

Towards an explanatory model for e-health interventions for support and education in cancer care

An integrative review

FÖRFATTARE	Filipa Ventura
KURS	OM5150 Examensarbete för master i Omvårdnad 30 högskolepoäng Fristående kurs
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OMFATTNING	30 högskolepoäng
HANDLEDARE	Joakim Öhlén Ingalill Koinberg
EXAMINATOR	Ingela Skärsäter
Institutionen för Vårdvetenskap och hälsa	

Sahlgrenska akademien



Kurs, kurskod: Examensarbete för master i Omvårdnad, 30 hp, OM5150

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Författare: Filipa Ventura

Handledare: Joakim Öhlén, Ingalill Koinberg

Examinerande lärare: Ingela Skärsäter

SVENSK SAMMANFATTNING

Under de senaste åren har utvecklingen av stödjande och undervisningsinriktade interventioner för cancerpatienter ökat på internet. Patienter söker information och stöd för att kunna hantera sjukdom och vara delaktig i vård och behandling. Forskningen har inte kunnat visa om interventionerna leder till förväntade resultat, som: ökad kunskap, upplevelse av stöd, ökad delaktighet och egenvårdsförmåga.

För att få mer kunskap om den teoretiska processen som grundar dessa interventioner, hur de har utformats och till vem de är anpassade har en integrativ review genomförts. På basis av denna kunskap, har en förklarande modell framställs. I ramberättelsen kommer modellen att diskuteras i relation till *empowerment* begreppet.

Sökning för artiklar som överensstämde med urvalkriterierna genomfördes i PubMed, Cinahl och PsycINFO. Studier från 2000-2010 som rapporterade om undervisningsinriktade och stödjande interventioner som genomförts via internet eller med hjälp av en CD-ROM eller DVD inkluderades för granskning. Interventionens målgrupp var vuxna patienter med cancer. Arton kvantitativa empiriska studier utgjorde det slutliga urvalet. Kvinnor med diagnos av bröstcancer var den vanligaste målgruppen. Samtliga interventioner hade som syfte att ge information, undervisning, emotionellt stöd och förbättra egenvårdsförmågan. Gemensamt för nästan alla interventioner så fanns det någon pedagogisk teori. Resultaten visade att patienterna ökade sin förmåga att ta till sig: information och kunskap om hälso- och sjukvård, till delaktighet i vård och behandling. Patienternas upplevde ett ökat socialt stöd och välbefinnande och hade en ökade förmågan att hantera sin sjukdom genom egenvårdsinsatser.

Även om dessa interventioner har haft positiva effekter, stödjer de sig i varierande teoretiska strukturer som inte förklarar hur individen förändras av att använda interventionen. Därigenom, kan också utfallet som mätts ifrågasättas som en exklusiv effekt av programmet. Mer kunskap behövs om teorier som bekräftar individens förändringsprocess och leder till de förväntade resultaten. *Empowerment* i ljuset av självbestämmande (self-determination) teorier kan ge den önskade teoretiska strukturen till dessa interventioner.

Nyckelord: Cancer, Dator, Integrative review, Interaktiv, Internet, Patient undervisning, Stöd.

ABSTRACT

This integrative review aims at providing an overview of supportive educational e-health programs, which have been offered to cancer patients, in order to gather more knowledge as to how such interventions have been designed, implemented and who is to benefit from such approaches. Moreover, in this comprehensive summary, the resulting explanatory model is discussed in the light of empowerment.

Following the methodological suggestions of Whittmore (2005) PubMed, CINAHL and PsycINFO were searched for abstracts matching the eligibility criteria since the year 2000 until November 2010. Articles were considered for inclusion if they concerned supportive educational interventions, delivered through the Internet or resorting to a CD-ROM or DVD, and having adult patients diagnosed with cancer as the target population.

Eighteen quantitative empirical studies constituted the final sample of this research review. The most common target population was women with breast cancer. The overall purposes of the reviewed interventions were: to provide informational, educational and emotional support; and to improve self-care behaviours. Mainly pedagogical theories gave structure to the interventions. Outcomes that were positively affected were: healthcare information and knowledge, healthcare participation, social support, quality of life, self-care ability, and coping.

Supportive educational e-health interventions have been developed in the past few years taking into advantage the increasingly use of the Internet by patients for search for health information and support. Nonetheless, more knowledge is needed regarding the process sustaining such interventions, and empowerment on the light of the self-determination theory is likely to contribute to the missing structure.

Keywords: Cancer, Computer, Integrative review, Interactive, Internet, Patient education, Support.

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Appendix 1. Manuscript: "Towards an explanatory model for supportive educational e-health interventions for cancer patients: an integrative review"

Introduction

Receiving a cancer diagnosis and initiating cancer treatment leads the patient and his/her family to a complex world where uncertainty and lack of control are some of the causes of anxiety and socio-physical impairment [1, 2]. Along with the shifting in caring models, where patient participation in healthcare decision-making is being enhanced, and the arising of the information and communication techniques, patients are increasingly resorting to the Internet to search for health information and support [3, 4]. In developed healthcare systems where efficiency and budget limitations are major concerns, such a tool as the Internet is irrefutably a cost-effective complement to the standard care for delivery of patient education and support [5]. Nonetheless, more knowledge is needed as to how these interventions are being planned and carried out, and who is to benefit from such approaches.

This study seeks to contribute to that understanding and, specifically in this comprehensive summary, discuss supportive educational e-health interventions in the light of patient empowerment.

Cancer patients' needs and e-health

Cancer patients are increasingly receiving treatment at outpatient's settings [6]. These individuals perceive good care when they a) are being empowered, that is to say being respected, listened to, given honest information and being valued; b) participate in treatment decision-making (discussing the treatment, but still letting the physician decide); and c) have a partnership in nursing care [7]. Even though the experienced needs will certainly vary during the illness/care trajectory and among individuals [8, 9], common aspects are still raised when patients are inquired about what they consider to be central in relation to their care and their illness. Having information about treatment side-effects, side-effects management, and follow-up care after completion of the treatment is one of those aspects. Having hope and emotional, psychosocial and practical support is the second most named aspect [10, 11].

If on one hand individuals can have a sense of normality when being cared for at outpatient settings, since they spend most of the time away from the hospital environment [12], attending an outpatient centre does require more self-care abilities on the other hand. In its turn, embracing self-care abilities entails specific health knowledge and self-efficacy behaviours. Such complex knowledge and behaviours are to be transmitted and taught to the individuals by healthcare professionals during short encounters, often with several weeks apart.

Succinctly, patients need information about their illness and treatment, knowledge regarding side-effects management, and overall support. These needs are not necessarily felt during the encounter with the healthcare professional, they might appear while being at home. By then, patients will resort to the Internet in order to satisfy their informational and supportive needs. However, the amount of information might be inaccurate and sometimes difficult for the patient to digest, leading to confusion and increased stress. At the same time healthcare professionals are being challenged to satisfy those needs in cost- and time-effective ways and are therefore exploring the online delivery of such information, knowledge and support.

Along with this tendency, interactive health communication systems (IHCS) have been developed using the Internet as one of the main tools for delivering online information and support as a complement to traditional care [13]. These systems belong to a subsystem of e-health interventions, that is to say, interventions that resort to information and communication technology to improve or enable health and healthcare [14].

Interactive health communication systems have been relaying information, enabling informed decision-making, and promoting healthy behaviours, peer information exchange and emotional support, and self-care. Such functions, since delivered by the Internet, are available as a 24 hours service and are self-paced, allowing the patient/user to access the service whenever they need it at their own rhythm. The information is packed, accurate and person-centred, reducing the risk for confusion and anxiety [13, 15].

Empowering interventions and e-health

Empowerment is a construct that has been growing in importance along with new caring trends, by which individuals want to be more informed and active in their healthcare. Responding to economical and organizational challenges, and recognizing that resources are sometimes lacking to truly facilitate patient participation and self-care, healthcare professionals have been seeking to deliver empowerment online [3-5, 16]. Interventions for patients and their families that have been included under the empowering-processes umbrella are those that aim at: educate for self-care and disease management; promote the involvement on decision-making; and give support [16]. By sharing the same goals, such interventions have the potential to contribute to a theoretical framework for the supportive educational e-health interventions that are being approached on the present study.

Healthcare empowerment

The first references to empowerment appeared in the 1960s based on the ideology of social action and were connected to the beginning of self-help groups. The main underlying assumption is that the individual is responsible for his/her actions and choices, as well as, for the consequences of those. The concept has become to be used across several fields, such as, political science, economics, social work, psychology, sociology and nursing, being primarily seen as the opposite to powerlessness [17-20].

The definition proposed by Rappaport (1987) is by far the one that is most cited [4, 21]. According to this author, empowerment refers to “a mechanism by which people, organizations, and communities gain mastery over their affairs” [21]. This definition has been developed when applied to the different disciplines. Zimmerman (1988), followed Rappaport’s work very closely and explains empowerment as “the ability of individuals to gain control socially, politically, economically and psychologically through access to information, knowledge and skills, decision-making, individual self-efficacy, community participation and perceived control” [18]. When elaborating on psychological empowerment, Zimmerman defends that it represents a proactive approach to life, while critically understanding the socio-political environment.

Furthermore, a distinction is made regarding empowering processes and empowered outcomes. Empowering processes are those that allow for opportunities: to acquire, develop and practice skills; to learn about resources; to work with others towards a common goal; to create and or expand one’s social network. Empowered outcomes on the other hand are considered to be mastery and control, resource mobilization and participation. According to Zimmerman, a global measure of empowerment is unlikely to exist, since empowerment assumes different forms for different people, in different contexts, and fluctuates over time [18].

In the field of nursing, Gibson (1991) has suggested that empowerment is “a process of helping people to assert control over the factors which affect their lives”. Gibson’s concept analysis would retrieve that empowerment can be seen as a process or as an outcome, as other researchers studying empowerment had concluded. When adopting the process lens one would find that empowerment is not about changing the individuals’ structure, but rather integrating new components to the existing structure; is not about having more power, but rather feel more powerful.

Such processes are meant to increase individuals’ awareness to potential stressors in their daily lives, to develop a readiness to act on those stressors and to adapt management strategies [19]. Regarding health, empowerment has been associated with health promotion initiatives – “a

process of enabling people to increase control over and to improve their own health”. Assuming that the individual is responsible for his own choices and the consequences that come with it, the nurse has a role of “resource mobilizer” [19]. In that sense, nurses strive for the patient to have access to the needed resources, so that he/she can find a new balance and have increased quality of life despite the illness.

In the field of nursing research, empowerment can be considered as the dependent variable, factors that lead to patient empowerment, or as the independent variable, outcomes of an empowering process. Gibson (1991) suggests that factors leading to patient empowerment can be: providing support, participatory decision-making, collaboration, negotiation, education and counselling. Patient outcomes are, on the other hand, identified as: self-efficacy, sense of control, sense of mastery, growth, sense of connectedness, improved health and improved well-being.

Most recently, Johnson (2011) took upon some critics that have been made to the construct of empowerment and proposed a model of healthcare empowerment. According to Johnson (2011), empowerment refers to “the process or the state of participation in healthcare that is characterized as: engaged, informed, collaborative, committed and tolerant of uncertainty”. This definition is informed by the self-determination theory and follows the guiding principles proposed by Aujoulat, et al (2007), that is to say, empowerment-based interventions have to be patient-centred and aim at developing psychosocial skills, rather than being disease specific [4, 17].

In an empowerment intervention that is grounded on the self-determination theory, the goals should be autonomously regulated. That is to say, the patient is the one to define which health-related goals are to be reached. In that sense, empowering goals and outcomes should not be predefined by healthcare professionals. Moreover, empowering actions should not be planned on the basis of a disease or treatment. According to the principles of self-determination, the patient is responsible for his/her own actions and consequences of those actions. By empowering an individual and their family we will be increasing his/her competence for dealing with the health problem and the environment and enhancing the capacity of being related to self and others [17].

Empowering e-health interventions

As it is continually expanding, a concrete definition of e-health is difficult to achieve, there are however some authors that have tried to clarify the concept [14, 22]. Eysenbach (2001), talks about the meaning of the “e” in “e-health” and explains that it should be understood beyond the “electronic” that it stands for in order to come closer to the concept’s applicability. According to

this author, “e” represents efficiency, evidence based, equity and empowerment to name a few [22].

Several studies have been carried out for appraisal of the effectiveness of empowering e-health interventions [16]. However, some inconsistencies are still found regarding the definition of empowerment [17, 20]. Some researchers believe that the construct may assume different features depending on the context and population being studied, while others seek a functional and accurate definition so that the construct can be used in practice, as well as, in theory across contexts. Indeed, empowerment tend to be defined a) on the grounds of assumptions that are barely supported by evidence, or b) based on the outcomes that are expected to be achieved, leading to confusion regarding the constructs dimensions across studies [17, 23, 24].

Patient empowerment, on the light of the self-determination theory, has the potential to provide the desired structure to supportive educational e-health interventions. However, an accurate definition of empowerment is needed, where the different dimensions of the construct, antecedents and results are depicted [20].

Research Question and Aim

Even though the Internet is increasingly being used to search for health information and support, it will most probably not serve all individuals, or at least will serve individuals differently. To have a theoretical framework that informs the development of supportive educational e-health interventions is important in order to be able to coherently design, implement and evaluate such person-centred interventions [20]. Hence, this integrative review aims at providing an overview of supportive educational e-health programs, which have been offered to cancer patients, and subsequently to analyse them in order to identify an explanatory model for this kind of interventions.

The overarching research question underlying this review is therefore formulated as follows: Which framework is giving structure to supportive educational e-health programs? Moreover, this review enquires about: Which supportive educational interventions have been offered to cancer patients? What are the main features of the offered programs? Which are the theoretical frameworks and health outcomes of such programs? Are there any process mediators or outcomes predictors?

Method

A literature review is the first step to be taken when initiating a research study in a specific field. More than just providing an overview of the state of evidence on the chosen topic, the researcher may identify aspects that are underdeveloped or missing, thereby justifying the need for a new study [25]. The state of knowledge on the topic and the clinical problem being addressed will determine the review method, and consequently the scope, sampling frame and analytical method that will be followed [26].

More than just doing a systematic research to summarize the state of the art, this study aims at analysing the resulting findings and synthesizing them on an explanatory model. In so doing the integrative review was considered to be the appropriate approach for the present study. According to Whittmore & Knafl (2005), such reviews involve five stages: problem identification, literature search, data evaluation, data analysis and presentation of results. On the surface, these steps are appropriate to any literature research [25, 27]. However, when analysing them closely some specificities arise. Whittmore & Knafl (2005) have made some modifications in order to incorporate aspects specifically related to the integrative review approach [28].

Having identified the research problem in relation to supportive educational e-health interventions for cancer patients, where more knowledge is needed regarding: a) how the interventions are being designed, b) how they lead to the expected results, and c) who is benefiting of such interventions, a literature search plan was developed.

Searching and selecting the literature

For the purpose of this review, supportive educational e-health interventions are those that resort to information and communication technologies for delivering of information, and psychosocial and emotional support to cancer patients. These interventions are here seen as tools that might be interactive in the way that allow the user to control and access specific contents related to his/her needs. Such contents might be presented in a variety of multimedia formats (video, sound, text, and graphics).

The above definition gave structure to the literature search that was carried out on PubMed (1950-2010), CINAHL (1982-2010), PsycINFO (1872-2010). Abstracts were selected for further reading if they matched the following keywords: “cancer patients”; “patient education” and/or support (psychosocial, psychological, social); intervention, program, system or model; and web*, computer*, interact*, multimedia or Internet. The literature search took place during November 2010 and was limited to journal articles written in English.

Target population on this review referred to individuals older than 18 years, diagnosed with cancer about to start treatment, under treatment, in transition to survivorship, or during survivorship. Interventions had to be led by healthcare professionals and could resort to videos, audiotapes or CD-ROMs, since these materials can constitute the precursor of interactive computer-based interventions [29]. Studies reporting on online support groups were excluded since they were exclusively supportive interventions and were expected to have other theoretical frameworks.

Descriptive studies analyzing health information websites, as well as, studies that reported the development (phase I) or exclusively usability, acceptability or feasibility (phase II) of supportive educational interventions were excluded [30], since they did not elaborated on intervention components that were considered important for the construction of the intervention model (*e.g.* predictors of use, health outcomes). Dubious articles were discussed with the reviewer supervisors and included if a consensus was reached. Among the resulting articles, twenty-eight research reviews were found, of each 10 were related to the present review. These secondary sources were also searched for eligible articles [25]. From the initial 435 citations, only 18 articles fitted the eligibility criteria and were taken into analysis (Fig.1).

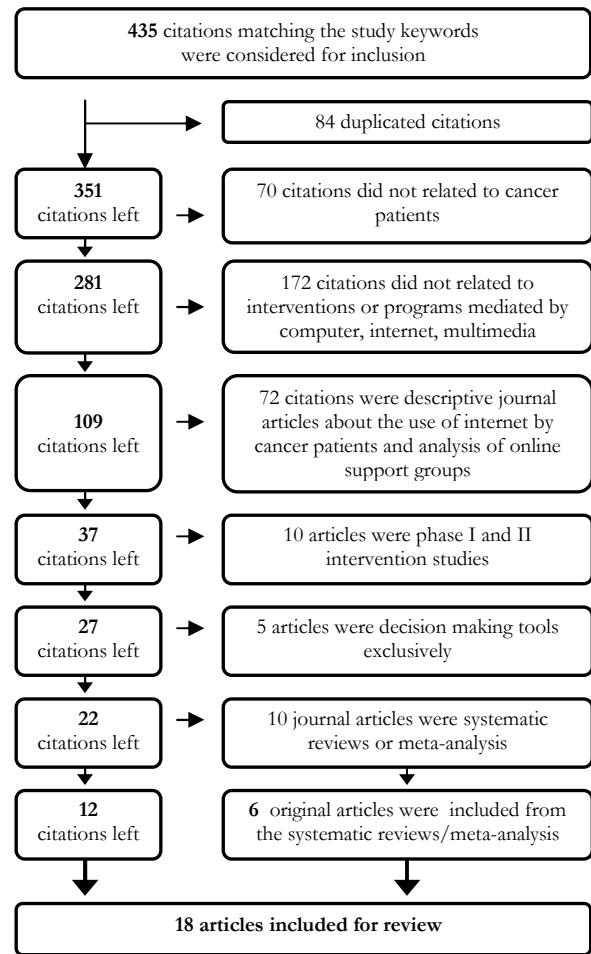


Fig. 1 – Flow-chart for the inclusion process

Analysis and synthesis of the literature

Criteria for methodological analysis of primary sources are expected to vary depending on the research design [28]. Still, some constructs are believed to affect primary studies quality. A methodological matrix created on the bases of Whitemore (2005) suggestions was kept allowing the examination of the several studies regarding their research design and methodological processes.

When analysing primary sources, a constant comparison method should be taken. Such a method allows the extraction of data into systematic categories and further facilitates comparison and abstraction in order to identify patterns, variations and eventual relationships. This stage of data analysis encompasses five sub-steps: data reduction, data display, data comparison, conclusion drawing and verification [28]. Data was coded and displayed in a review matrix containing the following domains in relation to each study: author, year, country, aim, sample, intervention, instruments and outcomes, and conclusions. Aiming to go further and understand specific aspects of the interventions being proposed on each study a similar register was kept for the characteristics of the intervention including: author and year; intervention's designation; purpose; patient group; theoretical framework for the intervention; evidence-at-hand; format and access, intervention/control group, presentation style and interveners; contents' source, subject and layout; utilization patterns; and outcomes.

Results

After reviewing the eligible articles and further selection, eighteen articles were included in this integrative review, fifteen were from USA, one from Canada, one from Australia and one from The Netherlands. All articles reported on empirical studies, adopting a quantitative research design.

Description of the reviewed studies

All studies described with more or less detail evidence-at-hand that calls for the development of supportive educational computer-based interventions. Summarizing the evidence, patients need and seek for support and information to deal with cancer, treatment side-effects and to make informed decisions in the context of healthcare [31-35]. Moreover, most of the cancer treatments are being administered at outpatient settings where the time is constraining [36]. Interactive support and information is a cost-effective way of complementing the standard healthcare, available whenever the individual needs it.

Samples from two-arm studies varied from 45 to 250 participants, being the most common target population breast cancer patients (67%) [31-33, 35-43]. Most of the articles (67%) aimed at accessing the programs effectiveness, being common outcome variables: information amount/knowledge gain, social support, information competence, healthcare participation, quality of life (frequently measured as physical, emotional, social/family well-being), negative emotions (anxiety, depression, and emotional, psychological or overall distress), patient satisfaction, coping and self-care behaviours.

Interventions' characteristics, predictors and mediators

Seven (39%) articles [31, 32, 37-39, 41, 43] reported on the use of the CHES (Comprehensive Health Enhancement Support System), being the other articles of other specific supportive educational tools. Overall they aim at provide educational (78%) [36, 44-46], informational (50%) [31, 32, 34, 37-39, 41, 43], and emotional (39%) [31, 32, 37-39, 41, 43] support; improve self-care behaviours (11%) [35, 47]; reduce distress (11%) [42, 46]; and increase preparedness (6%) [42].

Orem's Theory of Self-Care [35, 47], Self-Determination Theory [31, 39], Comprehensive Model of Information Seeking [32], and Andersen & Newman's Behavioural Model of Health Service Use [34], were some of the theoretical structure behind the measurements. However, few studies stated a theory endorsing the intervention itself. In this regard Bandura's social learning theory was found to be the most common theoretical framework supporting the interventions [39, 41-43]. Other theories supporting the interventions were Communities of Practice [31, 39, 41], Cognitive Learning Theory [43], and Adult Learning Theory [47]. Two pedagogical perspectives were discussed: the constructivist and transmission perspectives[41].

Regarding the format and access, a computer-based tool was used in 89% of the interventions (web-pages, CD-ROM, or DVD predecessor). One intervention consisted of video, and another one used audiotapes. Three studies specify the duration of the tools [35, 42, 47]. All computer-based interventions were self-paced, and seven (44%) were exclusively delivered at the research setting.

Most of the interventions were constituted by informational services, but CHES interventions revealed yet two more kind of services: communication (peer-to-peer, patient-expert) and interactive services. Regarding the contents of the supportive educational interventions, 56% was person-centred. Utilization patterns were described in nine studies, accounting the CHES use for four of them.

Outcomes that are positively affected by these interventions are: healthcare information and knowledge [31-34, 37, 38, 41, 44, 45]; healthcare participation [31, 32, 37, 42, 43]; social support [31, 32, 37, 38]; quality of life [31, 32, 38, 39, 42], overall satisfaction [33, 34, 40, 42, 44, 45]; general health, physical function and side effects; self-care ability [35, 47]; coping with cancer [46].

Factors that might predict intervention's usage and effects are accounted for in nine articles (50%) [31, 32, 37-39, 41-43, 45]. These predictors can be structured into socio-demographic factors, disease-related factors, and psychosocial factors. In addition to the usage predictors, there is yet another group of factors that might act as a filter to expected outcomes. Total time spent in the

intervention does not seem to predict benefits, rather the selective use of the different services that constitute the intervention [37]. This selective use of the different services is explained by demographic or/and disease-related factors.

Based on the previous results' description, a model was created to illustrate supportive educational interventions (Fig. 2).

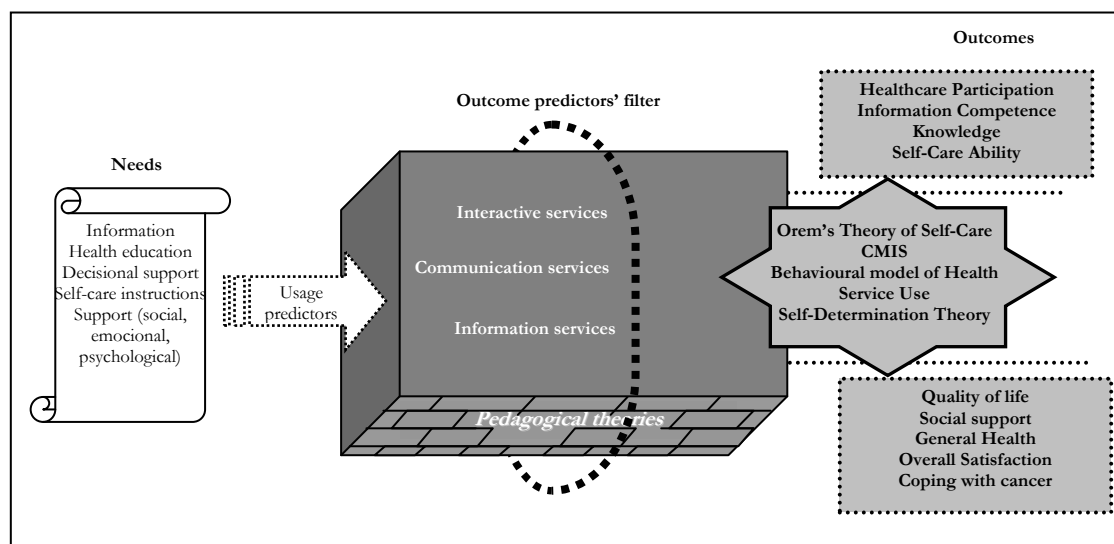


Fig. 2 – Supportive Educational Interventions' Model

The explanatory model depicts the different components of the reviewed interventions, from the needs that justify the existence of the intervention (information, health education, decisional support, self-care instructions and overall support), to the usage predictors that determine who is likely to use the intervention and more specifically who is more expected to use a particular service within the intervention. Once in the intervention, using more or less a particular service will affect the outcomes. To that fact contribute the outcome predictors. The theories explaining the behavioural changes, and thereby sustaining the intervention itself, have been mostly pedagogical. However, a few theories have been identified for explanation of the outcomes and form therefore a component that is placed outside the “intervention” box. Despite this fact, some of the outcomes can still be expected to result from a pedagogical intervention (healthcare participation, information competence, knowledge, and self-care ability) and form therefore a distinct group.

Discussion

Aiming at gather more knowledge about the black box of supportive educational e-health interventions, an integrative review was done. Initiating this research review, only interventions

designed with the purpose of giving both support and education were searched. However, very few abstracts were retrieved, stressing the need to expand the search whereas interventions that were exclusively educational or exclusively supportive came to be included. Still, 18 articles constitute the final sampling, making somehow difficult the construction of the explanatory model. Nonetheless, it is a synthesis of the findings and is considered to be starting point for elaboration on this topic.

As named before, in this comprehensive summary this discussion gives rum to the interpretation of the depicted model on the light of patient empowerment. Regarding the theoretical frameworks found to sustain this kind of interventions, is worth noticing that it had its origins in the pedagogical traditions. In that sense, such interventions seem to be closer to the purpose of giving education, leaving supportive purposes rootless.

Contrarily to what was expected, very few interventions had empowerment as a fundamental construct, nevertheless self-determination theory was referred in two studies [32, 39]. Empowerment models go beyond the strictly educational purposes to include promotion of involvement in treatment decision-making and support [16]. Thereby, such models could give the comprehensive theoretical structure for supportive educational interventions.

As it has been depicted on the suggested model for supportive educational e-health interventions, certain individuals will be more attracted to use these tools than others, and once they have decided for using it, they will most probably use it differently conditioning the outcomes of the intervention. Such characteristics are represented on the model by “usage predictors” and “outcomes predictors”, respectively. Seeing this process on the light of empowerment underpinned on the self-determination theory, different individuals are expected to have different needs. While being responsible for their own actions and the consequences that those might have, individuals are expected to choose different tools to rely on, and even if relying on the same tool they might use it in different times during the illness/care trajectory, and in different ways [17, 23].

Hence, understanding who the individuals in need of supportive educational e-health interventions are, and how they use those interventions is important. According to Gibson (1991), patients who find themselves in situations where their experience an actual or potential lost of power are in need of empowerment. During those situations individuals can sense distrust or hopelessness, feel alienation from resources; their sense of pride, determination and self-reliance are threatened; feelings of support and of belonging are absent [19].

The greatest contribution for the knowledge regarding the usage predictors in the depicted model came for the studies using CHES, where socio-demographic, as well as, disease-related factors have been identified. In those studies, older individuals would use less a discussion group and participants with a higher educational level would use less the participant-expert communication service. As for the disease-related factors, late-stage cancer patients use more the interactive services and the discussion group, post-chemotherapy participants use more the information services, post-mastectomy women use interactive services more, and post-radiation participants use less participant-expert communication services. Lower levels of quality of life, social support, and healthcare competence at baseline lead to an increased use of interactive and communication services [32].

The above reasoning is also supported by Harris & Vernot (2004), where contradictory evidence regarding patient empowerment is presented. Patient empowerment is still very connected to the construct of control. Common assumptions are that individuals need to be empowered in order to control their healthcare, and such control benefits the patients. Moreover, information is assumed to empower patients. However, not all individuals want to be in control, and they certainly have different desires regarding their level of participation in healthcare and involvement in decision-making [3]. Assuming that every patient wants to be in control of their healthcare can lead to information overload that in turn might increase confusion and anxiety, or to the imposition of self-care behaviours that the patient is not ready to embrace. Regarding control and patient participation is essentially to understand that responsibility is to be shared more than given, if such negative effects are to be avoided [24]. Yet, assuming that the individual does want to participate and gain mastery of their situation, giving information might not be enough in an empowering process [3]. Information alone is not likely to change health-behaviours. One needs training, support and the possibility to discuss that information with peers and experts [3, 17].

The model resulting from the integrative review depicts outcomes that were organized in two different groups. This division was made on the grounds of the theoretical framework that might have lead to such results. In other words, increased knowledge, improved health information competence, and healthcare participation can be expected to result from pedagogical processes; whereas quality of life, general health, overall satisfaction and coping might have a weaker connection to those processes, since they are unlikely to be exclusively resulting from educational interventions. This leads the reasoning in yet another direction. In which extent did the supportive educational/empowering e-health intervention contributed to the measured outcomes? Are the constructs being measured a direct outcome of the intervention?

In order to answer those questions, the framework giving structure to the intervention needs to be understood, which leads back to the theoretical framework upon which the intervention was designed. The outcomes being measured have to be a natural result of the intervention process and have to represent the individual's goals in their essence. In the reviewed studies, researchers seemed to be more concerned with supporting their outcomes on specific theories, rather than having a coherent framework that explained the all chain: beginning with the antecedents, to the process that allows behavioural changes, and ending in the expected outcomes. When adopting an empowering framework the major objective of the supportive and educational process is not specific to a disease or treatment [4, 17]. Instead, the ultimate purpose is to help the individual to develop or reinforce psychosocial skills. After participating in such an intervention, a patient would probably not feel support but he/she would know where and how to seek it; the knowledge level is certainly an important measure, but the individual's sense of self-efficacy might say more about the coping process that the patient is going through. In order for the outcomes to be connected to an empowering process, the self-determination theory and patient-centred principles can never be forgotten.

Such reasoning could lead us to the conclusion that every individual experiencing illness seeks empowerment as enlightened by the principle of self-determination. However, one person's goals are certainly different (experiences, preferences and priorities are unique to the individual) in comparison to another, even if ill with the same disease. Assessing patients' preferences regarding treatment decision-making and involvement in their healthcare; and identifying their information and support needs is important. Moreover, such an assessment should be made continually during the illness/care trajectory since such preferences and knowledge levels are expected to vary. Person-centred approaches are needed to guide empowering interventions [7-9, 17], and the challenge to create supportive educational e-health interventions that are coherent with those underlying principles is launched.

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