Nucare, a coping skills training intervention for oncology patients and families: Participants’ motivations and expectations

By Linda Edgar and Suzanne Watt

Abstract

This study looks at the relationship between intention, self-efficacy, and beliefs as components of readiness to learn in a population dealing with a cancer diagnosis who attended the Nucare program, a coping skills training intervention. The subjects completed a short questionnaire and/or participated in a focus group as part of the intervention. We found a positive relationship between participants finding the intervention useful and their levels of self-efficacy and beliefs in their ability to change their coping strategies.

Understanding that patients believe that coping is important to their well-being helps nurses plan interventions to teach and promote the use of coping skills to patients and families. Nucare may be selected as a useful guide to practice.

Cancer is the second most common cause of death in Canada as reported by Health Canada (1997). Canadian Cancer Statistics (2003) reports 41% of men and 38% of women will develop cancer in their lifetime, and 27% of men and 23% of women will die of the disease. Cancer evokes feelings of distress in patients, their families, and friends, from diagnosis to well beyond the completion of treatment. Research examining psychological distress has reported that clinically significant levels of emotional distress are observed in roughly one-third of mixed cancer samples at various points through the cancer trajectory (Farber, Weinerman, & Kuypers, 1984; Trask et al., 2001). Although screening is recommended to detect patients at risk for distress, concordance between patient and staff evaluations has not been encouraging (Trask et al., 2002). Patients themselves frequently seem to be astute detectors of their own distress (Trask et al., 2002), and are able to seek out and take advantage of available support and educational services (Edgar, Remmer, Rosberger, & Fournier, 2000). Specifically, they make efforts to change their current circumstances and state of mood, health, feelings, or social functioning through their coping strategies. There has been a paucity of research examining the factors that are linked to patients’ decisions to engage in psychoeducational programs, and their perceptions of the outcomes of their participation. What makes an individual ready to join such a program and what contributes to his or her perceptions of success?

The purpose of this paper is to examine patients’ participation in a psychoeducational coping skills training program, called Nucare, and to describe the components of the program.

Background

Coping

Folkman and Lazarus (1988) defined coping as “cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p.310). The specifics of these efforts are constantly modified to accommodate the continuous change of the person-environment relationship as evaluated and re-evaluated by the individual. Coping, therefore, involves behaviour, thought, or action strategies that will modify the situation causing distress. These strategies can be problem-focused if the situation can be changed, or emotion-focused if the situation cannot be changed.

Factors affecting learning outcomes

Devine and Westlake (1995) looked at the effects of psychoeducational interventions in adult cancer patients through the meta-analysis of 116 studies. They found that many types of psychoeducational interventions were beneficial in decreasing anxiety, depression, nausea, and pain, and in increasing knowledge and helping individuals cope with chronic illness and life-threatening diseases. Some involve support groups using individual and/or group sessions, others are geared to psychosocial interventions, while some focus on cognitive-behavioural interventions, and still others combine some or all of the above. A review of the literature indicates that a variety of interventions have been successful. However, there is little research on how the process of learning occurs and what individual factors affect subsequent behaviour change or intent to change.

Learning can involve changing a behavioural response to a stimulus in order to reduce tension produced by this stimulus. To elevate the new, desired response to the level of a habit, this new response must be practised repeatedly. It can then become ingrained in the repertoire of responses readily accessible to the person (Babcock & Miller, 1994). From social-cognitive theory, it is understood that to be successful, the individual needs to want to change, to feel confident that he will be able to change, and to feel that the perceived outcome is worth the effort to change (Anderson, Winett, & Wojcik, 2000). Motivation is the driver of most human activity, and self-efficacy is the perception that one can use lessons learned and methods used in one situation to deal with another (Jackson & Aiken, 2000). Setting realistic goals and reaching them improves self-efficacy and promotes better use of coping skills. Together, these concepts of self-efficacy and motivation are predictors of quality of life outcomes (Grahn, Stigmar, & Ekdahl, 2001). Bandura (1977) defines efficacy expectation as the belief that an individual can be successful at performing a certain behaviour necessary to generate a given outcome. Bandura’s self-efficacy theory (1997) states that individuals evaluate themselves in terms of their ability to participate in self-care activities that will generate appropriate outcomes. Self-efficacy, or the expectation that an individual can master appropriate skills, will influence whether the individual will attempt to adopt and/or persist in adopting coping behaviours.

One element of personal coping resources is the feeling of perceived control over a given situation (Grahn et al., 2001). Uncertainty must be reduced to increase the sense of control. Uncertainty can result from inadequate understanding of a given situation, absence of alternate solutions to the problem, lack of information, and doubt about one’s role in the situation or of the outcomes resulting from the choice of intervention. Dealing effectively with uncertainty involves getting more information, seeking advice, weighing pros and cons, anticipating the situation, and

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simulating the event in one’s mind to better predict which intervention would be best in the given situation (Lipshitz & Strauss, 1997).

Individuals who are usually in control of their environment tend to claim higher satisfaction, more confidence, enjoyment, and trust, and show more initiative and persistence. They are usually in better physical and psychological health and are more compliant with medical prescriptions than those who feel controlled by external factors and internal pressure (Senécal, Nouwen, & White, 2000). According to Hardy, Barkham, Shapiro, Reynolds, and Rees (1995), treatment outcomes are contingent upon the patients’ expectations of benefit.

Readiness to learn depends on the emotional status of the person. Babcock and Miller (1994) refer to McHatton’s description of four stages of emotional adjustment that progress to readiness to learn using Maslow’s grading of needs: impact involving anxiety, despair, and loss of control; regression with denial, flight, and need to be surrounded; acknowledgement including doubt, loss of self-confidence, and loss of self-esteem; and finally reconstruction characterized by the need to regain control and confidence. In this context, self-efficacy, confidence, and the perceived importance of coping are overlapping variables that are necessary prerequisites to learning new ways of coping.

The Nucare intervention

Nucare (an acronym derived from nursing, cancer, research) is a psychosocial educational intervention offered to cancer patients and their families to help them develop skills helpful in coping with cancer. The intervention involves three two-hour sessions where the following seven coping skills are discussed: active problem-solving, ways of thinking, communication, use of social support, goal setting, healthy lifestyle, and relaxation training. The following is a brief description of the specific components of Nucare:

1) **Problem-solving techniques:** Each patient was taught a specific series of steps in problem-solving. A neutral example was first used to illustrate and practise the steps before patients’ own problems were used in a practical application of the techniques.

2) **Goal setting:** Setting graduated and attainable goals constitutes a realistic means of accomplishing tasks that are timely and relevant, and that provide a sense of perceived personal control. Patients were encouraged to set either short- or longer-term goals.

3) **Cognitive reappraisal:** Patients were taught to be more cognizant of and identify those thought patterns that contribute to negative mood. The awareness that patients could control their thoughts was often sufficient to provide positive change and improved mood. Patients were encouraged to practise identifying facts, thoughts, and feelings. First, patients recognized that their uncomfortable feelings emerged not only from facts, but also from their cognitive appraisals about their situation. Second, we taught patients how to reappraise or reframe negative, distorted, or catastrophic thoughts to make them more controllable and less distressing. The emphasis was placed on the relationship between cognitive reappraisal and an enhanced sense of personal control.

4) **Relaxation training:** Relaxation has been clearly shown to be effective as a treatment strategy for stress-related conditions. Relaxation training was introduced to patients as the second step in problem-solving (i.e., taking time out to develop a different perspective). Progressive muscle relaxation with guided imagery was most frequently used. An audiotape was provided for home use.

5) **Effective use of social support:** Patients were supported in identifying and acquiring sources of information and social support including tangible and emotional aid, and determining the adequacy of their own social support network.

6) **Communication:** Instruction was given regarding learning how to use “I” statements, to develop assertive behaviours, how to say “no”, and strategies to foster good doctor-patient relationships.

7) **Components of a healthy lifestyle:** The following topics were briefly discussed because all were considered to affect health: hope, spirituality, laughter, diet, exercise, and handling fatigue.

Figure One presents one page from the coping skills workbook used in Nucare.

The process of changing behaviour is discussed within the context of the seven skills in Nucare in relation to a) the necessity to practise new skills from 30 to 60 times; and b) the impact that a small amount of change can have on one’s well-being and coping. The focus of Nucare is on discovering and using one’s strengths to achieve realistic goals deemed important to the individual through restoring a sense of personal control. The interactive, yet didactic sessions allow participants to ask questions, discuss the different interventions, and give support to one another. Each participant receives a comprehensive workbook with simple instructions, exercises related to real-world situations and interpersonal relationships, and notes of encouragement to persist in practising the skills. The results of a comprehensive program of research on Nucare within the format of three large randomized clinical trials have clearly pointed to its effectiveness in reducing distress and enhancing good coping (Edgar, Rosberger, & Collet, 2001; Edgar, Rosberger, Collet, & Fournier, 2002; Edgar, Rosberger, & Nowlis, 1992).

Nucare uses research-based evidence showing that coping, using planful goal-directed problem-solving, positive reappraisal, and confrontive coping, has a strong influence on one’s emotional response to stressful stimuli and that “problem-solving and positive reappraisal contributed to an improved emotional state” (Folkman & Lazarus, 1988, p. 314).

The Nucare manual is a 72-page, user-friendly, interactive workbook that guides individuals in evaluating their current skills and in suggesting new ones that may be more appropriate for their needs. The workbook includes practice directions, worksheets, space for reflection, and a quick quiz on each skill. It is written simply and clearly, as shown in Figure One, and emphasizes the necessity for the practice of new skills (30 to 60 times), along with the reminder that only a small amount of change in coping is required. Studies have indicated that interventions which included printed materials for
patients to keep for future reference produced a larger effect on knowledge than those that did not (Devine & Westlake, 1995).

The Nucare intervention is based on the principles of changing the relationship between the individual and his/her environment using the McGill Model of Nursing. Coping, the ability to deal with a difficult situation, and human development are the major dimensions of the multifaceted construct of health within the model. The goal of coping is to reduce tension or diminish the problem and, additionally, to develop an expertise (mastery) in problem-solving. The outcomes of good coping include improved health, improved family problem-solving skills, better satisfaction with the outcomes of the decisions taken, and improved quality of life (Gottlieb & Rowat, 1987).

In the McGill Model of Nursing, development occurs through discovering the active and latent resources in the individual and his/her family as well as in the surrounding social system, activating these resources, and maintaining and adapting them according to circumstances. The individual is an active participant, able to learn new ways of coping and problem-solving while understanding that solutions lie within the self and family. This model assumes that the person wants to take responsibility for his/her health and that the needed resources, strengths, and energy exist within the self and the family (Gottlieb & Rowat, 1987).

The role of the nurse in this model is to promote health through teaching, using approaches that meet the learning needs of the patient, his/her needs, and coping style. The patient is the principal validator of the nurse’s assessment.

Method

Participants

This descriptive study used a convenience sample of Nucare workshop participants. Twenty individuals responded to a post-intervention telephone follow-up and/or attended a focus group. They attended two Nucare group sessions of two hours each and were contacted by telephone two to four months later for a follow-up questionnaire. At that time, these individuals were also invited to participate in a focus group one month later.

The participants were offered the Nucare intervention at a McGill University Teaching Hospital in Montreal through the Hope and Cope department, a volunteer peer support organization responsible for support and educational programs directed at oncology patients and their families. Participants either responded to posters inviting them to the sessions or were encouraged to attend by members of the health care team. However, they made the decision themselves about when and whether to participate, knowing that we were interested in how helpful they found the program and would obtain their input through a telephone questionnaire.

Hope and Cope volunteers receive 20 hours of orientation and training in preparation for their volunteer roles with cancer patients and families. This training includes how to conduct telephone conversations to evaluate various services offered. Hope and Cope volunteers telephoned 27 Nucare workshop participants for the follow-up questionnaire and were able to reach 20 of them.

The questionnaire developed to evaluate the program was based on a questionnaire used to evaluate similar items in another study (Schwarzer & Renner, 2000). It consisted of six questions assessing: The value of the intervention, by asking, “How helpful were the workshops?”; the individual’s intention to change, or interest in making a shift in their coping by “How much do you want to make a change in your way of coping?”; their perception of their self-efficacy by, “How confident are you that you will use some of the skills you have learned?” and “Can you give me an example of how you have used or practised one of the skills?”; outcome expectations and beliefs in the importance of good coping by, “How much do you agree with this sentence?”; “How I cope is important to my well-being”; and the need for further discussion, “Would you be interested in attending a follow-up session?” The questions consisted of four-point Likert Scale items, (from “not at all” to “very much”) which assessed the intentions, self-efficacy, and outcome expectations and beliefs of the participants.

We then invited participants to attend a focus group on the benefits of, and the barriers to, the helpfulness of the intervention. Ten individuals, eight women and two men, responded and met in the hospital setting where they talked about their ability to cope and the role of Nucare in relation to their coping skills. The descriptive data from the focus group were analyzed using content analysis and a search for themes related to the questionnaire.

Results

Part One: The questionnaire

Twenty-six of the 27 prospective participants were women. Of the 27 individuals, one woman did not have time to participate and one woman was in hospital due to her illness and could not participate. Four women and one man could not be reached, for an attrition rate of 26%. Three answered only part of the questionnaire.

Nineteen respondents were patients (95% of the sample) and one was a close friend of a patient (5% of the sample). There were no spouses or relatives of patients in the sample.

The indicators derived from the questionnaire included: helpfulness, intention, self-efficacy, and expectations or beliefs. Intention to change was reported as ‘very much’ by seven respondents (35%) of those surveyed. Three participants (15%) said they needed to change a ‘fair amount’ and seven (35%) needed only ‘a little change.’

Eight respondents or 40% expressed their sense of self-efficacy saying that they were ‘very confident’ they would use the skills learned during the intervention. Four respondents (20%) said they were ‘fairly confident’, while six (30%) said they were only ‘a little confident’ they would use the skills. Fourteen respondents (70%) gave a narrative example of how they used the skills they had learned. These included assessing the situation before acting, differentiating between an actual situation and perception, problem-solving, understanding the need for support, and being able to seek it. Some reported using the relaxation techniques. One respondent said she was better able to be honest about her feelings and communicate them to others. Another was better able to value herself and felt less guilty about saying “no” when she had something planned for herself. Goal setting was reflected by another respondent. Some said they were better able to identify their emotions and thoughts.

Outcome expectation and beliefs were measured using one question where 95% showed they had great expectations and believed that coping was an important part of well-being. One respondent said she had fair expectations.

To examine the relationship between these three variables, we performed Pearson’s correlation analysis. There was a significant positive correlation between the evaluation of the program and self-efficacy (r = 0.48, p < 0.05), and the evaluation of the program and the expectation and beliefs of the participants (r = 0.45, p < 0.05). None of the other variables showed any significant correlation.

Part Two: The focus group

Ten participants, including eight women and two men, gathered to reflect on the Nucare intervention. One woman said she used the book as an incentive to carry on with normal life activities. Another, who was diagnosed two years earlier, had to apply for work disability compensation after 19 years of employment. Her husband recently died of cancer. She used the book as a guide to help her through these stressors and to begin to allow herself to do what she likes. Another woman said she kept the book open on her night table and would randomly choose a page to reread. Two women who practised the ways of thinking skill over 30 times now use “the facts, thoughts and feelings” schema to help their children cope with their own life challenges. One man said he always knew the material presented, but the seminar and book had placed labels on his knowledge. He is now
a successful volunteer in Hope and Cope, the volunteer peer support organization that organizes the Nucare program.

One participant said she was now taking courses at a local university in wellness lifestyles. Another participant felt that when she worked she was “like an Energizer bunny” and defined by her work. Now, with the help of the program and the book, she knows that one small change makes a difference in how she deals with life issues, improving her quality of life. A participant who was treated for non-Hodgkins lymphoma five years ago expressed the need to keep active. He is a volunteer at the hospital and occupies his time with painting and other activities. He said he always has “a super-duper day,” giving and receiving social support. One recently-diagnosed woman was able to reframe her disease so that it became her “little mountain,” instead of a force dominating her life. She learned to cope by setting small goals.

One man felt that the intervention provided him with skills to change his way of thinking and helped put a framework around his thinking. This was helpful in putting his illness in its place, allowing room for him to continue living and setting goals. A patient with advanced disease said that the program helped put structure in her life. In reviewing the “facts, thoughts and feelings” tool, she felt better able to cope with her illness and other events in her life. Another reported that throughout her treatment she was encouraged to say every day that she was going to win. She felt, however, that her goal of “going to win” was very strenuous, and a hard target to aim for. Her friend, who also attended the workshop, bought her an Olympic hat that became symbolic of the ups and downs of her cancer treatment while keeping the ultimate goal in sight. She said that when her friend gave her the hat, she felt greatly supported and knew her friend understood her concerns and fears. The friend stated that she felt much more able to be a real support and part of the team working together.

The themes that emerged from the focus group seemed to reflect a sense of self-efficacy and learning that occurred in the sessions. The examples above indicate the use of the skills and beneficial outcomes that were important to the participants.

The workbook was an important part of the intervention from the participants’ viewpoint. Most stated that they referred to it frequently, needed it for reaffirmation of what they were doing, and knowing it was there at their fingertips gave them a sense of security.

Two aspects of Nucare seemed to be especially important to the participants: 1) The knowledge that only a small amount of change is needed to obtain a good result was reassuring. Participants felt capable of small changes rather than the large ones they had assumed were necessary. 2) Participants practised some of the skills, understanding that practice was essential to make these skills feel like second nature.

Participants expressed the importance of the intervention in relation to an increase in their self-efficacy. They learned to give themselves permission to do what they wanted, including spending time on themselves without feeling guilty. Setting small goals that can be achieved also helped them gain confidence.

Discussion

The workbook was an important part of the intervention. Many participants reported needing to and wanting to review the material frequently. Some used the workbook as a guide to help them learn the coping skills and reinforce those they already had. The book validated their feelings and gave them permission to focus on themselves without guilt. It is clear that written material is important for reinforcement, support, and knowledge.

Many studies, including our own, did not include data reflecting to what extent home practice was performed (Devine & Westlake, 1995). So, we cannot support or challenge the assumption that practice influences outcomes. However, it is evident that knowing that practice is an inherent part of change, and that only small changes are needed, was important to the participants.

Bandura (1977) suggested that individuals are exposed through life to a differing variety of behaviour and self-efficacy facilitation experiences. Adding one intervention will not, therefore, affect everyone uniformly. The range of the responses on helpfulness of each of the skills taught in the intervention went from ‘not at all’ to ‘very much’. Although the questionnaire did not examine past experiences, we assumed that some participants had already been exposed to other situations that improved their coping skills. The range in responses to the perception of self-efficacy, from ‘a little’ to ‘very much’, where those with greater skills from the beginning would feel more confident than the others, also supports this theory.

Although 35% of the participants said they needed to make only a little change in their coping, the fact that they still participated fully in the program was of note. Patients may seek a validation of their present coping strategies and, thus, benefit from such a program.

The intention to explore new ways of coping or reaffirm their present practice seemed to encourage participation in the intervention. Respondents identified their need to change from ‘a little’ to ‘very much’, their decision to participate in the intervention. Intention to change is a precursor to attempt to change, however it does not translate necessarily into desire or ability to change within the same time period or at all (Whitehead, 2001).

Prochaska and Velicer (1997) presented five steps to decision-making necessary to implement change: precontemplation where the individual is not thinking about change; contemplation where the individual is thinking about needing to make changes, the choices that need to be made, and is looking at options; preparation where the individual starts taking small steps to make changes; action where the changes are made are still short-lived, less than six months; and maintenance where the changes the individual has made are long-lasting, more than six months. Participants in the Nucare program would appear to be in the contemplation stage where they are gathering information, or in the preparation stage where they are starting to take small steps toward change. Patients could be asked to reflect on current stage of readiness to change.

The significant moderate correlation between finding the intervention useful and self-efficacy suggests that the desire to increase their self-efficacy was part of the decision to come to the sessions. This relates to their readiness to learn and the timing of the intervention, as chosen by the participants.

The two concepts, that only a small amount of change is needed and that for a new skill to become second nature 30 to 60 times of practice is required, are proposed and reinforced repeatedly in the Nucare manual and in the sessions.

Respondents expressed positive expectations regarding outcomes of developing coping skills. They believed ‘a fair amount’ to ‘very much’ that coping was an important part of well-being. This belief supports the decision of individuals to participate in the workshops in the hope of increasing their ability to cope. Believing that coping was important may have led the participants to attend, or the workshops may have reinforced that belief. Correlation does not speak to causation, but it demonstrates that a relationship exists.

Limitations

These results cannot be generalized due to the small size and non-randomness of the sample. Expanding the Nucare program to other health care centres, including the questions on self-efficacy and stages of readiness to change, and following the participants over time would improve the impact of the results.

Implications for nursing

This study gives an important look at this intervention as it impacts on nursing and our understanding of how patients make choices about coping. Being aware of the participants’ belief that coping is important to well-being helps nurses plan coping interventions for their patients and their families. Taking into consideration that...
intention to change and ability to change do not necessarily go hand in hand, nurses can help promote change and facilitate decisions to change using the family as the patient unit, emphasizing to them that intention to change is, on its own, an important first step.

With results showing that the NuCare intervention is related to increasing self-efficacy, nurses should look at teaching and promoting coping skills with patients and family members, using NuCare as a guide to practice. One aspect of the intervention that the participants found especially helpful was the frequent reminders that practice is needed, but that a small degree of change can bring results. Establishing follow-up sessions at different intervals would be helpful, as 65% of respondents said they would like a follow-up session.

Future research

Over the past year, over 150 patients, their friends, or family members have participated in NuCare. We are now offering the program in the day and in the evening as we seek to respond to the needs of the population we serve. Future research could look at finding solutions to the barriers to participation as identified by the focus group, such as transportation, family responsibilities, and work schedules.

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Research could also look at participants in similar programs regarding their readiness to learn and their current stage of change and decision-making. This could affect the timing of interventions and what should be offered to individuals to optimize their ability to cope.

Conclusion

The study indicates there are correlations between finding this intervention useful and an increase in self-efficacy and the belief that coping is an important part of well-being. Timing may be important to success in learning, as allowing the participants to choose when they want to attend the sessions gives them the opportunity to decide when they are ready. Although the patients are ready to learn more about coping skills, this does not necessarily mean they are ready or able to change. However, they have gained knowledge and, with the manual at hand, can review the information and practise the skills when they are ready. Two aspects of the workshop were particularly noteworthy and can be incorporated into cancer nursing: that new coping skills must be practised; and that only a small amount of change is needed to achieve results. Brief psychoeducational coping workshops with follow-up are a useful addition to cancer care and fall within the scope of cancer nursing.