How can eHealth enhance adherence to cancer therapy and supportive care?

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SUMMARY
eHealth is currently a hot topic, but is certainly not a new one. The use of communications technology to relay health-related information or provide medical services has been around since the advent of this technology. It has been primarily over the last decade that eHealth has seen a global expansion, due to the far-reaching capabilities of the Internet and the widespread use of wireless technology. This paper will outline what eHealth is, what adherence is, and how eHealth can help with adherence, in cancer and supportive care particularly. It will discuss the current state of the art, and project into the future.
Keywords: telemedicine; compliance; use of electronic media for health

INTRODUCTION

eHealth is not new. Technology and communications systems have been used to contribute to health care at least since the beginning of the 20th century, when Willem Einthoven, a Dutch cardiologist, transmitted electrocardiogram results via telephone in 1906, to a hospital 1.5 km away [1]. Similarly, in the 1920s, the Reverend John Flynn (now on the Australian $20 banknote), along with Alfred Traeger, set up a radio system to connect remote outposts in the Australian Outback with central medical bases. Additionally, Flynn, using an idea from a World War I pilot, Lieutenant Clifford Peel, also initiated the Australian Inland Mission Aerial Medical Service in 1928; this would become the Royal Flying Doctor Service in 1942, which continues to provide medical care to Australians living in remote areas to this day [2]. The advent of the Internet and wireless networks over the last few decades, often referred to as the 'modern Gutenberg Press'[3], however, has seen a true globalisation of eHealth, due to the ability of large quantities of information to be disseminated rapidly, over vast distances and *en masse*.

The terms telemedicine, telehealth, mHealth, eMedicine, and mMedicine are often interchanged with eHealth, however, eHealth in fact encompasses these terms, which often causes confusion [4, 5]. eHealth is defined by the World Health Organisation as the transfer of health resources and health care by electronic means [5]. Firstly, it is the delivery of health information, for both professionals and consumers, through the Internet and telecommunications. Secondly, it is the use of information technology (IT) and e-commerce to improve public health services, for example through the education and training of health workers. Thirdly, it is the use of e-commerce and e-business practices in health system management [5]. The comprehensive complexity of eHealth, however, precludes exact evaluations [6], and the study of eHealth interventions on adherence, disease outcomes, and patient-reported outcomes are often marred by poor study designs and confusion regarding eHealth definitions [6, 7].

Nevertheless, the benefits of eHealth are wide and varied. Despite the significant cost of introduction of new information technology systems and software in medical centres, eHealth remains a cost-effective entity [8]. For example, purchase, installation, training and monitoring of an online eHealth system may cost millions; however, this is offset by reduced hospital admissions [9], reduced disease relapse [10], better adherence to treatment [9], patient reassurance that they are being monitored away from the clinical setting [11], reduced caregiver burden [12], reduced emergency room visits (especially for elderly patients) [12], more accurate reporting of symptoms [13], and clear audit trails in case of prescribing/administration errors [14, 15].

The benefits of eHealth, particularly in countries like Australia, Russia, Canada, Norway and Africa, where the majority of the land mass is sparsely populated, extend past providing better, personalised health care for individual patients and reducing costs for hospitals. Far-reaching benefits include lower carbon emissions due to the reduced need for patients and healthcare professionals (HCPs) to travel long distances [16], professional development for regional HCPs (through electronic interaction with urban specialists that they would not normally have) [17], more comprehensive and multidisciplinary treatment [18], increased benefit to communities (especially in remote communities, where the absence of one person

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can greatly impact dynamics) [17], and reduced productivity losses in the workplace [17].

Concerns regarding eHealth

Concerns exist regarding the reliability of information obtained online, as well as patient privacy and information security. Regulatory bodies such as the World Health Organization, the Medicines and Healthcare products Regulatory Agency, the Food and Drug Agency, and the National Health Service board have legal frameworks and usage guidelines in place to ensure that eHealth platforms are validated, secure, and reliable [19, 20]. These encourage the widespread establishment of evidence-based, guideline-centered digital platforms (websites, apps, social networks) with a high level of contribution from healthcare agencies [3, 11, 21]. Patients would no longer base decisions on incorrect medical information obtained from spurious online sources, but would be able to become actively engaged in treatment decisions with their HCPs, once again potentially enhancing treatment adherence and quality of life [3, 22].

Another concern is that the electronic situation turns people into numbers; Di Cerbo et al. [23] describe patients as, "… virtual entit[ies] dressed with 'binary clothes.'" It must be emphasized, therefore, that eHealth is a tool, not a replacement for human interaction [14]. It can support the clinicians to treat the patients, but it does not actually care. It takes away all the computable bits – and makes everything routine that can be made routine, which reduces errors. It also frees up time so that we can concentrate on the therapeutic clinical interactions.

ADHERENCE

It is estimated that three quarters of all healthcare spending is associated with chronic conditions [22]. With an expanding aged population, and relegation of more and more hitherto 'incurable' diseases to manageable, chronic conditions (such as HIV and cancer), the burden of a chronic condition such as cancer is considerable. Cancer survivorship requires long-term management, medication and supportive care. It follows that adherence to such long-term management becomes critically important [24], particularly as more and more patients are treated as outpatients, which represents approximately 90% of palliative and supportive care [10, 25].

Similarly to eHealth, the definition of adherence can also be unclear, particularly in quantitative studies, where a status of 'non-adherence' can range from a patient taking 80% or more of their prescribed medication, to 100% of the medication [26, 27]. Non-adherence can also include the over-taking of medications, particularly in cancer patients desperate for a cure [26]. The International Society for Pharmacoeconomics and Outcome Research defines adherence as, "… the degree or extent of conformity to the recommendations about day-to-day treatment by the pro-

vider with respect to the timing, dosage and frequency … for the duration of time from the initiation of the medication to discontinuation of therapy" [28]. According to the National Institute of Health Clinical Excellence (NICE), 30–50% of medications prescribed for chronic conditions (such as cancer) are not taken, which is a very high percentage [29]. With rapidly increasing numbers of cancer survivors worldwide, the burden of non-adherence is substantial [24], whether through increased hospital admissions, emergency specialist consults, or wastage of expensive medication.

Non-adherence is complex and systemic. It goes beyond a patient simply forgetting to take a few pills – it is also associated with the way in which HCPs behave, including the following of a recommended, evidence-based (rather than eminence-based) treatment guideline when prescribing care [30]. More rapid dissemination of guidelines through eHealth platforms, particularly those involved with prescribing of treatments and linked to patient records, will likely reduce the time it takes for a guideline to be adopted into routine practice [31].

Patient barriers to adherence can be intentional or unintentional. Intentional lack of compliance is usually due to personal beliefs or perceptions of the patient, but can also be caused by socio-economic factors, disease characteristics, symptom severity of adverse effects of treatment and complexity of the prescribed treatment [10, 27]. One intentional reason for non-adherence, particularly with antineoplastic regimens, is symptom severity, where patients may in fact 'titrate' their own dose if they are feeling unwell [32]. Due to the narrow therapeutic index of many anticancer drugs, especially targeted drugs, this can lead to suboptimal disease control [27]. eHealth can help here, by not only providing patients with real-time support, reminders and feedback, but can also provide information explaining why adherence is essential for disease control [33]. Unintentional non-adherence is much more likely; this is especially true for complex treatment regimens [11], as well as self-reporting errors (a patient reporting 100% adherence although they actually forgot to take medication) [29, 33], inability to pay for prescriptions [34] or simply forgetting to take the medication; these are often compounded by reduced cognitive capacity, which is common in older patients with chronic conditions [12, 35].

Addressing non-adherence is not about getting the patient to take more medicines per se. Rather, it is about exploring the patients' perspectives of the medicines, and the reasons why they may not want to – or are unable to – use them. Healthcare professionals have a duty to help patients to make informed decisions about treatment, and about how to use appropriately prescribed medicines to the best effect; however, the system often fails to support the patient to comply. This is where eHealth can make a huge difference.

HOW CAN eHEALTH HELP IMPROVE ADHERENCE?

With the increased use of interactive health management systems, the word 'patient' is gradually being changed to

'consumer.' Some baulk at this, whereas others see it as implying a much more involved, empowering role that includes making informed choices regarding their own health care [3]. The provision of eHealth services such as phone calls, short messaging service (SMS) alerts or alarmed pillboxes can be used to reduce non-adherence. While such remote monitoring has been shown to significantly reduce non-adherence [29], care must be taken so that the e-monitoring is not overly intrusive; some patients may feel as though they are being 'spied on' [12]. Again, eHealth can help here; by using feedback and patient reported outcomes (PROs), electronic interventions to promote adherence can be tailored to each 'consumer' based on their own needs and choices.

Doctors can be quite bad at adhering to evidence-based practice. Barriers used to justify physician non-adherence to evidence-based guidelines include local practice patterns ("we always do it this way") [36], or more abstract belief systems ("I don't need 'cook-book medicine,'" or, "the art of medicine is as important as the science"). An article in the Wall St Journal in 2002 opined, "Doctors and hospitals have long resisted joining the digital revolution. Now they have no choice." Rather than being seen as a change that needs to be resisted, this digital revolution provides a supportive framework for change for physicians, by providing more ready access to resources such as clinical guidelines, education and training, comprehensive and integrated patient records, real-time charting of symptom severity, and clinical decision support, to name but a few.

STATE-OF-THE-ART: THE GAP BETWEEN 'CURRENT' AND 'FUTURE' IS SHRINKING

As technology advances, which it does at an ever-increasing pace, personalised support innovations occur, as with the 17-year-old student who built a robot so his teacher could still communicate with his class while undergoing cancer treatment. He zooms through the halls and classrooms, and can carry on a conversation. Thanks to the robot, named after the teacher who inspired the project, Cormio is able to teach class from home [37]. Robots are already being used to formulate anti-neoplastic drugs, and 'smart pumps' allow for safe, automated infusion of drugs that significantly reduce medication errors [21, 38]. It is thus perhaps a matter of time before we will be using robots to help with physical care and rehabilitation by dealing with some of the drudgery of physical and supportive care. While this may seem far-fetched, consider that technologies such as washing machines and driers must have seemed futuristic when first introduced, but allowed more time for hospital staff to spend with patients, rather than being burdened with washing and drying of sheets, gowns and towels.

Current eHealth technologies that contribute to outpatient supportive care are wide and varied. They include video games [39] and eDiaries [40] to facilitate symptom reporting and management in young adults with cancer, and the use of electronic pill boxes to promote medica-

tion adherence in patients being treated at home [9]. Many electronic devices in place contribute directly to reduced rates of hospital admissions, adverse events and caregiver burden; these include, but are not limited to, user-triggered alarms, vital signs monitoring (including blood pressure, heart rate, oxygen saturation, and blood glucose levels), pressure pads (to monitor changes in activity), and motion sensors that activate lighting at night to prevent falls [12, 33].

The cost of setup for many comprehensive eHealth systems remains prohibitive in developing countries, whose priorities favour direct health measures, such as provision of clean drinking water, over complex IT systems [24, 41]. Nevertheless, technological advances may be able to circumvent these costs: the use of 'TV white space' in Botswana provides broadband internet access in a less costly, faster and farther-reaching fashion for previously unconnected populations, providing services in general healthcare, HIV, tuberculosis, pediatric medicine, dermatology and cervical cancer screening [42]. Future use could include provision of cancer supportive care.

In cancer treatment itself, eHealth includes the Electronic Health Record (EHR), which, as well as being a medical record, can record and disseminate tumour board decisions and facilitate telehealth consultations. One problem, perhaps, with all of these rapidly-developing technologies is the lack of full integration [14]. While EHRs are often linked to other eHealth systems, many systems are stand-alone electronic devices that require extra input and data transfer in order to contribute to a comprehensive patient record [12]. Web-based decision tools, Web-based protocols and order sets, and electronic tumour-based patient pathways are all useful. As with all health care, it enables clinician-led, patient-centred, evidence-based, data-driven care.

Computer provider order entry (CPOE) is one system by which medication prescribing has been revolutionized. The days where subjective interpretation of doctors' illegible scrawl could (and did) lead to gross errors in the prescribing, administration, and management of treatments are almost past [43]. Now, many CPOEs reduce transcription errors and ensure correct dosing and identification of potential drug interactions [14], and CPOEs linked to EHRs allow for patient-specific alerts to be generated based on information entered by prescribing physicians (for example, real-time calculation of renal function for drugs such as lithium, with an alert screen that requires physicians to review dose) [38].

eHEALTH, ADHERENCE AND SUPPORTIVE CARE

The inter-relationship between adherence to cancer treatment, eHealth and supportive care is strong. Supportive care makes excellent cancer care possible (MASCC); eHealth acts as a supportive care tool that enables successful cancer treatment and better supportive care. By getting the cancer treatment right, we reduce unnecessary treatment toxicity, respond to toxicity faster and ensure

evidence-based toxicity management. All this enhances patient outcome and reduces morbidity. It allows us to prevent issues rather than having to treat them.

Some people worry about the rise of eHealth potentially reducing human interaction, but it should be considered rather as a support, that frees up time for the human touches [11].

ePROs

It is becoming increasingly well accepted that 'patients know their symptoms best' and that PROs are essential in the environment of cancer supportive care [13, 44]. eHealth has improved this process through ePROs, which allow real-time reporting and recording of symptom burden, and in many cases, patients may feel more comfortable disclosing sensitive information in the privacy of the digital environment. eHealth enables web-based toxicity reporting through measurement scales (useful in clinical trials) [45], patient reported outcome measures (PROMs), prompting of clinicians, and provision of feedback loops to enhance care; for example, protocol management and production tool (PROMPT) is an eHealth system designed to support personalized cancer treatment and care [45]. It uses PROMs to gather outcomes for toxicity, distress and supportive care needs, and the website (http://www.promptcare.com.au/) enables patients to self-manage. It contains a suite of relevant resources, with each piece kept to a manageable size. It is linked to EviQ, the Australian on-line cancer treatment site [46] that provides HCPs, patients, their carers, and families access to evidence-based, best practice cancer treatment protocols and information.

Electronic administration systems

In South Australia, an electronic patient administration system (EPAS) is being introduced as an EHR across all the public hospitals. As a result, oncologists across the system have agreed to use the same protocols or order sets; 150 chemotherapy protocols have been agreed across the state, which means that there will for the first time be uniformity of drug doses, diluents, administration times and supportive care medications. Such uniformity significantly contributes to reducing medication errors and non-adherence [14, 47].

Cancer treatment and supportive care guidelines

The Multinational Association of Supportive Care in Cancer (MASCC) is already using eHealth to support patients across the world. All of MASCC's evidence-based supportive care guidelines are available on the website (www.mascc.org) and many of them are now being translated not only into multiple languages, but also into web-based and phone-based apps. For example, the MASCC Antiemesis Tool (MAT) was first created and posted in 2004. It is now available in eleven languages, obtained by the standard forward/backward translation process, and is available in both the Apple App Store, and in Google Play. It is the first iPhone/iPad application for cancer patients receiving chemotherapy that helps their doctors in evaluating if and how much the anti-cancer treatment is causing nausea and vomiting.

Cancer Council Australia has all its guidelines on a wiki platform so that they can be updated in real-time [48], and MASCC is moving to that system. The European Society of Medical Oncology has pocket guidelines and a mobile app [49]. In fact, the apps of today are the equivalent to the "pocket guides" that junior doctors used to carry in their white coat pockets – now just as easily accessible on their smart phones.

Decision support services

Decision support services exist for both clinicians and patients [31]. For HCPs, clinical decision support systems (CDSSs) are important and have been described as the 'most potent' way to improve physician adherence to guidelines and reduce errors [31, 38]. However, a lack of uniformity in coding of patient information to help with decision support technology has been identified as a barrier [50]. A 'care gap' has also been shown to exist between CDSS results (based on evidence-based guidelines) and practice, especially for patients with a shorter survival time [51]. Further development, including real-time integration with EHRs and ePROs, will only improve these systems [31, 38]. Web-based CDSSs that are also made available to patients improves chronic disease outcomes [22, 52]; in Australia, the Decision Assist Project (funded by the Australian Government under Specialist Palliative Care and Advance Care Planning Advisory Services), exists to "enhance the provision of palliative care and advance care planning services to the aged nationally" and is also available as a downloadable app [53].

THE FUTURE

One of the beauties of all these tools is that they are not bound by normal international boundaries. They are accessible wherever the Internet is, so that people around the world can all use the same tools – and share. eHealth not only bolsters already available health support, but also provides hitherto unavailable services, particularly in remote areas.

The future of supportive care involves having proper patient pathways developed for each tumor type [54], and available online so that patients and their carers can get access to them, and can see what may lie ahead, and what resources are available to help them. The system needs to be much better organized than it is currently, so that there are no big gaps in care. A study in NEJM showed that, on average, patients received 55% of recommended care [46]. It was broken down into preventive care (55%), acute care (53%) and chronic care (56%). A more comprehensive breakdown
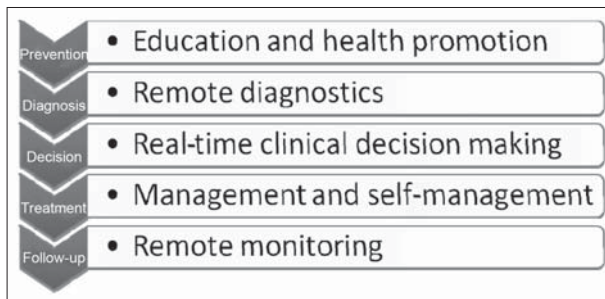
Figure 1. The patient journey and eHealth contributions to improve care

of the patient journey, along with eHealth contributions to improve patient care [15], is shown in Figure 1.

The Institute for Healthcare Improvement Triple Aim [55] is to have improved individual patient experience, improved cost-efficiency, and improved population care.

This is all highly relevant to cancer therapy and supportive care – and all made much easier with eHealth. Things have changed for the better in the past 10 years, but the embracing of eHealth is not uniform; effective evaluations of eHealth services to improve patient care, and eHealth integration into each step of the patient journey, are far from complete.

CONCLUSION

eHealth is a vital part of our future. It can do wonders for cancer treatment and for supportive care, and yet we cannot imagine what all those wonders might be. eHealth cannot replace human interaction and caring, but instead should provide a supportive framework to facilitate comprehensive patient care.

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Како електронско здравство може побољшати да се болесници придржавају препорученог лечења тумора и супортивне терапије?

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КРАТАК САДРЖАЈ
Иако је електронско здравство тренутно актуелна тема, свакако није и нова. Од самог увођења комуникационих технологија постоји могућност преноса информације у вези са здрављем и пружањем здравствене услуге. Последње деценије електронско здравство доживело је светску експанзију због могућности које пружају интернет и широко распрострањена бежична технологија. Овај рад представља кратак преглед о томе шта је електронско здравство и како може да помогне да се болесници придржавају терапијских препорука, посебно у области онкологије и палијативног збрињавања. У раду се дискутује о тренутно најсавременијим ставовима у овој области и могућности будућег развоја.

Кључне речи: телемедицина; привреженост; употреба електронских медија за здравље