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Development of a Cancer Self-management Education Programme for Women with Breast Cancer at the End of Primary Treatment

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Abstract

Breast cancer survivors have specific healthcare needs. As a result of their disease and treatment, they have to adapt to different physical and psychosocial late effects. Unfortunately, several studies have documented insufficiency in the survivorship healthcare system. The aim of this paper was to describe the process of development and testing of a novel Cancer Self-management Education programme (CSME programme) to improve patient-reported self-management and self-efficacy for patients with breast cancer who were at the end of primary treatment. The development of the educational programme was inspired by the Plan-Do-Study-Act (PDSA) circle and based on person-centred principles. It was conducted at a Danish university hospital. Nine oncology healthcare providers, two external experts in patient education and five patients were involved in the development and testing of the education programme. Implementation of dialogue-based tools was used as an educational learning instrument in the SCME programme. The PDSA approach to the development of the CSME programme resulted in a person-centred programme that could improve self-management and self-efficacy in the survivorship phase of patients with breast cancer.

Keywords Breast neoplasms · Survivors · Patient education · Learning · Information · Self-management · Educator training · Empowerment · Self-efficacy

Introduction

Breast cancer survivors have specific healthcare needs as a result of their disease and treatment [1], and have to adapt to different physical and psychosocial late-effects from disease and treatment [2]. Several studies have shown that healthcare systems do not meet the needs of the survivors, and there is thus a growing need for knowledge of optimised support of cancer survivors [3, 4]. New models of aftercare are currently being developed and evaluated [3, 4]. The Danish Health Authority recommends implementation of new aftercare models with an increased focus on self-management strategies to meet the needs of breast cancer survivors [5].

Self-management in cancer survivorship has been defined as "awareness and active participation by the person in their recovery, recuperation and rehabilitation, minimising the consequences of treatment, and promoting survival, health and well-being" [6]. This involves managing physical, psychological and social problems, consequences of the cancer disease and the treatment, understanding how and when to seek support, recognising and reporting signs and symptoms of possible disease recurrence and making lifestyle changes to promote health, well-being and survival.

Among patients with cancer and survivors, studies have found that a high degree of self-efficacy is associated with increased self-management behaviours and decreased physical and psychological symptoms [7]. Self-efficacy has therefore become the target of many self-management interventions [8–10].

Overall, development of new aftercare models involving self-management strategies to meet the needs and expectations of breast cancer survivors is warranted. Consequently, promotion of patient-centred research and the didactic planning of a patient education programme could be helpful for healthcare providers in the field of oncology. Such an educational programme could potentially improve patient-reported self-management and self-efficacy related to cancer [9, 11].

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The aim of this paper is to describe the process of developing and testing a novel Cancer Self-management Education programme (CSME programme) to improve patient-reported self-management and self-efficacy in patients with breast cancer at the end of primary treatment.

Methods

The study was conducted at Department of Oncology, Aarhus University Hospital, Denmark. The development process was inspired by the Plan-Do-Study-Act (PDSA) cycle framework [12, 13], which is a systematic approach of series of steps to gain valuable learning and knowledge related to the continuous improvement of the CSME programme. The principles of PDSA promote the use of a small-scale, iterative approach to test an intervention. This enables rapid assessment and provides flexibility to adapt changes according to feedback to ensure fit-for-purpose solutions [14, 15]. Starting with small-scale tests provides users with freedom to act and learn with a minimal risk to patients and the organisation. By applying several rapid cycles in succession, substantial improvement can be achieved. Further, minimal resources are required, and the small-scale tests provide the opportunity to build evidence for change and engage more stakeholders as the confidence in the intervention increases [14, 15]. We identified all stakeholders in the process of developing and pre-testing the GE programme including interdisciplinary oncology healthcare providers, external healthcare education and pedagogical experts and patients. By involving all stakeholders in our project, we achieved valuable feedback, increased engagement in the project and subsequently increased the chances of implementation of the project in daily practice.

Cycle 1: The Format of the Planning Phase

In August 2014, the Department of Oncology decided to implement a CSME programme to empower patients with breast cancer at the end of primary treatment. The implementation of the CSME programme was led by a research nurse at Department of Oncology, who was also the primary developer and first author of this paper (Fig. 1).

In September 2014, the research nurse participated in the European Cancer Rehabilitation & Survivorship Symposium (ECRS) that brings together researchers and health professionals from all over Europe to increase knowledge and experiences on cancer rehabilitation and survivorship. This symposium was an inspiration in the planning phase of our study.

In October 2014, the development of the CSME programme was planned to include involvement of a team of interdisciplinary healthcare providers in the field of oncology, furthermore, to include involvement of external healthcare education and pedagogical experts within the field of person-centred methods in CSME programmes and involvement of patients to pre-test the CSME programme.

In November 2014, we recruited an interdisciplinary team, consisting of seven healthcare providers (three nurses, a physiotherapist, a dietician, a clinical oncologist and a psychologist), all members of the staff at the Department of Oncology with more than 10 years of experience in the field of oncology. The healthcare providers were recruited during a meeting for the oncology staff specialised in breast cancer. At this meeting, the new Danish Health Authority follow-up programme was presented with recommendations for the implementation of a new aftercare model to empower patients with breast cancer [5].

Cycle 2: Involvement of Oncology Healthcare Providers

The healthcare providers participated in three 2-h meetings between November 2014 and February 2015. The process during the meetings involved ideation, presentation and discussion of the content sessions of the CSME programme addressing the expressed needs of women with breast cancer identified in the literature [1, 4]. Results from a literature review were presented at the first meeting. The results presented were the most prevalent needs throughout the breast cancer trajectory: “The possible side effects of treatment”, “How to deal with side effects”, “Being informed about things you can do to get well”, “Being informed about the benefits of treatments”, “Being informed about remission”, “Uncertainty about the future” and “Fear of the cancer spreading or returning”. Based on the presented results from the literature review, the healthcare providers developed the goals and the content sessions of the CSME programme.

The goals of the CSME programme were (1) to empower patients by providing them with information and skills, (2) to increase the patients’ self-confidence and (3) to enable the patients to move on and ahead by providing self-management strategies, support and network.

The content of the CSME programme was planned to include 2 days with six sessions (Table 1).

Day one: (1) A clinical breast cancer oncologist gave a lecture about the rationale behind follow-up visits and signs and symptoms of recurrence of the cancer; (2) a physiotherapist and a nurse from the Department of Oncology programme “Body & Cancer” gave advice on how to keep the body in shape and how to deal with fatigue and (3) a nurse specialised in breast cancer care provided information about possible treatment-related side effects and late effects.

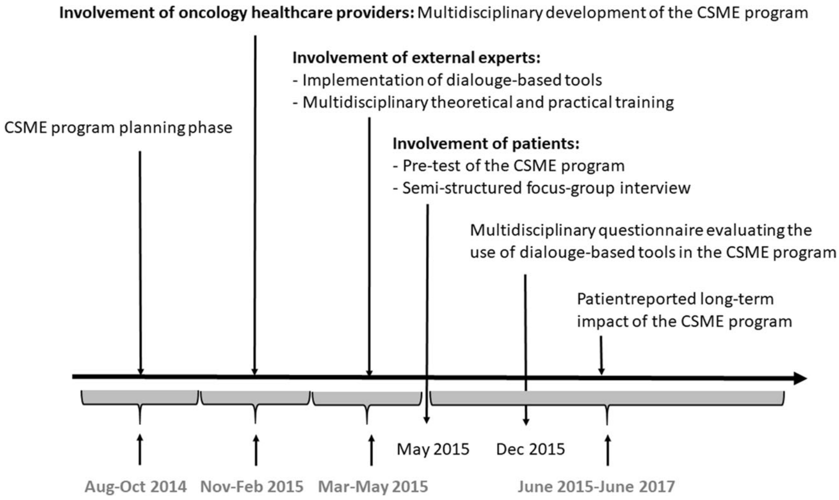

Fig. 1 The trajectory of a Cancer Self-management Education Programme

Day two: (4) A dietician gave a lecture on healthy diet and gave advice about changing the diet if necessary and how to lose or gain weight; (5) a specially trained nurse discussed womanhood and sexual issues and (6) a psychologist talked about stress management, problem-solving, coping and cognitive reframing to examine and deal with negative thoughts.

There was a break between each teaching session. The main purpose of these breaks was to share ‘cancer stories and experiences’, while eating light refreshments. The patients were encouraged to stay in contact after termination of the CSME programme.

Cycle 3. Involvement of External Expert Support

In March 2015, two external experts from the Patient Education Research Unit at Steno Diabetes Centre Copenhagen (SDCC) were involved to improve the educational skills of the oncology healthcare providers. The Patient Education Research Unit at SDCC set up a 1-day educational learning programme and held educational lectures specifically related to dialogue-based tools to be used by the healthcare providers to empower the women with breast cancer. The primary aim of the dialogue tools was to inspire and support the healthcare providers in tailoring patient education to meet the individual needs and challenges of women with breast cancer and to ensure that participants engage in dialogue with peers as well as with the healthcare providers [16]. The lectures included a theoretical presentation of the dialogue-based tools. The core principles of the dialogue-based tools are the following:

Participation Participants in patient education should discover and develop their own abilities to handle life after breast cancer treatment. Thus, all the tools strive towards creating participation and dialogue among patients. By using images, quotations, and statements, the patients are encouraged to articulate their thoughts, experiences and considerations and to share them with others.

Dialogue The tools are means to enable a person-centred, dialogue-based approach to education, but they cannot stand alone. They can be integrated in different education sessions and require oncology healthcare providers to hold the necessary professional and educational competences.

Flexibility The tools can be used in a flexible manner. The oncology healthcare providers can choose to use a single tool or combine tools for a new education programme. The tools should be adapted to fit the local context and not the other way around.

The dialogue-based tools build on two health education models: The Balancing Person, which describes how patients experience living with a chronic condition and the daily challenges involved and the Health Education Juggler, which describes the competencies necessary for educators to deliver dialogue-based and person-centred patient education [17].

The potential of tools to help create participatory patient education is contingent on conditions such as the ability of healthcare providers to facilitate participation and active involvement in group-based education. The Patient Education Research Unit (SDCC) planned a 1-day practical shoulder-to-shoulder skills training programme in April 2015. At this training programme, the healthcare providers were taught how to use the dialogue-based tools in practice by attending rehabilitation courses for patients with chronic conditions at a public health centre. Finally, the healthcare providers received a printed version of the content of the dialogue tools that explained the theoretical background of how and why to use the tools.

Table 1 The planned draft of the CSME programme

Day 1	Themes	Patient achieved goal	Content	Dialogue tools
15 min	Introduction	To present themselves in an alternative manner and to get to know the other participants	• Welcome • Agenda of the programme	Picture cards From a pile of cards illustrating different persons, each patient is invited to pick up the card that best represents who they are. Then all patients are encouraged to explain to each other why they have chosen this card and why they participate in the patient education programme
75 min	Follow-up visits and signs and symptoms of disease recurrence	To get rid of false rumours related to follow-up visits To identify and rectify misunderstandings related to follow-up visits To act properly to signs and symptoms of disease recurrence To achieve a realistic understanding of when and why to follow-up after breast cancer treatment	• DBCG recommendations for follow-up • The Danish Health Authority recommendations for follow-up • The rational for follow-up • Mammography (young age/old age) • Signs and symptoms of disease recurrence	Value quotations A number of statements and questions concerning the follow-up procedures is chosen to be considered alone and then in pairs and at last discussed in plenum Questions: - Which type of examinations are essential in follow-up visits? - Have you experienced signs and symptoms of disease recurrence? Which actions did you take? Statements: - “When having no signs and symptoms of disease recurrence, a CT scan is still essential in the follow-up procedure” - “When having no signs and symptoms of disease recurrence, recommendations for follow-up still involve a follow-up visit every third month”
15 min	Pause			
60 min	Physical activity and fatigue	To feel motivated to make physical training as a part of everyday life despite experiencing fatigue	• Definition of physical activity • The Danish Health Authority’s recommendations for physical activity • Recommendations for physical activity after breast cancer surgery (lymphedema) • Definition of fatigue • How to cope having fatigue • Physical activity and rehabilitation • Links	5-min physical activity in the teaching room The patients experience physical activity (and feel safe when doing it) in the presence of a healthcare professional, who also explains how the body reacts to physical activity A question concerning physical activity and fatigue is chosen to be considered alone and then in pairs and at last discussed in plenum. Question: Have you experienced fatigue during your treatment period? Which actions did you take?
15 min	Pause			
75 min	Treatment-related side effects and late effects	To act properly to treatment-related side effects and late effects To get rid of false rumours/myths related to side effects and late effects	• Definition of side-effects and late-effects • Different breast cancer treatments related to side effects and late effects • Most prevalent late effects: - arm or shoulder range of motion decreased - hot flushes - memory or concentration problems - osteoporosis - mouth or vaginal dryness - pain - weight changes - sleep disturbance	Challenge sentence A number of statements and questions concerning late-effects are chosen to be considered alone or in pairs to bring experience-based knowledge about side-effects and late-effects into teaching. Personal experiences provide new perspectives to the experiences being told, creating a confident and trustworthy situation related to treatment-related side-effects and late-effects E.g. statements of experiences concerning late-effects: - “Late-effects only occur within a few months after end of treatment”. - “You may not lose weight during hormone therapy”

Table 1 (continued)

Day 1	Themes	Patient achieved goal	Content	Dialogue tools
			• Links	E.g. questions of experiences concerning late-effects: - What kind of late-effects have you experienced? Which actions did you take?
15 min	Summing up day 1			
Day 2	Themes	Patient achieved goal	Content	Dialogue tools
15 min	Reflections from day 1	To express reflections from day 1	• Welcome • To ask about immediate situation • To summarise day 1 • To ask if the patients have thought of something from day 1	Picture cards Each patient chooses a dialogue card with pictures that represent their emotional feelings and they explain why they have chosen this card E.g. a picture card showing a calender – the participant explains that she has gained knowledge that late effects may occur up to months or years after end of treatment, making her more confident in being able to act properly to these late effects in the future
60 min	Healthy diets	To encourage to eat healthy as a part of their everyday life To get rid of false rumours/myths related to a healthy diet To achieve a realistic understanding of a healthy diet	• Definition of a healthy diet • "Six per day" • "Ten pieces of healthy diet advice" • Body weight • Healthy diet supplements • Healthy diet for patients with cancer • Links ("Body & cancer" etc.)	Patient quotations Patient quotes relating to a healthy diet to be discussed in plenum. E.g. quotes: - "You must abstain from alcohol after breast cancer" - "A dietary supplement of fish oil is better than eating fish"
15 min	Pause			
60 min	Womanhood and sexual issues	To feel safe to talk about womanhood and sexual issues with a partner To act properly to treatment-related effects on womanhood and sexual issues	• What is sexuality? • Definition of sexuality • Treatment-related effects on sexuality and womanhood • Advantage of intimacy and sex • Desire (spontaneous) • Vaginal dryness • Links	10-min movie of sexual issues related to cancer Narratives from experienced patients in the movie show how similar patients with cancer succeed in changing their sexual habits or solving a sexual problem To inspire the patients to tell their own stories related to womanhood and sexual issues, a question is chosen to be considered in pairs after seeing the movie: "What effect has your breast cancer diagnosis had on your sexuality and intimacy"?
15 min	Pause			
90 min	Psychological effects, coping and actions	To act properly to psychological effects To gain knowledge of psychological reactions after breast cancer	• Definition of crisis • Definition of grief • Definition of stress • Fear of cancer recurrence • Psychological acceptance • Psychological advice	Story-telling Story-telling about the Chinese vase that break and then is glued back together.
15 min	Summing up days 1 and 2			

Cycle 4. Implementation of Dialogue-Based Tools as an Educational Learning Instrument in the CSME Programme

The implementation of dialogue-based tools as an educational learning instrument in the CSME programme was derived from social cognition theory and self-efficacy [18, 19]. When using a social cognition theory perspective, the function of the individual is seen as a product of a dynamic interaction between personal behaviour and environmental factors [18, 19]. The core of the social cognition theory is the concept of self-efficacy, which is defined as" an individual's estimation of own competencies to organise and execute practices necessary for attaining designated types of performances" [18, 19]. The estimation of own competencies evolves from own experiences and mirrors experiences of others. Thus, according to this theory, self-management skills will be improved by increasing the self-esteem of the individual. The specific dialogue-based tools, to be used in the CSME programme were developed by the healthcare providers during two 2-hour meetings between April 2015 and May 2015. The research nurse conducted the meetings, and oncology healthcare providers responded to the following questions: "What is the purpose of the session?", "Which dialogue-based tools, methods and elements should the session include?", and "What is the most important message of the session?" related to the oncology healthcare providers' own session [20, 21]. The questions were used as inspiration for the development of the dialogue-based tools used in the sessions. For illustration, the oncology healthcare providers used dialogue-based tools to encourage the women with breast cancer to share experiences of how to manage their intrusive thoughts. Thus, the women could reflect upon the experiences of the other participants and pick up positive behavioural strategies, which they found applicable in their own situation, based on the success stories from other women. Another example of promoting self-management behaviour of the patients during each session included practising 'myth detection' and how to rethink myths through gathering evidence, challenging self-defeating thoughts through positive rephrasing based on what they learnt from observing other women with breast cancer (Table 1).

Cycle 5. The Involvement of Patients to Pre-Test the CSME Programme

In May 2015, five women treated for primary breast cancer finishing their primary treatment were invited to participate in a pre-test of the CSME programme. After the pre-test, a semi-structured focus group interview was conducted to evaluate the CSME programme and included the following questions to each of the six sessions: (1) To which extent were your expectations to the content of the session fulfilled?, (2) How do you evaluate the applicability of the session?, (3) How do you evaluate the usability of dialogue-based tools in the session?, and (4) Did you miss any information in the session?

The interview lasted 2 h and was audio-recorded and conducted by a psychologist at Department of Oncology. From the analysis, three categories were formed: *Information and related actions* (The women stated that they preferred detailed information during each of the teaching sessions); *Setting and methods of delivering information* (Generally, the need for being involved and sharing experiences during each educational session was seen as important by the responders) and *Patient adherence to programme* (the end of breast cancer treatment was identified as the optimal time to participate in a CSME programme). The analysis led to the following important adjustments to the CSME programme: (1) The didactic approach was extended to include written material as a supplement to each session (presentation slides from each session were printed as handouts to all women at the beginning of the session), (2) Each session was prolonged by nearly 15 min and (3) To be aware of the value of using combinations of dialogue-based tools to articulate difficult issues and to improve self-management capabilities.

Cycle 6. Oncology Healthcare Providers Test the Dialogue-Based Tools in the CSME Programme

In December 2015, all of the seven healthcare providers filled out a questionnaire after completing three CSME programme sessions at the Department of Oncology. The aim was to explore healthcare providers' experiences of implementing the dialogue tools in practice and explore whether the tools assisted healthcare providers in generating participatory patient education. The results were presented and discussed at a 2-h meeting. All of the healthcare providers described how the tool helped participants to open up and discuss fears and worries related to their condition. Furthermore, the healthcare providers expressed that they felt the tools were generally usable and feasible and ensured a patient-centred approach.

None of the healthcare providers expressed a need for more training to become confident in using the tools for the CSME programme sessions. Thus, the tools helped educators facilitate participatory patient education, and healthcare providers felt that the tools matched participants' needs and preferences. No changes were made after testing the dialogue-based tools.

Cycle 7. The Long-Term Impact of the CSME Programme on Patient-Reported Outcomes

A study was designed as a longitudinal observation follow-up study, testing the long-term impact of the CSME programme. A total of five CSME programmes were completed between June 2015 and June 2016 involving 93 patients with breast cancer. Inclusion criteria were women above 18 years of age, diagnosed and treated for primary breast cancer with curative intent who had received chemotherapy. Of the invited women, 69% (93 patients) consented to participate in the CSME programme. Questionnaires were administered at baseline before attending the CSME programme (93 participants), at 3 months (93 participants), 6 months (68 participants) and at 12 months (51 participants) after attending the GE-programme. The questionnaires included socio-demographic characteristics, the Health Education Impact Questionnaire (heiQ) and the Cancer-related Self-efficacy Questionnaire (CBI-B). The collection of follow-up data ended in June 2017 and patient-reported outcome will be presented in a separate study. Statistically significant improvements from baseline to 12 months were found for the heiQ subscales: “Self-monitoring and insight” and “skill and technique acquisition”. Furthermore, CBI-B was statistically significantly improved from baseline to 12 months.

Discussion

Using the PDSA cycle approach made it possible to develop and pre-test our intervention, the CSME programme, in a short period of time and assess its suitability and efficacy in a structured and well-defined way [12–15]. The CSME programme was conducted as planned and the healthcare providers felt confident in using the dialogue-based tools. The programme was meaningful to the women with breast cancer as 68% of the women with breast cancer consented to participate; all of the women completed the CSME programme at the end of primary treatment.

In accordance with our findings, other studies have demonstrated that the use of dialogue-based tools such as pictures and game elements in patient education is a promising method to support healthcare providers in facilitating person-centredness and active involvement of patients [16, 22, 23].

This study clarifies how education of the healthcare providers is crucial to the successful use of dialogue tools in patient education. Although education and time can be barriers to implementation, introduction seminars can be provided to healthcare providers who want to implement the tools in clinical practice. Even though the healthcare providers play an important role in the successful implementation of changes in patient education, there is often very limited focus on upgrading the skills of healthcare providers.

The process of patient involvement to pre-test the CSME programme is supported by the national political agenda in Denmark and a new national cancer plan launched by the government and the Ministry of Health, with a strong focus on patient involvement to ensure patient-centred cancer care [24].

The increased political focus on patient involvement in health care is due to a relatively new acknowledgement among decision-makers that patients want to participate in decisions about their own care; this is also documented by recent national surveys [25]. In our study, we involve patients already in the pre-test phase, as our intervention is built on well-established theories and experiences among oncology healthcare providers from previous patient education programmes. However, in a time where more and more patients request to be more involved in their own treatment and aftercare, the potential for also involving these patients in planning both the research and education programme should be used in future research within the field of patient education. The patient perspective would contribute to knowledge from previous research.

Conclusion

The PDSA approach to develop a CSME programme resulted in a person-centred education programme with the potential to improve self-management and self-efficacy in the aftercare of cancer survivors.

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