment characteristics, recorded in the Hospital files and those self-reported by our patients is not known and this could be the goal of a next study.

Importantly all patients visited non-oncology HCPs, while about half of them visited 2-9 HCPs, pointing to a multimorbidity status in our cohort. Multimorbidity and associated polypharmacy, with drug-drug interactions and other adverse events can increase cancer patient's toxicity and healthcare burden and highlights the need for good communication between HCPs [21]. This need for enhanced communication can be met with the use of CureCancer, according to the users' experience and responses.

Working status, social profile, and financial toxicity: Cancer diagnosis was related to changes at work, such as retirement, not contract renewal, or job change due to cancer therapy. The negative consequences of cancer therapy on employment, associated with financial problems and increased financial toxicity and reduced Health-Related Quality of Life were also reported by others [22, 23]. The living alone status and children at School can also add to patients' burden and financial toxicity [1, 2, 24].

Patient communities: Although patient communities were reported as the main environment to connect with others and obtain trustclinicsofoncology.com ed information, few patients, in the present study, participated in patients' communities, possibly due to cultural differences [16]. Strengths and weaknesses

CureCancer had a positive impact on cancer supportive care fulfilling most of the qualities for a digital platform to re-form oncology care, particularly during periods of pandemics [3, 10]. The study is limited by its feasibility and satisfaction assessment nature.

6. Conclusions

CureCancer was feasible and users were satisfied. Integration of CureCancer in the routine practice is expected to increase therapeutic success and reduce the costs of care. CureCancer can also map social/work/economic issues following cancer diagnosis, as patients disclosed, to advise health care policy. The efficiency of self-reporting of symptoms, in real-time, can also increase the accuracy of clinical trial results and assist treatment decision making.

Patients were successful to report accurate information on their demographics. The level of agreement between the patient-reported disease and treatment characteristics and the hospital files, remains to be assessed, particularly when patients are asked to describe prior cancer therapies, possibly associated with a recall bias. This investigation could be an interesting purpose of the next project.

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