Step by Step

Understanding and promoting physical activity in breast cancer survivors

Caroline Charlier

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PROEFSCHRIFT

ter verkrijging van de graad van doctor
aan de Open Universiteit
op gezag van de rector magnificus
prof. mr. A. Oskamp ten overstaan van een door het
College voor promoties
ingestelde commissie in het openbaar te verdedigen

op vrijdag 18 januari 2013 te Heerlen
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door
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CONTENTS

1

General introduction

1. Breast cancer burden:
trends, incidence and survival

Breast cancer is the most common cancer among women in most developed countries. In Belgium, there is a one in ten probability of women developing breast cancer in their lifetime (before the age of 75). In 2009, the crude incidence rate[1] of breast cancer among Belgian women was up to 175 new cases per 100 000 person years. Incidence increases slowly from the age of 20 years, and then sharply rises between 40 and 60 years, followed by a slight decrease (Figure 1.1) (Belgian Cancer Registry, 2012).

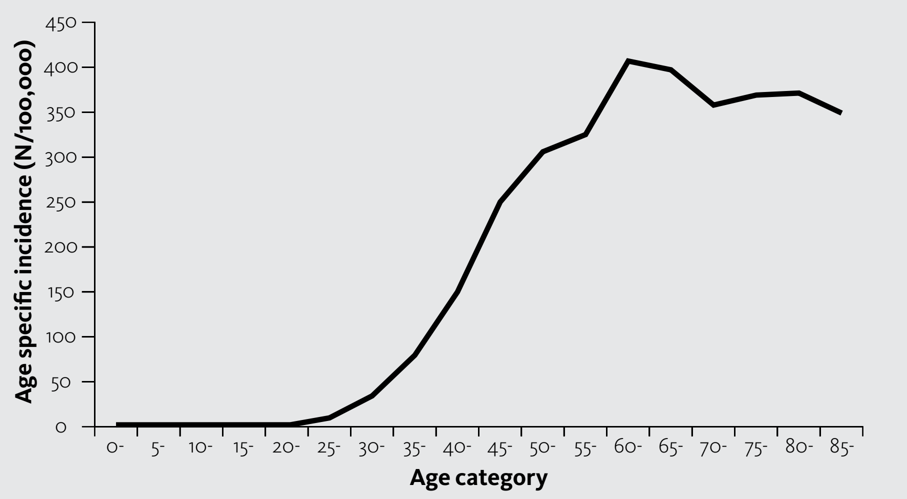

Figure 1.1. Age-specific incidence rates for Belgium in 2009 (Belgian Cancer Registry, 2012)

During the past five years a significant decreasing trend in mortality has been seen in Belgium (especially in the Flemish region). The decrease is most apparent in women younger than 50 (Autier et al, 2010). These reductions in mortality reflect better targeting of effective treatments and response to treatment and have led to an increase in middle-aged breast cancer survivors. Many of these women are presumed to be working and have responsibilities as mothers, caregivers of ageing parents and spouses, though a number of them are still experiencing cancer-related physical and psychological complaints. Consequently, there is a growing group of breast cancer survivors with distinct public health needs (Hewitt et al, 2006). Raising awareness of cancer survivorship should lead to follow-up care plans that include cancer-related as well as public health care. Before strategies for optimal follow-up care are identified, the challenges of survivorship are described in the next section.

[1] Crude rates (CR) are calculated by dividing the number of new cases in a given year by the total female population for the year and expressed per 100, 000 person-years.

2. Health and quality of life among breast cancer survivors

2.1. The transition from patient to survivor

Survivorship after breast cancer has no clear and uniform definition. According to the National Coalition of Cancer Survivorship (NCCS), the term 'survivorship' denotes the period after the diagnosis of breast cancer untill the end of life (Ganz, 2009). Others believe that survivorship starts when the primary treatment for breast cancer is completed (Feuerstein, 2007). One's preference for one or the other definition depends on the user perspective and the questions to be answered. In this thesis, a survivor is someone who has successfully completed primary treatment (radiation, chemotherapy or surgery) for breast cancer. Women who were receiving hormone or immune therapy during follow-up are also considered as breast cancer survivors, as these therapies may be given to patients for years.

In this definition, survivorship starts when the initial treatment ends. To respect the various characteristics of this period the 'early' survival can be distinguished from 'long-term survivorship' (Aziz, 2002). Long-term survivorship is roughly equated with 'cure' (Mullan, 1985). The effects of the cancer experience are thought to be perceived more indirectly and women are assumed to resume their daily routine. This is contrary to the 'early survival', where the physical and psychological side-effects of cancer and its treatment are often more visible. The focus in this period lies on 'recovery' and women are engaged in a process of moving from being a patient to being a survivor (Hewitt et al, 2006). The timeframe of this period is somewhat arbitrary, but three to six months post-treatment is a reasonable assumption (Courneya et al, 2001). Few studies on survivorship use a defined time interval, however, and consequently fail in describing the acute nature of this period. Describing this period as a distinctive phase in the cancer trajectory is essential in cancer care planning and the term 'transition period' will be used in this thesis to describe this recovery period (Spence et al, 2010).

As the challenges during this recovery period (see below) may differ between younger and older breast cancer survivors, both groups may be distinguished when discussing recovery and re-integration issues (Wochna Loerzel and Aroian, 2011). Indeed, younger women often face extra concerns about children, premature menopause and work-related issues (Stava et al, 2006; Manuel et al, 2007). Older women often experience age-related symptoms in addition to the current cancer-related side effects. Moreover, non-cancer-related concerns often overshadow concerns from having had breast cancer (Wochna Loerzel and Aroian, 2011). As differentiating between processes of recovery after cancer and processes of aging is beyond the scope of this thesis, the following discussion and studies will not concern women of retired age (65+).

2.1.1. Specific nature of the transition period

The end of active treatment for breast cancer is often associated with increased distress (Lethborg et al, 2000; Deshields et al, 2005; Costanzo et al, 2007) as a result of the prevalence of physical complaints, affected psychological functioning and social isolation.

Physical distress

It is nowadays recognised that women who have completed primary treatment for breast cancer suffer from a variety of cancer- and treatment-related physical side-effects. Fatigue is a frequently reported symptom after cancer and is experienced by one out of three breast cancer survivors (Servaes et al, 2002). The National Comprehensive Cancer Network defines cancer-related fatigue as “a distressing, persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning” (NCCN, 2005). Furthermore, women after breast cancer can report post-treatment impairments in upper limb and upper body structure resulting in impaired physical functioning. The incidence of lymphoedema varies from 6% to 30% after breast cancer treatment and impaired shoulder movements, pain and numbness are often reported by breast cancer survivors. However, incidence rates show considerable variability among survivors (Kärki et al, 2005; Hayes et al, 2008; Smoot et al, 2010). Breast cancer survivors are also at increased risk of premature menopause and more than half of all women taking tamoxifen[2] suffer from hormone-related symptoms (hot flushes, sweats, palpitations and urinary incontinence) (Avis et al, 2005). Weight gain is often reported as a consequence of the onset of menopause or the adjuvant chemotherapy received (Pinto and Trunzo, 2004; Trédan et al, 2010).

The net result is that women have to deal with concerns about suffering from long-lasting symptoms and impaired physical functioning. An increased sense of vulnerability arises, as women are at the same time expected to return to everyday life, resuming family roles and occupational activities, and are often pressured by the expectations of friends and family to return to normal (Knobf, 2007).

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[2] Tamoxifen (Soltamox) blocks the actions of estrogen and is used to treat and prevent some types of breast cancer

Psychological distress

Besides physical complaints, psychological functioning can also be affected by the cancer experience because of decreased self-esteem, body image problems, anxiety and depression (Knobf, 2007). Treatment-related physical consequences may devalue a woman's view of herself (Bertero and Chamberlain, 2007) and approximately half of the women diagnosed with breast cancer report body image problems during the first year of survivorship (Pinto and Trunzo, 2004; Fobair et al, 2006; Helms et al, 2008). Anxiety often increases at the end of therapy and feelings of anxiety can occur in 45% to 80% of women in the first months following therapy (Knobf, 2000; Bender et al, 2001; Knobf et al, 2007). Women often perceive the end of treatment as 'losing a safety net' because regular appointments with medical staff decrease and the active treatment plan disappears (Allen et al, 2009). In addition, fear of a recurrence and concerns about long-term health may arise which can influence future perspectives and overall well-being (Vickberg, 2003; Lebel et al, 2009). Most recurrences are detected within five years of diagnosis, with a peak rate of recurrence during the second year following diagnosis (Burstein and Winer, 2005; Emens and Davidson, 2003). Moreover, lower survival rates in breast cancer survivors are also owed to the onset of secondary diseases (cardiovascular risk, diabetes, obesity, osteoporosis) and secondary tumours (Emens and Davidson, 2003).

Although a higher distress level is noted in the majority of breast cancer survivors at some points in their cancer trajectory (Knobf, 2000), lower percentages of women are found to be clinically depressed (10%-30%) (Deshields et al, 2005) and only a minority of breast cancer survivors develops a post-traumatic stress disorder (Vachon, 2006). In assessing factors that contribute to effective coping with cancer it is important to understand the development of chronic elevated stress conditions and clinical levels of distress (Merckaert et al, 2010).

Altered social environment

It was stated by Jensen and colleagues (1994) that any disruption in self also causes a disruption in relationships. Indeed, some women after breast cancer tend to isolate themselves owing to their loss of control of physical functioning (Bertero and Chamberlain, 2007)(for example, after breast surgery or due to hair loss). Also, lifestyle changes like discontinued employment could further reinforce the feelings of isolation. However, sources of support can appear during treatment and women can profit from a 'safety net' created by medical staff, other cancer patients and significant others. After treatment, those contacts decrease and the woman's role as a cancer patient slowly disappears. Women struggle with resuming family, work and social responsibilities. Sometimes the social environment expects women to be strong because treatment, and so the cancer, is over and some feelings of pressure from their environment can be felt. This can result in feelings of desolation, loneliness and vulnerability (Avis et al, 2005; Allen et al, 2009).

Benefit-finding, personal growth and teachable moment

Although the cancer experience is seen as a distressing and disrupting event, there is an increased awareness in both research and clinical settings on some perceived benefits of experiencing a life-threatening event. People who experience cancer are often engaged in a process of benefit-finding, also described as 'personal or post-traumatic growth'. Increasingly, researchers are assessing how positive emotions and beliefs foster patterns of information-seeking, coping, and social behaviour that may have lasting benefits for mental and physical health (Aspinwall and McNamara, 2005). Within prevention and health promotion among cancer patients, this personal growth is often seen as a 'teachable moment' (Demark-Whanefried et al, 2005).

2.1.2. Post-treatment adjustment

Despite the presence of a certain distress level, the majority of women adjust well to the post-treatment situation. However, previous studies showed marked individual variation in distress suggesting different patterns of adjustment among breast cancer survivors (Millar et al, 2005). It is recognized that the psychological responses to an illness-related condition are also influenced by the personal perception of the illness (Park et al, 2008), the perceived social support and the coping strategies employed (Knobf, 2007). These concepts will be briefly described below.

Consistent with Leventhal's common-sense model, representations of illness can be characterized along five dimensions. (1) The *identity* of an illness which represents concrete signs and symptoms indicating the presence (or absence) of the illness. (2) The perceived *consequence*s identified as the perceived effects of illness (emotional, physical, social or economic). (3) The perceived *cause*, which can be biological, emotional, psychological, environmental or behaviour-related. (4) The *timeline* which considers the perceived timeframe for the development and duration and (5) the *curability and controllability* which assess the extent to which individuals perceive they or others can control, treat or limit the progression of their illness. These mental representations provide a framework for coping with illness and understanding it. Breast cancer survivors believe they have moderate control over their cancer, they perceive their cancer to have moderate to severe consequences for their lives, and they see their cancer rather more as an acute than a chronic condition (Costanzo et al, 2010). Furthermore, perception of less severe consequences and higher controllability beliefs are associated with better quality of life and lower distress levels (Hagger and Orbell, 2003; Millar et al, 2005; Rozema et al, 2009).

Also, social support is thought to be important to the recovery of cancer survivors (Kroenke et al, 2006). Social support assists women with psychological and social adaption to the disease and its treatment, buffers the stressors they face and improves their quality of life. Social support can be divided into instrumental, informational and emotional support (van Sonderen, 1993). Instrumental support refers to perceived practical assistance. Expectations and constructive feedback are defined by informational support and showing that someone is loved, esteemed, valued and cared for is considered as emotional support. An approach that combines emotional and informational support is assumed to be most effective (Bloom et al, 2008) for adjustment after cancer. In the months following treatment completion social support begins to wane, however, because 'the cancer' becomes less visible and prominent for family and friends. Social networks may change because of the cancer experience and a lack of social support is often seen in single women or those who do not have close relatives or children (Kroenke et al, 2006).

Most studies of cancer survivors link the coping strategy with adjustment to cancer (Holland and Holahan, 2003). According to Endler and colleagues (2004) coping can be assessed across three dimensions: problem-oriented coping (dealing with the problem at hand), emotion-oriented coping (concentrating on the resultant emotions) and avoidance coping (trying to avoid the problem). Most patients use several coping strategies which may vary over time (Hervatin et al, 2011). Their effect on the experienced distress and quality of life depends upon the stage of disease and treatment process (Holland and Holahan, 2003). It is suggested that women who are actively involved during diagnosis and treatment, as well as in their recovery, have a more positive quality of life through task-oriented coping (problem-solving and restructuring their lifestyles) (Royak-Schaler, 1991). However, also avoidance and denial may lessen the psychological sequelae of the diagnosis and treatment for breast cancer (Carver et al, 1993).

Adjustment to the post-cancer situation defined by higher levels of psychological well-being and positive health behaviours is not only explained by the independent influences of illness perceptions, social support and coping. Previous research supports the interactive relations between each (Holland and Holahan, 2003; Knobf, 2007; Park et al, 2008). Therefore the interplay between those variables must be taken into account in the prediction of adjustment after cancer.

2.1.3. Challenges of the transition period

Considering the specific nature of the transition period, women are faced with a range of challenges in the first months following treatment completion for breast cancer. First they need *to recover* from physical and psychological side-effects from the cancer and its treatment. Second, they are supposed *to re-integrate to normal life, resume family roles and return to work*. Last, women should adopt a healthy lifestyle *to prevent secondary diseases, long-lasting symptoms and cancer recurrence*.

The report 'From Cancer Patient to Cancer Survivor: Lost in Transition', states that "The transition from active treatment to post-treatment care is critical to long-term health. If care is not planned and coordinated, cancer survivors are left without knowledge of their heightened risks and a follow-up plan of action"(Hewitt et al, 2006). It further states that the adoption of a healthy lifestyle, in which physical activity plays an important role, can contribute to this follow-up plan as it partially meets the above mentioned challenges. The important benefits of incorporating physical activity in the recovery and rehabilitation of cancer survivors are also confirmed by others (Spence et al, 2010; Courneya and Friendenreich, 2011).

2.2. Definitions and benefits of physical activity

The terms 'physical activity and exercise' and 'physical fitness and health-related physical fitness' need to be explained, as they are regularly used terms in health promotion and rehabilitation.

Physical activity is defined as "any bodily movement produced by the contraction of skeletal muscles to increase energy expenditure above the basal level, including physical activity during leisure time, occupation, transport, household chores, gardening and self-care" (Caspersen et al, 1985). *Exercise* is a form of leisure-time physical activity that is "planned, structured, repetitive and purposive in a sense that improvement in one or more components of physical fitness is the objective (fitness, performance or health)" (Caspersen et al, 1985). Both physical activity and exercise can influence *physical fitness* which is defined as a set of attributes that individuals have or achieve (Caspersen et al, 1985). Physical fitness can be health-related (relevant for all people) or skill-related (more relevant for athletic ability). *Health-related fitness* refers to the components of physical fitness that are directly related to the health of an individual and typically includes cardiorespiratory fitness, musculoskeletal fitness (endurance, strength, flexibility and balance) and body composition. As physical activity will be included in rehabilitation after cancer, physical activity in this thesis refers to *health-related physical activity* which is the minimum recommended dose of activity needed to guarantee physiological health effects (Laitakari et al, 1996) and includes lifestyle activities as well as exercise. Studies have shown that regular physical activity is beneficial in relieving cancer-related symptoms and improving quality of life in breast cancer survivors (Schmitz et al, 2011). Moreover, adherence to regular physical activity may also be beneficial in increasing overall survival (Irwin al, 2009). The relevant evidence and the mechanisms through which physical activity can support women's transition from patient to survivor are briefly explained in this section.

2.2.1. Physical activity may support physical and psychological recovery after breast cancer

Regular physical activity is an effective way of reducing side-effects owing to inactivity and the disease itself and its treatment (Knols et al, 2005). In most studies, the post-treatment benefits of exercise and physical activity relate to improved cardiorespiratory fitness, muscle strength, haemoglobin concentration, body image, mental health and quality of life and decreased fatigue, depression and anxiety levels (Swartz, 2004; Irwin et al, 2008; Craft et al, 2012). Evidence of these benefits is still not proven on the meta-analytical level, because of the limited availability of studies, different study procedures, lack of standardization of physical activity intensity and a variety of examined outcome variables; for example, not including survivors in a needs-based approach, reporting on short-term interventions and including cancer patients as well as cancer survivors may lead to lower effect sizes of physical activity interventions. This may further underestimate the important role of physical activity in recovery after cancer (Schmitz et al, 2005; McNeely et al, 2006; Speck et al, 2010).

In general, physical activity is likely to be beneficial and feasible for most breast cancer survivors and plays an increasing role in follow-up care in breast cancer survivors (Doyle et al, 2006; Hayes et al, 2009; Schmitz et al, 2011). Questions regarding the type and intensity of physical activity remain unanswered.

2.2.2. Physical activity facilitates reintegration after breast cancer

The duration of the early survival period is highly variable but continues until any major loss of function is recovered and participation in former activities and relationships is resumed. It could also be defined as reintegration, which not only implies returning to the workplace (professional reintegration), but also refers to the return to previous social life. This goal is often explained by breast cancer patients as 'return to normal' (Larsson et al, 2008).

Physical activity can facilitate professional and social reintegration through its contribution to the recovery of physical and psychological functioning. Benefits of physical activity such as enhanced quality of life, better self-esteem and good personal control make women more self-confident (Thune, 2011; Larsson et al, 2008; Speck et al, 2010). Encouraging women to be physically active can increase their participation in community activities as well as in household and daily life activities which further support reintegration.

2.2.3. Physical activity may increase survival

Although it is clear that physical activity is associated with many benefits for the cancer survivor, the impact of physical activity on survival remains to be determined. Some studies suggest that breast cancer survivors who report being physically active are at lower risk of disease-related mortality (Holmes et al, 2005; Holick et al, 2008), with the greatest benefit found among women who walk three to five hours per week. Also, a recent meta-analysis supports the notion that post-diagnosis physical activity could reduce breast cancer death by 34%, all-causes mortality by 41% and disease recurrence by 24% (Ibrahim and Al-Homaidh, 2010). These findings are confirmed by Holick and colleagues (2008). In contrast, the World Health Organization concludes in its report on ‘Food, Nutrition, Physical Activity and the Prevention of Cancer’ that there is still a lack of high-quality studies that confirm the beneficial effect of physical activity on breast cancer recurrence or mortality (WCRF, 2007).

Alongside its possible role in the prevention of a cancer recurrence, a healthy lifestyle, including physical activity can decrease the development of co-morbid conditions like cardiovascular disease, diabetes, obesity and osteoporosis (Kruk, 2007; Doyle et al, 2006). Moderate physical activity during and after treatment may also help survivors to maintain lean muscle mass while avoiding excess body fat (Herman et al, 2005; Schmitz et al, 2005; Irwin, 2009). Figure 1.2 summarizes the benefits of physical activity for both, recovery and prevention after breast cancer.

Considering the benefits of physical activity, promoting physical activity among breast cancer survivors seems to be important. To provide a rationale for developing interventions to promote physical activity for this population, it will be appropriate to first clarify the supportive care needs for physical activity among breast cancer survivors.

- maintained and improved fitness
- better balance and reduced risk of falls and broken bones
- reduced risk of heart disease
- prevents osteoporosis
- improves blood flow and prevents blood clots
- reduced fatigue
- reduced anxiety and depression
- reduced nausea
- better quality of life
- improves ability to manage on one's own and reduces dependence on others
- improves self-esteem
- increased ability to maintain social networks
- better ability to maintain stable weight
- encourages a healthy and varied diet
- possible improved survival

Figure 1.2. Possible benefits of regular physical activity (Thune et al, 2010)

2.3. Supportive care needs for physical activity

The existing literature on supportive care needs in cancer survivors does not provide a conceptual definition of 'need'. In general, a need is something that is necessary for organisms to live a healthy life. Further specifications of this definition depend on one's view of need. Objectively, need exists when there is a difference between a person's actual state and the optimal level of health or functioning (Vivar and McQueen, 2005). Consequently, need is influenced by current standards and culture. Subjectively, however, need is a desire for an action expressed by the individual herself which is also influenced by psychosocial perception. Such need is more intrinsic as it derives from the person. Within the context of self-regulation of a behaviour, a need expressed by the person can motivate participation in the behaviour (Milne et al, 2008).

Both definitions are applicable to physical activity. In this thesis we use the term supportive care needs for physical activity to refer to the need for physical activity promotion, counselling and support. As physical activity contributes to health care, as well as to health promotion, both objective and subjective supportive care needs for physical activity are considered in this section.

2.3.1. Objective supportive care need

Determining one's physical activity level can be seen as a more 'objective' parameter of the actual need for physical activity promotion. If the physical activity level is below current standards or recommendations, a need for physical activity promotion is assumed.

According to the World Cancer Research Fund's guidelines for cancer prevention, cancer survivors must follow the recommendations for cancer prevention, which include being 'moderately physically active for at least 30 minutes every day' (WCRF, 2007). According to the American College of Sport Medicine, survivors must follow the Physical Activity Guideline for Americans, which includes 'being moderate physically active for at least 30 minutes of a minimum five days a week' (Schmitz et al, 2011). Both guidelines, however, recommend survivors to limit sedentary behaviours.

The lack of uniformity in measuring physical activity inhibits a clear view on the natural progression of physical activity after breast cancer diagnosis. Longitudinal studies offer modest evidence for a decrease of physical activity levels during treatment, followed by an increase post-treatment (Andrykowski et al, 2007; Littman et al, 2010). Variation in physical activity levels based on time was rather small, but differences between individuals were substantial, ranging from the completely sedentary to the highly active (Pinto et al, 2002; Harrison et al, 2009; Devoogt et al, 2010). Cross-sectional data also confirm that only 20% to 58% of breast cancer survivors met physical activity recommendations (Emery et al, 2009). One study reporting on accelerometer-based data revealed that breast cancer survivors spent the major proportion of their waking time in light intensity activities (33%) or in sedentary time (66%) (Lynch, 2010). More accelero- and pedometer-based data are required to validate these findings.

The results do suggest, however, that an important proportion of breast cancer survivors may profit from physical activity promotion. Women who did not reach recommended levels (objective supportive care need) tended to be older and overweight and perceived less social support (Pinto et al, 2002; Irwin et al, 2004; Emery et al, 2009).

2.3.2. Subjective supportive care need

Women express a need for information and support regarding persistent treatment effects, emotional distress and lifestyle changes during the first year post-treatment (Thewis et al, 2004; Capiello et al, 2007). Larsson and colleagues (2008) clarify the desire or need for information and guidance about exercise and physical activity expressed by breast cancer survivors as follows: "The experience of physical activity is described as a necessity to have a high compliance to instructions as it is a conceived prerequisite of getting back to normal life" (Larsson et al, 2008). Moreover, a great interest in exercise counselling was found among survivors (76% - 84%) (Jones and Courneya, 2002; Gjerset et al, 2010).

Seemingly there is a need (objective and subjective) for physical activity promotion among breast cancer survivors to facilitate their adherence to recommended levels of physical activity but questions of who experiences the greatest need and how it should be met remain unanswered.

3. **Planning physical activity promotion** in cancer survivors

Health promotion and health promotion interventions, including the promotion of a physically active lifestyle, usually take place at population level (primary prevention). A frequently recommended and popular model for guiding the development of such interventions is the Model for Planned Health Promotion of Population Health (McKenzie and Smeltzer, 2001; Brug et al, 2012) (Figure 1.3). According to this model, the first two steps in health promotion planning are the identification of health problems and quality of life and potential risk behaviours. The determinants of these risk behaviours must be identified (step 3) and translated into intervention goals, change strategies and methods resulting in an intervention (step 4) that can be implemented and disseminated (step 5). Successful examples of prevention programmes in cancer screening and counselling for health behavioural change illustrate the utility of the model for prevention and its usability across different types of healthcare organizations (Glasgow, 2002).

Figure 1.3. The Model of Planned Promotion of Population Health (Brug J, 2012)

Some researchers advocate the use of these prevention models in the management of chronic diseases and follow-up care for cancer survivors (Glasgow, 2002; Tramm et al, 2011). When this model is applied to cancer survivors, illness and care-related perspectives not embedded in the model might need to be considered to ensure that the data are analysed in a contextually relevant way. The earlier part of this introduction ‘Health and quality of life among breast cancer survivors’ provides a good account of the first two steps of the prevention model. It highlights the current health problems among breast cancer survivors and identifies the benefits of physical activity and potential risk of inactivity in breast cancer survivors.

The following section will explore the next three steps of the model by reviewing the working mechanisms in public health interventions and the state of the art in breast cancer survivors.

3.1. Determinants of physical activity

3.1.1. Proximal (theory-based) determinants of physical activity

Several social cognitive models and theoretical frameworks have been developed to identify sets of factors allowing for the optimal explanation and prediction of health behaviour. Most traditional social cognitive models of behavioural change, such as the Theory of Planned Behaviour (Ajzen, 1991) focus on psychosocial factors. They generally assume that intention is the most proximal and powerful predictor of behaviour. Intention, in turn, is influenced by a person’s attitude towards physical activity, the perception of social opinion (subjective norm) and the person’s belief that they have control over their participation in physical activity, even when facing certain barriers (perceived behaviour control). Bandura’s Social Cognitive Theory (Bandura, 1998) also states that a person’s confidence in their ability to adopt physical activity (self-efficacy) and the belief that being physically active will produce a specific outcome (outcome expectations) determines their participation in physical activity. Furthermore, this model highlights the interactions between personal factors, attributes of the behaviour and the environment.

Both models have also proved to be effective in explaining physical activity among cancer survivors (Courneya et al, 2002; Courneya et al, 2006; Andrykowski et al, 2006; Rogers et al, 2006), with no preference on a leading model (Wood et al, 2008). As determinants of these models overlap to a certain extent, further discussion will focus on the essential factors common to these models, namely attitudes (perceived benefits and barriers), social influences and self-efficacy, rather than concentrating on just one theoretical model (Blanchard et al, 2002; Andrykowski et al, 2007; Rogers et al, 2008).

Attitudes are thought to be the common-sense representations that individuals hold in relation to an active lifestyle (Eagly and Chaiken 1993) and can be determined by a total set of behavioural beliefs (perceived benefits and barriers). Within those beliefs the cognitive ones can be distinguished from the more emotional ones and they each contribute respectively to instrumental and affective attitudes. For affective attitude the perceived benefit or barrier (e.g. enjoyment) relates to the individual's own self. Instrumental attitude is guided by beliefs relying on women's outcome expectations of being physically active. Social influence addresses the perception of significant others that one is physically active (subjective norm), the extent to which significant others are participating in physical activity (modelling) and the perceived support. Self-efficacy, finally, is defined as a patient's own belief in his or her ability to be sufficiently physically active and their confidence in their ability to overcome barriers to physical activity participation.

There is some evidence that health condition does not change the population-based determinants of physical activity (Rhodes and Blanchard, 2007). A socially supportive environment, self-efficacy and enjoyment positively influence physical activity in the general population and among cancer survivors (De Bourdeaudhuij and Sallis, 2002; Rhodes and Blanchard, 2007; Rogers et al, 2008) whereas for both populations, lack of interest, followed by lack of time, are important barriers (Rhodes and Blanchard, 2007). However, the role of determinants regarding health and fatigue may differ between the general population and cancer survivors and the need for future studies to assess more disease-specific health-related determinants is argued.

Owing to the specific characteristics of the transition period it can be supposed that physical activity beliefs and barriers are influenced by current physical and psychological complaints and the substantial risk of a breast cancer recurrence. Yet few studies report on those cancer-related beliefs. Courneya and colleagues note that most cancer survivors believe that physical activity could improve their energy level and overall well-being, followed by the belief that physical activity can help them get their mind of cancer and feeling more like they had a normal lifestyle. The belief that physical activity can reduce cancer recurrence risk is supported by a minority of survivors (Courneya et al, 2006). It is also noted that cancer survivors give more attention to exercise programmes that are approved by their physician and there is growing evidence that oncologists play an important role in enhancing exercise levels among cancer patients (Jones et al, 2004; Courneya et al, 2006; Blaney et al, 2011; Karvinen et al, 2011). Insight into these cancer-related correlates is often limited to descriptive analyses which preclude further conclusions on their possible role in explaining physical activity. Moreover, no studies are available that look for concurrent influences of both general and cancer-related beliefs in explaining post-treatment levels of physical activity. Consequently, no consistent evidence exists for distinguishing health promotion interventions across the cancer continuum (from primary prevention to rehabilitation).

Besides the possible 'underestimated' role of cancer-related determinants, researchers also underscore the importance of illness-related factors, personality and self-regulation processes in explaining physical activity after breast cancer. Identifying factors associated with physical activity in cancer survivors, whether or not related to previous models will result in a broader understanding of physical activity in cancer survivors. This should allow for interventions tailored to significant factors related to the specific nature of the transition period.

3.1.2. Distal determinants of physical activity

In cancer survivors, not only may immediate physical activity-related determinants (proximal factors) be important in explaining physical activity behaviour but also more distal factors which might be partly related to the past illness condition. Typical examples of these more distal factors are socio-economic status, age and personality. For breast cancer survivors we suspect that illness-related factors will also influence women's physical activity level.

Perceived distress, social support, illness perceptions, coping and behaviour

As noted earlier, breast cancer survivors can suffer from a certain amount of physical and psychological distress. There is evidence that distress influences health behaviour and health behavioural change among cancer survivors (Park and Allison, 2007). For example, fatigue and arm morbidities can contribute to poorer physical functioning and less physical activity (Kärki et al, 2005; Bower et al, 2006; Perkins et al, 2009; Lee et al, 2011). General psychological distress (e.g. depression, lower self-esteem and body image problems) may also impede engagement in a physically active lifestyle (Pinto and Trunzo 2004; Bertero and Chamberlain, 2007; Hong et al, 2007; Emery et al, 2009). Cancer-related psychological distress in terms of anxiety about the fear of recurrence might, however, motivate survivors to engage in health behaviours such as physical activity (Mullens et al, 2004), although no consistent evidence exists at present (Reardon and Aydin, 1993; Chambers et al, 2009).

Park and colleagues (2008) suggest that the role of distress in explaining behaviour must be seen in combination with perceived control and social support and through the use of coping strategies (stress-coping model). The few studies reporting on coping and physical activity in cancer survivors suggest a positive influence of active coping in the adoption of an active lifestyle (Reardon and Aydin, 1993; Park et al, 2008). Perceived control (cause and controllability beliefs) is subsequently thought to guide behaviours to prevent recurrence among breast cancer survivors, but this association relates more to changes in dietary habits and less to physical activity (Rabin and Pinto, 2006; Costanzo et al, 2010).

Self-regulation of behaviour

Previously reported theoretical models do not fully explain why intention does or does not lead to the adoption of a healthy lifestyle. Besides the illness-related factors that might partially explain this intention-behaviour gap, action-oriented self-regulation models must also be considered.

The central principle of self-regulation models is that through the formation of action goals and pursuit of these goals even in the face of difficulties (i.e. coping with difficulties and frustration) successful transformation of motivation into action and maintenance can be accomplished. Self-regulation models provide various strategies for action initiation and goal pursuit, such as forming implementation intentions, goal-setting and feedback, action-planning and building on self-monitoring through skills training (Gollwitzer, 1999; Sniehotta, 2009). The body of evidence regarding the efficacy and applicability of these strategies in modifying complex health-related behaviour is growing in non-clinical (Rhodes and Pfaeffli, 2010) and clinical populations (Conn et al, 2008).

3.2. Intervention development

During the past two decades, interventions including physical activity have continued to be developed to address issues relative to therapy side-effects and increased survivorship. Interventions vary substantially across the existing literature (Holtzman et al, 2004). Some interventions, however, are mainly focused on the beneficial effects of physical activity on physical and psychological well-being (targeting supportive cancer care), whereas others are focused on the post-intervention effects on adherence to physical activity (targeting behavioural change). Intervention content (*exercise* versus *physical activity*) and delivery as well as recommendations may differ according to the preset target.

Overall, the majority of interventions in breast cancer survivors are 'exercise-based'. These exercise interventions (whether supervised or home-based) often differ from physical activity lifestyle interventions, in which survivors are supported to incorporate physical activity during daily life. In the literature as well as in clinical settings, both strategies are often considered separately

(Schmitz, 2011). As exercise interventions profit from a longer history in terms of physical activity research in cancer survivors than physical activity lifestyle interventions (Courneya, 2009), we briefly report on the current state within the field of exercise interventions before exploring physical activity lifestyle interventions.

3.2.1. Exercise interventions

An increasing number of studies have examined exercise interventions during and after treatment in breast cancer survivors (Speck et al, 2010). They mostly involve an extended post-treatment time period. A recent review, including exercise interventions of a maximal 12 months' post-treatment for all cancer patients, identifies ten studies (Spence et al, 2010). Six studies incorporate only aerobic exercise (cycling, walking, ball games and swimming) and four incorporate aerobic and resistance training. Flexibility exercises are included as part of the warm-up or cool-down in two studies. None of these studies include methods to support behavioural change and encourage long-term physical activity.

More studies are found if cancer survivors for more than two years post-treatment are also included, and the majority concern breast cancer survivors (Speck et al, 2010; Vanderstraeten et al, 2011). In general, aerobic or combined (aerobic and resistance) approaches are the most common interventions in cancer survivors, typically of moderate to vigorous intensity, three to five times a week, for 30 to 45 min per session (Speck et al, 2010). A number of them also include psychological counselling (Van Weert et al, 2008) or are behavioural change interventions (Speck et al, 2010). It is suggested that in programmes combining physical training and psycho-education, the physical training component mainly accounts for the outcome benefits (May et al, 2009). Moreover, aerobic interventions contribute more to an increased quality of life and decreased fatigue compared with strength training programmes (Vanderstraeten et al, 2011).

Depending on their delivery, interventions can be divided into group programmes including aerobic and/or non-aerobic exercises, group programmes including exercises and psycho-education sessions (Van Weert et al, 2008) and home-based programmes using telephone counselling or print materials (Pinto et al, 2005; Vallance et al, 2007). Yet no evidence exists on a meta-level with regard to the preferred delivery, groups or individual sessions, and up to now the effect of the group cohesion on post-intervention effects is unknown. Furthermore, considering the heterogeneity of preferences among breast cancer survivors (Gjerset et al, 2010), no priority can be given to face-to-face or distance home-based programmes, or individual versus group programmes.

A current intervention programme in Belgium is called 'onco-rehabilitation', defined as a 12- week group programme combining physical training (individual training and group sports) twice a week with psycho-education once a week. It aims at improvements in patients' quality of life, functioning, and cancer side-effects such as fatigue. The programme is run in hospitals and rehabilitation centres and is multidisciplinary; it is led by rehabilitation specialists, physiotherapists, psychologists, dieticians and social workers (Van Weert et al, 2008). The results of such multimodal rehabilitation programmes are mixed, however, possibly reflecting the inclusion of patients on the basis of cancer diagnosis rather than rehabilitation needs (Johansson et al, 2008).

Nonetheless, all interventions are deemed safe and feasible for breast cancer survivors. Overall adherence rates are high (ranging from 69% for a home-based walking programme to 81% for a supervised walking programme) (Pinto et al, 2005; Latka et al, 2009), suggesting that survivors who participate in an intervention are highly motivated (Spence et al, 2010). These rates, however, should be viewed in the context of the percentage of cancer survivors approached regarding study participation. An average of 51% of cancer survivors agreed to or were found eligible for participation (Holtzman et al, 2004). Identifying survivors who are not likely to adhere to an exercise programme can support the development of appropriate strategies to increase long-term participation in physical activity among all survivors.

Few studies report on long-term exercise adherence after a structured exercise programme and conclude that follow-up exercise participation rates were not optimal (Courneya et al,2002; Vallance et al, 2007). Exercise interventions appeared to be insufficient in guiding behavioural changes and promoting lifelong physical activity. To fill the gap, research on determinants of physical activity and behavioural change increased recently (Courneya et al, 2009) and lifestyle interventions in cancer survivors are of increasing interest (Demark-Wahnefried et al, 2005; Stull et al, 2007). These interventions will be extensively discussed in the following section.

3.2.2. Lifestyle interventions

Most lifestyle interventions in cancer patients constitute multi-behaviour programmes including nutrition and diet, physical activity and sometimes smoking cessation. Some authors have suggested that interventions involving physical activity may receive better uptake and continued adherence if introduced post-treatment (Courneya et al, 2002; Demark-Wahnefried 2007), and if they are based on theoretical models of behavioural change. Besides efficacy, several strategic iterations may be necessary to create an intervention that not only has proved efficacy, but is also well-accepted and generalizable to the breast cancer population at large (Demark-Whanefried et al, 2007). Intervention content and channels of delivery must be considered in the development of interventions that best meet the needs of this vulnerable and increasing population (Stull et al, 2007).

Current interventions for promoting physical activity in cancer survivors

Van Weert and colleagues (2008) reviewed the evidence concerning the delivery of a structured physical activity programme for cancer survivors intended to improve physical well-being as well as exercise adherence and long-term physical activity. They stressed the importance of self-management and self-efficacy enhancing strategies (May et al, 2009) with an optimal transfer into daily activities. Subsequently, they developed a group physical training programme with individual and supervised exercise modules and a home-based walking programme. Although the programme was found to be effective, no information was given on the potential reach of the programme within the cancer survivor population.

A review of structured physical activity interventions in adults showed that most exercise programmes never reach the people who would benefit most (Glasgow et al, 2002). Unfortunately, this finding is also appropriate for women who survive breast cancer (Johansen, 2007; Cadmus et al, 2009). Given barriers like distance and time suggest the distinct need for home-based interventions. Print materials, telephone counselling and the Internet can be used to further guide self-management and self-efficacy strategies among these interventions and promote an active lifestyle (Stull et al, 2007).

Print materials could either be general, including standardized health education and information on all possible topics regarding survivorship (e.g. Facing Forwards -www.cancer.gov), or more tailored to the current behaviour (e.g. diet and exercise information) as guidebooks or workbooks. The latter are designed to influence self-efficacy and associated variables by emphasizing the benefits of the behaviour, detailing incremental tasks with a focus on overcoming barriers, and providing encouragement. Furthermore, workbooks could be personalized and information could be tailored to participants' current exercise level and dietary habits (e.g. the RENEW trial by Morey and colleagues (2009)) or to experienced barriers (e.g. the FRESH START trial by Demark-Wahnefried and colleagues (2007)). Studies using print materials suggest the added value of tailoring this information to women's experienced barriers, stage of readiness and progress (Mosher, 2008; Demark-Wahnefried, 2007). Vallance and colleagues (2007) developed a physical activity guidebook for breast cancer survivors based on the theoretical components of the Theory of Planned Behaviour (*Exercise for health: An exercise guide for breast cancer survivors*) and included written activities to facilitate participant engagement with the information. The guidebook was found to be effective for increasing physical activity in breast cancer survivors. Combining print-materials interventions with pedometers may, however, be more effective (Vallance et al, 2007). Additional to print materials, some interventions provide telephone counselling to further support behavioural change by discussing perceived barriers and progress and providing reinforcement upon attainment of the goals (Pinto et al, 2009; Hawkes et al, 2009). However, such approaches require a considerable amount of personal time and financial resources for developing the tailored workbooks and providing the telephone counselling. Moreover, the additional effect of the telephone counselling is not yet known (Castro and King, 2001). To overcome these shortcomings and to provide tailored feedback, computer-tailored advice is a topic of interest for health interventions. Computer-tailoring is a low-cost method that facilitates the delivery of personalized feedback to a large (and heterogeneous) population in a very systematic and theory-based way (Kroeze et al, 2006; Lustria et al, 2009; Krebs et al, 2010). Computer-tailored advice is a combination of information and change strategies intended to reach one specific person and related to the outcome of interest. The tailored advice is derived from an individual assessment and is selected by data-driven decision rules (Kreuter, 2000; Krebs et al, 2010), resulting in information that is optimally adapted to the specific individual characteristics of the participants. Several studies give promising indications that computer-tailored physical activity interventions are effective in healthy adults (Spittaels et al, 2007; Napolitano et al, 2003; Van Stralen et al, 2009).

Among disease conditions such as diabetes, computer-tailored advice is found to be a beneficial interactive medium for patient-centered support and greater patient autonomy and self-management (Glasgow, 2010). If the computer-tailored advice is disseminated through the Internet, the term web-based intervention is used. Barak and colleagues (2009) defines a web-based intervention as: “a primarily self-guided intervention programme that is executed by means of a prescriptive online programme operated through a website and used by consumers seeking health- and mental-health related assistance. The intervention programme itself attempts to create positive change and or improve/enhance knowledge, awareness, and understanding via the provision of sound health-related material and use of interactive web-based components.” Moreover, a web-based intervention offers the opportunity to the patient to participate within the programme in a more interactive way (e.g. use self- assessment and self-monitoring tools). It is likely that interactive online activities enhance patients understanding of programme content in a way that makes it more personalized and potentially facilitates a greater sense of ownership and connectedness to the programme itself (Glasgow, 2010). Moreover, referral links to additional relevant information can be included to improve knowledge and further assert the process of patient empowerment.

Promoting walking as part of an active lifestyle

Research into physical activity preferences shows that breast cancer survivors are positive with respect to recreational activities at home, particularly those of low to moderate intensity like walking (Jones and Courneya 2002; Milne et al, 2008; Gjerset et al, 2010). Therefore, most lifestyle interventions among cancer survivors promote walking. In most studies, participants are encouraged to begin with a goal of walking (exercising) for at least 10 min/day on at least two days/week. Goals then gradually increase to exercising for 30 min/day on at least five days/week (equal to current recommendations) (Vallance et al, 2007; Pinto et al, 2008). As constant tracking of bouts of activity during the day is rather impractical, step count goals are introduced. Steps can easily be counted by using a pedometer[3]. Step count goals are concrete and easy to remember and stress the importance of being physical active during daily activities (Choi et al, 2007). A recent review on walking interventions in cancer survivors advocates the use of defined step goals to improve daily walking in cancer survivors (Knols et al, 2010).

In the general population, 10 000 steps a day is accepted as a translation of the 30 min/day of moderate physical activity recommendation (Hatano, 1993). Daily activities in healthy adults usually approach 6000 to 7000 steps a day (Tudor-Locke and Bassett, 2004). An additional 30 minutes of moderate intensity walking accounts for 3100 to 4000 steps. Summing the steps during daily activities and during the recommended extra physical activity meets the 10 000 steps/day guideline.

A number of breast cancer survivors are far from achieving 6000 steps during daily activities (Matthews et al, 2007; Lynch et al, 2010). For these fairly inactive survivors, 10 000 steps a day may not be appropriate. In contrast, another study calculated a median value of 7409 steps/day among breast cancer survivors, which matched well with the general population (Tudor-Locke et Al, 2009). Individual step values ranged from 2800 steps a day to over 10 000 steps a day, indicating that achieving more than 10 000 steps/day is likely to be challenging for some (e.g. those taking fewer than 2500 steps/day), but not necessarily impossible for all survivors (e.g. those taking more than 9000 steps/day). Selecting personally relevant step goals, based on an individual's baseline step level, may be more appropriate.

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[3] Pedometers are small, lightweight instruments that count movement (steps).

It is suggested that increasing baseline levels by only 2000 to 2500 steps (15 to 20 minutes of walking) a day could already bring health benefits (Hill et al, 2003; Aoyagi and Shephard, 2009). Tudor-Locke argued that a threshold of 6500 to 8500 steps a day is needed for individuals living with disabilities or chronic illness (Tudor-Locke, 2009). Further research is needed, but any selected step goal should be an improvement on baseline levels and should be continued for a longer period (Sidman, 2002).

In the light of the studies reviewed according to the Model of Planned Promotion of Population Health, there is a strong rationale for further investigating the development and usability of pedometer-based computer-tailored physical activity advice for breast cancer survivors.

4. **Aims and outline** of the thesis

In order to optimize the reach and effect of supportive care for physical activity after breast cancer, this project was set up to provide more insight into the supportive care needed for physical activity and motivational aspects of physical activity among women during their transition to survivorship. Further insights will lead to the development of an appropriate intervention that will support recovery, re-integration and physical activity promotion after breast cancer. Overall goals were in line with the steps proposed in the Model of Planned Promotion of Population Health and encompassed (1) knowledge of physical activity levels and supportive care need for physical activity after breast cancer, (2) insight into the motivational aspects of physical activity after breast cancer and (3) the development and usability testing of an intervention.

To accomplish the first two goals, a cross-sectional study on sociodemographics, psychosocial and illness-related variables as well as supportive care needs for physical activity and physical activity habits was conducted in breast cancer patients three to six months post-treatment.

Chapter 2 aims to explain supportive care needs for physical activity with respect to the heterogeneity in perceived distress and adjustment among breast cancer survivors. This chapter uses a person-centered approach in which clusters of treatment-related and psychosocial factors among breast cancer survivors are identified. Subsequently, the differences in physical activity and supportive care needs for physical activity for the identified clusters are assessed.

Chapter 3 and **Chapter 4** use a variable-centered approach and try to retain the most important determinants for explaining physical activity after breast cancer. **Chapter 3** provides an integrated view of the most relevant and theory-based determinants of physical activity by including general as well as cancer-related determinants (proximal determinants of physical activity). It is followed by **Chapter 4** which further specifies the concurrent influence of illness-related and personal psychosocial factors on physical activity (distal determinants of physical activity).

Chapter 5 translates the results obtained from the cross-sectional study and discussed in previous chapters into practice by describing the development of a tailored physical activity intervention. Usability tests were performed to ameliorate the web-based physical activity intervention. Furthermore, semi-structured interviews on practical issues of the intervention were executed to give guidelines for further implementing this intervention in cancer care and cancer control programmes.

Chapter 6 summarizes the main findings and will discuss further implications for cancer care planning and follow-up care to support women's integration after breast cancer.

As the data-gathering in this project was funded for only two years, studies were combined into one large cross-sectional study. Consequently there might be some overlap between different articles. All articles were written to stand alone, however, and deal with a specific research question. Articles are published, in press or under review.

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2

Physical activity levels and supportive care needs for physical activity among breast cancer survivors with different psychosocial profiles: a cluster-analytical approach

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Abstract

The transition from breast cancer patient to survivor is associated with many treatment-related and psychosocial factors, which can influence health behaviour and associated needs. First, this study aimed to identify clusters of treatment-related and psychosocial factors among breast cancer survivors. Second, clusters' physical activity levels and care needs for physical activity were evaluated. Breast cancer survivors (n=440; 52 ± 8 years) (three weeks to six months post-treatment) completed self-reports on physical and psychological symptoms; illness representations; social support and coping; physical activity and care needs for physical activity. Analyses identified four clusters: (1) a low distress-active approach group; (2) a low distress-resigned approach group; (3) a high distress-active approach group and (4) a high distress-emotional approach group. Physical activity levels were higher in the low distress groups than in the high distress-emotional approach group. However, women with low distress and an active approach reported equal care needs for physical activity than women with high distress and an emotional approach.

These findings suggest that care needs for physical activity are unrelated to distress and actual physical activity levels. The results emphasize the importance of screening for needs and provide a framework supporting the referral of breast cancer survivors to tailored interventions.

Key words

Breast cancer, Survivor, Needs, Support, Physical activity, Adjustment

Introduction

Women who have just survived breast cancer, are still experiencing a variety of physical and psychosocial complaints (Allen et al, 2009). Subsequently, they have information and support needs following therapy, including supportive care needs for physical activity (PA) (Thewis et al, 2004; Capiello et al, 2007; Larsson et al, 2008).

Healthcare professionals recommend the use of screening instruments to identify breast cancer survivors' needs for support (Mehnert and Koch, 2008). However, two main questions arise when developing such screening instruments and referring patients to interventions (Merckaert et al, 2010). First, it is important to clarify the definition of a need for PA support. It is suggested that a need exists when there is a difference between a person's actual state (PA level) and the optimal level, noticed by the healthcare professional (Vivar and McQueen, 2005). A need can also be defined as "the requirement of some action or resource that is necessary, desirable, or useful to attain optimal well-being" (Sanson-Fisher et al, 2000), mostly indicated by the patient herself. From a clinical perspective, both definitions must be considered when referring breast cancer patients to PA interventions. Second, screening instruments must be sensitive to the concurrent influences of physical, psychological and social factors in explaining supportive care needs for PA (de Bock et al, 2004; Hodgkinson et al, 2007; Emery et al, 2009). Moreover, it is shown in the literature that those factors differ between breast cancer survivors (Rozema et al, 2009). For example, the intensity of the experienced fatigue and other co-morbidities, such as arm and breast problems, varies according to survivors' treatment type and adjustment to the cancer (De Jong et al, 2002; Ahles et al, 2005). In addition, breast cancer survivors differ in psychological functioning in terms of body image, future perspectives, anxiety and depression (Pinto and Trunzo, 2004; Avis et al, 2005). How women deal with the resulting distress is influenced by their perception of the illness (controllability beliefs, perceptions of the severity of impact of breast cancer and beliefs about disease course) (Costanzo et al, 2010), social support and coping strategies (Hepner et al, 2009). However, the extent to which this occurs for individuals may vary considerably (Larsson et al, 2008).

Given that psychosocial variables differ between breast cancer survivors and PA levels and that supportive care needs for PA are influenced by those variables, this study has two aims: (1) to cluster cancer survivors according to their symptoms and psychosocial variables with the aim to identify survivors with a homogenous psychosocial profile and (2) to look for differences in PA level and supportive care needs for PA among the resulting clusters.

Methods

Participants and procedures

The study had a cross-sectional design. Breast cancer survivors eligible for participation were (a) aged 18 to 65 years, (b) survivors of primary non-metastatic breast cancer, (c) three weeks to six months post-treatment (surgery, chemotherapy and/or radiation therapy) and (d) Dutch speaking. Ethical clearance was obtained from the ethical committee of Ghent University (B67020096619). A more detailed description of recruitment procedures is given elsewhere (Charlier et al, 2011).

Measures

Basic demographic, educational and medical information

Age, marital status, education, occupation, date of diagnosis, stage at diagnosis, received treatments and whether the women participated in structured exercises (fitness sessions and psychosocial education during 12 weeks offered in hospitals) were assessed.

Physical symptoms and psychosocial variables used in cluster analysis

Physical symptoms derived from symptom scales of The European Organisation for Research and Treatment of Cancer, Quality of Life Questionnaire-Breast Cancer (EORTC QoL-BR23) (Dutch version) (Aaronson et al, 1993). The EORTC QoL-BR23 is a 23-item breast-cancer specific questionnaire for evaluation of the site-specific information on QoL. *A symptom scale (*14 items*; α=.81)* was obtained by considering following subscales: therapy side effects, breast symptoms and arm symptoms. A higher score, indicated on a 4-point Likert scale, represented a higher ("worse") level of symptoms. *Fatigue* was measured by the Functional Assessment of Cancer Therapy – Fatigue questionnaire (FACIT-fatigue) (Dutch version). A higher score (rated on a 5-point Likert scale) indicates increased fatigue. This instrument has been used in breast cancer survivors and showed good reliability and validity (*13 items; α=.94*) (Alexander et al, 2009).

*Psychological functioning. Depression (*7-items*; α=.81)* and *anxiety (*7-items*; α=.83)* were measured by the Dutch version of the Hospital Anxiety and Depression Scale (HADS) (Spinhoven et al, 1997), with higher scores reflecting greater anxiety and depressive symptoms. The Rosenberg Self-Esteem Scale (RSE) was used to evaluate global *self-esteem* (10-items*; α=.88)*, which refers to an overall sense of personal worth (Rosenberg, 1965). Psychological functioning concerning *body image* was derived from the EORTC QoL-BR23 (Aaronson et al, 1993) (4 items*; α=.87).* A higher score represents better body image. Women expressed their worries about their health in the future on the one-item scale *future perceptive* from the EORTC QoL-BR23. A higher score indicates fewer worries. All items were rated on a 4-point Likert scale.

Illness representations were assessed using the Illness Perceptions Questionnaire-revised (IPQ-r) (Dutch version) (Moss-Morris et al, 2002). Seven subscales (using 5-point Likert scales) were of interest: *emotional representations (*experienced distress*;* 6-items; *α=.85*), *consequences* (effects and outcome; 6-items; *α=.77*), *timeline* (acute versus chronic course; 6-items; *α=.84*), *timeline cyclical* (cyclical nature; 4 items; *α=.86*), *illness coherence* (personal understanding; 5 items; α=.85) , *personal control* (personal capacity to control and cure the situation; 6-items; *α=.75*) and *treatment control* (5 items; *α=.58*). High scores on timeline, cyclical dimensions and consequences represent strong beliefs about chronicity and negative consequences of the post-treatment condition. High scores on coherence dimensions, personal and treatment control represent positive beliefs about controllability of post-treatment condition.

Social Support. The Dutch Social Support List – Interactions (SSL-I) and Discrepancies (SSL-D) (Van Sonderen, 1993) was used to assess different types of supportive interactions and the extent to which women experience a lack of social support. Interactions and discrepancies are measured regarding different types of social support. The six subscales were summed into a total SSL-I (34 items; *α=.92*) and SSL-D (34 items; *α=.91*) score. On the SSL-I, participants indicated how frequently certain social interactions happen to them on a 4-point Likert scale from 1 (seldom or never) to 4 (very often), with higher scores representing higher levels of social support. The SSL-D was recoded into: 0 (just right + it happens too often) and 1 (I would like it to happen more often), with higher scores indicating a greater lack of social support (Van Sonderen, 1993).

Coping strategies were measured using the Dutch version of the Coping Inventory for Stressful Situations (CISS-NL) (Endler et al, 2004). This 48-item questionnaire assesses three coping strategies (16-items each): problem-oriented coping (dealing with the problem at the hand; *α=.90*), emotion-oriented coping (concentrating on the resultant emotions; *α=.90*) and avoidance coping (trying to avoid the problem; *α=.85*). The use of these coping strategies was rated on a 5-point Likert scale from 1 (not at all) to 5 (very much).

PA level and supportive care needs for PA

PA levels and care needs for PA were evaluated in the identified clusters (second aim of the study). *PA level* was assessed using the long usual week Dutch version of the Flemish Physical Activity Questionnaire (FPAQ). The FPAQ was developed to collect detailed information on different dimensions of PA during a normal week and has been proven to be a reliable and valid questionnaire (Matton et al, 2007). For the present study, total PA was calculated and involved only activities with MET values (metabolic equivalent) equal to or more than three, following the values listed in Ainsworth's compendium for physical activity (Ainsworth, 2000). The '*total moderate-vigorous-intensity physical activity index*' *(total MVPA)* was computed by summing MVPA during household and gardening activities, occupation, transport and leisure time. All variables were expressed as the average time spent per week (min/week).

Respondents indicated three levels of *information need* in response to the question: "To what extent do you want information or support for PA, sport and exercise?" They answered on a three point Likert scale (not at all, somewhat, necessarily). The score was then dichotomized, with a score of zero corresponding to 'no need' and a score greater than zero as 'some need'.

Statistical analyses

Cluster analyses were used to generate psychosocial profiles based on physical symptoms, psychological functioning, illness representations, social support and coping. Before running analyses, all values were standardized into z-values. Univariate outliers (values of more than 3SD above or below the mean) and multivariate outliers (individuals with high Mahalanobis values) (Tabachnick and Fidell, 2007) were excluded. The analysis required a combination of hierarchical and non-hierarchical clustering methods (Gore, 2000). First, a hierarchical cluster analysis (Ward's method based on squared Euclidean differences) was used to identify cluster solutions. Second, the extracted initial cluster centers based on Ward's hierarchical method were used as non-random starting points in an iterative, non-hierarchical k-means clustering procedure.

The sample was then randomly split and stability of cluster solutions was examined by running the full two-step procedure (Ward, followed by k-means) on each half. The participants in each half were assigned to new clusters on the basis of their Euclidean distances to the cluster centers of the other half. These new clusters were then compared for agreement with the originals by means of Cohen's kappa (K). The two resulting kappa's were averaged, an agreement of at least 0.60 was considered acceptable (Asendorpf et al, 2001).

Cluster analysis was followed by Analyses of Variance (ANOVAs) and Tukey post-hoc tests to characterize the identified clusters on the variables used for clustering and to investigate differences for PA levels. To investigate differences for supportive care needs for PA according to psychosocial profile, a chi-square test was used. Follow-up chi-square tests between pairs of clusters were conducted to identify which of the clusters differed significantly from one other in supportive care need for PA.

Results

Participants

About 547 survivors (68% of the 802 breast cancer survivors who received a questionnaire) completed their questionnaire. Seventy-three participants were excluded for following reasons: outside the time interval (n=39), earlier diagnosis of (breast)cancer (n=25), older than 65 years (n=4), another diagnosis (n=2), metastases (n=2) and non-Dutch native language (n=1). Nine surveys could not be used due to missing data.

Data of 465 (57%) participants were included. Prior to conducting cluster analyses, we removed 22 univariate and three multivariate outliers resulting in 440 included participants Another thirty-five participants could not be clustered because of missing data on some variables. Women were on average 51.7 ± 8.21 years. The proportion of women with a high education level (college or university) was 41%. Thirty-three per cent of the women were working and another 35% was still unable to work. Almost all women received surgery (99%) and participants were on average 14 ± 7.5 weeks post-treatment.

Cluster analyses

Four clusters were retained: cluster 1 comprised a *'low distress-active approach' group* (n=86) reporting low physical and psychological distress, good control and high social support. Cluster 2 comprised a *'low distress-resigned approach' group* (n=131) characterized by low distress levels, but moderate control and support. These women also perceived their cancer to be a more chronic condition. Cluster 3 comprised a *'high distress-active approach' group* (n=98) reporting high levels of physical distress, moderate psychological distress but good personal control and social support and cluster 4 comprised a '*high distress-*

emotional approach' group (n=90) characterized by high physical and psychological distress and low levels of personal control and social support. These women held strong beliefs about the chronicity and negative consequences of their cancer.

The double-split cross-validation procedure resulted in an average kappa value across two randomly chosen subsamples of 0.94, providing significant evidence for the stability of the four cluster solution.

As shown in Table 2.1, cluster 1 (*low distress-active approach*) and cluster 4 (*high distress-emotional approach*) are quite distinct. All mean values differ at p<.001. Women in cluster 1 (*low distress-active approach*) reported minor physical symptoms and scored well on psychosocial functioning, with high levels of future perspectives, self-esteem and body image and very low depression and anxiety rates. These women also reported high personal control and good social support and were using more problem-oriented coping. In contrast women in cluster 4 (*high distress-emotional approach*), reported high physical symptom levels and scored worse on psychological functioning, with poor levels of future perspectives, self-esteem and body image and elevated depressed moods. These women used emotional coping more than the other clusters. The "intermediate" clusters, cluster 2 (*low distress-resigned approach*) and cluster 3 (*high distress-active approach*), hold similarities with both extreme groups. It was found that cluster 2 (*low distress-resigned approach*) was not significantly different from cluster 1 (*low distress-active approach)* on any of the physical symptom scales, but differed in psychosocial variables with significant poorer personal control and social interactions. These women also reported significant lower levels of problem-oriented and avoidance coping comparable to cluster 4 (*high distress-emotional approach*), but were using significant less emotional coping. Women from cluster 3 (*high distress-active approach*), however, were not significantly different from cluster 4 (*high distress-emotional approach*) regarding the perceived symptoms and body image but reported significantly less anxiety and depressive symptoms and significantly better self-esteem. These women showed good personal control and high levels of social support and were frequently using problem-oriented and avoidance coping strategies.

Cluster characteristics

Age and working status (sociodemographic variables), chemotherapy and participation in an onco-revalidation programme (treatment-related variables) differed significantly among the four clusters (Table 2.2).

Women in cluster 2 (*low distress-resigned approach*) were significantly older compared to women in the other three clusters. Women in cluster 3 (*high distress-active approach*) reported significantly more chemotherapy compared to the other three clusters. Women in cluster 4 (*high distress-emotional approach*) were less likely to work compared to women in the other three clusters.

The highest participation rate in an onco-revalidation programme was found in cluster 3 (*high distress-active approach*) (25%), followed by cluster 1 (*low distress-active approach*) (13%) and cluster 4 (*high distress-emotional approach*) (13%). Women in cluster 2 (*low distress-resigned approach*) rarely participated in an onco-revalidation programme (5%).

Table 2.1. Mean scores of the constituting variables for the four extracted clusters together with F-values

	Range	Cluster 1 (n = 86)	Cluster 2 (n = 131)	Cluster 3 (n = 98)	Cluster 4 (n = 90)	F-value (effect)
Physical symptoms						
Symptoms	(0–100)	21.3 ± 13.7^{a}	18.1 ± 11.5^{a}	37.7 ± 16.7^{b}	33.0 ± 16.3^{b}	44.1***
Perceived fatigue	(0–52)	11.7 ± 7.5^{a}	9.4 ± 6.8^{a}	17.8 ± 9.2^{b}	24.4 ± 11.6^{c}	59.1***
Psychological functioning						
Future perspectives	(0-100)	70.2 ± 21.7^{a}	61.3 ± 23.3^{b}	39.5 ± 27.2^{c}	27.4 ± 23.7^{d}	62.3***
Body image	(0-100)	78.5 ± 23.8^{a}	77.3 ± 22.0^{a}	52.7 ± 26.9^{b}	46.9 ± 31.8^{b}	39.4***
Self-esteem	(0-30)	23.1 ± 3.3^{a}	20.6 ± 3.2^{b}	20.3 ± 3.4^{b}	15.4 ± 3.6^{c}	82.8***
Anxiety	(0-21)	4.1 ± 2.7^{a}	5.1 ± 2.6^{a}	7.4 ± 3.0^{b}	11.6 ± 3.1^{c}	130.4***
Depression	(0-21)	1.3 ± 1.3^{a}	2.9 ± 2.3^{b}	3.6 ± 2.2^{b}	8.2 ± 3.3^{c}	142.4***
Illness perceptions						
Emotional presentation	(6-30)	12.8 ± 3.6^{a}	14.6 ± 3.8^{b}	17.9 ± 3.8^{c}	21.2 ± 4.2^{d}	85.3***
Consequences	(6-30)	14.8 ± 4.2^{a}	15.5 ± 3.7^{a}	19.6 ± 3.5^{b}	21.2 ± 3.9^{c}	66.7***
Timeline	(6-30)	13.8 ± 4.8^{a}	19.0 ± 4.5^{b}	17.2 ± 4.1^{c}	19.1 ± 4.2^{b}	29.8***
Timeline cyclical	(4-20)	9.4 ± 3.7^{a}	10.8 ± 3.4^{b}	13.4 ± 2.9^{c}	13.3 ± 3.2^{c}	33.5***
Illness coherence	(5-25)	21.8 ± 2.5^{a}	19.6 ± 3.0^{b}	19.1 ± 3.0^{b}	16.8 ± 3.5^{c}	41.5***
Personal control	(6-30)	23.9 ± 3.1^{a}	19.6 ± 3.1^{b}	21.8 ± 3.0^{c}	18.6 ± 3.3^{b}	54.9***
Treatment control	(5-25)	19.7 ± 2.5^{a}	17.0 ± 2.4^{b}	18.4 ± 2.4^{c}	16.9 ± 2.5^{b}	28.6***
Social support						
Social interactions	(49-122)	84.5 ± 12.6^{a}	75.8 ± 11.5^{b}	88.0 ± 12.5^{a}	72.2 ± 12.5^{b}	35.3***
Social discrepancies	(0-23)	3.1 ± 4.9^{a}	3.6 ± 5.1^{a}	4.2 ± 4.8^{a}	10.3 ± 6.6^{b}	36.3***
Coping strategy						
Problem-oriented	(16-80)	59.7 ± 8.4^{a}	49.3 ± 9.6^{b}	53.0 ± 8.4^{c}	47.5 ± 9.9^{b}	31.5***
Emotional coping	(16-80)	29.1 ± 8.3^{a}	28.4 ± 8.5^{a}	33.5 ± 8.9^{b}	45.4 ± 10.5^{c}	73.0***
Avoidance coping	(16-80)	47.2 ± 10.1^{a}	35.2 ± 8.0^{b}	48.0 ± 8.8^{a}	37.3 ± 8.0^{b}	60.2***

Note. Means in the same row that do not share superscripts differ at p 0.01 in the Tukey honestly significant difference comparison
*p ≤.05; ** p ≤.01; *** p ≤.001

Table 2.2. Actual values and differences between clusters for age, treatment-related variables, PA level and supportive need for PA

	Cluster 1 (n=86)		Cluster 2 (n=131)		Cluster 3 (n=98)		Cluster 4 (n=90)		F (X²)
	M ± SD	n (%)	M ± SD	n (%)	M ± SD	n (%)	M ± SD	n (%)	
Age	50 ± 7.6^{a}		55 ± 7.8^{b}		49 ± 7.8^{a}		51 ± 8.6^{a}		11.7***
Weeks post treatment	13 ± 7.9		15 ± 6.9		13 ± 7.4		15 ± 8.0		2.6*
Treatment									
Chemotherapy		47 (55%)^{a}		53 (41%)^{b}		69 (71%)^{c}		41 (46%)^{a,b}	(22.7***)
Radiotherapy		76 (88%)		109 (83%)		88 (92%)		74 (82%)	
Hormonal therapy		70 (82%)		97 (75%)		76 (78%)		67 (74%)	
Estrogen inhibitors		54 (77%)		73 (78%)		53 (72%)		44 (69%)	
Aromatase inhibitors		16 (23%)		21 (22%)		21 (28%)		20 (31%)	
Immunotherapy		12 (14%)		10 (7%)		16 (17%)		10 (11%)	
Structured exercise		11 (13%)^{a}		6 (5%)^{b}		24 (25%)^{c}		12 (13%)^{a}	(19.6***)
Working		36 (42%)^{a}		50 (38%)^{a}		34 (35%)^{a}		17 (19%)^{b}	(12.6**)
Total MVPA	411 ± 347^{a}		359 ± 381^{a}		303 ± 294^{a,b}		232 ± 255^{b}		5.0**
Need PA support		56 (65%)^{a,b,c}		70 (55%)^{b}		73 (75%)^{c}		59 (66%)^{a,b,c}	(10.3*)

Note. Means in the same row that do not share superscripts differ at p 0.05
*p ≤.05;
** p ≤.01;
*** p ≤.001

Differences in PA level and supportive care needs for PA between clusters

PA levels differ significantly among clusters (F(3,401)=4.96; p=.002) (Table 2.2 – Figure 2.1). Post-hoc analyses revealed significant lower PA levels in cluster 4 (*high distress-emotional approach*) in comparison with PA levels in cluster 1 (*low distress-active approach*) and cluster 2 (*low distress-resigned approach*).

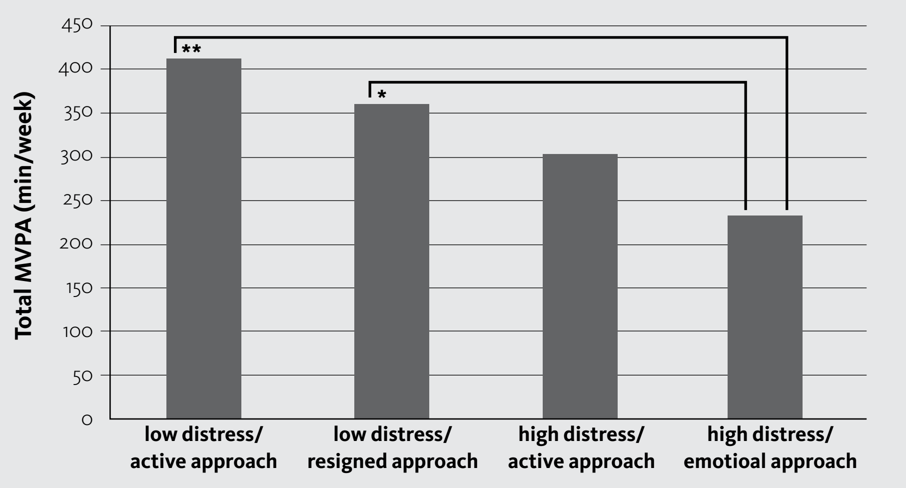

Figure 2.1. Between cluster differences for total MVPA levels.
Significant differences between clusters are indicated as *p ≤.05; ** p ≤.01;***p≤.001

We then evaluated the distribution of need versus no need for PA support among the four clusters. In all four clusters, at least 55% of the women who had just survived breast cancer expressed a need for information and support for PA with the highest percentage (75%) found in cluster 3 (*high distress-active approach*) and the lowest (55%) in cluster 2 (*low distress-resigned approach*) (χ^2 = 10.1; p =.001). An equal level of need was found in cluster 1 (*low distress-active approach*) (65%) and cluster 4 (*high distress-emotional approach*) (66%) functioning group (χ^2 = .01; p =.90) (Figure 2.2).

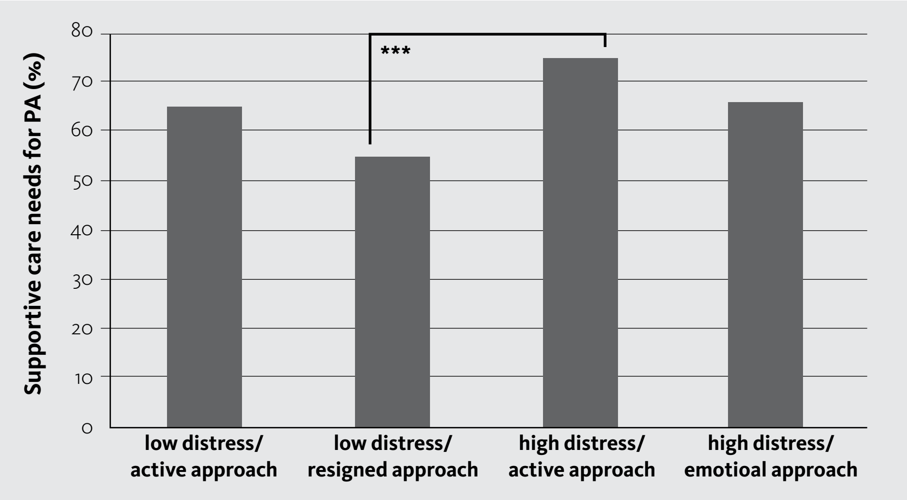

Figure 2.2. Between cluster differences for supportive care needs for PA
Significant differences between clusters are indicated as *p ≤.05; ** p ≤.01;***p≤.001

Discussion

The aims of the present study were twofold: (1) to cluster cancer survivors according to their symptoms and psychosocial variables and (2) to look for differences in PA level and supportive care needs for PA among the resulting psychosocial profiles of breast cancer survivors.

Our study shows that different profiles of breast cancer survivors can be detected in their adjustment to cancer. Moreover, PA level and supportive care need for PA may vary between the resulting clusters. Based on physical symptoms and psychological functioning, two groups arise: a group who rarely suffers from fatigue and co-morbidities and reported good emotional well-being (*low distress group*) and a contrasting group reporting more symptoms, higher levels of anxiety, high emotional representation and poor future perspectives (*high distress group*). Within each *distress* group, women differ in their response to the experienced situation (perceived control, social support and coping strategies) resulting in women with a more *active approach*, a rather *resigned approach* and a more *emotional approach*. As a consequence we revealed four clusters: (1) *low distress-active approach*; (2) *low distress-resigned approach*; (3) *high distress-active approach* and (4) *high distress-emotional approach*. Those clusters vary in PA levels with women in the high distress group (only significant for cluster 4) reporting lower levels of PA compared to the women in the low distress groups (clusters 1 and 2). If need for PA support is defined as the actual PA level, it seems that especially cluster 4 (*high distress-emotional approach*) had the greatest need for PA support. Unexpectedly, women in cluster 1 (*low distress-active approach*) revealed an equal supportive care need for PA as their counterparts in cluster 4 (*high distress-emotional approach*). This finding suggests that supportive care needs for PA are unrelated to perceived distress and actual PA levels and advocates the screening of supportive care needs for PA in all survivors. This is in contrast with the literature concerning general needs (information on physical functioning and psychosocial concerns), where higher distress predicts higher support needs (de Bock et al, 2004; Hodgkinson et al, 2007).

Some studies suggest that especially younger women express supportive care needs, others reported on the influence of social support, or on the received treatment (Harrison et al, 2009; Gjerset et al, 2010). As, in our study, we can not distinguish between clusters on one variable that is associated with need, it seems that the interplay of the included distress and adjustment variables is important in understanding the supportive care need for PA. An integrated concept of adjustment, distress, age and treatment must be considered in the development of screening instruments and should assist the design of future studies considering supportive care need for PA.

In our study, 64% of the breast cancer survivors reported a supportive care need for PA which confirms that the majority of cancer survivors express interest in support for PA, especially in the period when they complete primary cancer treatment and enter into their re-integration process (Beckjord et al, 2008; Gjerset et al, 2010; Asendorpf et al, 2001; Rogers et al, 2009; Hewitt et al, 2006) However, previous studies reported that the need for support was largely unmet and low participation rates in structured PA programmes and health services were often noticed (Zebrack, 2008; Findley and Sambamoorthi, 2009). The reasons including different preferences in support (Thewis et al, 2004; Carter et al, 2010), motivational readiness (Latka et al, 2009), lack of time and selection bias by the medical staff. Hence, not only is addressing survivors' supportive care needs for PA essential (Beckjord et al, 2008), but also referral to additional support and access to information must be considered as strategies to meet the supportive care needs for PA in breast cancer patients post-treatment. If we analyze our clusters based on distress, psychosocial variables in accordance with PA levels, need for support and social participation, our resulting clusters can give a rationale for suggestions for the referral of post-treatment interventions for breast cancer survivors.

Women in cluster 1 (*low distress-active approach*) are characterized by their high levels of personal control. Those women seem to have a great motivation of their own to succeed, however, they reported high levels of support need.

As 42% of those women were working, they could suffer from scheduling difficulties. Providing interventions focusing on self-determination and empowerment could be more suitable for them, including strategies to incorporate PA into their daily activities (Rogers et al, 2009) so that these women would feel supported in their process of re-integration. Women in cluster 2 (*low distress-resigned approach*) were more likely to accept their condition, even when they experienced it as more chronic. As a consequence, they reported less supportive needs for PA. These women are probably hardly motivated to participate in an exercise programme. They could benefit from motivational counseling by caregivers and by supporting them to use low effort strategies for PA such as pedometer based interventions with adapted step goals Demark-Wahnefried et al, 2005; De Greef et al, 2011). In contrast, women in cluster 3 (*high distress-active approach*) are seeking opportunities to control and support their cancer condition. Consequently, they reported the greatest need for support. However, this group also reported the highest participation rates in structured PA programmes (onco-revalidation). It seems that these women rely on powerful others (like health and medical professionals) to support them in their re-integration process, enhancing their feelings of control and perceived support (Berglund et al, 1997). Those women could benefit from structured exercise programmes (Gjerset et al, 2010), however, those programmes must enhance their self-regulation to take care of their own health, without increasing their feelings of "treatment dependency". Lastly, the women in cluster 4 (*high distress-emotional approach*) are emotionally overwhelmed by their cancer condition, reporting low levels of control and tending to a more clinical, emotionally dysfunctional group. These women could benefit first from therapy for their anxiety and depression before focusing on PA promotion (Hodgkinson et al, 2007).

Some limitations of this study have to be addressed. First, total PA level results relied on self-reporting, which is subject to possible over reporting (Rzewnicki et al, 2003). In addition, total scores were calculated by summing all minutes of PA of the separate domains which leads to possible overestimation of the total score. As a consequence PA levels in our study are rather high. Nevertheless, previous studies also found PA levels that were consistent with recommended guidelines in the period immediately following primary treatment for breast cancer (Emery et al, 2009; Costanzo et al, 2010). Second, as this study focused on a broad range of concepts of distress and adjustment, resulting in the inclusion of a wide number of questionnaires, a selection among questionnaires had to be made. Only the breast module of the EORTC-C30 was assessed, as this questionnaire was specifically related to our research questions, without assessing the core questionnaire of the

EORTC-C30. As a result, unfortunately, no conclusion could be drawn on clusters' general quality of life. Third, nothing is known about the PA status and psychosocial variables of non-respondents. It could be that non-respondents found it too intrusive to complete a lifestyle questionnaire that refers repeatedly to the period before their cancer. In addition, non-respondents could also be less interested in PA, implicating a selection bias of respondents who were reporting higher interest and thus higher levels of PA. Despite this limitation the response rate was good (68%) compared to other studies on PA in cancer survivors (range 28% to 58%) (Rogers et al, 2008).

The present study represents important implications toward developing PA interventions that are relevant to a large number of breast cancer survivors. Our study reveals four meaningful profiles (based on distress and approach) of breast cancer survivors who may vary in PA level and supportive care needs for PA. Women in the high distress group with an emotional approach reported less PA. However, supportive care need for PA was unrelated to perceived distress and actual PA level. Women with low distress and an active approach reported an equal need compared to women with high distress and an emotional approach and women in the high distress-active approach group reported the greatest need. These findings underscore the importance of screening for support needs and tailored interventions.

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3

The contribution of general and cancer-related variables in explaining physical activity in a breast cancer population three weeks to six months post-treatment

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Abstract

OBJECTIVE: Physical activity determinants are subject to change when confronted with the diagnosis “cancer” and new cancer-related determinants appears. The aim of the present study is to compare the contribution of cancer-related determinants with more general ones in explaining physical activity three weeks to six months post-treatment.

METHODS: A theory based and validated questionnaire was used to identify physical activity levels (total and domain-specific) and associated determinants among 464 breast cancer survivors (aged 18 to 65 year) three weeks to six months post-treatment.

RESULTS: Descriptive analyses showed higher scores for general determinants in comparison with cancer-related determinants. Nevertheless, results of regression analyses showed that both, general and cancer-related determinants explained total and domain-specific physical activity. Self-efficacy, enjoyment, social support, lack of time and lack of company were important general determinants. The perception of returning to normal life, cancer-related barriers (fatigue, lack of energy and physical side-effects) and self-efficacy in overcoming these barriers were important cancer-related determinants. Although results differed according to the women’s working status and the physical activity domain, in both groups, general self-efficacy explained most physical activity types.

CONCLUSION: Comparable with the general population, enhancing breast cancer survivors’ self-efficacy in being sufficiently physical active seems to be important in physical activity interventions post-treatment. However, interventions should be tailored to the experienced symptoms and working status of the women.

Key words

Cancer, oncology, survivorship, physical activity, exercise, determinants

Introduction

As a consequence of the increasing survival rates in breast cancer patients (Berrino et al, 2007; Verdeccchia et al, 2008; Gondos et al, 2008; Rosso et al, 2010) a growing number of breast cancer survivors appears (Autier et al, 2010). Although some of them recover with a renewed sense of life, most survivors also suffer from a variety of medical, functional and psychosocial consequences of breast cancer and its treatment (Anderson-Hanley et al, 2003; Schultz et al, 2005). Therefore, physical and psychosocial interventions are warranted to facilitate full recovery (Cramp and Daniel, 2008). Physical activity (PA) can assist recovery (Hewitt et al, 2006; Eakin et al, 2007). To profit from health benefits of PA, like increased quality of life and improved survival (Penedo et al, 2005; Knols et al, 2005; Holmes et al, 2005; Demark-Wahnefried et al, 2007; Pierce et al, 2007; Ibrahim and Al-Homaidh, 2010), cancer survivors should be moderately physically active for at least 30 minutes on five days per week (WHO, 2007). Unfortunately, many survivors do not reach these recommendation (Lynch et al, 2010; Devoogdt et al, 2010). Subsequently, PA promotion in cancer survivors is warranted (Alfano et al, 2009).

The transition period from patient to survivor is seen as an ideal period for health promotion because it represents a time for self-reflection and personal change (Harper et al, 2007; Costanzo et al, 2010). Knowledge of the psychosocial predictors of PA in survivors in this specific period (< 6 months post-treatment) is necessary for the development of future interventions as well as to identify those survivors who may need help in their adoption of a healthy lifestyle.

Within the general population, attitude, social influences and self-efficacy are important variables in explaining PA (Eyler, 2003). Attitude is an individual's evaluation of self-performance of an active lifestyle and can be determined by a total set of behaviour beliefs (perceived benefits and barriers). Social influence addresses the perception of significant others on PA (subjective norm), the extent to which significant others are participating in PA (modelling) and the perceived support. Self-efficacy, finally, is defined as a patient's own belief in his or her ability to be sufficiently physical active and the confidence in the ability to overcome barriers to PA participation.

Descriptive studies on cancer patients' perceived benefits and barriers, social influences and self-efficacy showed some differences in comparison to those of the general population (Nelson et al, 1991; Rogers et al, 2006; Miedema et al, 2008). One study suggested that breast cancer survivors reported higher perceived benefits and barriers for PA (Miedema et al, 2008), but results are mixed (Rhodes et al, 2007). Other studies confirmed the presence of an additional set of PA determinants specifically related to the women's health status (Courneya et al, 2006; Milne et al, 2007; Miedema et al, 2008; Rogers et al, 2008). However, the importance of these cancer-related determinants in explaining PA in cancer survivors remains unclear. Research is needed to clarify in what way both general and cancer-related determinants explain PA to allow for better tailoring of future interventions.

The first aim of the present study is to explore the general and cancer-related determinants of PA in a breast cancer population within six months post-treatment. Secondly, the contribution of the cancer-related determinants in comparison with the more general ones in explaining total and domain-specific PA will be investigated.

Method

Participants and procedures

Patients were referred through several Belgium hospitals. Breast cancer survivors eligible for participation were (a) aged 18 to 65 years, (b) survivors of primary non-metastatic breast cancer, (c) 3 weeks to 6 months post-treatment (surgery, chemotherapy and/or radiation therapy) and (d) Dutch speaking. Pregnancy and severe neurological, psychological and cognitive dysfunctions were exclusion criteria. Younger women often report very different recovery and re-integration issues and other physical problems than older women (Manual et al, 2007). As differentiating between both age groups would be too complicate for this study, survivors of retired age were not the focus of this study. After receiving an informed consent, questionnaires were sent to all participants, followed by a reminder after two weeks. Ethical clearance was obtained from the ethical committee of the Ghent University (B67020096619).

Questionnaires

Basic demographic, educational and medical information

The questionnaire assessed age, marital status, education, occupation, date of diagnosis, received treatments and whether they participated in an oncologic revalidation programme (fitness sessions and psychosocial education during 12 weeks).

Determinants of physical activity

A newly designed questionnaire on psychosocial determinants derived from previous questionnaires in non-diseased (Sallis et al, 1986; De Bourdeaudhuij and Sallis, 2002) and cancer populations (Rogers et al, 2006; Courneya et al, 2006; Rogers et al, 2008). These questionnaires were widely used and showed good reliability and validity (De Bourdeaudhuij and Sallis, 2002; Rogers et al, 2006). Table 3.1 includes an overview of included subscales and items per subscale of the general and cancer-related determinants. Associated Cronbach alpha's are also indicated in table 3.1. All items were scored on a five-point Likert scale.

Levels of physical activity

To assess PA, the long version of the Flemish Physical Activity Questionnaire (FPAQ) was used. The FPAQ was developed to collect detailed information on different dimensions of PA during a usual week and has been proven to be a reliable and valid questionnaire (Matton et al, 2007). Four activity variables were calculated which involved only activities with MET values equal or more than three (activity levels during household and gardening, transportation, occupation and leisure time) (Ainsworth et al, 2000). In addition a '*total moderate-vigorous-intensity PA index*' *(total MVPA)* was computed by summing those four variables. All variables were expressed as the average time spent per week (min/week). Possible outliers among the four types of PA were truncated to 960 min/week.

Total days/week of MVPA was measured with a self-reported single item of the Dutch Short Questionnaire to Assess Health Enhancing Physical Activity (SQUASH) (Wendel-Vos et al, 2003): 'On how many days a week are you, in total, moderately physically active for at least 30 minutes?. Although single-item self-reports may be less accurate, studies provided support for the validity and reliability of single-item self-reports of PA (Iwai et al, 2001).

Table 3.1. Descriptives for PA determinants in non-working and working breast cancer survivors

Subscales	Description of items	Cronbach's alpha	Non-working M(SD)	Non-working % agree	Working M(SD)	Working % agree	Δ
Attitude	*Being sufficiently physically active is*						
Instrumental attitude	*important; healthy*	(.78)	4.4(0.6)	98	4.5(0.5)	99	
Affective attitude	*satisfying; pleasant; enjoyable*	(.83)	3.7(0.8)	63	3.7(0.9)	62	
Perceived Benefits							
General							
Health benefits	*Feeling less depressed/ less stressed; losing weight; strengthening muscles/bones*	(.70)	3.7(0.6)	69	3.6(0.6)	62	
Social benefits	*Meeting new people*		3.6(0.9)	58	3.5(0.9)	52	
Cancer related							
Health benefits	*Feeling less tired; decreased current symptoms; better health; decreased risk of cancer recurrence/secondary diseases*	(.80)	3.5(0.6)	51	3.5(0.6)	55	
Social benefits	*Perceiving return to normal life (as before the cancer)*		3.7(0.8)	65	3.8(0.9)	70	
Perceived barriers							
General							
Lack of time			2.8(1.1)	25	3.2(1.0)	38	***
Lack of interest	*Lack of interest/discipline/pleasure; disappointment in PA*	(.83)	2.6(1.0)	21	2.5(0.9)	19	
Lack of company			2.6(1.1)	5	2.5(1.1)	18	
Lack of facilities	*Lack of equipment/skills/facilities/knowledge*	(.86)	2.2(1.0)	12	2.0(0.9)	6	*
Perceived obstacles	*Bad weather; personal problems*	(.30)	2.5(0.8)	15	2.3(0.8)	15	
Cancer related							
Physical side-effects	*(anxiety for) Pain and oedema; inflammations and injuries; incontinence*	(.67)	2.0(0.9)	7	1.8(0.8)	1	
Body image	*Being too shy or embarrassed to do PA*		1.8(1.3)	12	1.6(0.9)	5	**
Fatigue			2.9(1.2)	28	2.6(1.1)	19	**
Lack of energy			3.2(1.1)	39	3.1(1.0)	31	

Social influences						
General						
Social norm	*My partner/family/friends want me to be physically active*	(.85)	3.1(1.0)	45	3.1(1.1)	50
Modelling	*How frequently does/do your partner, family/friends participate in PA*	(.73)	2.5(1.0)	20	2.6(0.9)	20
Social support	*How frequently are you doing PA together with partner/ family/friends*	(.54)	2.2(0.9)	7	2.1(0.8)	5
Cancer related						
Social norm[a]	*My physician wants me to be regularly physical active*		3.7(1.0)	64	3.5(1.0)	54
Social norm[b]	*Other survivors want me to be regularly physical active*		3.2(1.0)	42	3.0(1.1)	32
Modelling	*How frequently do other survivors participate in PA*		2.5(1.0)	16	1.2(1.5)	10
Social support	*How frequently are you doing PA with other survivors*		2.2(0.9)	11	1.4(0.8)	4
Self-efficacy						
General						
Self-efficacy	*I feel confident to be sufficiently physically active; I find it difficult to be sufficiently physically active*	(.64)	3.1(1.0)	40	3.3(0.9)	45
Barrier self-efficacy	*I feel confident to be sufficiently physically active even when having no company; suffering from muscles aches; being depressed or stressed; spending too much time at work; having much household work; family and friends require more time; an important life event occurs*	(.86)	2.9(0.7)	22	2.8(0.8)	21
Cancer related						
Barrier self-efficacy	*I feel confident to be sufficiently physically active even when suffering from current symptoms/arm symptoms/fatigue*	(.78)	2.6(0.8)	16	2.6(0.8)	12

[a] by physician; [b] by other survivors

Significant differences between working and non-working group (Δ) are indicated as

* $p \leq .05$;

** $p \leq .01$;

***$p \leq .001$

For ease of interpretation the percentage of participants endorsing a 4 or 5 on the various 5-point scales ((strongly) agree, (very) often, (extremely) confident) were calculated.

Statistical analyses

Analyses were carried out using SPSS 15.0. Data analyses included basic descriptive statistics for all respondents. As the working status of participants had a major impact upon regression analyses and differences in both PA behaviour and determinants were quite substantial for non-working and working participants, we expect that interventions should be tailored to working status. Therefore analyses were stratified for the working and non-working group. Statistical differences for the continuous variables were analysed using an independent t-test. Chi-square tests were used for categorical variables.

To get an independent view of the contribution of general versus cancer-related determinants of MVPA, separate multiple regression analyses were conducted using two blocks. Preliminary analyses were conducted to ensure no multicollinearity. For both analyses relevant socio-demographic variables were entered in a first block. General determinants (analysis 1) or cancer-related variables (analysis 2) were entered as a second block. To generate a total model, a third analysis was conducted, in which the significant general and cancer-related determinants ($p \leq .10$) were entered together in the second block, controlled for time post-treatment, chemo-and radiotherapy. Before running the regression analyses, all variables with non-significant bivariate correlations with PA ($p > .10$) were omitted (represented by lines in the tables).

Results

Study population

Of the 802 breast cancer survivors who had received a questionnaire, 547 (68%) returned their questionnaire. Seventy-three participants did not meet the inclusion criteria (39 were outside the time interval, 25 had an earlier diagnosis of (breast)cancer, 4 were older than 65 years, 2 had another diagnosis, 2 reported metastases and 1 had another native language). Ten surveys could not be used due to unrealistic outliers in MVPA levels (1) and missing data (9).

Subsequently, data of 464 participants (58%) were included in the analyses. Of those, 32% (n = 148) were at work at the time of testing. General characteristics for the working and non-working group are described in table 3.2.

Table 3.2. Sociodemographic and medical characteristics and PA levels in non-working and working breast cancer survivors

	Non-working (n = 316)		Working (n = 148)		
	M(SD)	**N(%)**	**M(SD)**	**N(%)**	**Δ**
Age	53.1 (8.21)		49.3 (7.45)		***
Weeks post treatment	13.2 (7.54)		16.2 (6.79)		***
Marital state					
Married/ living together		234 (75.0)		109 (73.7)	
Single		78 (25.0)		39 (26.4)	
Education					
Primary school		36 (11.8)		3 (2.03)	***
Secondary school		172 (56.4)		61 (41.2)	
Higher education		78 (25.6)		67 (45.3)	***
University		19 (6.2)		17 (11.5)	
Employment					
Employed		-		148 (100)	
Disabled		161 (51.1)		-	
Retired/No job		154 (48.8)		-	
Treatment					
Surgery		313 (99.6)		147 (99.3)	
Chemotherapy		171 (54.6)		65 (43.9)	***
Radiotherapy		272 (86.4)		126 (85.1)	
Current hormonal therapy		241 (76.5)		113 (76.4)	
Current immunotherapy		39 (12.5)		11 (7.43)	
Onco-revalidation		51 (16.1)		11 (7.43)	*
Levels of moderated PA (min/week)					
Total MVPA	255 (241)		532 (402)		***
Leisure Time	91 (148)		92 (132)		
Household	59 (114)		71 (130)		*
Transportation	74 (135)		105 (167)		
Days of ≥ 30 min MVPA	1.4 (1.8)		1.4 (1.9)		

* p ≤.05;
** p ≤.01;
***p≤.001

Current levels of physical activity and psychosocial determinants

Minutes per week of MVPA for all PA domains are described in table 3.2. The proportion of respondents that reported less than 210 minutes per week of MVPA was 54% in the non-working group and 25% in the working group. In both groups 51% was never moderately physically active for at least 30 minutes a day.

As table 3.1 shows, more women agreed with the general health benefits of PA in comparison with the cancer-related health benefits. Women also reported a higher confidence in overcoming general barriers than the cancer-related ones. Fatigue and lack of energy were most frequently perceived as a barrier, followed by the more general ones.

Association of general and cancer-related determinants with different domains of physical activity in the non-working group of breast cancer survivors

Standardized regression coefficients in the non-working group are reported in table 3.3 and 3.4 for the general and cancer-related determinants. After controlling for demographics, the models including *general determinants* explained 16 to 17% of the variance in MVPA. The model including *cancer-related determinants* contributed in the explanation of the variance in all domains of PA with most variance explained for total MVPA (18%), followed by 11% of the variance in total days/week of at least 30 minutes MVPA and leisure-time MVPA.

The model based on both *general and cancer-related determinants* (table 3.5) contributed in the explanation for total MVPA (20%), total days/week of at least 30 minutes MVPA (14%), leisure-time MVPA (14%), household (8%) and transportation (4%). The significant determinants of the separate models remained important in the total model. General self-efficacy and enjoyment in PA (affective attitude) had a unique contribution in the explanation of PA depending on PA domain. The perception of returning to normal life, fatigue and lack of energy were significant cancer-related determinants.

Association of general and cancer-related determinants with different domains of physical activity in the working group of breast cancer survivors

Standardized regression coefficients in the working group are reported in table 3.3 and 3.4 for the general and cancer-related determinants. After controlling for demographics, the models including *general determinants* explained 13% to 26% of the variance in different MVPA domains. The model including the *cancer-related determinants* contributed in the explanation of the variance in all domains of PA with the exception of household PA, with most variance explained for leisure-time MVPA (18%), followed by 15% of the variance in total days/week of at least 30 minutes MVPA.

The model based on both *general and cancer-related determinants* (Table 3.5) contributed in the explanation of total MVPA (14%), total days/week of at least 30 minutes MVPA (22%), leisure-time MVPA (26%) and transportation MVPA (13%). Social support (from relatives and friends) and barriers (lack of company and lack of time) were also important *general determinants* in addition to the general self-efficacy and the affective attitude. Perceived benefits (returning to normal life) and barriers (physical side-effects) were important *cancer-related determinants* depending on the PA domain. The self-efficacy in overcoming cancer-related barriers had a unique contribution in all PA domains.

Table 3.3. Hierarchical regression analyses of physical activity in non-working (n = 316) and working (n = 148) cancer survivors based on general determinants

	Total MVPA (Beta)		Days (Beta)		Leisure (Beta)		Household (Beta)		Transportation (Beta)	
	Non-working	Working	Non-working	Working	Non-working	Working	Non-working	Working	Non-working	Working
Block 1 (ΔR^2)	(.03**)	(.08***)	(.03**)	(---)	(.11***)	(.05**)	(.01*)	(.09**)	(---)	(---)
Age	---	---	-.12*	---	---	---	---	.06	---	---
Education level	---	-.25***	.10^{a}	---	.11*	---	-.13*	-.15^{a}	---	---
Marital state	---	---	---	---	---	---	---	.16^{a}	---	---
Onco revalidation	.16**	---	---	---	.25***	.21**	---	---	---	---
Block 2 (ΔR^2)	(.17***)	(.13***)	(.17***)	(.25***)	(.16***)	(.26***)	(.07)	(.02)	(.02)	(.14**)
Instrumental attitude	.02	---	-.01	.09	.04	---	---	---	---	---
Affective attitude	.09	.12	.22**	.05	.17*	.20^{a}	---	---	.08	.08
Perceived general health benefit	.05	---	-.08	.12	.00	.07	---	---	.06	---
Perceived general social benefit	---	---	---	---	---	---	---	---	---	---
Lack of time	---	---	---	---	-.08	---	---	---	---	-.21**
Lack of interest	.07	---	-.14	-.10	.03	-.04	---	---	---	-.02
Lack of company	.00	---	-.11	-.09	-.06	-.13^{a}	---	---	---	---
Lack of facilities	-.07	---	.08	---	-.01	---	-.02	.00	---	-.07
Perceived obstacles	-.05	---	-.03	---	.03	---	-.04	.14	---	---
General social norm	---	---	---	---	---	---	---	---	---	---
General modelling	---	---	---	---	.10	.00	---	-.06	---	---
General social support	.03	.11	-.01	.14^{a}	-.02	.13	---	---	---	.16^{a}
Self-efficacy general	.28***	.22**	.06	.17^{a}	.19**	.10	.24**	---	---	.05
General barrier self-efficacy	.06	.00	.07	.03	.00	.06	.00	---	---	---
Full model statistics										
Multiple R^2	.20***	.21***	.20***	.25***	.27***	.32***	.08***	.12**	.02	.14*

Beta: standardized regression coefficients in full model $^{*}p \leq .05$; $^{**} p \leq .01$; $^{***} p \leq .001$; $^{a} p \leq .10$

Table 3.4. Hierarchical regression analyses of physical activity in non-working (n = 316) and working (n = 148) cancer survivors based on cancer-related determinants

	Total MVPA (Beta)		**Days (Beta)**		**Leisure (Beta)**		**Household (Beta)**		**Transportation (Beta)**	
	Non-working	**Working**	**Non-working**	**Working**	**Non-working**	**Working**	**Non-working**	**Working**	**Non-working**	**Working**
Block 1 (Δ R²)	(.03**)	(.08**)	(.03*)	(---)	(.11***)	(.05**)	(.01*)	(.09*)	(---)	(---)
Age	---	---	-.12*	---	---	---	---	.06	---	---
Education level	---	-.33***	.10^{a}	---	.13*	---	-.10^{a}	-.17*	---	---
Marital state	---	---	---	---	---	---	---	.19*	---	---
Onco-revalidation	.12^{a}	---	---	---	.19**	.16*	---	---	---	---
Block 2 (Δ R²)	(.18***)	(.13***)	(.11***)	(.15***)	(.11***)	(.18***)	(.07***)	(.03)	(.04**)	(.06*)
Perceived cancer health benefit	.02	---	---	---	.07	.20**	---	---	---	---
Perceived cancer social benefit	.18**	---	.13*	.22**	.09	---	---	---	.13*	---
Physical side-effects	-.11^{a}	-.18*	-.08	---	-.07	---	-.07	---	---	---
Body image	---	---	-.01	---	-.07	---	.00	---	---	---
Fatigue	-.27***	---	.01	---	-.07	---	-.23**	.14	-.15**	---
Lack of energy	.00	-.06	-.18*	-.05	-.08	---	.03	-.09	---	-.10
Social norm physician	---	---	---	---	---	.13^{a}	---	---	---	---
Social norm survivors	---	---	-.10	---	---	---	---	---	---	---
Modelling survivors	.04	---	---	---	.07	---	---	---	---	---
Social support survivors	.02	---	.07	.14^{a}	.04	.04	---	---	---	---
Cancer barrier self-efficacy	.07	.25**	.07	.20*	.09	.29***	.06	.17^{a}	---	.18*
Full model statistics										
Multiple R²	.22***	.21***	.14***	.15***	.22***	.23***	.09***	.13**	.04**	.06*

beta: standardized regression coefficients in full model *$p \leq .05$; ** $p \leq .01$; *** $p \leq .001$; ^{a} $p \leq .10$

Table 3.5. Hierarchical regression analyses of physical activity in non-working (n = 316) and working (n = 148) cancer survivors based on general and cancer-related determinants

	Total MVPA (Beta)		Days (Beta)		Leisure (Beta)		Household (Beta)		Transportation (Beta)	
	Non-working	Working	Non-working	Working	Non-working	Working	Non-working	Working	Non-working	Working
Block 1 (Δ R²)	(.03**)	(.13***)	(.05**)	(---)	(.11***)	(.05**)	(.01*)	(.06**)	(---)	(---)
Chemotherapy	---	-.09	-.17**	---	.00	---	---	---	---	---
Radiotherapy	---	-.16*	---	---	---	---	---	---	---	---
Time post-treatment	---	---	---	---	---	---	---	---	---	---
Age	---	---	-.18**	---	---	---	---	---	---	---
Education level	---	-.28***	.10^{a}	---	.12*	---	-.11^{a}	---	---	---
Marital state	---	---	---	---	---	---	---	.25**	---	---
Onco revalidation	.16*	---	---	---	.26***	.20**	---	---	---	---
Block 2 (Δ R²)	(.20***)	(.14***)	(.14***)	(.22***)	(.14***)	(.26***)	(.08***)	(.02)	(.04*)	(.13***)
Affective attitude	---	---	.25***		.21***	.27***	---	---	---	---
Lack of time	---	---	---	---	---	---	---	---	---	-.22**
Lack of company	---	---	---	---	---	-.16*	---	---	---	---
General social support	---	---	---	.19*	---	---	---	---	---	.19*
Self-efficacy general	.20***	.21*	---	.18*	.22***	---	.15*	---	---	---
Perceived cancer health benefit	---	---	---	---	---	.08	---	---	---	---
Perceived cancer social benefit	.17***	---	.05	.17*	---	---	---	---	.13*	---
Physical side-effects	-.08	-.14^{a}	---	---	---	---	---	---	---	---
Fatigue	-.18**	---	---	---	---	---	-.17*	---	-.15**	---
Lack of energy	---	---	-.18**	---	---	---	---	---	---	---
Subjective norm oncologist	---	---	---	---	---	.27^{a}	---	---	---	---
Social support survivors	---	---	---	.09	---	---	---	---	---	---
Cancer barrier self-efficacy	---	.17*	---	.10	---	.18*	---	.15^{a}	---	.11
Full model statistics										
Multiple R²	.23***	.27***	.19***	.22***	.25***	.31***	.10***	.08**	.04**	.13***

Beta: standardized regression coefficients in full model $^{*}p \leq .05$; $^{**}p \leq .01$; $^{***}p \leq .001$; $^{a}p \leq .10$

Discussion

Study aims were twofold: (1) to explore general and cancer-related determinants of PA in a breast cancer population within six months post-treatment and (2) to identify the contribution of the cancer-related determinants and general determinants in explaining total and domain-specific PA.

Based on descriptive analyses for general and cancer-related determinants, our findings confirm the positive outlook and the desire to re-integrate in normal life reported by breast cancer survivors (Milne et al, 2007; Loescher et al, 1990). But findings also indicate that the feasibility and positive role of PA in the recovery of cancer is still not sufficiently known among women who survived breast cancer. Therefore, it is encouraging that more than half of the breast cancer survivors reported that their physician wanted them to be physically active (64% in the non-working group and 54% in the working group). Physicians must be aware of lower confidence of survivors in the positive effects of PA on cancer-related health and in the feasibility when suffering from cancer-related problems.

Furthermore, our study showed that both general and cancer-related determinants were important in explaining PA. Considering general determinants, self-efficacy, enjoyment, social support (accompanying by relatives and friends) and barriers (lack of company and lack of time) contributed to the explanation of PA. These findings did not differ from the general population and support the notion that general determinants of PA also remain important in explaining PA after a diagnosis and treatment for breast cancer (Rhodes et al, 2007; Pan SY, 2009). General self-efficacy and enjoyment proved fundamental and important determinants in explaining PA for all survivors. In contrast, the relationship of social support, lack of time and lack of company with PA was more dynamic and dependent on the working status of the women. Only in working breast cancer survivors, lack of time and company prevented them from PA, whereas social support from partner and friends contributed to more PA.

Differences between the non-working and working group also appeared to be important when considering the cancer-related determinants. Only return to normal life, as a benefit of PA was found to be an important determinant in both working and non-working survivors. In the non-working group, the amount of PA was also explained by the perceived cancer-related barriers. Fatigue, lack of energy and physical side-effects prevented survivors who were (still) not working after their treatment from being more active. In the working group, the self-efficacy of overcoming those cancer-related barriers explained most of the variance in PA.

The impact of working status on the explanation of PA is a notable finding since the post-treatment period is known as an unstable period due to the individuals' progress of re-integration (Allen et al, 2009). It confirms the need of tailoring interventions to the patient's own situation in contrast with standardized programmes. Interventions targeting non-working breast cancer survivors should focus on symptom management and should teach survivors to change their perception of the current symptoms as a barrier for PA or should support them to choose activities that do not interfere with those barriers. Interventions targeting working breast cancer survivors must support them overcoming cancer-related symptoms and increase their self-efficacy to continue PA even when suffering the cancer-related symptoms.

Our study showed that self-efficacy contributed to the explanation of PA in most domains in both non-working and working groups. Many studies already supported this relationship, however those studies often defined PA as exercise during leisure time or participation in structured exercise programmes (Rabin and Pinto, 2006; Rogers et al, 2008; Pinto and Trunzo, 2009). Furthermore, our results showed that self-efficacy was also important in explaining daily activities such as household activities, gardening and active transportation. Social influences and health benefits were of minor importance. The belief that PA can reduce fatigue and improve survival (decrease risk of recurrence and secondary diseases) could only predict leisure-time PA in a working population. However, it is possible that social influences and health benefits contribute to PA through the concept of self-efficacy (McAuley et al, 2003; Rogers et al, 2008). Further research is needed to clarify the possible mediating role of self-efficacy on those variables.

The present study is a unique contribution to the literature on PA in breast cancer survivors. First of all, this study examined a broad range of PA domains in breast cancer survivors and showed that the relative contribution of general and cancer-related determinants differed between these PA domains (Rogers et al, 2011). Leisure-time PA was mainly explained by the general determinants (enjoyment and general self-efficacy) and no significant relation with the cancer-related symptoms was found. Since previous studies were focused on leisure-time PA, the importance of cancer-related symptoms could be underestimated (Miedema et al, 2008). Second, the present study focused on a population that just survived breast cancer and transitioned from patient to survivor. The post-treatment period is seen as a period of uncertainty with a variety of new challenges, higher stress levels and changed social influences (Allen et al, 2009). To capture the transition period's acute nature, our study focused on a well defined time interval (3 weeks to 6 months post-treatment). As a consequence, this study gives new perspectives for PA promotion in survivorship by reporting on the importance of working status and the perception of returning to normal life in explaining PA. As our results showed, working status was related to essential differences in associated determinants. Finally, this study included a large variety of important and relevant psychosocial determinants of PA, instead of only focusing on constructs of one major theoretical model (Wood, 2008). This leads to better understanding the relative influence of several determinants.

Unfortunately, some limitations are present. The data relied on self-reports of PA, which are subject to possible overreporting (Rzewnicki et al, 2003). Despite truncating PA levels, total MVPA values remained high. Total scores were calculated by summing all minutes of moderate or vigorous activities of the separated PA domains which leads to possible overestimation of the total score. Accordingly, as for some cancer patients activities of light intensity during household (e.g. ironing, washing dishes, making beds) and work (e.g. standing during teaching, custodial work) (<3MET) are perceived as rather moderate to vigorous activities (Servaes et al, 2007), higher subjective levels of MVPA could be reported in this population.

We conclude that although mean values differ, both general and cancer-related determinants are important in explaining PA in breast cancer survivors. Interventions should be tailored to the working status and the domain of PA that is targeted. For women in the transition from patient to survivor, PA seems to be an important tool to return to normal life. Subsequently PA, including daily activities, should be encouraged.

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4

Treatment-related and psychosocial variables in explaining physical activity in women three weeks to six months post-treatment of breast-cancer

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Abstract

OBJECTIVE: This study examined treatment-related and psychosocial variables in explaining total and leisure-time physical activity in breast cancer survivors three weeks to six months post-treatment.

METHODS: A questionnaire was used to measure total and leisure-time physical activity and relevant determinants among 464 breast cancer survivors (aged 18 to 65 years).

RESULTS: Personal control was an important overall determinant in explaining physical activity in breast cancer survivors. The impact of treatment-related variables and psychological functioning depended on the working status of the women. Fatigue and poor body image prevented non-working women from being sufficiently physically active. In working women, chemotherapy and arm symptoms negatively influenced physical activity, whereas therapy side-effects (headaches, hot flashes, feeling unwell) and poor body image positively influenced physical activity. Social support and coping strategies could not explain post-treatment physical activity levels.

CONCLUSION: Personal control, treatment-related variables and psychological functioning influenced physical activity after cancer treatment. Relations depended on the working status of the women.

CLINICAL IMPLICATIONS: Incorporating self-control methods in physical activity interventions after breast cancer could be helpful. Furthermore, interventions should be tailored to the experienced symptoms (fatigue, arm-problems, body image) and working status of women.

Keywords

Physical activity, exercise, cancer survivor, determinants, psychosocial variables

Introduction

The post-treatment period in cancer patients is often described as a stressful event (Mullens et al, 2004). A sense of vulnerability can persist as a result of exposure to physical and psychosocial symptoms and the fear of recurrence. Accordingly, many survivors feel abandoned as contact with the medical staff decreases and a certain safety net disappears. Besides those negative consequences, there are also positive aspects after surviving breast cancer. Indeed, survivors are often engage in a process of re-interpreting meaning of life (Cordova et al, 2001; Aspinwall and McNamara, 2005).

The way women deal with their transition from cancer patient to survivor is related to many factors, namely treatment-related aspects, personal and social resources and coping responses (Schulz and Mohamed, 2004). Those factors can also influence health behaviour and behaviour changes after cancer (Park et al, 2008).

One health behaviour that seems important for cancer survivors is participating in physical activity (PA). PA contributes to revalidation after cancer through its beneficial effect on the experienced symptoms and quality of life (Penedo and Dahn, 2005; Knols et al, 2005). Moreover, regular PA can positively influence survival and the prevalence of 'secondary' diseases (Holmes et al, 2005; Pierce et al, 2007), and is likely to reduce the risk of breast cancer recurrence (Ibrahim and Al-Homaidh, 2010). To profit from the health benefits of PA, cancer survivors are recommended to be physically active as a part of everyday life (WCRF, 2007). Further, moderate rather than vigorous intensity activities are beneficial to decrease the symptoms experienced by breast cancer survivors (Rogers et al, 2011). Consequently, health interventions for breast cancer survivors should consider a broad range of PA types and should not only focus on exercise programmes and sports participation.

To identify the determinants of the adoption of an active lifestyle post-treatment, a variety of physical and psychosocial resources must be considered (Taylor et al, 2010). Among breast cancer patients, treatment-related aspects, psychological functioning, illness perceptions, social support, and coping responses have been found to influence PA (Reardon and Aydin, 1993; Harper et al, 2007; Emery et al, 2009). However, few studies have examined these associations, resulting in mixed findings (Park and Allison, 2007).

First, some studies have examined the influence of medical and physical factors on PA. Fatigue and arm symptoms, which are common side effects of breast cancer, contribute to poorer physical functioning and PA, even when treatment has been completed (Kärki et al, 2005; Bower et al, 2006; Perkins et al, 2009; Lee et al, 2011). Secondly, it is argued that PA is influenced by a change in psychological functioning post-treatment through lower self-esteem, body image problems and higher anxiety and depression levels after cancer (Bertero and Chamberlain, 2007; Pinto and Trunzo, 2004). In a healthy population, lower self-esteem and body image problems are associated with reduced levels of PA (Schmalz, 2010) and one study reporting on body image in cancer survivors found similar results (Whitehead and Lavelle, 2009). Depression and anxiety showed mixed relations with PA behaviour (Park and Allison, 2007). In several studies, depressive mood and anxiety among women treated for breast cancer were associated with lower physical activity levels (Emery et al, 2009; Reardon and Aydin, 1993; Hong et al, 2007; Chambres et al, 2009), while other studies found that higher baseline depression, anxiety and fear of recurrence might motivate survivors to engage in positive health behaviours such as PA (Mullens et al, 2004; Pinto et al, 2002). These contrasting results suggest that other factors may interact in the relation of psychological functioning and PA (Park and Allison, 2007). Indeed, a third group of factors that must be considered are illness representations. There is preliminary evidence that causal and controllability beliefs (two aspects of illness representation) guide behaviours to prevent recurrence among breast cancer survivors (Jorgensen et al, 2009; Costanzo et al, 2010), although no significant associations were found for PA (Rabin and Pinto, 2006; Costanzo et al, 2010). Further, a few studies that have reported on the relation between PA and controllability (personal and treatment control) and timeline (course of the disease) beliefs considered the experienced symptoms and post-treatment condition. Social support also seems to be an important factor in making adaptive changes. For example, lack of social support was identified as a significant barrier for leisure-time PA (Pinto et al, 2002; Emery et al, 2009). However, strong social support in terms of providing practical assistance with everyday tasks may result in passive and care-dependent patients (Gill et al, 1987), which could be linked to lower levels of household and transportation PA. These associations remain unclear as the influence of different types of social support on PA has not been studied yet in a breast cancer survivor population. As a final point, it is argued that coping also has an impact on health behaviours (Park et al, 2008). Approach coping (e.g. problem solving, reappraisal) is related to positive behavioural change and avoidant coping is related to negative behavioural change (Park et al, 2008). However, only one study has confirmed these findings for the association with PA (Reardon and Aydin, 1993).

As treatment-related variables, psychosocial functioning and coping responses have rarely been examined within the same study, so there is still an incomplete understanding of how those factors are related to PA in breast cancer patients 3 weeks to 6 months post-treatment. Therefore, the purpose of this study was to evaluate the coherent associations of (a) treatment-related variables (b) psychological functioning, (c) illness representations, (d) social support and (e) coping on total PA and PA during leisure time in breast cancer survivors following the cessation of treatment.

Methods

Participants and procedure

Patients were referred through oncologists, gynaecologists and breast cancer nurses based on the breast cancer patients file in different Belgium hospitals. To be eligible for the study, participants had to be: (a) aged between 18 and 65 years; (b) survivor of a primer non-metastatic breast carcinoma; (c) completed surgery, chemotherapy and/or radiation treatment three weeks to six months ago; (d) Dutch speaking. Patients were excluded in case of (a) any neurological, severe psychological, cognitive problems; (b) pregnancy. All patients received an informed consent with a description of the study. After permission was granted, questionnaires were sent to all patients and returned via a pre-paid envelope after completion. If no reaction was received within 2 weeks, patients were contacted again to stimulate participation. The study had a cross-sectional design. Ethical clearance was obtained from the ethical committee of the Ghent University (B67020096619).

Measures

Basic demographic, educational and medical information. Questionnaire assessed age, marital status, education, occupation, date of diagnosis, stage at diagnosis and received treatments. It was also noted if women participated in ‘onco-revalidation’(fitness sessions and psychosocial education during 12 weeks).

Physical symptoms were derived from symptom scales of The European Organisation for Research and Treatment of Cancer, Quality of Life Questionnaire-Breast Cancer (EORTC QoL-BR23) (Aaronson et al, 1993; Fayers et al, 2001). The EORTC QLQ-BR23 is a 23-item breast cancer-specific questionnaire for evaluation of the site-specific information on QOL. Three symptoms scales were considered: *therapy side effects (7 items; Cronbach’s α=.76)*, *breast symp-*

toms (4 items; α=.80) and *arm symptoms (3 items; α=.71)*. A higher score indicated on a 4-point Likert scale represented a higher ("worse") level of symptoms. *Fatigue* was measured by the Functional Assessment of Cancer Therapy – Fatigue questionnaire (FACIT-fatigue). A higher score (rated on a 5-point Likert scale) indicates an increased fatigue. This instrument has been used in breast cancer survivors and showed good reliability and validity (*13 items; α=.94*) (Alexander et al, 2009).

Psychological functioning. *Depression* was measured by the depression subscale of the Hospital Anxiety and Depression Scale (HADS) *(7-items; α=.84)* (Zigmond and Snaith, 1983; Spinhoven et al, 1997), with higher scores reflecting greater depressive symptoms. The Rosenberg Self-Esteem Scale (RSE) was used to evaluate global *self-esteem*, which refers to an overall sense of personal worth (Rosenberg, 1965). Psychological functioning concerning *body image* was derived from the EORTC QoL-BR23 (Aaronson et al, 1993; Fayers et al, 2001) (4 items; *α=.87)*. A higher score represent a better body image. Women expressed their worries about their health in the future on the one-item scale *future perceptive* from the EORTC QoL-BR23. A higher score indicates fewer worries. All items of HADS, RSE and EORTC QoL-BR23 were rated on a 4-point Likert scale.

Illness representations were assessed using the Illness Perceptions Questionnaire-revised (IPQ-r) (Moss-Morris et al, 2002). Five subscales (6 items each, using 5-point Likert scales) were of interest: *timeline* (acute versus chronic course; *α=.84*), *consequences* (effects and outcome of the disease; *α=.78*), *emotional representations* (experienced distress; *α=.86*), personal control (personal capacity to control and cure the situation; *α=.75*) and *treatment control* (*α=.58*). An additional item assessed the perceived *causal attribution* of physical activity in the development of the cancer. High scores on timeline and consequences represent strong beliefs about chronicity and negative consequences of the post-treatment condition. High scores on personal and treatment control represent positive beliefs about controllability of the post-treatment condition.

Social Support. The Social Support List – Interactions (SSL-I) (Van Sonderen, 1993) was used to assess different types of supportive interactions: *instrumental support* (practical assistance; *7 items; α=.66*); *informative support* (expectations and constructive feedback; *4 items; α=.66*) and *emotional support* (showing that one is loved, esteemed, valued and cared for; *19 items*; *α=.92*). The latter scale was obtained by summing items of following subscales: everyday emotional support, emotional support with problems, esteem support and social companionship. Participants indicate how frequently certain social interactions happen to them on a 4-point Likert scale from 1 (seldom or never) to 4 (very often).

Participants' **coping strategies** were measured using the Dutch version of the Coping Inventory for Stressful Situations (CISS-NL) (Endler and Parker, 1990; Endler et al, 2004). This 48-item questionnaire assesses three coping strategies (*16-items each*): *problem-oriented coping* (dealing with the problem at the hand; *α=.91*), *emotion-oriented coping* (concentrating on the resultant emotions; *α=.90*) and *avoidance coping* (seeking distraction and seeking company; *α=.85*). The use of these coping strategies were rated on a 5-point Likert scale from 1 (not at all) to 5 (very much).

To assess **physical activity**, the long version of the Flemish Physical Activity Questionnaire (FPAQ) was used. The FPAQ was developed to collect information on different dimensions of PA during a usual week and has been proven to be reliable and valid (Matton et al, 2007). For the present study, total physical activity and physical activity during leisure time were calculated and involved only activities with MET values equal or more than three (Ainsworth et al, 2000). The '*total moderate-vigorous-intensity physical activity index*' *(total MVPA)* was computed by summing MVPA during household and gardening activities, MVPA during occupation, transport and leisure time. All variables were expressed as the average time spent per week (min/week).

Statistical analyses

Analyses were carried out using SPSS 15.0 package. Data analyses included basic descriptive statistics for all respondents. As differences in both PA behaviour and determinants were quite substantial, we expects different approaches are needed for working and non-working women. Therefore analyses were stratified for working status. Differences between the working and non-working group for continuous variables were analysed using independent t-test. Chi-square tests were used for categorical variables. Separate multiple regression analyses were conducted to examine the contribution of (1) treatment-related aspects, (2) psychological functioning, (3) illness representations, (4) social support and (5) coping to the explanation of total MVPA and leisure-time MVPA within both the working and non-working group. All regression analyses were controlled for participation in onco-revalidation and weeks post-treatment. To generate a general regression model, all significant factors ($p \leq .10$) of the five regression analyses were entered together in a final multiple linear regression analysis. For all analyses a *p*-value < 0.05 was considered significant.

Results

Study population

Of the 802 breast cancer survivors who received a questionnaire, 547 (68%) returned their questionnaire. Seventy-three participants did not meet the inclusion criteria (39 were outside the time interval, 25 had an earlier diagnosis of (breast)cancer, 4 were older than 65 years, 2 had another diagnosis, 2 reported metastases and 1 had another native language). Ten surveys could not be used due to missing data.

Data of 464 participants (64%) were included in the analyses. Of those, 32% (n = 148) were (still or again) at work. Non-working breast cancer survivors reported a mean age of 53.1 years (SD=8.2) and were on average 13.2 weeks post-treatment (SD=7.4). Working breast cancer survivors were 49.3 years (SD=7.5) and were on average 16.2 weeks post-treatment (SD=6.8). Non-working survivors reported significantly less total MVPA (t (462)=-8.6; p<.001), whereas MVPA during leisure time did not differ between the non-working and working group. Participation rate for ‘onco-revalidation’ was 16% for non-working and 7% for working survivors.

Table 4.1 shows means of studies variables for working and non-working women. Non-working survivors reported relatively more physical symptoms, lower psychological functioning and perceived more negative illness representations. Subsequently, non-working survivors reported higher levels of instrumental support (t(453) = 2.1;p<.05) and used less problem-oriented (t(449)=-3.3;p<.001) and avoidance coping (t(449)=-2.7;p<.05) but more emotional-oriented coping (t(449)=.26;p<.05) compared to working survivors.

Table 4.1. Means and mean differences for physical and psychosocial variables, illness representations, social support and coping in non-working and working breast cancer survivors.

		Non-working group		Working group		
	Range	**M**	**SD**	**M**	**SD**	**Δ**
Physical symptoms						
Side-effects	(0-100)	27.6	21.9	23.5	19.3	4.1*
Arm symptoms	(0-100)	26.8	25.5	24.5	21.3	2.3
Breast symptoms	(0-100)	34.1	33.3	30.5	24.5	3.6
Fatigue	(0-52)	16.9	11.6	13.5	9.3	3.4***
Psychological functioning						
Depression	(0-21)	4.7	4.0	2.9	2.9	1.8***
Self-esteem	(0-30)	19.2	4.4	21.0	4.2	- 1.8***
Body image	(0-100)	64.2	29.3	66.2	30.5	- 0.2
Future perspectives	(0-100)	49.4	30.6	51.1	29.7	- 1.7
Illness representations						
Timeline	(6-30)	17.4	4.8	18.0	5.2	- 0.6
Consequences	(6-30)	18.2	4.8	16.4	4.7	1.8***
Causes	(1-5)	2.1	1.0	2.0	0.9	0.1
Personal control	(6-30)	20.3	4.1	21.5	3.6	- 1.2**
Treatment control	(5-25)	17.8	2.8	18.1	2.7	- 0.3
Emotional representation	(6-30)	17.1	5.1	15.6	5.0	1.5**
Support						
Emotional support	(23-92)	58.3	11.1	58.0	10.7	0.3
Instrumental support	(7-28)	13.0	3.0	12.4	3.1	0.6*
Informative support	(4-16)	8.0	2.0	8.3	2.0	- 0.3
Coping						
Problem-oriented	(16-80)	50.3	11.1	53.8	10.0	- 3.3***
Emotional-oriented	(16-80)	34.7	11.8	31.8	10.6	2.9**
Avoidance coping	(16-80)	39.8	10.7	42.7	10.2	- 2.7**

*p ≤.05; ** p ≤.01; *** p ≤.001; [a] p≤.10

Regression analyses in the non-working group of breast cancer survivors

Separate regression analyses in the non-working group showed that most variance in total MVPA was explained by the model based on treatment-related variables (10%) and the model based on illness representations (9%), whereas the other models based on respectively psychological functioning (6%), social support (2%) or coping strategies (4%) explained smaller variances (Table 4.2). Only the models based on treatment-related variables (6%), psychological functioning (6%) and illness representations (6%) contributed also significantly to explaining the variance in MVPA during leisure time.

Table 4.2. Separate regression analyses of physical activity in non-working (n=316) and working (n = 146) breast cancer survivors for treatment-related and psychosocial variables.

	Non-working group				Working Group			
	Total MVPA		Leisure MVPA		Total MVPA		Leisure	
	R²	Beta	R²	Beta	R²	Beta	R²	Beta
Medical/physical aspects	.10***		.06**		.16***		.03	
Chemotherapy		-.02		.06		-.21**		.04
Radiotherapy		-.01		-.03		-.15^{a}		-.07
Side-effects		.03		-.09		.33***		.10
Arm symptoms		-.11^{a}		-.09		-.21**		-.11
Breast symptoms		.02		.01		-.01		-.01
Fatigue		-.29***		-.15*		-.16^{a}		-.11
Psychological functioning	.06**		.06**		.01		.10**	
Depression		-.16*		-.14*		-.07		-.19*
Self-esteem		.01		-.02		.01		.16^{a}
Body image		.10		.20**		-.01		-.15^{a}
Future perspectives		.03		-.08		-.04		-.10
Illness representations	.09***		.06**		.05		.12**	
Timeline		.10		.07		.02		.13
Consequences		-.10		-.06		.08		.00
Causes		-.19***		-.12*		-.08		.00
Personal control		.18**		.20**		.20^{a}		.36***
Treatment control		.00		-.06		.01		.01
Emotional representation		-.03		-.04		.01		.12
Social Support	.02^{a}		.01		.03		.01	
Emotional support		.12^{a}		.13^{a}		.15		.08
Instrumental support		-.02		-.08		.05		.06
Informative support		-.16*		-.08		-.02		-.02
Coping	.04**		.01		.02		.03	
Problem-oriented		-.07		-.05		.05		.10
Emotional-oriented		-.18**		-.07		-.10		.00
Avoidance coping		.02		.10^{a}		-.14		.12

'beta' Standardized regression coefficients *p ≤.05; ** p ≤.01; *** p ≤.001; ^{a} p≤.10

As table 4.2 shows, increased fatigue and arm symptoms, as *treatment-related variables* and higher depression and poor body image as *psychological functioning* explained lower levels of MVPA, although the association of body image was only significant for leisure-time MVPA. Perceiving less personal control and attributing the cancer to a lack of PA (cause) were important *illness representations* associated with lower levels of total and leisure-time MVPA.

Concerning *social support*, women who received less emotional support also reported lower levels of total and leisure-time PA, whereas those who received less informative support reported higher levels of total MVPA. Moreover, using more emotion-oriented coping strategies explained lower levels of total MVPA whereas using more avoidance coping strategies tended to explain more leisure-time MVPA.

The general model (Table 4.3) based on significant factors of the separate regression analyses explained 15% of the variance in total MVPA and 9% of the variance in leisure-time MVPA.

Higher levels of total MVPA were explained by less fatigue (beta=-.20) and less attribution of PA to the development of their cancer (beta=-.17), but more personal control (beta= .13). More leisure-time MVPA was explained by better body image (beta=.16), fewer perceived causes (beta=-.12) and higher personal control (beta=.13).

Table 4.3. Regression analyses of physical activity in non-working (n=316) and working (n = 146) breast cancer survivors based on treatment-related and psychosocial variables.

	Non – working group				Working group			
	Total MVPA		Leisure MVPA		Total MVPA		Leisure MVPA	
	R^2	Beta	R^2	Beta	R^2	Beta	R^2	Beta
Chemotherapy		---		---		-.24**		---
Radiotherapy		---		---		-.14^{a}		---
Side-effects		---		---		.36***		---
Arm symptoms		-.11^{a}		---		-.22*		---
Fatigue		-.20**		-.11		-.15^{a}		---
Depression		-.02		.02		---		-.10
Self-esteem		---		---		---		.14
Body image		---		.16**		---		-.18*
Timeline		---		---		---		---
Causes		-.17**		-.12*		---		---
Personal control		.13**		.13*		.23**		.25**
Emotional support		-.02		-.05		---		---
Informative support		-.11^{a}		---		---		---
Emotional-oriented		.00		---		---		---
Avoidance coping		---		.06		---		---
Full model statistics								
Multiple R^2	.15***		.09***		.21***		.15***	

‘Beta’ standardized regression coefficients, *p ≤.05; ** p ≤.01; *** p ≤.001; ^{a} p≤.10

Regression analyses in the working group of breast cancer survivors

In the working group, separate regression analyses showed that only the model based on treatment-related variables (16%) significantly explained total MVPA, whereas only the models based on psychological functioning (10%) and illness representations (12%) explained leisure-time MVPA (Table 4.2). Receiving chemo- and radiotherapy, having fewer therapy side-effects, more arm symptoms and more fatigue symptoms were *treatment-related variables* that explained lower levels of total MVPA. Further, lower depression and body image but higher self-esteem were important *psychological variables* in explaining more leisure-time MVPA, while higher personal control was the only *illness representation* that explained both higher levels of total and leisure-time MVPA. The regression analyses with social variables and those with coping revealed any significant data.

Finally, the general model (table 4.3) based on significant factors of the separate regression analyses explained 21% of the variance in total MVPA and 15% of the variance in leisure-time MVPA. Higher levels of total MVPA were explained by receiving chemotherapy (beta=-.24) and radiotherapy (beta=-.14), more side-effects (beta=.36), less arm symptoms (beta=-.22) and higher perceived personal control (beta=.23). Further, higher levels of leisure-time MVPA was explained by lower body image (beta=-.18) and higher personal control (beta=.25).

Discussion and conclusion

Discussion

This study examined the influence of treatment-related variables, psychological functioning, illness representations, social support and coping strategies on physical activity in a population of breast cancer patients who have transitioned from patient to survivor.

When considering the general regression model, our study showed that personal control was an important overall determinant in explaining PA. In the present study, personal control was defined as the personal capacity to manage the post-treatment condition which is characterized by (long-lasting) side-effects and ongoing therapy (three out of five women received hormonal therapy). Interestingly, it is also in this phase of the cancer trajectory that women could experience a strong sense of control (Henselmans et al, 2009). They are no longer monitored strictly and are assumed to get back to life as usual, without cancer playing a major role. Besides, a high sense of personal control can promote positive attributions about one's own role in limiting the negative impact of the disease (Hobfoll and Walfisch, 1986). Being more physically active can assist in this process of re-integration. However, previous research that focused on illness representations and health behaviour in cancer survivors did not reveal a major role of controllability beliefs in guiding PA behaviour after cancer. In these studies, controllability was often defined differently, as strategies that can cure the cancer or prevent a recurrence (Jorgensen et al, 2009; Costanzo et al, 2010). Our results indicate that further research and interventions, including personal control, should focus on the controllable aspects of cancer such as reducing the impact of the cancer on daily living (Thompson, 2001). The findings also denote to broaden the scope of control concepts from control on the behaviour (PA) to control on the post-cancerous situation. Further interventions for promoting PA could profit from theories from PA promotion models and theories from chronic care models.

Besides the importance of personal control, treatment-related symptoms and psychological functioning also determined PA after treatment for breast cancer. Treatment-related aspects (received therapy, side/arm symptoms and fatigue) only contributed to explaining total MVPA and did not interfere with leisure-time MVPA, whereas psychological variables (body image and depression) were only important in explaining leisure-time MVPA. The overall importance of depression in explaining MVPA disappeared when considering the general model and only body image remained as an important determinant of leisure-time PA. Although the accumulated literature indicates that body image problems are affected by breast cancer treatment during the first year of survivorship (Pinto and Trunzo, 2004; Fobair et al, 2006; Bertero and Chamberlain, 2007), few studies have examined the association with PA. One qualitative study in older breast cancer survivors found body image problems to be an important barrier for PA participation (Pinto et al, 2002). Encouraging women to be physically active in their home environment can overcome this barrier. Moreover, Pinto and Trunzo (2004) demonstrated that breast cancer survivors who exercised reported better body esteem than their sedentary peers. This suggests that being physically active might offer a protection against poor body image.

Some noteworthy findings of this study are the differences between non-working and working cancer survivors. Fatigue, arm symptoms and personal control were relevant variables in explaining PA independent from women's working status. In contrast, the impact of received treatment, therapy side-effects, body image and causal attribution on explaining PA depended on the working status of the women. In our study, working survivors reporting more therapy side-effects (headaches, hot flashes, feeling unwell) and lower body image, participated more in MVPA. Those results are rather surprising and differ from previous studies (Pinto et al, 2002; Rogers et al, 2011). However, our findings could indicate that working breast cancer survivors might be more active in seeking solutions (like being physical active) to deal with the experienced symptoms. Conversely, non-working women who attributed their cancer to a lack of PA did not report more post-treatment PA. It seems that non-working women are less able to increase their PA behaviour, even if they belief that a lack of PA contributed to their cancer. Further research is needed to understand these differences, in particular the relation of side-effects (including menopausal symptoms) and PA. It could be that the transition from pre to post-menopause interact with the relation of side-effects and more PA. Menopausal symptoms must be differentiated from other cancer-related symptoms as they are both in a different way related with PA.

In contrast with the literature, coping strategies, social support and cancer-related worries seemed less important in explaining PA after breast cancer treatment (Park and Allison, 2007). For coping strategies, mainly the lack of an association between problem-oriented coping and PA contradict previous conclusions on the important role of adaptive coping on positive changes in exercise habits (Reardon and Aydin, 1993; Park et al, 2008). Our study only noted that non-working women, using avoidance coping, tended to participate more in leisure-time PA. This might be explained by their increased contribution in ‘seeking company’ to avoid their current stress and problems which could imply the participation in (group) exercise programmes and other sports activities. In that way, avoidance coping tended to be an active coping style, which is in the literature often associated with the engagement in health behaviours (Park et al, 2008). The present study used the Coping Inventory for Stressful Situations (CISS-NL) which assessed how women manage stressful situations without specifying the nature of the stressors to the cancer situation. It may be that coping strategies differ according to general or cancer-related stressful situations. Another result of this study which contradicts previous studies (Harper et al, 2007; Emery et al, 2009) was the weak association between social support and MVPA. However, those studies who underscore the important role of social support do not specify this association for the transition period. As this period is characterized by diminished support and social isolation (Bloom et al, 2008), the availability of social support must be taken into account when considering social support as an important resource for PA habits. Furthermore, our study did not specify social support for PA but considered more general concepts of support. At last, this study did not confirm the possible role of cancer-related worries on PA levels in women who just survived their breast cancer (Harper et al, 2007). In this study, cancer-related worries were examined through the concepts of future perspectives (worries about their health in the future) and emotional representations (actual worries due to the cancer). Comparable to Chambers and colleagues, we can conclude that factors apart from cancer-related worries may be important in influencing PA after cancer (Chambres et al, 2009).

Strengths of this study include the use of a broad range of treatment-related and psychosocial variables to understand physical activity in breast cancer survivors (Park and Allison, 2007). Consequently, it was possible to test these variables in an aggregated context which led to more comprehensive results compared to previous studies. Secondly, by distinguishing leisure-time PA from total PA, more domain-specific information was provided. Only two recent studies have distinguished different PA domains among cancer survivors [Devoogdt et al, 2010; Rogers et al, 2011). Both indicated the need to target a broad range of PA types when examining PA determinants, since associated factors differed between different types of PA. Our study is the first study that examines both treatment-related and psychosocial correlates on both total and leisure-time PA.

Limitations of this study include the use of self-reports of PA, which are subject to possible over reporting (Rzewnicki et al, 2003). In addition, total scores were calculated by summing all minutes of MVPA of the separate domains which leads to possible overestimation of the total score. Besides, as for some cancer patients activities of light intensity during household and work (<3MET) are perceived as rather moderate to vigorous activities (Servaes et al, 2007), higher subjective levels of MVPA could be reported in this population. Secondly, the cross-sectional study design precludes conclusions relative to causal relationships among the tested variables. Finally, because the main objective was to look for the contribution of illness-related and psychosocial functioning in explaining PA, no specific attitudes, beliefs (e.g. self-efficacy) (Charlier et al, 2011) and environmental variables towards PA were analyzed. Both types of determinants must also be considered in intervention development and future research.

Conclusion

Breast cancer survivors perceiving low personal control on their post-treatment condition are at increased risk for an inactive lifestyle. In addition, those survivors suffering from fatigue and arm symptoms also reported less PA during daily activities. Body image problems mainly prevent non-working women from participating in leisure-time PA whereas working women were more physically active, even when suffering from poor body image or therapy side-effects (headaches, hot flashes, feeling unwell).

Practical implications

As survivors perceiving more control on the post-treatment condition reported more PA, this argues for interventions that can increase perceptions of control or real controllability. This contributes to the growing focus in health-care on patient-centered care, self-management of illness and patient empowerment (Rotegard et al, 2010; Rotegard et al, 2011). To enhance personal control in the post-treatment condition, survivors should receive information on how the impact of cancer on their daily life can be reduced. To ensure that this information will be implemented in daily life, advice should be tailored to real-life situations. From this perspective, home-based interventions that assist survivors in their transition from patient to survivors could be beneficial (Pinto et al, 2005; Vallance et al, 2007). Moreover, those interventions should be delivered as structured, progressive, skills-training programmes that ensure success and control at each stage before progression to the next (van Weert et al, 2008).

Furthermore, extra advice should be given for those experience fatigue, arm symptoms and poorer body image that can arise as a consequence of the cancer. Especially, non-working survivors could benefit from cognitive therapy to improve their well-being and body image which will facilitate an active lifestyle. Advice should also include practical tips (e.g. ‘plan your activities on those moments when fatigue is less’ or ‘start with being active in your familiar environment when suffering from low self-image’).

Overall, the previous suggestions argue for tailored advice. Among diseased conditions, computer (web-based) tailored advice is found a beneficial interactive medium to provide patient centered support and to increase patient autonomy and self-management (Glasgow, 2010). Future studies may focus on the development and feasibility of web-based PA advice for breast cancer survivors.

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5

The design and feasibility of a pedometer-based computer-tailored physical activity advice for breast cancer survivors three weeks to six months post-treatment

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Abstract

BACKGROUND: Healthy women are encouraged to take 10 000 steps a day to receive health benefits. It is well recognized that breast cancer survivors can also benefit from an active lifestyle and an increased daily step count. This study aimed to adapt a computer-tailored step advice for the general population, into a feasible advice for breast cancer survivors and to test its usability.

METHODS: First, several adaptations were done to the original intervention; cancer-related physical activity barriers and beliefs were added to the original advice, together with self-management strategies to improve survivors' personal control. Second, the adapted advice was evaluated in two phases. Phase 1 involved a usability testing in healthy women and breast cancer survivors followed by adequate refinements of the website. Phase 2 involved a process evaluation during three weeks in breast cancer survivors.

RESULTS: Preliminary usability testing (phase 1) revealed some problems related to the misinterpretation of the online assessment. After refining the questionnaire and advice, survivors evaluated the advice as interesting, attractive to read, comprehensible and credible. Specifically inactive survivors found the advice novel, but too long. The process evaluation (phase 2) indicated that the majority of the women reported increased steps counts, predominantly derived from an increased participation in household activities and walking. Monitoring step counts by using a pedometer was perceived as an important motivator to be more active.

CONCLUSION: This study provides initial support for the usability of a pedometer-based computer- tailored physical activity advice for breast cancer survivors. This study precedes a randomized controlled trial which will be needed to determine the efficacy of the newly developed advice.

Keywords

Breast cancer survivor, Internet, Physical activity, Step-counts, Computer-tailoring

Background

Nowadays, follow-up care for patients who just completed primary treatment for breast cancer receives increased priority (Hewitt et al, 2006). Providing breast cancer survivors with a plan to control their cancer and associated symptoms supports patients' re-integration process and can prevent secondary diseases and long-term symptoms (Knols et al, 2005; Holmes et al, 2005). The participation in physical activity (PA) has become an integrated part of the follow-up programmes for breast cancer survivors (WCRF, 2007). In general, PA can be defined as 'all types of movement that increases energy expenditure' and capture a broad range of activities including walking, household and gardening, outdoor life, exercise and training (Caspersen et al, 1985). Individuals of all ages, healthy or ill can benefit from being active (WCRF, 2007). In breast cancer survivors, PA contributes to the prevention of late side-effects and secondary diseases and it supports breast cancer survivors' process of rehabilitation (Speck et al, 2010). Moreover, PA is seen by survivors of breast cancer as an important tool to return to 'normal' life which includes activities of daily living and occupation (Charlier et al, 2011; Larsson et al, 2008).

Promoting PA in breast cancer survivors is therefore an important task for the society in general and for healthcare in particular. As breast cancer becomes the leading cancer in European women and the mean 5-year survival reaches almost 80% (Rosso et al, 2010), a growing population of breast cancer survivors of all ages arises. Consequently, the promotion of PA must reach breast cancer survivors of all age groups, those being professionally active or retired, including those suffering from cancer-related symptoms. In addition, women reveal different beliefs about PA (Rhodes and Blanchard, 2007) and, especially in this population, suffer from specific, individual barriers for PA. Therefore interventions for PA promotion targeting a broad range of breast cancer survivors should be tailored to the individual characteristics and needs of these women and the intervention should also be easily accessible.

To accomplish this goal, a cross-sectional study was conducted on general and cancer-related psychosocial correlates of PA in breast cancer patients 3 weeks to 6 months post-treatment, as a preparatory step to guide further intervention development (Charlier et al, 2011; Charlier et al, 2012). Cancer-related barriers such as fatigue, lack of energy and physical side-effects and the meaning of PA as a way to return to normal life were found to be important cancer-related determinants in breast cancer survivors. In addition, experienced symptoms (fatigue, arm symptoms and body image) and perceived personal control on their post-treatment situation influenced PA after cancer treatment. Though cancer-related determinants were important, the results also illustrated that general determinants (e.g. lack of time, enjoyment and self-efficacy), reported by breast cancer survivors, did not differ from those in a non-diseased population (Charlier et al, 2011). This is in line with the study of Rhodes and Blanchard (2007) who generally provided evidence that health condition does not affect the determinants of PA completely. In that way, it seemed that theoretically based advice developed for primary prevention in the general population could be used as the basic component in promoting PA in breast cancer survivors.

To further tailor the interventions to the survivors' beliefs and barriers for PA, some interventions used a combined approach using print materials and telephone counselling (Vallance et al, 2007). However, those approaches can be expensive and time-consuming. In the general population, researchers advocated the use of computer-tailored PA advice (Kroeze et al, 2006; Lustria et al, 2009; Krebs et al, 2010), as it is a method to provide personally advice in a very systematic and theoretically based way. Computer-tailoring is a low-cost method that facilitates the delivery of personalized feedback to a large (and heterogeneous) population. The tailored advice is derived from an individual assessment and is selected by data-driven decision rules (Kreuter, 2000; Krebs et al, 2010), resulting in information optimally adapted to the specific individual characteristics. Several studies give promising indications that computer- tailored PA interventions are effective in healthy adults (Napolitano et al, 2003; Spittaels et al, 2007; Vandelanotte et al, 2007; Van Stralen et al, 2009).

Apart from receiving tailored advice, survivors should also be provided with practical methods to increase their self-control and monitoring abilities of their PA achievements (Van Weert et al, 2008). Prior studies suggested home-based step goal interventions to incorporate self-control and monitoring methods and to promote PA during daily activities (Irwin et al, 2008; Knols et al, 2010). These interventions are based on pedometer use which counts the steps taken throughout a day either by going for a long walk or by accumulating steps during daily activities.

Only a few studies reported on pedometer-based interventions in breast cancer survivors (Matthews et al, 2007; Vallence et al, 2007; Irwin, 2008). The results of these studies suggest that step counts are only likely to improve in breast cancer survivors when a realistic step goal is defined (Knols et al, 2010). In the general population, 10 000 steps/day are recommended to produce health benefits (Hatano, 1993; Tudor-Locke et al, 2011). For older people and for those with chronic diseases, however, less strenuous individual goal settings, based on their baseline step level, may be more appropriate (Tudor-Locke et al, 2009). In that way these tailored goals are more self-generated and positively motivated, as otherwise motivation will fade more easily.

Our research group already developed a pedometer-based and computer-tailored advice for the general population, which was well accepted and easily applicable in real-life settings (De Cocker et al, 2012).

The purpose of this study was to give an insight in the conversion of the pedometer-based computer-tailored advice for the general population into an adapted version for breast cancer survivors. Furthermore, a usability and process evaluation was conducted.

Methods

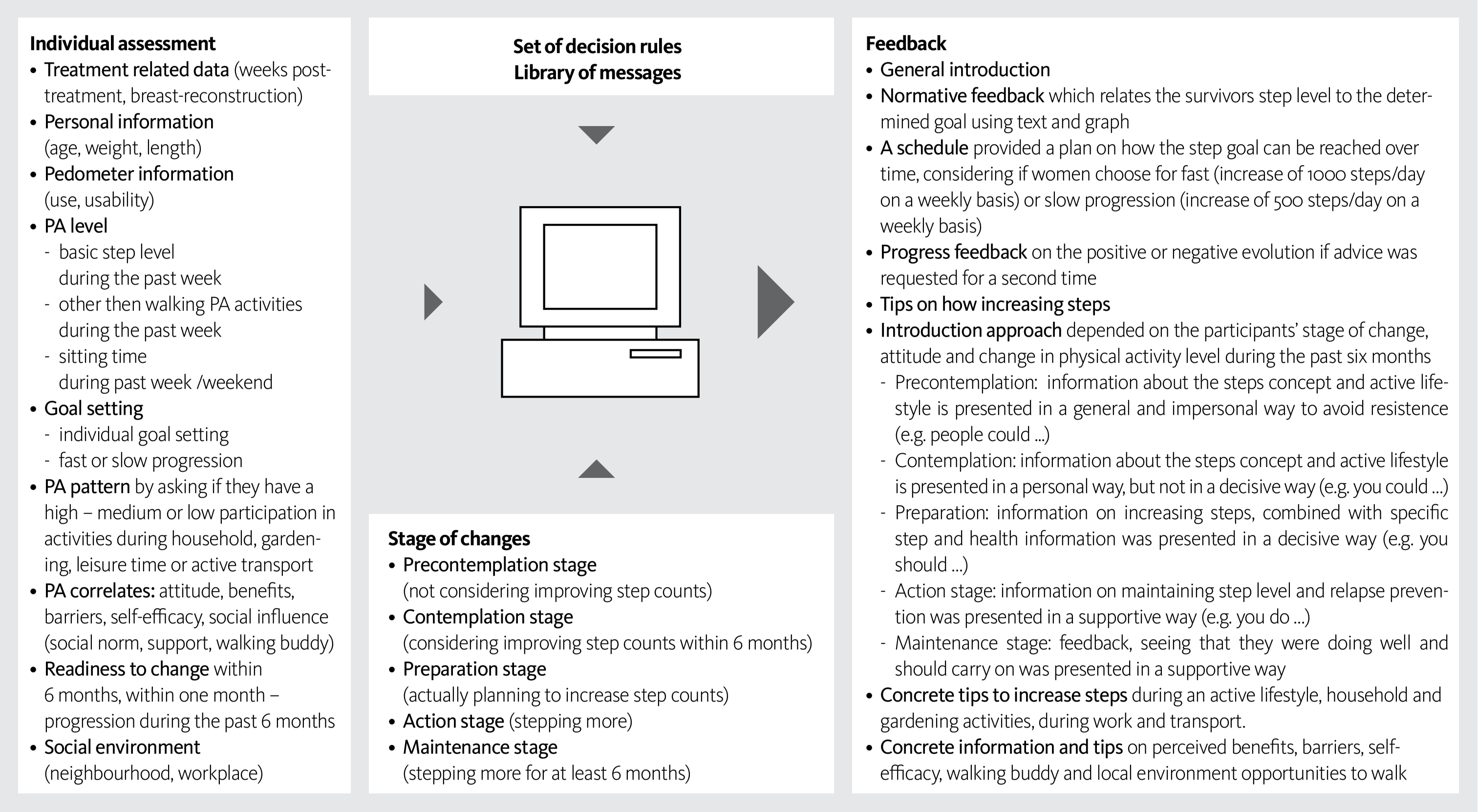
Adaptation process of the pedometer-based computer-tailored advice

Adaptations were guided by results of a prior cross-sectional study (Charlier et al, 2011; Charlier et al, 2012).

General approach and structure of the website

In the original advice, participants had to log into a website using a username and password, and then complete a baseline assessment on (1) sociodemographics, (2) participants' perceived barriers and beliefs of being physically active and (3) baseline step levels (assessed by wearing a pedometer for seven consecutive days) (De Cocker et al, 2012). Immediately after completing all questions, tailored feedback was provided. The feedback was based on the Theory of Planned Behaviour (Ajzen, 1985) and aspects of the Transtheoretical Model (Prochaska et al, 1992).

The *general approach and structure* of the new website remained the same as the original website (see Figure 5.1). As the advice focused on breast cancer survivors, patients still under treatment were excluded from receiving the PA advice. Moreover to respect the post-treatment healing process, women who were less than three weeks post-treatment for their breast cancer (radiotherapy, chemotherapy and surgery)(Courneya and Friedenreich, 2001) or less than six weeks post-surgery for breast reconstruction (www.cancer.org) were also excluded from receiving the PA advice. As a consequence, illness related screening questions were added to the baseline assessment. Women not meeting the inclusion criteria, received feedback that PA on low to moderate intensity, like walking, was not contra-indicated, but that participating in a step-goal programme could lay too much stress on their body at this moment. They were also advised to follow the (post-sur-



Individual assessment

- **Treatment related data** (weeks post-treatment, breast-reconstruction)
- **Personal information** (age, weight, length)
- **Pedometer information** (use, usability)
- **PA level**
  - basic step level during the past week
  - other then walking PA activities during the past week
  - sitting time during past week /weekend
- **Goal setting**
  - individual goal setting
  - fast or slow progression
- **PA pattern** by asking if they have a high – medium or low participation in activities during household, gardening, leisure time or active transport
- **PA correlates:** attitude, benefits, barriers, self-efficacy, social influence (social norm, support, walking buddy)
- **Readiness to change** within 6 months, within one month – progression during the past 6 months
- **Social environment** (neighbourhood, workplace)

Set of decision rules
Library of messages

Stage of changes

- **Precontemplation stage** (not considering improving step counts)
- **Contemplation stage** (considering improving step counts within 6 months)
- **Preparation stage** (actually planning to increase step counts)
- **Action stage** (stepping more)
- **Maintenance stage** (stepping more for at least 6 months)

Feedback

- **General introduction**
- **Normative feedback** which relates the survivors step level to the determined goal using text and graph
- **A schedule** provided a plan on how the step goal can be reached over time, considering if women choose for fast (increase of 1000 steps/day on a weekly basis) or slow progression (increase of 500 steps/day on a weekly basis)
- **Progress feedback** on the positive or negative evolution if advice was requested for a second time
- **Tips on how increasing steps**
- **Introduction approach** depended on the participants' stage of change, attitude and change in physical activity level during the past six months
  - Precontemplation: information about the steps concept and active lifestyle is presented in a general and impersonal way to avoid resistence (e.g. people could ...)
  - Contemplation: information about the steps concept and active lifestyle is presented in a personal way, but not in a decisive way (e.g. you could ...)
  - Preparation: information on increasing steps, combined with specific step and health information was presented in a decisive way (e.g. you should ...)
  - Action stage: information on maintaining step level and relapse prevention was presented in a supportive way (e.g. you do ...)
  - Maintenance stage: feedback, seeing that they were doing well and should carry on was presented in a supportive way
- **Concrete tips to increase steps** during an active lifestyle, household and gardening activities, during work and transport.
- **Concrete information and tips** on perceived benefits, barriers, self-efficacy, walking buddy and local environment opportunities to walk

Figure 5.1. Framework for tailored advice through the internet derived from De Cocker et al, 2012

gery) guidelines and exercises given by breast cancer nurses to optimise recovery and were encouraged to participate later. Additionally, survivors who suffered from certain serious complaints as described in Table 5.1 (Schwartz, 2008; Vallance et al, 2007), or who had a BMI lower than 17 were also excluded from receiving the PA advice and were referred to their general practitioner (Humpel and Iverson, 2005).

Table 5.1. Warning signs (Vallance et al, 2007)

1. Irregular pulse
2. Extreme tiredness (increased with the tiredness during treatment)
3. Unusual muscle weakness
4. Joint or bone pain
5. Leg pain or cramps
6. Chest pain
7. Sudden onset of nausea during exercise
8. Dizziness, blurred vision, fainting
9. Shortness of breath or difficulty breathing
10. Fever or shaking with chills
11. Numbness or loss of feeling in hands and feeds
12. Unintentionally weight loss

To make the website more attractive for breast cancer survivors, some adaptations on *website name, design and welcomes page* were made. A previous cross-sectional study noted a large variety in moderate to vigorous PA levels (MVPA) among breast cancer survivors (Charlier et al, 2011) with 51% of the sample not meeting the PA recommendation of 30 minutes of MVPA on 5 or more days a week. For inactive survivors, a website name that emphasized high levels of PA could be perceived as a barrier for requesting the advice. To make the website more accessible for those inactive survivors the website name was changed from 'stepadvice, 10 000 steps a day' into 'step*by*step'. 'Step*by*step' refers in the first place to the pedometer-based approach and will invite the women to start on their baseline level and to increase their baseline level progressively. Second, 'step*by*step' refers to the belief expressed by breast cancer survivors that PA could assist in their return to normal life (Charlier et al, 2011). Women were encouraged to rebuild their life step *by* step, which was further explained on the welcome page (Table 5.2). The beneficial effects of PA on health and quality of life were less stressed, as some survivors may perceive this as a threat (e.g. because I was not active enough, I have had cancer).

Theoretical framework, individual assessment and decision rules

Previous studies showed that both general and cancer-related determinants for PA were important to underpin health behaviour change interventions in breast cancer survivors (Charlier et al, 2011; Rhodes and Blanchard, 2007). Therefore, the Theory of Planned Behaviour (Azjen, 1985) and aspects of the Stages of Changes concept from the Transtheoretical Model (Prochaska et al, 1992) remained the theoretical basis for the decision rules. The organisation of the feedback in accordance with these models is illustrated in Figure 5.1 and additional information was given elsewhere (De Cocker et al, 2012).

To further adapt the website to the post-cancer situation, the theoretic al framework was extended by including cancer-related beliefs of PA, by explicitly expressing understanding for participants' post-cancer situation and by including self-management principles to improve survivors' personal control. This implicated adaptations of the individual assessment, the intervention messages and some decision rules (De Vries and Brug, 1999).

Adding tailored advices for cancer-related beliefs

Messages concerning cancer-related benefits of PA, cancer-related barriers for PA and the self-efficacy when suffering from cancer-related problems were added (Table 5.3). The messages concerning the social support and modelling were adapted to include the potential social influence of the medical staff and other survivors. Women were also referred to evidence-based websites of patient organisations if they were looking for a walking buddy or organised walking and exercise programmes for breast cancer survivors.

Tailored approach related to the diagnosis of breast cancer

To avoid resistance and to optimally attune the intervention to the individuals' PA level and the readiness to change of each individual participant, the intervention for the general population considered the 'Stage of Changes' (Figure 5.1). In the introduction, relevant information was provided according to the participants 'readiness to change', while pressure and control was minimized.

In addition, in the intervention for breast cancer survivors, women's feelings and perspectives were even more acknowledged by showing empathy for the intrusive characteristics and consequences of their diagnosis. This was done especially if women were rather inactive, or indicated that their activity level had decreased after diagnosis (see Table 5.3).

Improving personal control and self-management on the cancer-related situation

Previous results indicated that apart from the importance of self-efficacy on being physically active also personal control on the post-cancer situation determined a more active lifestyle in the population of cancer survivors (Charlier et al, 2012). Consequently, the new advice also aimed to improve personal control, defined as the extent to which women perceive themselves able to control their cancer-related situation (Moss-Morris et al, 2002). In addition to highlight the health benefits of PA, we added extra information on the supportive role of PA to improve control on their physical, psychological and social situation post-treatment. Furthermore, women received concrete tips to improve control on their perceived cancer related problems. As providing additional information on women's post-treatment condition could increase women's empowerment and personal control, they were referred to specific approved and evidence-based professional sites for more information if needed (e.g. cancer information sites, sites with dieticians).

Further, personal control was also integrated in the intervention by inviting women to be physical active during daily activities (like household and child care). Since during treatment some tasks were taken over by family members, women could be confronted with a possible 'illness benefit' and should be encouraged to re-organise tasks (Allen et al, 2009). Furthermore, within the concrete tips to increase step levels, women were also invited to take part in previous social, family and work related activities which should help women in their return to 'normal life'.

Individual step goals

Previous studies showed that interventions aimed at improving PA levels in breast cancer survivors should increase personal control on the post-treatment condition and self-efficacy for PA (Rogers et al, 2008; Charlier et al, 2011; Charlier et al, 2012). This underpins the need for interventions that can increase perceptions of control or real controllability. Facing inactive survivors with a step goal of 10000 steps (step goal for the general population) could result in inversed effects, namely discouragement and a decreased controllability (Tudor-Locke, 2002). Therefore, step goal setting was adapted for those women whose baseline step count was less than 6000 steps/day. Instead of the 10000 steps a day, women received a personal goal, which was 2000 steps more than baseline counts (Hill et al, 2003; Tudor-Locke et al, 2004). Once they had achieved their personal goal, women were encouraged to ask for a second advice, and to reach the 10000 steps a day in a follow-up goal. For more active women (more than 6000 steps a day) the guideline was set at

10000 steps a day, comparable to current recommendations. All participants could choose whether they could make fast or slow progression (an increase of either 1000 or 500 steps/day on a weekly basis). At last, the options to increase their step counts were tailored to their own preferences (during daily activities, during leisure time, during active transport).

If women indicated that they were recently less active, information was given on possible relapses and on how to handle them. Furthermore, women were advised to see their general practitioner if their decrease was due to more cancer-related complaints and symptoms.

Table 5.2. Adaptations made in the general approach and structure of the website

	Highlights of the intervention – adaptations of the website and advice	Intervention Strategy	Theoretical model
Website name	Changing the website name into StepByStep, re-active after breast cancer	Showing understanding for their situation	Interpersonal and social support theories Self-regulation: realistic goal setting
	'StepByStep' does not include a recommended step goal	Not stressing on recommended levels, trying not to de-motivate inactive survivors	
Welcomes page	More suitable the survivors' situation: rebuilding their lives	Showing knowledge on their situation	Illness perceptions: Personal control Self-management principles Interpersonal and social support theories
	Not only focusing on the benefit of PA for their health	Not judging their situation	
	Adaptations of the pictures	Avoiding stereotyping	

Table 5.3. Adaptations made to the theoretical framework, individual assessment and decision rules

	Highlights of the intervention – adaptations of the website and advice	Intervention Strategy	Theoretical model
Tailored advice on cancer-related beliefs	Providing additional information on cancer-related benefits for PA (return to normal life, less fatigue, decreased risk for relapse)	Confirming the perceived beliefs to increase intervention effects in the survivors population	Theory of planned behaviour: behavioural beliefs
	Providing additional information on cancer-related barriers for being sufficiently physically active (fatigue, lack of energy, arm-shoulder problems, oedema, self-image problems, hot flushes)	Tailored advice on the two most important perceived barriers Improving credibility by using information from identifiable sources	Theory of planned behaviour: control beliefs
	Providing information on cancer-related situations in which it was difficult to be sufficiently physically active (if too tired, if suffering from arm- and shoulder problems)	Tailored advice on those situations with low or medium self-efficacy Improving credibility by using information from identifiable sources	Theory of planned behaviour: control beliefs
	Including the recommendation of the medical staff (if they were encouraged by them) to support the importance and feasibility of step advice	Improving the credibility of the advice, creating a more obligatory nature of being physical active	Theory of planned behaviour: normative beliefs
	Providing additional information on seeking social support through the contact of other physically active survivors A link to websites with information on local possibilities of physical activities for cancer patients	Highlight the endorsement of other survivors in PA Reinforcement and extending perceived environment by providing opportunities for the patient to interact and communicate with other survivors	Perceived environment Interpersonal and social support theories
	Choice of options tailored to preferences – extra focus on daily activities – social contacts	Enhancing self-management	Personal control

Tailored approach to their diagnosis	If women decreased their PA the previous 6 months, this decrease was linked with the possible influence of the cancer and its treatment	Providing empathy and understanding while addressing women's specific concerns	Interpersonal and social support theories
	Warning signs Link for further information on cancer specific sites.	Empowering by giving information	Knowledge Self-management
Tailored advice including PA in daily activities	Women were advised to discuss household tasks if they were reorganised due to the cancer Women were advised search in the neighbourhood for social activities	Enhancing self-management and increasing real controllability on post-cancer situation	Personal control
Step-advice	Providing advice in text and graphic format about individuals' PA level compared with the individual recommended step goal	Personal and normative feedback	Awareness
	Sedentary survivors could choose an individual step goal	Improving motivation by using self-generated and positively formulated goals	Self-regulation theory: goal setting
	Women can choose for fast progression (an increase of 500 steps/day on a weekly basis) or slow progression (an increase of 1000 steps/day on a weekly basis)	Improving the feasibility of the step advice – providing perceptions of controllability	Self-regulation theory: setting implementation intentions – planning of goal realisation
	An action plan will be provided through a weekly schema	Enhancing self-management by increasing involvement of the women	Social-Cognitive Theory: improving self-efficacy
	Monitoring by pedometer use	Enhancing self-management and increasing real controllability	Self-regulation: controlling goal realisation

Usability testing and process evaluation

The test procedure of the adapted intervention consisted of two phases (Figure 5.2). A first phase involved a *preliminary usability* testing to detect most important user problems. Accordingly, the website was refined. In a second phase, a *process evaluation* took place to test user performance, user's satisfaction, acceptability of the advice and feasibility of the intervention. This procedure was based on the concept of a "hermeneutical circle" as described by Snodgrass and Coyne (1992) which is an iterative process of implementing a design, learning and understanding from discussion and feedback, and making subsequent design refinements (Figure 5.2). All participants of the preliminary usability testing and process evaluation completed an informed consent form and the study protocol was approved by the Ethical Committee of the Ghent University (B670201112085).

Preliminary usability testing and refinements of the website (Phase 1)

A *preliminary usability testing* was performed in three healthy women and six breast cancer patients (Figure 5.2). According to Nielsen (1994) only five users are needed to discover the most important errors during usability testing, thus having nine participants was adequate. The usability testing involved a list of tasks performed by the users of the website, while observers watched and took notes (log into the website, reading the welcome page, completing the online assessment and reading the advice). Participants were invited to say anything that came into their mind during the process. The research assistant recorded the length of the sessions and made notes about any problems encountered during the sessions. Afterwards, required refinements of the online assessment questionnaire and tailored messages were done.

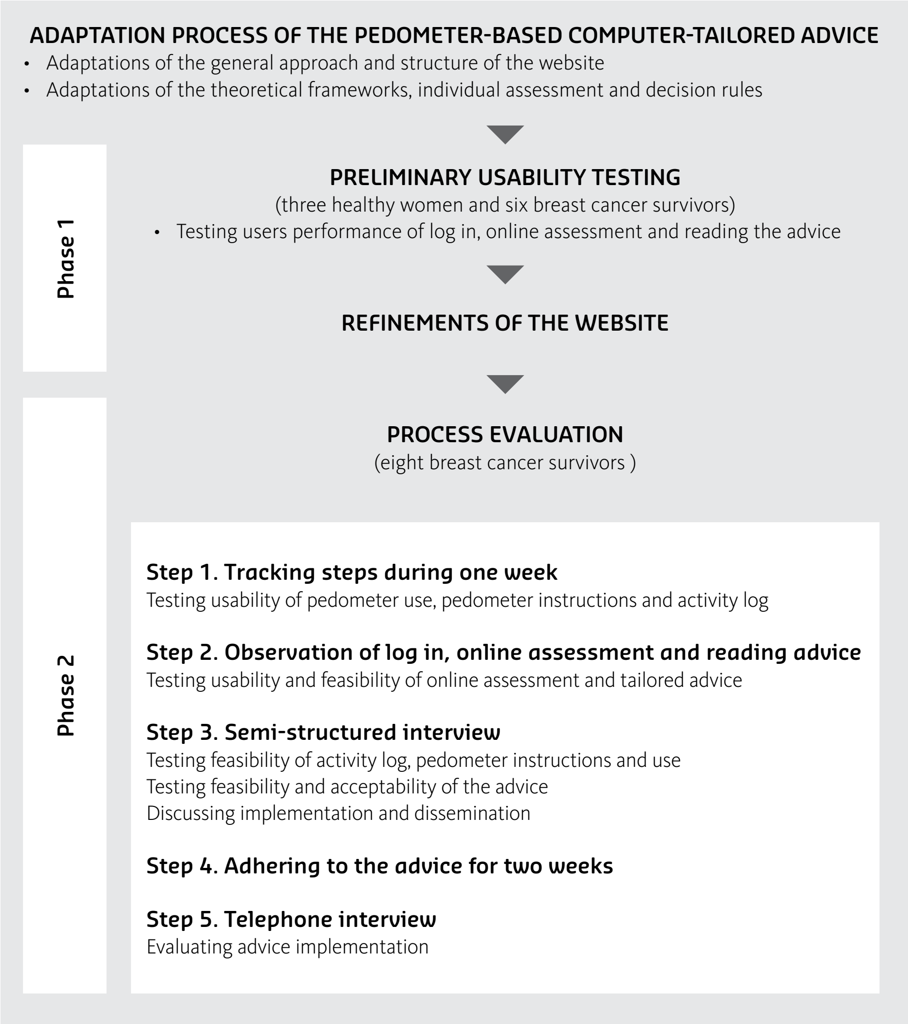


Figure 5.2. Development and evaluation protocol of the pedometer- based computer- tailored physical activity advice for breast cancer patients

Process evaluation (Phase 2)

For the process evaluation, breast cancer survivors were recruited on the radiotherapy department in one hospital (Hasselt, Belgium). Eligible women were between 18 and 65 years, three weeks post-treatment for a primary non-metastatic breast cancer and were not participating in an exercise programme for breast cancer survivors. The *process evaluation* lasted three weeks and women were asked to track their steps during week one using a pedometer (*step 1*); to complete the online assessment and to read the advice (*step 2*); to discuss the advice (*step 3*); to adhere to the advice during weeks two and three (*step 4*), and to discuss it afterwards (*step 5*). Figure 5.2 explains the consecutive steps in relation with the used measurements and the obtained results (testing of usability, feasibility, acceptability).

After providing informed consent, an envelope containing a pedometer (Omron Walking style III) (Holbrook et al, 2009), an activity log for seven consecutive days and information on how to use these instruments was sent to the selected participants and an appointment for a home visit (one week later) was set (*step 1*). Women were instructed to wear a pedometer (around the neck or waist) for seven consecutive days without changing their usual lifestyle. They were requested to record the date, daily steps taken, and the type and duration of non-ambulatory activities in the activity log.

After a week steps monitoring, a *usability testing (step 2)* and *semi-structured interview (step 3)* took place at home. Participants logged into the website (www.stappenadvies.be/stapvoorstap) using a confidential username and password. Women completed the online assessment and read the advice. The procedure was similar to the usability testing of Phase 1. The duration of completing the questionnaire and reading the advice was recorded by the interviewer (*step 2*). Afterwards, a *semi-structured interview* (*step 3*) was conducted. Participants were asked to report sociodemographics (age, weeks post-treatment, education level (primary education, secondary education, higher education and university), Internet use (daily, weekly, monthly, never) and Internet access at home (yes/no). Feasibility was tested by asking participants on practical use and problems with the pedometer instructions, wearing the pedometer and completing the questionnaire. Furthermore, the acceptability and satisfaction with the advice was rated by the women on a 5-point Likert scale. Women could indicate whether or not the advice was interesting, attractive, personal, comprehensible, reliable, credible and irritating. They were also asked whether the advice included new information for them and if they perceived it to be too long. Overall satisfaction with the advice was rated on a scale ranging from 0 (very unsatisfied) to 10 (very satisfied). All women evaluated the tailored advice with respect to spelling, content and representativeness in open-ended questions. Women were also asked for their preferences for disseminating the advice (through breast cancer nurses, medical staff, their physician or through information sessions; including a face to face introduction or only by a written introduction sent by post).

As the last part, women were invited to adhere to the advice during two weeks (*step 4*) and were asked to participate in a telephone interview afterwards (*step 5*) (Figure 2). Women were asked what they had done with the advice: read it, discussed it with others, saved it, printed it or reread it later. Women were further asked if and how they have increased their steps (during household and gardening activities, during active transportation, at work or during leisure time). Possible problems or perceived barriers in achieving their personal step goals were registered.

Results

Preliminary usability testing and refinements of the website

Participants

Three healthy women, respectively 38 years, 45 years and 62 years old, pre-tested the website. They all used the Internet on a daily basis. The six breast cancer survivors involved in the pre-testing were on average 41 ± 8 years old and were between four and fifteen weeks post-treatment. Three women used the Internet every day, two women used the Internet once a week and one woman reported using the Internet once a month.

Preliminary usability testing

No problems were perceived during the log-in procedure and reading the welcome page. *Healthy women* indicated that it was not always clear how many answer possibilities that must be designated for questions on exercise barriers and beliefs. However, all women received an advice and no further problems were detected. From the *six breast cancer survivors*, only two women received an advice. Four women were excluded from receiving the advice as they indicated that they either still receive treatment (hormone therapy), or indicated that they sometimes suffer from the indicated symptoms. They found the question on perceived symptoms too limiting. It was also noted that some breast cancer survivors (n=3) tended to misinterpret the term ‘usual’, they interpreted it as referring to ‘pre-diagnostic behaviour’ rather than ‘current post-treatment behaviour’ (e.g. how many minutes did you spent being sedentary in a usual week?). Two women suggested including a link to national information sites for more information on cancer specific problems each time the advice was provided.

Refinements to the website

The following refinements were done, based on the preliminary usability testing: a) Answer requirements for each question were specified (e.g. indicate the two most important barriers). b) The term ‘post-treatment’ was further defined as the period following surgery, chemotherapy and/or radiotherapy. c) ‘Usual

PA behaviour' was specified the PA behaviour during the past week. d) The question on perceived complaints was excluded, instead the advice for all participants now included the symptoms related to potential perceived complaints as warning signs. e) Women suffering from the identified symptoms were referred to their general practitioner before starting the programme. f) Women were also referred to evidence-based information sites when they preferred more information.

Process evaluation

Participants

Eight women participated in the process evaluation and were on average 50 ± 7,1 years old. Post-treatment duration varied between four weeks (three women), eight weeks (two women), five months (one woman) to six months (two women). Seven women were highly educated (college or university). Only one woman had no access to the Internet at home and mobile internet was used. All women used the Internet at least once a week, with four of them on a daily basis.

Baseline average step counts varied between 4606 steps a day up to 11 100 steps a day. Two women additionally ran or bicycled for on average 20 minutes a day, which increased their baseline step levels by 3000 steps. Consequently, advice was given for one inactive woman (< 5000 steps a day), four low active women (between 5000 and 7499 steps a day) and three active women (> 10000 steps a day). Three 'low active' survivors received a step goal of 2000 steps more than their baseline levels. More active survivors were encouraged to reach population level recommendations (10 000 steps a day).

Usability of the website

All participants logged into the website and received an advice. They spent on average 14,3 ± 4,2 minutes (ranging from 10 minutes up to 21 minutes) on completing the questionnaire. Reading the advice took on average 10,3 ± 7,2 additional minutes (ranging from 3 minutes for high active survivors up to 24 minutes for low active and inactive survivors). Whilst reading two women indicated that the advice was too long, however they persevered and continued reading the complete advice.

Acceptability of the advice

With the exception of one (revealing no opinion), everyone agreed that the advice was interesting and attractive to read (three strongly agreed). Everyone agreed that the advice was comprehensible (four strongly agreed), reliable (three strongly agreed) and credible (four strongly agreed). Two out of eight had no opinion regarding the level of personalisation of the advice, five perceived the advice as personally relevant and one woman indicated that the advice was not perceived as personally written for her. Three women already knew most of the information, another three indicated that the information was new for them. For two women, the amount of information was somewhat too much (length of the advice). Three out of five inactive women found the information novel, but too long. Active women tended to perceive the advice as less tailored to themselves (less personal).

While consulting the advice, one woman used one of the provided links. After reading, all participants aimed to implement the advice immediately. After two weeks, five women actual increased their steps, mainly through increasing household and gardening activities and by going for a walk. All women recognized the strength of wearing a pedometer, they reported that it was a strong motivator and three of them indicated that they already increased their steps before receiving the advice. One woman reported on increased fatigue and leg pain after following the advice.

Feasibility of the intervention process

All women agreed that the information on the intervention and pedometer use was understandable. No women noted problems with wearing the pedometer, five women wore it around the neck and three preferred wearing the pedometer on the waist.

Dissemination and implementation

Concerning the dissemination and implementation, the perception of the women was that physicians were the best source to refer patients to the website, followed by physiotherapists and breast cancer nurses. Both, information by post or face to face were identified as potentially good ways to inform former patients about the website. Less interest was shown for an information session.

Discussion

This paper described the adaptation of a web- and pedometer-based advice targeting the general population into an advice for breast cancer survivors. Usability, feasibility and acceptability of the adapted website and advice were evaluated.

Although the website was already implemented in the general population, this study showed the value of performing an extra usability testing in the target population. This will ensure that breast cancer survivors had the ability to access, understand, and use the web-based information (Wichansky, 2000; Currie, 2005). Problems that occurred during the preliminary testing mainly consisted ambiguities in the online assessment. To provide tailored advice, it is crucial that questions are correctly interpreted and that the assessment is clearly related to the present situation. Therefore, extra attention was given on refining the online assessment, with the result that the problems of phase 1 did not occur in phase 2 testing. However, despite rigorous usability testing the misinterpretation of questions and personalised advice can never be totally eradicated in self-guided therapies. Therefore, to further decrease the problem of misinterpretation, users can be recommended to discuss the internet-based advice with professionals like their general practitioner, caregivers or the intervention team if they perceived some ambiguity (Mayer et al, 2007).

To improve breast cancer survivors' self-efficacy and personal control, information on cancer-related barriers as well as self-management strategies on perceived symptoms was added to the advice. The adapted advice was then tested on its feasibility and acceptability. On the whole, the advice was well accepted and the majority perceived the advice as interesting, attractive, comprehensible and credible. This finding is comparable with the results on acceptability of the existed advice tested on 32 users from the general population (De Cocker et al, 2012). However, differences in answers among the users in this study were observed regarding the questions on the personalization of the advice, the novelty of the information and the length of the advice. It seemed that inactive women (less than 6000 steps a day) in particular experienced the advice as novel, but also as too long. Those women spent on average thirteen minutes on reading the advice. As tailoring provides a selection of messages related to an individual assessment, tailoring should ideally lead to brief and to the point messages. However, inactive women may be most in need for information , which increases the length of the advice by giving extra information on perceived barriers, barrier-related self-efficacy and social influences. According to information-processing experts, apart from the length of the information, the presentation of comprehensible and personal relevant information is also important (Wentzel-Larsen et al, 2011). As low-active women (< 6000 steps a day) perceived the information as novel and personally relevant it is likely that the advice was acceptable in terms of presentation and relevance. However, care must be taken that length will not deter the recipient from reading it all. Possibilities to print the advice and re-read it afterwards must be encouraged.

The new intervention also differed from the original intervention as it applied individual and preset step goals. Goals were tailored to baseline levels, but were not self-selected by the woman. One may assume that self-selecting goals will be more effective as it may increase one's involvement in the process (Siegert et al, 2004). However, an approach of pre-setting goals tailored to baseline level may be both efficient and effective (Tudor-Locke et al, 2009). Self-selecting a goal presumed that individuals are very well informed about their baseline step level and the required increase (e.g. 2000 steps more) and we believed that this was too difficult for an online assessment in this rather heterogeneous population (Charlier et al, 2012). Consequently we opted to use pre-set goals tailored to baseline levels. An increase of 2000 steps represents about 1 mile (1.6 km) of walking and takes about 15-20 minutes to complete. Moreover, an increase of 2000 steps a day aligns well with the increase in steps that is observed after pedometer-based interventions in healthy adults (Tudor-Locke et al, 2011). In breast cancer survivors, an increase of approximately 1500 steps a day was seen after walking programme of respectively three and six months (Irwin et al, 2008; Matthews et al, 2007). Moreover, some studies in diseased populations showed that an increase of 2000 steps a day could already support health gain (Hill et al, 2003; Garber et al, 2011). It is believed that each improvement from the baseline step level may already reveal some beneficial effects, if it is sustainable for a longer period (Sidman, 2002). However, at this moment there is limited data available on the required amount for increasing steps in breast cancer survivors to obtain health benefits (Irwin, 2009; Rogers et al, 2011).

Limitations and strengths

The present study provides strong initial support for the usability and acceptability of a web-and pedometer-based intervention among breast cancer survivors. Although, our sample of respectively six and eight breast cancer survivors was large enough to detect most common users problems (Nielsen, 1994), the sample was too small to allow us to examine whether factors related to participants (e.g. age and grade level), cancer and its treatment (e.g. perceived side-effects, illness perceptions), or Internet experience were related to the usability and acceptability of the intervention. Despite this limitation, the present study provides a detailed description of the development and usability process of a novel home-based physical activity intervention for breast cancer survivors. Furthermore, intervention development was guided by results of prior determinant studies in the target population and a broad consultation of physical activity beliefs and adjustment issues in breast cancer survivors (Charlier et al, 2011; Charlier et al, 2012). This user-centered development process contributes to more suitably tailored advice and a more representative intervention approach (Stinson et al, 2010). For example, the advice showed empathy for the intrusive characteristics and consequences of the diagnosis, but also encouraged women to reintegrate in normal life.

Recommendations for future research

Further efforts are needed to handle with the dilemma that inactive survivors, who are in need for information, may receive a too long advice. This argues for further analyzing the strengths and weaknesses of the advice in different subgroups of survivors (e.g. which information is perceived irrelevant for the inactive versus the active survivors). According to this point, differences in usability and feasibility among subgroups based on grade level and social-economic status may also be analysed. As results in this study mainly derived from highly educated women, little is know about the usability in low educated women.

There is also a strong need to further test the intervention on its efficacy and reach, as proven efficacy is an essential precondition for further implementation. Institutions involved in cancer planning and cancer control recommend the use of guiding models to test interventions in cancer survivors (e.g. RE-AIM framework) (White et al, 2009). These models emphasize the importance of including information on dissemination and implementation in daily practice. In the current study, survivors seemed to appreciate the dissemination of the intervention through oncologists and general practitioners. The usability and organization of the delivery of the intervention through physicians must be further studied. Physicians could also benefit from guidelines to guide the referral of breast cancer patients to the developed interventions (Glasgow et al, 2011). Questions on which survivor should benefit most of the developed intervention must be answered in the future.

Conclusion

Overall, we can conclude that a pedometer-based computer-tailored physical activity advice for the general population was adapted successfully into an appropriate and feasible intervention for breast cancer survivors. By adding cancer-related assessments and advice and providing step-goals based on baseline levels, the specific needs and characteristics of breast cancer survivors are recognized. Furthermore, by providing a home-based and computer-tailored intervention, based on encouraging physical activity through natural occurring activities, the present intervention broadens the reach of physical activity promotion to breast cancer patients who enter survivorship.

Competing interests

The authors declare that they have no competing interests.

Author's contributions

CC contributed to adaptations of the website, usability and process evaluation, analysis of results, and wrote the manuscript. LL, HS and IDB contributed to adaptations of the website, usability and process evaluation and analysis of results and revised the manuscript. JB contributed to the recruitment of the patients and revised the paper. CV, KDC and HS contributed to the design of the original website and its effect evaluation and revised the manuscript. EVH, EP revised the manuscript.

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6

General discussion

During the transition from breast cancer patient to breast cancer survivor, women may experience many physical and psychosocial symptoms (Allen et al, 2009). Given the beneficial effects of physical activity on most of these symptoms, promoting physical activity would seem to be beneficial in follow-up care after cancer (Hewitt et al, 2006). A clear vision on the motivational aspects of physical activity, however, precedes the development of appropriate and effective interventions.

The presented studies attempted to accomplish the following goals, which were in line with the Model of Planned Promotion of Public Health (Brug et al, 2012). First, the project aimed to identify and understand physical activity levels and supportive care need for physical activity among breast cancer survivors during their transition to survivorship (*Chapter 2*). Second, the project attempted to determine motivational factors related to physical activity (*Chapter 3* and *Chapter 4*) in breast cancer survivors three weeks to six months post-treatment. Finally, an intervention to stimulate physical activity among breast cancer survivors was developed and its usability was tested (*Chapter 5*).

In the general discussion, the main findings of each part of this thesis will be presented, followed by a discussion of findings, methodological issues and recommendations for practice and future research.

1. Main findings

1.1. Physical activity and suportive care needs for physical activity

A cross-sectional study was conducted to identify physical activity behaviour and supportive care need for physical activity among breast cancer survivors three weeks to six months post-treatment. Answers to the question 'How many days a week do you participate in at least 30 minutes of moderate to vigorous physical activity?' showed that half of the women were never moderately physically active for at least 30 minutes a day. Moreover, only 10% of the women reported that they were engaged in 30 minutes of moderate to vigorous physical activity on five days a week (meeting the current recommendations). When mean values of physical activity were assessed by summing the minutes per week reported to be spent in moderate and vigorous activities such as housework and gardening, active transportation, occupation and leisure time, much higher levels were retrieved. Those mean levels were above the public health recommendations of 150 to 210 minutes a week (on average 323 ± 334 min/week). However, physical activity levels were spread on a broad range from 29% inactive women (mean values below 60 min/week) to 28% highly active women (mean values above 420 min/week). Given this heterogeneity among breast cancer survivors' physical activity levels, it can be assumed that not all breast cancer survivors need support or perceive a need for support in adhering to an active lifestyle. This finding was further clarified by evaluating the supportive care need for physical activity perceived by the women themselves. Six out of ten women expressed a supportive care need for physical activity. The interest of cancer survivors in supportive care for physical activity during their transition from patient to survivor was noted previously (Rogers et al, 2009; Gjerset et al, 2010) but the existing literature failed to explain individual differences.

It was expected that the individual level of distress and the level of adjustment in particular explained the individual differences in physical activity and supportive care need for physical activity. To investigate the presence and nature of subgroups of breast cancer survivors, the study in *Chapter 2* used a cluster analytic approach. Four meaningful clusters were revealed: (1) a low distress-active approach group, (2) a low distress-resigned approach group, (3) a high distress-active approach group and (4) a high distress-emotional approach group. These findings suggest different patterns of recovery after breast cancer, rather than a fixed recovery model (Knobf et al,2011).

Subsequently, clusters' physical activity levels and expressed needs for physical activity were analysed. Cluster characteristics are summarized in Table 6.1. Survivors in the low distress groups reported more physical activity than those in the high distress-emotional approach group. Supportive care needs for physical activity were, however, unrelated to perceived distress and actual physical activity levels. Our results emphasize the importance of screening for care needs and developing physical activity interventions tailored to the individual.

The resulting clusters (Table 6.1) offer a rationale for the coordination of follow-up care. Knowledge of the presence of these clusters among healthcare professionals could facilitate the referral to appropriate (physical activity) interventions resulting in a broad range of breast cancer survivors being reached.

Table 6.1. Physical activity and supportive need in four clusters of breast cancer survivors based on distress and adjustment

Cluster 1	**Low distress** • few symptoms and little fatigue • low anxiety and depression, good body image, strong self-esteem and **good future perspectives**	**Active approach** • perceive their cancer as **acute** and report **strong** personal control • have **many social** interactions • mostly use **problem-solving** coping	**Physical activity (PA) and expressed need** • report most PA • 13% participate in oncologic rehabilitation • 42% is (again) working • 65% report a supportive care need for PA
Cluster 2	**Low distress** • few symptoms and little fatigue • low anxiety and depression, good body image, good self-esteem and **moderate future perspectives**	**Resigned approach** • perceive their cancer as **chronic** and report **moderate** personal control • have **moderate social** interactions • use no specific coping style	**Physical activity and expressed need** • report 2nd most PA • 5% participate in oncologic rehabilitation • 38% is (again) working • 55% report a supportive care need for PA
Cluster 3	**High distress** • more symptoms and fatigue • moderate anxiety, **moderate body image, good self-esteem** and **low future perspectives**	**Active approach** • perceive their cancer as **chronic** and report **good** personal control • have **many social** interactions • mostly use **avoidance** coping style	**Physical activity and expressed need** • report 3rd most PA • 25% participate in oncologic rehabilitation • 35% is (again) working • 75% report a supportive care need for PA
Cluster 4	**High distress** • more symptoms and fatigue • **high anxiety and depression**, low body image, low self-esteem and low future perspectives	**Emotional approach** • perceive their cancer as **chronic** and report **moderate** personal control • have **few social** interactions • mostly use **emotional** coping style	**Physical activity and expressed need** • report least PA • 13% participate in oncologic rehabilitation • 19% is (again) working • 66% report a supportive care need for PA

1.2. Determinants of physical activity among breast cancer survivors

Research on physical activity determinants in cancer survivors has increased since the benefits of physical activity in cancer survivors have been recognized. Most studies included a narrow range of motivational determinants, generally based on one theoretical model. This resulted in interventions based on theoretical models such as the Theory of Planned Behaviour and the Social Cognitive Theory without inclusion of more environmental and situational determinants (Pinto and Ciccolo, 2011). Our study extended the literature by combining general as well as cancer-related motivational determinants (*Chapter 3*). In order to obtain a deeper insight into the specific nature of the transition period, also illness-related and personal variables were explored (*Chapter 4*).

General and cancer-related physical activity determinants for working and non-working survivors (*Chapter 3*) are presented in Table 6.2. For total physical activity in non-working versus working breast cancer survivors, the model based on general determinants explained respectively 20% and 21% of the variance; the model based on cancer-related determinants contributed for respectively 22% and 21% and the model based on illness-related and personal variables explained respectively 15% and 21%. For leisure time physical activity in non-working versus working breast cancer survivors, the model based on general determinants explained respectively 27% and 32% of the variance; the model based on cancer-related determinants contributed for 22% versus 23% and the model based on illness-related and personal variables explained respectively 9% and 15%. The results showed similarities with population-based determinants but also underlined the importance of the inclusion of cancer-related barriers, benefits and social influences for a full understanding of physical activity in women who had just survived breast cancer. Illness-related and personal determinants (*Chapter 4*) are also presented in Table 6.2. Particularly, breast cancer survivors perceiving low personal control in their post-treatment condition and those suffering from fatigue and arm symptoms were at increased risk of an inactive lifestyle.

Of note were the overall findings reported in both studies (*Chapter 3* and *Chapter 4*). First, both studies emphasized the important role of control concepts. Self-efficacy (or behaviour control) (*Chapter 3*) and personal control (*Chapter 4*) were found to be fundamental and important determinants explaining physical activity during daily living as well as during leisure time for both working and non-working cancer survivors. Additional to this finding was the relation between perceiving 'return to normal life' as a benefit of physical activity and the physical activity level. Women who reported that physical activity assisted them to return to normal (re-integrate with life as it was before their cancer diagnosis), were more likely to report an active lifestyle.

Table 6.2. Determinants of total and leisure-time physical activity for working and non-working

	Active lifestyle during daily activities		**Physical activity during leisure-time**	
	Non-working survivors	**Working survivors**	**Non-working survivors**	**Working survivors**
Attitude			Enjoying being physical active	Enjoying being physical active
Perceived Benefits	Belief in the beneficial effect of physical activity to support return to normal life		Belief in the beneficial effect of physical activity to support return to normal life	Belief in the beneficial effect of physical activity to support return to normal life
Self-Efficacy	Self-efficacy of being physical active	Self-efficacy of being physical active Self-efficacy of being physical active when suffering from cancer-related barriers	Self-efficacy of being physical active	Self-efficacy of being physical active Self-efficacy of being physical active when suffering from cancer-related barriers
Perceived Barriers	Cancer-related fatigue* Arm symptoms* Inflammations and injuries*	Lack of energy* Arm symptoms* Inflammations and injuries* Chemotherapy * Lack of time* Side-effects (menopausal)	Positive body image	Lack of company* Negative body image
Social Influences				Social support: being active together with partner or friends Social norm: opinion of a doctor of being physical active
Illness Perceptions	Personal control on the situation post-treatment	Personal control on the situation post-treatment	Personal control on the situation post-treatment Contributing their cancer to inactivity*	Personal control on the situation post-treatment

* determinants are negatively related with physical activity

Considering the stressful and uncontrollable nature of the transition period, concepts of control are rather challenging for many breast cancer survivors. Lack of time and lack of a companion with whom to practice physical activity, as well as the perceived fatigue, arm symptoms (pain, stiffness and lymphoedema) and body image, contributed to the explanation of physical activity. The pattern of association varied depending on working status (working or non-working) and type of activity (active lifestyle versus leisure-time physical activity). For example, body image only contributed to the explanation of leisure-time physical activity. In the non-working population, a better body image was associated with higher physical activity levels, whereas the association became negative in the working population. All these results are clear indications of the large diversity in our population. Overall, results (*Chapter 3* and *Chapter 4*) suggested that working breast cancer survivors might be more active in terms of seeking solutions (like being physically active) to deal with the experienced symptoms in comparison with their non-working counterparts. Furthermore, results indicated that besides the universal impact of self-efficacy, personal control and cancer-related social beliefs, additional associated factors differed between the types of physical activity. Total physical activity (including all daily activities) was also determined by cancer-related barriers like fatigue, lack of energy and arm symptoms, whereas pleasure and enjoyment, social support and body image had an additional influence on leisure-time physical activity.

Our results suggested some potential strategies for developing effective interventions that meet the needs of a rather heterogeneous sample of breast cancer survivors. These strategies may include the improvement of control in the performance of physical activity and the improvement of control in the post-treatment situation. Further, providing tailored advice on perceived physical activity beliefs may also serve as a useful strategy to promote physical activity among breast cancer survivors.

1.3. Physical activity promotion through pedometer-based computer-tailored advice

Based on the results of the cross-sectional study, a pedometer-based computer-tailored advice for breast cancer survivors was developed. Through computer-tailoring, physical activity advice can be adapted optimally to breast cancers' individual characteristics (socio-demographics, illness-related and physical activity-related factors). To provide practical methods to increase survivors' self-control and monitoring abilities of being physically active, a step goal intervention based on pedometer use was considered. A realistic step goal encourages people to reach that goal. In our intervention, goals were adapted to baseline step counts. Therefore, a goal of 2000 steps above baseline level was set for inactive and low active breast cancer survivors. More active survivors were encouraged to achieve 10 000 steps a day, which is the current recommendation for the general population.

The website and intervention were tested for usability, feasibility and acceptability in two phases. In Phase 1, three healthy and six breast cancer survivors tested the usability of the website. Misinterpretation of the questions was the most frequently reported user problem and required refinements were done. In Phase 2, eight survivors tested the use and feasibility of the website, pedometer and step advice for three weeks. Overall, women were positive about the tailored advice. It seemed that low active women in particular perceived the advice as novel. Moreover, all survivors reported the strong motivational effect of wearing a pedometer and counting their steps during the day. Future research is needed to test the efficacy of the intervention.

2. Discussion of findings

This thesis aimed at clarifying the intervention approach of physical activity promotion in breast cancer survivors three weeks to six months post-treatment. In this section, we discuss some noteworthy considerations as regards understanding supportive care need for physical activity and determinants of physical activity in this specific population. Finally, we explore the prior considerations in relation to the developed intervention.

2.1. Understanding a supportive care need for physical activity

This thesis identified the presence and uniqueness of four profiles of breast cancer survivors which confirmed the diversity of individual response after breast cancer (Knobf, 2011). Apart from physical and psychological distress, other factors distinguished the four clusters, specifically personal (e.g. self-esteem, future perspectives) and illness-related factors (e.g. personal control, perceived chronicity), social resources and coping strategies. We could not find a unique variable that differentiated between all clusters, which suggested that several variables are needed to characterize profiles of breast cancer survivors post-treatment (Knobf, 2011). Knowledge of these different profiles among breast cancer survivors may assist clinicians, healthcare providers and researchers in understanding perceived need.

Currently, there is little clinical and scientific basis for detecting survivors who need support for physical activity. Screening survivors for their physical activity level or perceived distress was insufficient to identify those survivors needing or perceiving a supportive care need for physical activity. As stated in the literature, not the actual physical activity level, but the change in physical activity level may determine women's participation and interest in physical activity counselling (Gjerset et al, 2010). In our study, women with a low level of distress and an active approach who have high levels of physical activity report the same supportive care need for physical activity as women in the high distress groups, who are less physically active. We assume that the need expressed by survivors with a low distress and an active approach derives from a desire to improve their overall health and a wish to return to a normal and active lifestyle (Sanson-Fisher et al, 2000). For other survivors (women with a high distress level) the need expressed may derive from a need and desire to control their physical and psychological recovery after cancer (Vivar and McQueen, 2005). In addition, the perceived supportive care need for physical activity in women with high distress can further be stressed by their active approach (the high distress-active approach group). These women were also reporting perceived needs on other topics, suggesting their high information seeking coping style (Pauwels, 2012). Understanding the mechanisms of one's perceived need can contribute to a more targeted referral (Eheman et al, 2009).

2.2. Understanding the influence of general and cancer-related determinants on physical activity in breast cancer survivors

This thesis provides a broad perspective on the underlying mechanisms of physical activity among women after the completion of breast cancer treatment. We noticed that the constructs from the traditional cognitive models, such as the Theory of Planned Behavior and Social Cognitive Theory (proximal determinants), that are used to explain physical activity in a healthy population (as primary prevention), can also be applied to the former breast cancer population. Adding cancer-related determinants improved the explained variance of physical activity after cancer, especially in relation to total physical activity. For the understanding of physical activity in cancer survivors, illness and treatment-related factors, not directly related to physical activity, also need to be considered. The model based on these more distal determinants (not explicitly linked to physical activity) made an almost equal contribution to the explanation of total physical activity as the model based on the general and cancer-related proximal physical activity-directed determinants. Illness and treatment-related determinants were less important, however, in explaining leisure-time physical activity.

These findings allow us to make some suggestions for the ongoing debate in health promotion literature on whether a cancer diagnosis affects the underlying mechanisms of physical activity (Rhodes and Blanchard, 2007). In the studies reported in this thesis, the role of the cancer experience varied substantially in explaining total physical activity and leisure-time physical activity. Cancer-related symptoms interrupt physical activity during household, occupation and transportation. For leisure-time physical activity, the role of cancer-related barriers was rather secondary to the role of more affective beliefs like pleasure and enjoyment, with the exception of body image.

Rhodes and Blanchard (2007) also stated that determinants of more volitional physical activity (like leisure-time physical activity) are fundamental and in accordance with beliefs already prevalent before the cancer diagnosis (Rhodes and Blanchard, 2007). Therefore, it is assumed that a cancer diagnosis does not change affective feelings for physical activity and consequently does not change motivation and participation in terms of leisure-time activities either. However, the motivation and participation in physical activity during daily life can be impeded due to the cancer diagnosis. Encouraging physical activity during daily life can be especially important for inactive breast cancer survivors who are not motivated to undertake leisure-time physical activity. For this group, strategies to improve personal and cancer-related conditions are needed to facilitate the uptake of a physically active lifestyle.

2.3. Understanding the versatile role of control concepts in explaining physical activity in breast cancer survivors

Within the literature on health promotion and cancer survivorship, the concept of control is often narrowed to behavioural control or self-efficacy (Andrykowski et al, 2006; Rogers et al, 2008). If ‘control’ is considered from a ‘health promotion’ perspective, control (or *self-efficacy*) represents the resources and skills individuals believe they can use in order to achieve desired outcomes (e.g. being physically active to become less fatigued). If control is considered from a ‘chronic care’ perspective, control (or *personal control*) is an appraisal of the extent to which individuals believe they can control outcomes themselves (e.g. cancer-related fatigue or recurrence risk). In general it is assumed that individuals who have a sense of personal control are more likely to engage in healthy behaviours (Park et al, 2008). Yet there is still no agreement on the role of personal control in the promotion of physical activity among cancer survivors (Park and Allison, 2007). The lack of convincing evidence is a consequence of the different definitions used for personal control. In previous studies control was defined as 'control on the course of cancer' (Park et al, 2008; Costanzo et al, 2010) or 'control on a cancer recurrence' (Rabin and Pinto, 2006). In our study personal control was clearly defined as the personal capacity to manage the post-treatment condition, which is characterized by (long-lasting) side-effects and ongoing therapy. Moreover we did not find any evidence to support the role of cancer-related worries and the risk of a recurrence as a motivator to adopt a healthy lifestyle by improving post-treatment physical activity levels as was supposed by prior studies (Rabin and Pinto, 2006; Wood, 2008).

2.4. Development of post-treatment physical activity interventions for breast cancer survivors

Overall, our results stress the importance of considering health promotion models as well as chronic care models in the development of post-treatment physical activity interventions for breast cancer survivors. This calls for adding *patient-oriented* and *self-regulation strategies* as well as *symptom management* to the existing '*self-efficacy enhancing*' physical activity programmes developed for primary prevention (Rotegård et al, 2011). In this thesis, this was achieved by adapting a home-based, computer-tailored intervention using pedometers for the general population in a suitable intervention for breast cancer survivors. Preliminary results suggest that the intervention was well accepted by the target population. In *Chapter 5* we explain in detail how our intervention implemented self-efficacy and self-management strategies (Table 5.3 and Table 5.4). Given the literature and the preliminary results, there are clear indications that pedometer use as well as tailoring the advice to women's characteristics may contributes to women's processes of self-management and self-regulation (Pinto et al, 2009).

All survivors reported the strong motivational effect of wearing a pedometer. The effectiveness of self-monitoring physical activity behaviour was reported in earlier studies, including those on breast cancer survivors (Conn et al, 2008; Knols et al, 2010). Self-monitoring (through pedometer use) provides women with real-time information and may increase their awareness of existing behaviour (Conn et al, 2008), which could further trigger *processes of self-regulation*. Presetting realistic step goals will foster this process of self-regulation (Tudor-Locke and Lutes, 2009). In breast cancer survivors, an increase of approximately 1500 steps a day was seen in women wearing a pedometer (Irwin et al, 2008; Matthews et al, 2007). Since performance accomplishment (e.g. going for a walk) or mastery will be an important way to increase *behavioural control*, we can assume that wearing a pedometer also increases *self-efficacy* in terms of being physically active, which was an important motivator for adhering to an active lifestyle.

In our intervention we opted for web-based tailored advice. Providing tailored advice through the Internet could reinforce the implementation of *self-management strategies* by providing personally relevant information on cancer-related issues or behavioural issues, only when needed (Lustria et al, 2009; Krebs et al, 2010). Tailored advice could strengthen the working mechanisms of *self-efficacy* by proposing activities closely related to women's preferences and respecting their preference for a fast or slow improvement (Knols et al, 2010). Tailored advice will support the process of self-regulation by providing goals tailored to the individual's baseline level (Tudor-Locke and Lutes, 2009). Additionally, cancer patients who use the Internet feel empowered in terms of managing their health, and feel more involved in partnerships with their physicians and in making decisions about their treatment (Bass et al, 2006; Newlon et al, 2009).

3. Methodological issues

In this section, the most important strengths and limitations regarding the recruitment strategy, study design and measurements of our cross-sectional study are discussed. The methodological issues of the development study have already been discussed in *Chapter 5*.

3.1. Study strenghts

The strengths of the cross-sectional study were (a) the high participation rates, (b) the narrowly-defined survivorship phase and (c) an integrated approach to understanding physical activity in breast cancer survivors.

3.1.1. Response rates and sample size

Participants in our cross-sectional study were recruited through breast cancer nurses at fifteen Flemish hospitals including local as well as university hospitals. In total, 802 patients agreed to participate and received questionnaires, of which 547 (68%) were returned. This initial response rate is quite high compared with other studies on cancer survivors (e.g. range 28% to 58%) (Blanchard et al, 2002; Rogers et al, 2008). Thanks to the recruitment of a heterogeneous and large sample (n=465), recruited from different hospitals and regions, our results are likely to be representative of the large group of women who have recently completed their breast cancer treatment (Blanchard et al, 2002; Courneya et al, 2006; Blaney et al, 2011). Moreover, our large sample size improved statistical power and allowed us to study subgroups and differences between subgroups (e.g. working versus non-working survivors) (Biau et al, 2008).

3.1.2. Selection of women during their transition from breast cancer patient to survivor

As we were focusing on the transition from breast cancer patient to survivor, we selected women who had completed their treatment three weeks to six months earlier. Studies capturing this time period are very scarce and prior studies often do not distinguish between the ‘early’ survival and ‘long-term’ survivorship (Aziz, 2002). Albeit our chosen time-interval is somewhat arbitrary, other authors have defined this period as a separate phase on the cancer continuum (Courneya and Friendereich, 2011; Costanzo et al, 2010). Moreover, capturing the six months interval is close to real life as women are often offered rehabilitation possibilities (including physical activity) soon after treatment and are presumed to go back to work within six months post-treatment (Tamminga et al, 2010). The studies presented in this thesis made an important contribution to the survivorship literature through their clear definition and identification of the transition period. A six-month period allows for discussion of recovery as well as reintegration (activation and participation) and prevention, the three main aims of women in the transition phase from breast cancer patient to survivor.

3.1.3. An integrated approach to understanding physical activity in breast cancer survivors

In this thesis, a multitude of psychosocial determinants was included to allow for understanding physical activity in an aggregated context. This resulted in more comprehensive results than in previous studies (Park and Allison, 2007). Additionally, the relation of the psychosocial determinants and physical activity was analysed from a variable-centred (regression analyses) and a person-centred perspective (cluster analyses). The use of a person-centred approach is novel in studies on physical activity determinants in breast cancer survivors.

Regression analyses allowed for identification of relationships among independent (e.g. distress) and dependent variables (e.g. physical activity level) whereas cluster analyses allowed for grouping of cases based on the independent variables and identification of the nature of meaningful subgroups of breast cancer survivors, along with their prevalence. Identifying such clusters can contribute to our understanding of how the complex dimensions of distress and adjustment interact, and how these subgroups may differ in terms of supportive care needs and physical activity levels (Park and Allison, 2007). Considering results of both regression analyses and cluster analyses permits us to sketch the broad role of physical activity in early breast cancer survivors, and elicits important considerations and practical implications.

3.2. STUDY LIMITATIONS

In interpretation of the results discussed in this thesis, some important limitations of the study should be taken into consideration. Limitations concern (a) the lack of information on non-responders, (b) the use of self-reports and (c) the cross-sectional nature of the study design.

3.2.1. Lack of information on non-responders

We do not have any information on the non-responders (32%). Information on non-responders or knowing the differences between responders and non-responders is an added value in terms of the generalization of results (Galea and Tracy, 2007). It could be that women suffering distress and poor adjustment dropped out because the questionnaire was perceived as too intrusive. The opposite could also be true, namely that those women who were feeling well, might have declined participation because they perceived the questions as related to others (those who were still suffering).

3.2.2. Use of self-reports

Results in this thesis relied on the use of self-reports regarding the assessment of physical activity and supportive care need for physical activity, the assessment of determinants for physical activity (general as well as cancer-related) and the assessment of illness-related and psychosocial variables. We opted for self-reports as they allowed us to collect a large amount of data in a relatively short time at low cost. Furthermore, self-reports are efficient at collecting information on a wide range of topics, including personal facts, attitudes, behaviours and opinions (Sallis and Saelens, 2000).

Some important limitations must be considered, however, because self-reports are influenced by psychological, sociological, linguistic, experiential and contextual variables (Harrison et al, 1996; Lanyon and Goodstein, 1997). In this section we discuss the problem of over-reporting in the assessment of physical activity and the psychometric properties of the selected instruments.

Measuring physical activity through self-reports involves the report of leisure-time activities as well as the recall of different acts that are embedded in daily activities. As this is a cognitively difficult task, a possible recall bias and a misreporting of actual levels can occur. This process is further influenced by social desirability and misinterpretation of questions (Sallis and Saelens, 2000; Motl et al, 2005). 'Moderate intensity' in particular can be misinterpreted by cancer survivors, who may perceive activities that are of low intensity for a healthy person to be activities of moderate or high intensity for themselves (Servaes et al, 2007; Doyle et al, 2006). With respect to physical activity, these processes mostly lead to over-reporting of actual physical activity levels. In previous chapters, we reported the rather high median values of moderate to vigorous physical activity found in our studies. When we further analysed the proportion of women who actually met current recommendations,[4] results were more in accordance with the literature (Devoogdt et al, 2010). On average, 54% of non-working and 25% of working survivors did not meet the 210 min/week guidelines and 51% in both groups reported never being physically active for at least 30 minutes a day. Further, Emery et al (2009), found a physical activity increase in the first 18 months after diagnosis to a peak level that was consistent with recommended guidelines for physical activity followed by a steady decline over the subsequent 42 months. As our study reported on physical activity levels of women 14 months at most post-diagnosis, the reported physical activity levels are analogous with the noted increase in the study by Emery and colleagues (2009).

The quality of self-report measures is to a large extent dependent on their psychometric properties, in particular their reliability and validity (Squires et al, 2011). For all self-reports used in our study, indications of validity were found and most questionnaires were already used in (Dutch speaking) populations of cancer survivors (Servaes et al, 2002; Rozema et al, 2009; Devoogdt et al, 2010). Psychometric characteristics of included questionnaires are further discussed in the relevant chapters (*Chapter 2*, *Chapter 3* and *Chapter 4*).

Nevertheless, the reliability of our questionnaire could have been compromised because of the inclusion of many concepts, which made it quite demanding to complete (Edwards et al, 2004). Indeed, participants' concentration and motivation could have diminished during the process. Reliability is concerned with random error. Since decreased mental effort during long surveys and questionnaires increases random error their reliability will be

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[4] Recommendation following WCRF/AICR (2007): be moderately physically active, equivalent to brisk walking, for at least 30 minutes a day (can be incorporated in occupational, transport, household or leisure time) Following ACSM: be moderately physically active for 30 minutes a day for at least five days a week or perform vigorous-intensity aerobic physical activity for a minimum of 20 min on three days each week.

poorer compared with that of answers provided by motivated and focused participants (Krosnick, 1991). A recent study revealed that changes in awareness during completion of a long questionnaire constitute a more complex process and also depend on the context and the individual items (Wentzel-Larsen et al, 2011). Our questionnaire was divided into two parts, one part for the physical and psychological variables, another for the questions concerning physical activity and perceived needs. As both parts concerned different topics and content, this might have had a positive effect on concentration and motivation. Furthermore, we pre-tested our questionnaire with five breast cancer survivors and they all confirmed its feasibility. Moreover, the high response rates illustrate that many women remained motivated to finish the questionnaire. This is further confirmed by the few missing data (only nine participants were excluded because of missing data) and no evident trend of decreased item response rate throughout the questionnaire.

3.2.3. Cross-sectional nature of the study design

Owing to the cross-sectional study design, no conclusions on temporal and causal relations between determinants and physical activity could be drawn. This precluded conclusions on the predictive strengths of the identified correlates of physical activity. The lack of results on temporal relationships further implies that no conclusions on behavioural change can be inferred. We opted for a cross-sectional design, however, as it allows for a quick and overall snapshot of a certain population and permits conclusions to be drawn about relationships between a large number of variables. Through identification of some important characteristics of the selected population and thorough exploration of the data, some important preliminary data arise that can support further research (see recommendations for future research).

3.2.4. Lack of an effect evaluation of the developed intervention

To ensure that the current physical activity intervention was developed in a systematic and evidence based way, the Model of Planned Health Promotion of Population Health was used as a guiding model. However, the criteria for the last steps of this model, namely the implementation, dissemination and evaluation were only partly met. Despite that chapter 5 provides data on the process evaluation of the pedometer-based computer-tailored physical activity advice for breast cancer survivors, the results on the effect of the intervention on physical activity levels, step counts and quality of life parameters among breast cancer survivors are not known yet. As these results are a prerequisite to support the implementation of the intervention, an effect evaluation is an essential step. This point is further discussed under recommendations for future research.

Thereby, results of the current process evaluation should be interpreted with caution as they derive from a small sample. Moreover, the high prevalence of high educated women forms an important concern for the recruitment procedure of the future effect evaluation. Efforts must be done to include low as well as high educated women.

4. Recommendations for practice

In Belgium, physical activity interventions are often organized as oncological rehabilitation programmes. These programmes mainly focus on supporting the physical and psychological recovery after breast cancer (Charlier et al, 2008) and usually include group-based exercises. Less attention is paid for supporting the adherence to an active lifestyle and the adoption of home-based physical activity. Actual participation in these group exercise programmes is rather low (Zebrack et al, 2008; Findley and Sambamoorthi, 2009). In this thesis we noted that 60 % of the study population perceived a supportive care need for physical activity but only 13% were participating in an oncological rehabilitation programme. As has been described in the literature the individual exercise preferences and pre-diagnosis sport participation can have an important effect on their motivation to participate in a group-based exercise programme (Courneya et al,2002; Carter et al, 2010). Furthermore, older age, lack of time and distance could be perceived as a barrier. A positive stimulus, however, was the recommendation of a physician to participate in such a programme or to become physically active (Jones et al, 2005). With more than 54% of the patients included in our cross-sectional study indicating that their physician wanted them to be physically active, we notice a positive trend in physicians' attitude towards physical activity promotion (Demark-Whanefried et al, 2000). However, there is still 40% of the physicians who did not discuss physical activity with their patients.

Considering the benefits of physical activity for breast cancer survivors and the reported supportive care need by patients themselves, supporting and discussing physical activity should be a part of the standard follow-up care for breast cancer survivors (Irwin, 2009; Doyle et al, 2006; WCRF, 2007; Schmitz et al, 2011). Most physicians and health care providers reported that they miss sufficient background to discuss physical activity with their patients or to refer patients to appropriate interventions. In the following section some recommendations are made for discussing, referring and organizing physical activity interventions during follow-up care for breast cancer. They all stress the importance of broadening the scope from oncological rehabilitation (in-hospital group exercise sessions) to tailored physical activity interventions (promotion of an active lifestyle during daily life).

4.1. Discussion of 'controllable' events related to exercise beliefs

Discussing controllable events closely related to women's exercise beliefs could be helpful in motivating women to become more active. Results suggest that women are more driven to participate in an active lifestyle because it contributes to their process of reintegration (belief of return to a normal life and the perception of control). Home-based interventions and encouragement of physical activities during daily life can reinforce these feelings of returning to normal.

Whereas more than two-thirds of the participants in the cross-sectional study believed that physical activity could contribute to their return to normal, only half of the women believed that physical activity could also be helpful for their cancer-related symptoms, risk of a recurrence and risk of secondary disease. As survivors do not automatically expect a positive influence of physical activity on their cancer-related symptoms, it is advisable to promote and explain the benefits of physical activity for their perceived symptoms (Courneya et al, 2006).

4.2. Possibility of self-selection bias

Physicians and healthcare providers should be aware of a possible self-selection bias when physical activity is offered as a structured exercise programme (e.g. oncological rehabilitation). As participating in such an exercise programme can be seen as physical activity during leisure time, insights from this thesis suggest that women who are already convinced of the joy, pleasure and benefits of physical activity participate in such programmes and that those who would benefit most (women who are not naturally motivated, have a poor body image or low self-efficacy for being physically active) are more often overlooked.

That joy and pleasure are not necessary to participate in an active lifestyle is a promising finding. It advocates the promotion of physical activity during daily life, particularly since recent studies report on the associated benefits of physical activity during housework and gardening, transportation and occupation (George et al, 2010; Rogers et al, 2011).

The likelihood of self-selection bias is further supported by the results of the cluster analysis. It was noticed that within the high-distress groups, women with an active approach (characterized by good levels of personal control, social support and self-esteem) particularly participated in oncological rehabilitation. Lower participation rates were found among their counterparts (characterized by high distress and an emotional approach). Healthcare providers must be aware that post-treatment interventions should also reach the most vulnerable group, namely women with high distress and an emotional approach, who are not actively seeking support (Ramanadhan and Viswanath, 2006). Raising awareness among clinicians of survivors' levels of distress and adjustment may facilitate the identification of survivors with a supportive care need and may improve the reach of current or new intervention options.

4.3. Referral of breast cancer survivors to appropriate interventions

On the basis of the studies described in this thesis, it is recommended to refer breast cancer patients to appropriate and personalized interventions after treatment completion. This may improve the effectiveness of promoting physical activity during the follow-up care for breast cancer. Moreover, women with an active approach towards their cancer-related situation should be particularly encouraged to take responsibility for their own health. This could partially be achieved with the developed step advice intervention. In anticipation of further data on the effectiveness of the intervention one might assume that the advice will be suitable for women assigned to the low distress-active approach group as it may contribute to their process of empowerment. Women in the low distress-resigned approach group may also appreciate the step advice since it requires moderate effort and it is applicable in daily life. The advice can also provide added value to group programmes for women in the high distress-active approach group, as it encourages them to become detached from the medical context. Women with high distress, who tended to be clinically depressed, are likely to profit more from more intensive and face-to-face interventions before receiving home-based advices (Craft et al, 2012).

Our study provided a first step in understanding physical activity and physical activity promotion after breast cancer. Further exploration of the main findings and the intervention developed in this thesis could provide some meaningful directions for the organization of physical activity interventions in follow-up care after cancer.

5. Recommendations for future research

5.1. Implementing longitudinal research

To go beyond the findings of the cross-sectional study, it is recommended to track physical activity and physical activity beliefs as well as distress and adjustment over time.

First, longitudinal research ought to clarify how women will adjust over time. In the literature different patterns of recovery after breast cancer are reported which range from a resilience or recovery pattern to patterns of persistent distress (Helgeson et al, 2004; Knobf, 2011). Insight into how the four clusters identified in this thesis will adjust over time may allow us to tailor the physical activity advice to survivors' patterns of recovery. Longitudinal research could also contribute to the identification of breast cancer survivors at risk of disturbed adjustment. Linking survivors to physical activity interventions closely related to their perceived need, distress and adjustment may improve the efficacy of these interventions (Park et al, 2009; Williams et al, 2007; Knobf, 2011).

Second, this thesis was a first step in providing some insight into the determinants of physical activity after breast cancer. Longitudinal designs must clarify the role of general and cancer-related as well as illness-related variables in 'predicting' physical activity levels after breast cancer. Future research must clarify if survivors suffering from fatigue and arm symptoms are at increased risk of developing an inactive lifestyle (owing to low participation in daily life activities). It could also be examined whether survivors who lack motivation for physical activity after treatment completion will indeed participate less in leisure-time activities and oncological rehabilitation programmes after their treatment. In that way, longitudinal research would contribute to the identification of breast cancer survivors at risk of an inactive lifestyle.

5.2. Further exploration of relevant determinants of physical activity in cancer survivors

Although the regression models presented in this thesis explained on average 20% of the variance of total physical activity among breast cancer survivors, more than 70% remains unexplained. Other psychological variables deriving from pre-motivational models like protection motivation theory (Wood, 2008) could further increase the explained variance. These models presume knowledge of health risk (perceived vulnerability) and awareness of personal physical activity level before factors such as attitude and self-efficacy become relevant in explaining physical activity. Moreover, the role of pre-diagnosis activity levels and actual fitness level is also not included in the explanation of current physical activity behaviour. Pre-diagnosis activity levels are well associated with physical activity levels post-treatment (Courneya et al, 2004). However, pre-diagnosis activity levels were less associated with the self-efficacy for being active after breast cancer treatment (Rogers et al, 2008) .

Moreover, the extent to which situational demands (e.g. relational problems, return to work) or other goal intentions conflict with the motivation of being sufficiently active could also be an interesting point for further research in this specific population.

At last, we did not include any determinant on the physical environmental level, for example living in a rural versus urban neighborhood or the availability of sport and rehabilitation facilities which could also influence physical activity behavior among breast cancer survivors (Cunnigham and Michael, 2004; Rogers et al, 2009).

5.3. Further exploration of the pedometer-based computer-tailored physical activity advice

In this thesis, the Model for Planned Health Promotion of Population Health was used to develop tailored advice for breast cancer survivors. It did not include the last steps of the model, which argue for future research. We consequently recommend testing the feasibility and efficacy of the developed intervention, comparison of the developed intervention with other intervention strategies and the study of optimal conditions for the implementation and dissemination of the intervention.

5.3.1. Recommendations for testing feasibility and efficacy of the advice

As no major problems were detected during the pre-tests, we suggest that the pedometer-based computer-tailored physical activity advice is a usable and feasible intervention for breast cancer survivors. Tests of feasibility and efficacy in a randomized controlled trial are recommended. *Feasibility testing* could include drop-out analyses during the intervention (Courneya et al, 2002). Extra information could be gathered by comparing characteristics of non-attendees with the cluster-specific characteristics identified in this thesis. To test *the* *efficacy of the intervention*, post-intervention effects on physical activity levels and subsequently quality of life and fatigue must be analysed. Tests of the post-treatment effects are recommended, especially those concerning behavioural change, on different time intervals (three months, six months and one year post-intervention) (Glasgow et al, 2002).

5.3.2. Including different intervention strategies

Further randomized controlled trials, including tailored and standard advice, or group exercise programmes are needed to explore the added value of tailoring physical activity advice in the breast cancer population. Consequently, trials including advice with and without pedometer use could also clarify the added value of monitoring steps and providing step goals in promoting physical activity among women after the completion of their primary treatment.

Continued efforts to refine answers as to what type of intervention (e.g. web-advice versus oncological rehabilitation programme) works well for whom and under what conditions will foster evidence-based applications for physical activity interventions after breast cancer (Glasgow, 2002; Johansen, 2007).

5.3.3. Studying optimal conditions for the implementation and dissemination of the advice

Results of the process evaluation (*Chapter 5*) and cross-sectional study (Pauwels et al, 2011) showed a positive attitude among breast cancer survivors towards physical activity promotion through the Internet. Further research is needed, however, on the number and characteristics of survivors who will actually request the advice after receiving information and access to the website. A study testing the website in the general population noted that 70% of the participants requested the advice at least once. The most frequently mentioned reasons for not requesting the Internet advice were lack of time and computer problems (De Cocker et al, 2012).

As regards dissemination, the results of the process evaluation showed that breast cancer patients value the opinion and referral of a doctor or specialist to the developed web-based intervention. Moreover, working women who were encouraged by their physician to be physically active on a regular basis participated more in leisure-time activities (*Chapter 3*). Consequently, disseminating the Internet-based intervention through oncologists would seem to be a worthwhile option. Recent studies reported on the positive attitude of physicians towards their patients' health-related Internet use (Kim and Kim, 2009; van Uden-Kraan et al, 2010). Future research must clarify physicians' attitude towards referring patients to the developed intervention, and to develop strategies to influence these attitudes positively.

6. Conclusion

Breast cancer patients enter survivorship with a heterogeneity of interpersonal and treatment-related characteristics which influence their adjustment, physical activity levels and supportive care needs for physical activity. Overall, women tend to strive to retake control and return to normal and three out of five believe that physical activity can contribute to this process of re-integration. Subsequently, three out of five breast cancer survivors report a need for information and support related to an active lifestyle, exercise and physical activity.

This thesis argues for tailoring physical activity interventions to individuals' physical activity beliefs and barriers, taking into account their existing levels of distress and adjustment to assist adherence to lifelong physical activity. A home-based physical activity intervention based on individual step goals and tailored advice was developed. Furthermore, this thesis identified the presence of four profiles based on distress and adjustment among breast cancer survivors. Knowledge of the characteristics of these profiles and associated needs may stimulate reflection in clinical practice and research for further refinement of physical activity promotion in follow-up care for breast cancer.

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Summary

In recent years, interest in physical activity from a breast cancer perspective has changed. The initial interest in physical activity was predominantly focused on the general healthy population (primary prevention of cancer), followed by interest in including physical activity in rehabilitation during and after cancer. Recently, physical activity has also been acknowledged within prevention models and health promotion models for cancer survivors (prevention of late side-effects, secondary disease and breast cancer recurrence). The increased number of former breast cancer women suffering from short- and long-term side-effects calls for effective rehabilitation and health promotion strategies. Insight into survivors' physical activity levels, supportive care needs for physical activity and physical activity determinants will provide a thorough basis for the development of appropriate interventions that will support physical activity promotion after breast cancer.

In a first step (*Chapter 2*), physical activity levels and supportive care needs for physical activity were studied among women during their transition from breast cancer patient to survivor (n=465), three weeks to six months post-treatment. Results showed a wide variance in physical activity levels among breast cancer survivors. This variance suggests that meeting the recommendations of physical activity is a challenge for some, but not necessarily impossible for all survivors. When we explicitly asked women if they perceived a supportive care need for physical activity, six out of ten expressed a need for support. For a better understanding of the diversity in observed and perceived needs among women during their transition into survivorship, women's perceived distress and adjustment to their post-cancer condition were further clarified. A cluster analytic approach was used to investigate the presence and nature of subgroups of breast cancer survivors. Four meaningful clusters were revealed: (1) a low distress-active approach group, (2) a low distress-resigned approach group, (3) a high distress-active approach group and (4) a high distress-emotional approach group. Subsequently, clusters' physical activity levels and expressed needs for physical activity were analysed. The results showed that supportive care needs for physical activity were unrelated to perceived distress and actual physical activity levels. This emphasizes the need for additional screening for distress and adjustment in order to better understand women's supportive care need for physical activity. Knowledge of the presence of these clusters among healthcare professionals could make them more aware of the unique needs and tailored approaches and could facilitate the referral to appropriate (physical activity) interventions resulting in reaching a broad range of breast cancer survivors.

A subsequent step was to understand the influential factors of physical activity of women during the transition from patient to survivor. In health behavioural research, it is believed that the constructs used in behavioural theories provide general determinants that can be helpful to understand “why” or “why not” people are physically active. These and more cancer-related determinants were studied in *Chapter 3*. The present study found, in line with the literature, some evidence for the positive role of self-efficacy, enjoyment and social support and the negative influence of experienced barriers (lack of time and lack of company) in explaining physical activity among breast cancer survivors. Additional, several relevant cancer-related determinants of physical activity were indicated. Survivors’ physically active behavior was positively influenced by the belief that physical activity was helpful in the return to ‘normal’ life and the positive opinion of a physician. Barriers like lack of energy, perceived fatigue and low self-efficacy because of fatigue and arm symptoms revealed a negative relation with physical activity levels. Subsequently, it was recommended to broaden the scope of underlying mechanisms of physical activity among breast cancer survivors with personal and illness-related factors. *Chapter 4* showed that breast cancer survivors perceiving low personal control of their post-treatment and illness-related condition reported low levels of physical activity. Survivors suffering from fatigue and arm symptoms also reported less physical activity during daily activities, although fatigue and arm symptoms did not interrupt with leisure-time physical activity.

It was notable that identified determinants varied by working status (working or non-working) and type of activity (active lifestyle versus leisure-time physical activity). For example, body image problems mainly prevent non-working women from participating in leisure-time physical activity whereas working women were more physically active, even when suffering from poor body image or therapy side-effects. Overall, the results (*Chapter 3* and *Chapter 4*) suggested that working breast cancer survivors might be more active in seeking solutions (like being physically active) to deal with the experienced symptoms in comparison with their non-working counterparts. Furthermore, results indicated that participation in total physical activity (including all daily activities) was impeded more by the cancer experience than was leisure-time physical activity.

In a final step, home-based and computer-tailored advice, based on increasing steps through naturally occurring activities, was developed (*Chapter 5*). Goals of 2000 steps more than baseline counts were recommended for inactive survivors, whereas active survivors were encouraged to take 10 000 steps a day. If necessary, tailored advice was given on physical activity beliefs and barriers and cancer-related problems. The advice was pre-tested for usability and feasibility for three weeks. All participants were positive about the usability and feasibility of the tailored advice. Less active women in particular perceived the advice as novel and personally relevant. Moreover, all survivors reported the strong motivational effect of wearing a pedometer. Initial results indicate that the intervention is potentially very relevant for women who are in transition from breast cancer patient to survivor, although further research on the efficacy, implementation and dissemination of the intervention is needed.

In the final chapter, the main findings of this thesis were discussed. Several methodological and theoretical considerations were presented, as well as implications for practice and further research. Overall, we can conclude that the population of breast cancer survivors is characterized by a heterogeneity of personal and illness-related characteristics and physical activity beliefs which may influence their physical activity levels and supportive care needs for physical activity. Health promotion among cancer survivors could benefit from tailored approaches based on encouraging physical activity through naturally occurring activities. Knowledge of breast cancer survivors' level of distress and adjustment to the post-cancerous condition by healthcare providers could facilitate the identification of survivors at need of further support and their referral to tailored interventions.

Samenvatting

De focus en interesse in ‘beweging en borstkanker’ heeft de voorbije jaren een belangrijke evolutie gekend. Aanvankelijk werd beweging voornamelijk bestudeerd bij de gezonde populatie als mogelijke invloedsfactor op de ontwikkeling van borstkanker. Vervolgens werd beweging ook opgenomen in de revalidatie tijdens en na borstkanker om het herstelproces te ondersteunen. Daarnaast kan een actieve levensstijl na borstkanker bijdragen tot het voorkomen van latere nevenwerkingen, secundaire aandoeningen en mogelijk herval na borstkanker. Daar het aantal vrouwen dat lijdt aan de korte- en lange termijngevolgen van borstkanker sterk toeneemt, is er zowel nood aan efficiënte revalidatie strategieën als strategieën om een actieve levensstijl bij deze risicogroep te promoten. Inzicht in het beweeggedrag en de determinanten binnen de groep van ex-borstkankerpatiënten alsook de ervaren nood voor bewegingsondersteuning vormt een belangrijke basis voor de ontwikkeling van aangepaste bewegingsinterventies na borstkanker.

In een eerste stap *(Hoofdstuk 2)* werd het beweeggedrag en de ervaren nood aan bewegingsondersteuning bestudeerd bij vrouwen die de actieve behandeling voor borstkanker drie weken tot zes maanden geleden hadden beëindigd (n=465). Het beweeggedrag kende grote individuele verschillen, gaande van zeer inactieve tot zeer actieve vrouwen. Hieruit kan verondersteld worden dat het halen van de vooropgestelde bewegingsnormen voor sommige ex-borstkankerpatiënten een uitdaging vormt, maar niet onmogelijk is voor alle ex-borstkankerpatiënten. Wanneer er expliciet gevraagd werd naar de ervaren nood voor bewegingsinformatie en ondersteuning gaf zes op tien vrouwen aan hieraan nood te hebben. Om deze opgemerkte diversiteit van geobserveerde en ervaren nood bij deze vrouwen na borstkanker beter te begrijpen, werd hun ervaren stress (als resultaat van de aanwezige fysieke en psychologische nevenwerkingen) en hun aanvaardingsproces verder uitgeklaard. Aan de hand van een clusteranalyse werd gezocht naar karakteristieken van eventueel aanwezige subgroepen binnen de groep ex-borstkankerpatiënten die net hun behandeling hadden beëindigd. Vier betekenisvolle clusters werden terug gevonden: (1) een lage distress-actieve aanpak groep, (2) een lage distress-berustende aanpak groep, (3) een hoge distress-actieve aanpak groep en (4) een hoge distress-emotionele aanpak groep. Distress moet hier begrepen worden als de resultante van de ervaren stress en de mate waarin deze stress het (emotionele) welzijn van de vrouw beïnvloedt. Voor iedere groep werd vervolgens het beweeggedrag en de ervaren nood aan bewegingsondersteuning geanalyseerd. De resultaten toonden aan dat de ervaren nood niet noodzakelijk geassocieerd was met het eigenlijke beweeggedrag en de ervaren distress. Het is bij deze aangewezen om naast het kennen van de ervaren stress en het eigenlijke beweeggedrag, eveneens het aanvaardingsproces van de vrouw te begrijpen, om zo de al dan niet ervaren nood aan verdere ondersteuning breder en binnen de juiste context te kunnen plaatsen. Het (h)erkennen van de gevonden clusters door zorgverleners kan hen bewust maken van de unieke noden en de aangepaste aanpak vereist bij deze populatie. Daarnaast kunnen de gevonden clusters een kader bieden om ex-borstkankerpatiënten naar aangepaste interventies door te verwijzen, zodat een groter aantal patiënten kan bereikt worden en kan genieten van de mogelijke voordelen van een actieve levensstijl op hun herstelproces en algemene gezondheid.

Een volgende stap binnen deze thesis was het identificeren van de invloedsfactoren van beweging zoals deze ervaren werden bij ex-borstkankerpatiënten. Binnen bewegingsonderzoek wordt verondersteld dat algemene determinanten, afgeleid van de gedragsverklarende theorieën, bijdragen tot het begrijpen waarom personen al dan niet voldoende actief zijn. Deze algemene en meer kanker- specifieke determinanten zijn bestudeerd in *Hoofdstuk 3*. Deze studie vond, gelijklopend met de literatuur, enige evidentie voor de positieve invloed van eigen-effectiviteit, plezierbeleving en sociale steun en de negatieve invloed van ervaren hindernissen zoals tekort aan tijd en/of gezelschap op het beweeggedrag van ex-borstkankerpatiënten. Daarnaast werden ook verschillende kanker-specifieke determinanten belangrijk geacht in het verklaren van het beweeggedrag. Ex-borstankerpatiënten waren geneigd meer te bewegen indien ze geloofden dat beweging bijdraagt tot het heropnemen van het leven zoals voor de kanker. Hindernissen zoals een tekort aan energie, ervaren vermoeidheid alsook een laag vertrouwen in de mogelijkheid actief te zijn ondanks de ervaren vermoeidheid beïnvloedden het beweeggedrag negatief.

Vervolgens werd aangeraden om eveneens ziekte en persoons-gerelateerde factoren te bestuderen als mogelijke invloedsfactoren op het beweeggedrag van vrouwen die net hun behandeling voor borstkanker hadden beëindigd. *Hoofdstuk 4* toonde de belangrijke positieve invloed van het ervaren van controle over de situatie na de kanker op het beweeggedrag van ex-borstkankerpatiënten aan. Ex-borstkankerpatiënten die lijden aan vermoeidheid en armproblemen waren minder geneigd om te participeren in beweging tijdens dagdagelijkse activiteiten, hoewel deze klachten minder bepalend waren voor bewegingsactiviteiten tijdens de vrije tijd.

Opmerkelijk was dat, voor beide studies *(Hoofdstuk 3 en 4)*, de teruggevonden invloedsfactoren verschilden afhankelijk van de werksituatie (werkende versus niet-werkende) van de ex-borstkankerpatiënten en het type activiteit (beweging tijdens dagdagelijkse activiteiten versus beweging tijdens de vrije tijd) dat verklaard werd. Bijvoorbeeld, een laag lichaamsbeeld hinderde voornamelijk niet-werkende vrouwen om actief te zijn tijdens hun vrije tijd. In tegenstelling waren werkende vrouwen met een laag lichaamsbeeld en behandelingsgebonden nevenwerkingen eerder geneigd om meer actief te zijn tijdens hun vrije tijd. Er kan verondersteld worden dat werkende vrouwen meer geneigd zijn oplossingen te zoeken (zoals meer te bewegen) om om te gaan met hun ervaren klachten in vergelijking met hun niet-werkende lotgenoten. Daarnaast kan opgemerkt worden dat de kankerdiagnose voornamelijk de deelname aan een actieve levensstijl tijdens dagdagelijkse activiteiten aantastte, meer nog dan de deelname aan bewegingsactiviteiten tijdens de vrije tijd.

In een laatste stap werd een thuisinterventie op basis van een 'computer-tailored' advies ontwikkeld *(Hoofdstuk 5)*. Het advies betrof het verhogen van het dagelijkse 'stappen' aantal door meer actief te zijn in dagdagelijkse activiteiten. Stapdoelen van 2000 stappen extra werd aangeraden aan de eerder 'inactieve' ex-borstkankerpatiënten, daar waar actieve ex-borstkankerpatiënten werden aangemoedigd om de gezondheidsnorm van 10 000 stappen per dag te halen. Indien nodig werd aangepast advies gegeven voor de opgegeven voordelen, hindernissen en kanker-gerelateerde klachten. Het advies werd vervolgens getest op zijn gebruiksvriendelijkheid en haalbaarheid gedurende drie weken. Alle deelnemers waren positief. Voornamelijk inactieve vrouwen ervoeren het advies als nieuw en persoonlijk relevant. Alle vrouwen, daarentegen, gaven aan dat het dragen van een stappenteller hen motiveerde om meer te stappen. Deze initiële resultaten tonen aan dat een stappeninterventie met 'tailored' advies potentieel relevant kan zijn om bewegingsondersteuning te bieden aan vrouwen die net hun behandeling voor borstkanker hebben beëindigd. Verder onderzoek is nodig om de effectiviteit van de interventie aan te tonen en de implementatie te toetsen.

In een laatste hoofdstuk, *Hoofdstuk 6*, werd een verdere verdieping gegeven van de hoofdbevindingen van de gerapporteerde studies. Verschillende methodologische en theoretische overwegingen werden bediscussieerd. Daarnaast werden enkele aanbevelingen voor de praktijk en verder onderzoek geformuleerd.

In het algemeen kon gesteld worden dat de groep vrouwen die net hun actieve behandeling voor borstkanker hadden beëindigd gekenmerkt werd door een grote heterogeniteit in zowel persoonlijke als ziekte-gerelateerde variabelen alsook in ervaren bewegingsredenen. Het samenspel van deze factoren beïnvloedde het beweeggedrag en de ervaren nood aan verdere bewegingsondersteuning. Bewegingspromotie bij ex-borstkankerpatiënten is gebaat met interventies aangepast aan deze invloedsfactoren en interventies die een actieve levensstijl tijdens dagdagelijkse activiteiten promoten. Indien zorgverleners kennis hebben van de ervaren stress bij de vrouwen en inzicht hebben in hoe ieder individu hiermee omgaat, zou dit kunnen leiden tot een meer gerichte doorverwijzing naar meer aangepaste interventies.

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Caroline

About the author

Caroline Charlier was born on the 3th of March 1977 in Bonheiden. After completing secondary school in 1995 she started her studies physiotherapy at the faculty of Kinesiology and Rehabilitation Sciences at the University of Leuven. She obtained, cum laude, the degree of Master in the Kinesiology and Rehabilitation Sciences in 1999 and the degree of Sports Physiotherapy, summa cum laude, in 2000. During the last year of her studies, she also worked at the University of Leuven as a research assistant and started a research project on physical and psychosocial risk factors for developing chronic complaints after whiplash, under the supervision of Prof. Dr. Roeland Lysens.

In 2001, she went with her husband to Maaseik and started working as a physiotherapist. During these years she had the opportunity to translate her studies and scientific baggage into practice. In 2004, she started working as a docent physiotherapy at the PHL University College and participated as a researcher in the REVAL research institute. In the next four years she supervised research projects on physical activity programs for cancer patients and patients suffering from multiple sclerosis, under the supervision of Dr. Maria Wijmans and Prof. Dr. Bert Op 't Eynde. Her interest in the psychology of patients was further stimulated by her participation in a research project on quality of life and psychosocial adjustment in people suffering from chronic diseases (RA, MS, CVS) under the supervision of Prof. dr. Elke Van Hoof.

As she was triggered by the fact that most patients may benefit from being active but only a few were able to do so, she submitted a project considering physical activity promotion to the Flemish League against Cancer. After giving birth on her fourth child, she started her PhD project in 2009 at the Open University of the Netherlands under the supervision of Prof. Dr. Lilian Lechner and the Ghent University under the supervision of Prof. Dr. Ilse De Bourdeaudhuij. In the meantime she worked at the Belgium Cancer Centre, which allowed her to test the insights from practice and science to the political view.

During all these experiences and studies, she recognized her strong will to help people and returned to the micro-level of support. In December 2012, she will restart her activities as a physiotherapist, combining 'hands and knowledge' to heal patients.