



A review of mobile health features for adolescents and young adults with cancer diagnosis

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ABSTRACT

Adolescents with cancer seem to be a population with special needs for treatment and support as significant physical, cognitive, and psychosocial changes take place at this developmental stage. Interventions via portable and easily accessible devices have proven to be effective in dealing with health-related problems. Adolescents, due to their inherent ability to operate modern technological devices, could benefit from mobile health (mHealth) applications pointing out the necessity of their integration into medical practices and public health. After reviewing 40 articles, it appears that mHealth practices have the potential to overcome some of the obstacles that arise during the treatment process, aiming at optimal symptom management, better treatment outcome and therefore improvement in adolescents’ quality of life. MHealth interventions in the field of adolescent cancer, can offer services such as recording symptoms, improving communication with health care staff, enhancing adherence to therapy, accessing valid sources of information, providing social support, and implementing training in the management of distressing symptoms. This review concludes possible limitations and future research proposals underlying the need of creating a mHealth application that incorporates the aforementioned features.

Key Words: *mobile health, mHealth, adolescents, young adults, cancer, application features .*

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Introduction

Adolescent cancer

Adolescence is a special period, presenting unique developmental and psychosocial characteristics while being the age milestone between childhood and adulthood (1). The World Health Organization (WHO) defines adolescents as people aged 10-19 years old while recognizing that this range is fluid, as it varies by gender, biological, cultural, and socioeconomic factors (1). Every year, around 14,000 cases of adolescents and young adults with cancer are recorded in Europe (2). This population has unique care needs and requires individual support from the time of diagnosis, during medication, and after the cure, as cancer survivors (2).

Clearly, adolescence is characterized by significant physical and cognitive changes along with critical psychosocial challenges, related to self-identity, relationships with peers, development of autonomy, sexuality and future goal-setting (3,4). As a result, adolescents with cancer face more challenges (2). More specifically, prolonged hospitalization in combination with treatment side effects (e.g. hair loss, weight gain, scarring, infertility and amputation) often influences adolescents in terms of body image, health system confidence and self-esteem (2).

Mobile Health

WHO defines Mobile Health (mHealth) as "the medical practice and public health practice supported by mobile devices such as mobile phones, patient monitoring devices, personal digital assistants and other wireless devices" (5). It also includes the use of mobile and wireless applications (e.g. SMS text messages, applications, mobile devices and the use of social media) to provide health-related services (6). MHealth devices seem to be widespread, especially in children and adolescents, as supported by the meta-analysis of Ramsey et al. (7) which showed that 95% of adolescents reported owning or having access to a mobile phone, 73% to a smartphone and 87% to a desktop or laptop. Recent evaluations estimated that 95% of 13-17 years old own or have access to a smartphone, which they often carry with them and use regularly in order to stay connected (7). Regardless of the increased growth of mHealth applications, it is surprising that only a quarter of downloaded applications is being used just once (8). It is noteworthy that populations from lower socioeconomic status appear to have limited access to them, using smartphones up to 25%, a fact that could create selection bias, in terms of the benefits of mHealth interventions (9).

Key features

Symptom tracker

There is evidence that daily symptom monitoring is beneficial for 5–18 years old newly diagnosed cancer patients, providing early symptom recognition and proper medical response (13). Bradford et al. (14) in their research supported that when the recording of symptoms was inadequate, the rates of discomfort and unnecessary hospitalization appeared to increase (14). Deficient symptom control seems to influence medication tolerance, leading to long-term issues, and adversely affecting the quality of life both of the patient and his family (14). Current practices in symptom assessment required patients' accurate recall after one to six weeks during medical visits (15). Furthermore, in most cases, the frequency and severity of symptoms appear to be underestimated, resulting in discrepancies between self-reports and medical records (10). Correspondingly, a broad percentage of patients' symptoms and difficulties remain unspecified provoking difficulties in treatment (10). Finally, poor symptom management has been shown to be associated with the onset of Post-Traumatic Stress Disorder and other psychological problems (13).

Pain-related symptom tracker

Fortier et al. (16) at their study found that 100% of children diagnosed with leukemia, the most common diagnosis of childhood cancer, report pain during the first year (16). The feeling of pain, in particular, may come from the underlying disease, but for most children, it is iatrogenic or caused by the treatment itself (16). Acute pain requires immediate intervention, as its underestimation can lead to chronic pain, increasing its levels while limiting the patient's subsequent cooperation during medical visits (17). Cancer-related chronic pain is also accompanied by a variety of negative consequences such as high rates of functional disability, emotional and behavioral difficulties (e.g. anxiety and fear), parental anxiety, barriers to disease recovery, reduced sleep, and poorer overall quality of life.(2,17). MHealth services have the opportunity not only to improve but also to enrich pediatric pain management by providing developmentally appropriate and attractive delivering methods (2).

There is evidence that parents who are in charge of their children's treatment at home appear to under-treat the pain symptoms, despite the availability of

effective pharmacological and non-pharmacological interventions (12). In particular, in the study of Simon et al. (12), which included cases with clinically significant levels of pain presented that one-third of children receiving chemotherapy were not given analgesics at home (12). Pain management is a significant cost burden for the healthcare system, therefore it is necessary to find innovative treatment methods for chronic pain, with mHealth technologies being a promising alteration (12,18).

Communication with medical staff

Effective communication between doctors, patients and parents serves a significant role as it seems to enhance patients' sense of satisfaction and treatment compliance thus improving its outcome (10). As a matter of fact, the same researchers reported that the main factor for non-compliance with treatment in young patients is poor communication between doctors, patients and parents (10). Therefore, it becomes crucial to create new, alternative methods of communication, with the aim of providing patients both support and counseling for the management of distressing symptoms (10).

Adherence to treatment

The urge for autonomy and the neurodevelopmental changes that arise throughout adolescence (e.g. development of executive functions) are contrasted with the indicated adherence to treatment (19). As noted by Ross et al.(20) children with cancer appear to take responsibility over chemotherapy without being provided with the necessary medical supervision (20). There is evidence that non-compliance with the treatment plan could lead, on the one hand, to complications in the patient's health, and on the other hand to imminent death (20). Specifically for AYAs with chronic diseases, relatively low compliance with medication appears to be observed, bringing them into focus on establishing innovative programs for treatment plans (20).

Information provision

Proper information provision could moderate the distressing symptoms of treatment, during both the therapy process and the follow-up period (21). Mobile health interventions offer cancer patients the ability to manage the barriers occurring during treatment by providing information and training in self-care skills (22). Furthermore, providing information and education to patients and their parents can improve the experience of the disease as well as clinical outcomes (10). More specifically, it has been argued that knowledge enhance-

-ment is associated with reduced levels of stress in patients and their families, improvement of side-effects control and therefore reduction of symptoms severity (10).

Social support

Feelings of isolation may occur throughout the cancer trajectory and there has been an association between the absence of social support among cancer patients with poorer physiological and physical functioning, greater psychological distress, and reduced quality of life (23). A recent study indicates that cancer patients could benefit from web-based support interventions as they provide social encouragement and social bonding (24). As a result, adolescents with cancer had the opportunity to obtain healthier behaviours and obtain optimal ability to cope with illness outcomes and overall better psychological well-being (24).

Coping strategies

It is necessary to mention that adolescents during treatment are confronted with a variety of stressful experiences related to the disease and treatment, regarding the way they perceive the changes which occur and the urge to utilize appropriate behavioral and cognitive strategies in order to manage them (25). Furthermore, AYAs educated in self-management skills and coping strategies can monitor their health status, feel controlled and therefore experience less stress (2,26). Studies have shown that adolescents with a range of cognitive, behavioral, and emotional skills have the potential to maintain an optimal quality of life (2).

METHODS

The main purpose of this review is to search the existing features of mHealth interventions applied in adolescents and young adults with cancer. Bibliographical research was conducted focusing on any kind of adolescent cancer and mHealth interventions in various databases. Specifically, most of the included articles come from Scopus, Pubmed, and a few of them from Cochrane Library and W.H.O. The present review includes both adolescents and young adults respecting the wide age range of this developmental stage. The aforementioned research concluded in 40 articles, limited to the English language. Most of the articles were clinical trials while some of them were systematic reviews.

RESULTS

The present review indicates the most commonly used features of mHealth interventions implemented in the care of adolescents and young adults with cancer diagnoses.

The key features that our research detected were the following: symptom tracker, pain-related symptom tracker, communication with medical staff, adherence to treatment, information provision, social support, and coping strategies. More specifically, in this review communication with medical staff seemed to be highly important as it was the most frequently applied feature with 18 articles confirming it (4,9,10,12-14,17,18,20,21,25-29,36,39,40). Subsequently, also 17 studies included the feature of adherence to treatment (7,10-12,14-17,19,24-26,29,36,37,39,40). In addition, the symptom tracker was referred to 14 more articles (4,6,7,9,10,13,15,19,21,25,27,29,36).

Also, throughout literature there are more 14 studies encompassed the feature of information provision (4,7,9,10,12,18,21,24-27,29,36,40). Furthermore, pain-related symptom tracker was the following used feature with 13 studies confirming it (2,7,10,12-15,17-20,25,28). Also, the facility of social support was found in 13 researches (4,7,9,10,21,23-25,27,32-34,36,40). Finally, in this review, the least implied mHealth features was the feature of education in coping strategies that was included in 12 studies (2,7,11-13,17,18,20,25,28,35,40).

DISCUSSION

MHealth interventions can overcome some of the barriers related to adolescents' cancer treatment, hence improving their quality of life (10). Initially, the alternative solutions via electronic means could overcome some difficulties of face-to-face interventions, such as mobility limitations or patient's fatigue (11). It is also a fact that changes in treatment practices force children to spend less time in the hospital and more time at home (2). MHealth interventions have the ability to bridge this gap, as smartphones, for example, can be used in any place (e.g. home, school, hospital) and therefore provide real-time support (12). Pappot et al. (9) also argue that mobile devices have proved useful in populations of rural areas or lower socioeconomic groups, who may previously not have had access to health care interventions (9). In fact, mHealth services seemed to have been very effective in treating chronic diseases, especially during the period of the COVID-19 pandemic, when hospital access was limited (5).

Symptom tracker intervention

A valid mHealth intervention for the real-time symptom recording is the electronic calendars (eDiaries) offering the potential to minimize recall bias (14). In fact, patients often seem to positively evaluate the electronic recording of their

personal health data because it is easier and more reliable compared to traditional paper methods and simple recall (15).

Self-reports, as well as real-time symptom recording, are considered the "gold standard" for assessing symptom burden (27). Vaughn et al. (27) in their research reported that pain, nausea, vomiting, fatigue, bleeding, diarrhea, headache, itching, sleeping difficulties, and rashes were the most commonly electronically recorded symptoms (14,27). In addition, patients could add specific components, such as the intensity and the exact time of each symptom, as well as interventions that would be applied, thus improving symptom understanding (15,27).

It is noteworthy that the symptom tracking feature in the Kraftværkæt application was the most frequently used with positive reviews from users, as it contributed to the daily reminder of events and symptom progression (4). Also due to this feature, the patient can provide an electronic medical history during the medical visit improving the overview of symptom progression (4). In a review of 62 studies that used electronic pain diaries, patients reported high levels of compliance to therapy (19). Factors that seemed to facilitate calendars' compliance included the smaller size, the provision of a user manual, and the reminders for tracking symptoms (19). The portability of these devices and the availability of voice messages may also enhance data entry compliance (19).

Pain-related symptom tracker intervention

Jibb et al. (2) at their research, indicated that adolescents with cancer would want to develop practical skills for managing their disease (2). Smartphone-based real-time support and access to pain self-management programs offer patients the opportunity to manage their own symptoms the moment they occur (2). Correspondingly, increased feelings of autonomy and self-efficacy are noted as important factors that seem to contribute to behavioral change and successful pain management (2,17). The eDiaries mentioned above can also contribute to the electronic collection of pain-related data, which could also be used by healthcare professionals to help optimize treatment plans and pain management interventions (17).

Communication with medical staff intervention

The implementation of mHealth interventions could bridge the gap between the hospital and the home context, as medical staff could be able to intervene, regardless of the patient's caring environment (12,13).

Passardi et al. (29) in an attempt to optimize communication between cancer patients and doctors created a mobile application for patients and a web dashboard for health professionals. In particular, it enabled the medical staff to enter details into the treatment plan, set medication reminders, monitor treatment compliance and medication's side effects, while communicating with patients through a secure messaging system (29). In addition, one more application enabled patients to evaluate pain symptoms in real-time while allowing medical staff to intervene either directly or not, based on the severity of the symptoms (10). Finally, a mHealth application that allowed the recording of pain symptoms in children with cancer used an algorithm to evaluate whether immediate intervention is needed and thus send an automatic email to the appropriate medical staff (20).

Adherence to treatment intervention

MHealth interventions, and in particular mobile applications, could increase commitment to treatment plans through well-designed and developmentally appropriate methods which can promote entertainment as well (17,30,31). For example, in their application, Mehdizade et al.(10) added a function similar to a diary with features such as reminders for future medical appointments as well as the medication timing, preventing parents' and patients' disorganization and thus contributing to optimal compliance with the treatment plan (10).

Information provision intervention

One of the most common methods of providing information to cancer patients is the oral presentation during the clinical visits but it is supported that 40-80% of them is either immediately forgotten or misremembered (10). MHealth services could overcome this barrier by providing information modules via searching categories as well as training on essential aspects such as the disease, the symptom management and its treatment process (10). Furthermore, Hunter et al. (18) indicated in their research a web-based intervention that delivers educational information, via interactive multimedia means including movies, games, and animation. The study of Simon et al. (12) showed that when the recording of the pain symptom was in lower levels, the application, as a first intervention, provided families psycho-educational information applicable to the home environment.

Social support intervention

This review shows that the social support application fea-

-ture enables AYAs with cancer to share and receive information about the disease, support each other and thus contribute to the quality of life improvement (10,32-34). Accordingly, some mHealth applications give the user the opportunity to have an experience similar to online forums, where adolescents with cancer communicate with other patients, share experiences related to the disease and its treatment thus creating a network of emotional support (10,32,34). Specifically, users felt supported through the exchanging of personal experiences while mHealth applications have the potential to reduce family's socio-economic burden and stress as they provide communication with organizations and social services (10,34).

Coping strategies intervention

Research indicates that several mHealth applications attempt to contribute to patients' empowerment, self-management, and family psychoeducation on pain management (12,24,26,35). According to Govender et al. (25) referring to mHealth video games, the goal of empowerment, resilience and self-management is achieved through the "positive" addiction of the user. They, also, argue that video games are an upcoming practice, as they function by enhancing stress-sensitive mental processes, giving positive feedback to stress-regulating neurotransmitters (26). Noteworthy, a Hunter et al. (20) study on a mHealth application in mobile phones provided effective training strategies and skills for pain management such as diaphragmatic breathing, gradual muscle relaxation, guided imagery, distraction and mindfulness, regardless of the patient's care environment (20,29).

Limitations and further research

Consequently, criticism has been reported regarding both the content and the validity of the aforementioned features of mHealth applications (36). Firstly, a detailed protocol encompassing both medical staff and AYAs was lacking in most of the apps, while even fewer have established their effectiveness and prosperity in a wider audience (27,36). This limited perspective and the fact that some of the included studies presented poor methodological analysis, create barriers in the generalization of the results to an expanded population (26,27). Furthermore, few mHealth apps have been judged for their deficient evaluation and their design process as AYAs' contribution was limited (9). Empirical and repeated testing of mentioned features, as well as the evaluation of different adolescent caring environments rather than the hospital (e.g. home and school), was inadequate (2,37).

Moreover, it is worth mentioning that most of the studies' outcomes were synthesized by statements of AYAs, willing to share (38). This comes as a natural result as AYAs are characterized by fear of rejection and social judgment or introversion towards cancer-related topics (38). Undoubtedly, the under-resourced population has restricted access to mHealth interventions, potentially resulting in selection bias (9,38). In conclusion, future research should implement testing of feasibility and acceptability of mHealth interventions in the target population contextually, while further investigation should be made on their usability in underprivileged populations (38-40). Forthcoming testing of the effectiveness of mHealth services could also consider the implementation of all the aforementioned features in one single application.

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