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The role of eHealth in the delivery of care for patients with haematological cancers: a systematic literature review

Running title: The role of eHealth in haematological cancer care

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Abstract

Background

Haematological cancer survivors have significant unmet needs. The use of eHealth interventions has been shown to be effective in improving patient experiences and outcomes in other diseases. The aim of this review is to explore the role of eHealth interventions in the delivery of care for patients with haematological cancers across the illness trajectory.

Methods

A systematic narrative review approach using thematic analysis was used to identify the key issues and themes in the literature. Medical subject headings and keywords were used in several databases: Medline, Embase, PsycInfo CINAHL and The Cochrane Collaboration Cochrane Review Database. This review focuses on the use of eHealth interventions for patients with haematological cancer within any study design.

Results

23 studies were identified in this review. The studies were of varying design: RCTs (n=6); pre and post design (n=1); feasibility and acceptability (n=11) and varying methodological quality. Seven studies included patients with any cancer diagnosis rather than focusing specifically on haematology patients. Our thematic analysis identified four main categories of intervention: information provision (n=4); self-help (n=6); communication facilitation (n=5); patient reported outcome (PRO) recording or monitoring (n=8).

Conclusion

The clinical management of patients with haematological cancers, particularly those in survivorship, presents opportunities to explore eHealth approaches to improve patient care. This review highlights that eHealth tools may be acceptable and feasible to use with a haematology patient population, but more robust and well-designed trials that engage patients and health professionals are required to determine which and how interventions can be used most effectively.

Introduction

Haematological cancers, or blood cancers, are cancers that originate in the lymph nodes or bone marrow ¹. There are three main categories of haematological malignancy: lymphoma, leukaemia and plasma cell neoplasms ². Collectively, haematological cancers are the fifth most common cancer in Europe ³. Many patients experience significant physical side effects from treatment ^{4,5} as well as cognitive, psychological or financial impact ⁵. After completing treatment, many survivors experience late effects from their cancer treatment including cardiac problems, second cancers and infertility ⁶⁻¹⁰. As the incidence of haematological cancers is increasing ¹¹, there is a need to identify effective and scalable approaches to support patients across different stages of the illness trajectory. This is particularly important, given the multiple detrimental effects diagnosis and treatment has on quality of life (QOL) ⁷.

There is currently an international push for health care systems to incorporate eHealth solutions ¹²⁻¹⁴. Electronic tools can have many benefits when used in the oncology setting such as facilitating shared decision making, management and self-management, symptom monitoring and providing survivorship care packages ¹⁵. To date, the use of eHealth interventions in haematology has not been explored within a review. The aim of this narrative literature review is to explore the role of eHealth interventions in the delivery of care for patients with haematological cancers across the illness trajectory. Specific objectives will also be to explore the feasibility, acceptability and effectiveness of these interventions. This approach will outline the current landscape of eHealth approaches and their effectiveness for this patient group, whilst highlighting gaps in the literature and considerations for future research.

Methods

Medical subject headings, Boolean terms and keywords were used in several databases: Medline; Embase; PsycInfo; CINAHL; and The Cochrane Collaboration Cochrane Review Database. Given the recent advances in eHealth, an open search with no date restriction was considered unwarranted. The release of the iPhone in 2007 was a huge breakthrough in eHealth as it made the internet much more accessible. A Web of Science search shows the number of citations for eHealth begins to increase around this time with less than 150 citations per year pre-2006 and increasing every year to almost 9000 in 2018. Given these developments, the searches were restricted to publications from 2007 onwards. The full Medline search strategy is provided in Table 1; this search strategy was adapted for each database. Additional forward reference searching from relevant papers was also conducted. Searches were conducted in April 2019.

Selection

The broad inclusion criteria were designed to identify information about the types of interventions, including their function and structure, that may be acceptable to haematology patients as well as determining their effectiveness. Including studies at any stage of development and with a diverse range of methodologies facilitates a deeper understanding of eHealth interventions, their features and their outcomes ¹⁶.

Inclusion criteria

- Original articles published in English between January 2007 and April 2019
- Papers reporting on any haematological cancers, including studies where other non-haematological cancers were also included
- Studies that used an e-health (computer, web-based or mobile device systems) intervention
- Studies of any research design and methodology
- Assessment or evaluation of any of the following relating to the eHealth approach: usability; acceptability; feasibility; effectiveness; improvements in patient wellbeing, health status symptoms and side effects or QOL

Exclusion criteria

- Conference abstracts, grey literature, letters and opinion papers
- Studies where the primary focus was not feasibility and effectiveness of eHealth or its influence on the wellbeing, health status, symptoms, side effects or QOL of patients
- Studies where the primary objective of the intervention was not stated
- Standalone landline telephone interventions not incorporating an eHealth component
- Studies including participants under 16 years of age or where it was not possible to distinguish between those over and under 16

Data collection and analysis

Identified papers were collated in Endnote and duplicates removed. Titles and abstracts were reviewed (ST, SB). Full text was located for papers meeting inclusion criteria. All full text papers were reviewed independently (ST, SB) against inclusion criteria. Disagreements were discussed, papers re-reviewed and a consensus reached. A table (Table 2) developed by the research team to guide extraction of relevant information for review was then populated (ST). Studies were categorised according to the stages of the illness trajectory as defined by National Institute of Clinical Excellence (NICE) (Figure 1) ¹⁷. Given the broad range of methodologies included, a narrative approach was applied ¹⁸. Studies were grouped thematically according to the type of intervention. The methodological quality of the studies was assessed using the Mixed Methods Appraisal Tool (MMAT) ¹⁹. The MMAT describes four specific criteria that qualitative, quantitative and mixed methods studies have to meet to be classified as methodologically robust.

Results

The search retrieved 10,954 papers and 9,601 following removal of duplicates. Due to the broad range of search terms used to identify different types of eHealth intervention, the search identified a large number of papers that could be discounted at title and abstract review. Many studies were clinical drug trials which did not use eHealth interventions. Thirty-four papers were selected for full text review. Eleven studies were subsequently excluded (Figure 2) and 23 included (Table 2).

Included studies and participant details

All studies (n=23) were conducted in countries of very high human development ²⁰, with the largest number (n=9) conducted in the USA ²¹⁻²⁹. Thirteen of the studies included patients with any type of cancer; the percentage of haematology patients included in these samples ranged from 8-70%. Six studies included patients with any haematological cancer, whereas others focused on specific types. Interventions from included studies were designed to be used at various points across the illness trajectory. The stages were grouped where possible according to the categories listed in the NICE

guidance (Figure 1). The sample sizes in the included studies varied greatly, from 10 for a qualitative study to 8,690 for a quantitative cross-sectional study.

Methodological quality

Six studies were RCTs, one a pre/post-design and the remainder explored feasibility and acceptability using qualitative or quantitative approaches. Four of the five qualitative studies employed content analysis²⁹⁻³². Just under half of the studies (n=11) had a methodological quality rating of 50% or less, meeting two or less of the four MMAT grading criteria. Only three of six studies exploring effectiveness of an intervention provided sample size calculations³³⁻³⁵ and two^{34, 35} of these did not meet the required sample sizes.

Interventions

The intended role of the interventions could be grouped into four main categories: information provision (n=4); communication facilitation (n=5); patient reported outcome (PRO) recording or monitoring (n=8) self-help (n=6) (Table 2). Information and self-help interventions targeted the follow-up survivorship period whereas symptom monitoring interventions targeted the treatment stage (Figure 3). The categories of interventions are used to structure the results. ***Information provision***

Three papers^{21, 22, 26} described OncoLife, a web-based system providing tailored care plans for cancer survivors. Users complete questions then receive a personalised plan including health care and lifestyle advice. The majority of respondents spoke positively about the tool and found the content useful²¹; they felt more informed as a result of using OncoLife^{22, 26}. A further study³⁶ explored the use of information provision to help Non-Hodgkin's lymphoma patients understand and manage their treatment pathway. Participants felt information presented in the intervention was clear and helpful.

Self-help

Four of the six studies exploring self-help interventions were RCTs^{23, 24, 33, 34}. Each study used a form of psychological theory to facilitate disease and symptom management. Syrjala's²⁴ study explored web-based psychoeducational and cognitive behavioural therapy (CBT) techniques. The study demonstrated the potential feasibility of online interventions but effectiveness was not explored. In Rabin's²³ study, a website was developed using the trans theoretical model and social cognitive theory to promote physical activity in young adult cancer survivors. An increase in physical activity level for the intervention group was observed but was not statistically significant (p = 0.48).

Braamse's³³ and David's³⁴ studies evaluated self-help programs using Problem Solving Treatment³⁷ and CBT respectively. In both interventions, participants completed web-based assignments and had access to a psychologist for support. Braamse's³³ intervention was not effective at improving

psychological distress. David's³⁴ intervention had a significant effect on participants' 'fighting spirit' as measured by the Mental Adjustment Scale but not on distress.

One study³⁸ explored the feasibility of a web-based self-help intervention designed for patients who had experienced sexual or fertility problems. The intervention included information and access to discussion forums with other participants and clinicians. The intervention increased participants' knowledge and helped them to manage distress. The final self-help intervention study used qualitative methods to explore patient acceptability of an online yoga intervention²⁹. Participants reported positive effects including improved sleep, less fatigue and reduced stress.

Communication facilitation

Five interventions were designed to facilitate communication^{30-32, 39, 40}. Three studies by Hogberg explored the use of a patient/nurse web-based communication system; two present the results of qualitative interviews exploring participants' perceptions of web-based communication³⁹ and implementation issues³⁰. The third evaluated messages sent by participants using the system³¹. One study was part of a randomised trial³⁹. The others were qualitative studies which concluded that web-based communication is feasible and acceptable in this population and has the potential to enhance patient participation in care.

Two studies explored web-based resources including video clips and written material designed to facilitate communication^{32, 40}. The results of Van Bruinessen's study suggest the intervention may improve self-efficacy but the difference is too small to be conclusive. Cresswell's³² intervention, was shown to be applicable and acceptable for use in oncology.

PRO recording or monitoring

Eight studies used interventions designed to capture PRO data^{25, 28, 32, 35, 41-44}. In Kearney's³⁵ study, patients' record chemotherapy-related symptoms and nurses implement interventions in response to reported problems. The study was a pre/post-test design and results showed a significant improvement in nausea, vomiting and oral problems. Another study⁴² similarly aimed to monitor the trajectory of chemotherapy side effects by asking participants to complete an electronic questionnaire on the day of chemotherapy and then at home two weeks later. The results suggest symptoms are at their worst one week after treatment; a time when patients are not seen at the hospital, highlighting the potential value of remote monitoring.

Collado-Borrell's ⁴³ paper details the development of a mobile app designed to help patients receiving oral anti-cancer treatments to track their medication and side effects at home. The app has a number of different features: appointment and treatment logs and self-monitoring facilities. Although the primary feature is self-monitoring, there is also a facility for two-way communication with a pharmacist.

Three studies explored the feasibility of electronic monitoring or reporting of PRO data ^{25, 28, 41}. Hurria's ²⁵ paper compares electronic and manual tools for completion of a geriatric assessment and conclude that a computer-based assessment is feasible. A study ⁴¹ exploring the feasibility of routinely collecting PRO data from participants and the ability to link this data to blood results found that participants were willing and able to report PRO data. Henderson's ²⁸ study aimed to evaluate the use of the global Patient-Reported Outcomes Measurement Information System (PROMIS) scale in routine outpatient appointments of adolescents and young adults. The study found that routine assessment using the PROMIS global measure was feasible and reported that patients on treatment had lower global health scores. Clover's ⁴⁴ study was designed to test the validity of the PROMIS depression measure. The study confirmed validity of the measure in the oncology patient population. Apart from the brevity compared to other measures, it did not offer any further advantages in this patient population.

Cheville's ²⁷ study explored the effects of a complex intervention incorporating telerehabilitation, physical fitness and pain management. Participants in each arm remotely monitored their pain and activity levels by telephone or web-based surveys. Health professionals would track patient reports in arms 2 and 3 and would respond to pain alerts for arm 3 participants. The intervention was feasible and the convenience of remote rather than face to face intervention meant patients were more responsive to taking part. The study reports modest effects sizes for mobility and pain.

Discussion

This is the first review to provide an insight into the role of eHealth in haematological cancer. A diverse range of interventions were identified focusing on information provision, self-help techniques, communication facilitation and PRO monitoring or recording. The interventions targeted treatment and follow-up and none focused specifically on diagnosis, palliative care or end of life. Four studies (two self-help and two PRO interventions) reported a positive effect. The review has highlighted the limited research exploring the use of eHealth in haematology cancer. Fewer than half of all identified studies included haematological cancer patients only. Studies of mixed cancer groups included a small sample of haematology participants and results were not presented separately. All

the studies identified were conducted in countries of very high human development suggesting findings may not be representative, given the prevalence of haematological cancers in less developed countries ⁴⁵.

Three of the four studies exploring the provision of information assessed acceptability and feasibility of tailored care plans ^{21, 22, 26}. van de Poll-Franse's review reports the failure of many cancer survivorship interventions and highlights the importance of survivor engagement and supportive self-management rather than information provision alone ⁴⁶. The information provision interventions identified ^{21, 22, 26, 36}, were one-way communication tools. Tailored feedback, communication links with health professionals and peer-to-peer support may facilitate participant engagement and improve intervention effectiveness ⁴⁷. A survey exploring haematology patients' views of the use of ICT showed patients had a strong interest in the use of eHealth as an information tool; many looked up information before appointments ⁴⁸. There is a danger however that this information may not be accurate. It is important for patients to have trust worthy sources to access information. There is a wide range of web-based self-help tools which have been designed for use within the cancer patient and survivor populations and a proportion of these have been found to have positive effects on patient outcomes ^{47, 49-52}. In this review, only one self-help tool had a significantly positive effect ³⁴. The effect was modest and was only seen in one aspect of mental adjustment and psychological distress. Other online self-help tools that have demonstrated effectiveness have involved a greater number of online modules ^{50, 53}. As David ³⁴ suggests, the brevity of the tool could have contributed to the lack of significant effect. In some cases, patients needed health professional support to allow them to fully engage and benefit from online self-management tools ⁵⁴

There is a wealth of literature exploring the use of eHealth as a communication tool in oncology ⁵⁵⁻⁵⁷. A survey of haematology patients reported that the ability to communicate with health professionals was an important feature of online tools and 40% of patients said they wanted to communicate with health professionals in this way ⁴⁸. Van Bruinessen's ⁴⁰ communication facilitation intervention showed a significant increase in perceived efficacy but the intervention did not improve participants' confidence in communicating with health professionals. To improve effectiveness, a more interactive approach engaging both patients and health professionals may need to be considered ⁵⁸. Other studies using prompt lists to initiate discussion in oncology consultations have found this method useful and acceptable to patients and clinicians ⁵⁹.

Although, only limited, there is evidence in this review that some eHealth interventions may be effective in the haematology patient population with regards to decreasing chemotherapy side effects ³⁵, increasing physical activity ²³, reducing pain interference ²⁷ and improving psychological experiences ³⁴. Other studies have explored the impact of patient symptom reporting in oncology ⁶⁰, ⁶¹ but evidence of effectiveness is mixed ⁶²⁻⁶⁵. Research suggests that the routine collection of PRO via eHealth interventions could improve patient involvement in decision making by facilitating improved communication ⁶⁶. Feedback from patients regarding the routine PRO reporting suggests that it could improve patients' self-efficacy, knowledge and confidence with managing symptoms during treatment ⁶⁷. PROs have also been endorsed for use in clinical practice as a tool to identify patients in distress ⁶⁸. Brochmann's ⁴¹ study showed that patients were able and willing to complete regular PROs which could then be linked to blood test results. Studies in oncology ^{69,70} and other chronic diseases have also reported patient acceptability of routine collection of PROs ⁷¹.

Clinical implications

The potential for eHealth tools to support haematological patients should be considered in the context of growing oncology informatics literature. The full benefits of eHealth interventions at different stages of the illness trajectory need further investigation. The review presents limited evidence of the use of eHealth interventions during treatment and the studies identified include only a small number of haematological cancer patients. Further research is also needed to explore the benefits of eHealth tools for survivors and to determine where interventions could be used to help deliver survivorship care packages ⁷². The only interventions identified in this review specifically targeting the follow-up or survivorship period are self-help interventions ^{23,24,33}. Despite advances in eHealth, many barriers to implementation still exist ⁷³. There is a concern amongst health professionals that eHealth communication may result in problems being missed ⁷⁴, therefore health professional engagement is critical. Furthermore, understanding characteristics of individual patients is an important factor that can determine whether patients would support the use of and engage with eHealth tools ^{30,75}. The evidence of the effectiveness of eHealth interventions is still inconclusive at this stage but studies are continuing to emerge to support the role of eHealth in improving patient outcomes. Further research is needed to explore the long-term impact and sustainability of eHealth systems in clinical practice ⁷⁶.

Study limitations

This review has a number of limitations. The purpose was to explore the use of eHealth in haematology. Broadening the scope of the review may have identified evidence of interventions in

other disease groups that could be effective in haematology. The interventions identified are varied and many do not explore effectiveness so it is difficult to make firm conclusions about the impact of eHealth in haematology. The use of multiple and varied outcome measures across studies also limit the reliability of judgements about the effectiveness of eHealth interventions in haematology.

Conclusion

The clinical management of patients with haematological cancers, presents opportunities to explore eHealth approaches to improve patient care. With increasing demand to provide support to haematological patients, particularly in survivorship, future exploration of eHealth should explore what help and support these patients want and at what point in the trajectory these interventions should be administered. There is a need to engage with haematological cancer patients and health professionals to understand their specific needs and preferences for eHealth approaches. This will help to map out optimal workflow and delivery mechanisms in the provision of haematological cancer care.

Conflict of interest: None

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