

Helping Women with Breast Cancer to Cope with Hair Loss: An e-SIT Protocol

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Abstract. The emerging convergence of technology and health care is offering new methods and tools to help people cope with stressful upcoming events. To address the distress of chemotherapy and of alopecia in particular, and to facilitate anticipatory coping, we developed a two weeks e-health protocol based on Meichenbaum’s SIT intervention for helping women undergoing chemotherapy to cope with impeding hair loss. The paper aims to present the e-SIT protocol as a promising approach to facilitate coping and adjustment in breast cancer patients.

Keywords: e-health · SIT · Breast cancer · Hair loss · Coping · Well-being

1 Introduction

Chemotherapy treatment for breast cancer patients can have a profound impact on appearance, and is often experienced as distressing. Actually, hair loss is, for many patients, an unavoidable aspect of their chemotherapy treatment. According to a recent review [1], firstly, chemotherapy-induced hair loss is considered to be the most important side effect of chemotherapy. It is frequently ranked among the first three for breast cancer patients [2, 3], together with nausea and fatigue [4, 5]. Secondly, it is described by breast cancer women as causing distress and as being traumatizing [6–10] and may even be considered emblematic of the treatment and of cancer itself [7, 9, 11]. Thirdly, there might be an impact on body image [12] and self-esteem although not all studies reported this association. Indeed, while it is difficult to tease out whether differences in body image, self-esteem, or self-concept result from alopecia specifically, or more general adjustment to a cancer diagnosis and chemotherapy treatment, it is commonly recognized that many women experience a range of distressing side effects from chemotherapy treatment, including alopecia, which has a significant impact on their psychosocial well-being.

Some studies suggest that side effects are not experienced as distressing as patients can anticipate them [13–15]. However, up to now just a few studies have been focused

on the anticipation and preparation for an altered appearance [13]. Thus, the process of preparing patients for hair loss is a significant challenge for healthcare professionals. This preparation could be seen as a form of anticipatory coping - coping which involves the preparation for managing the stressful consequences of an upcoming event, which is likely or certain to occur [16]. Anticipatory coping could involve some activities like resource accumulation (information etc.), initial appraisal (assessment of the impact of the event), initial coping efforts (activities to prevent or minimize the event) and elicitation and use of feedback.

This type of coping might be effectively integrated within interventions aimed to help people to manage stressful or difficult events related to illness, such as hair loss due to chemotherapy. Frith and colleagues [13] demonstrated that the active management in coping with impending hair loss allows women to gain control over their situation. Control and management of negative emotions represent central concepts in psychological theories of well-being, adjustment and coping [17].

Stress inoculation training - SIT - [18, 19] represents a validated short, semistructured, and active approach to help people coping with difficult and specific situations. SIT is a type of training conceived to prepare individuals for stressful events by helping them in diminishing the potential for a negative cognitive, psychological, and behavioral reaction. SIT is based on the premise that to effectively manage stress, it is crucial to change the way people see the events and how to use their own coping skills. Thus, it is generally implemented through gradual and repeated exposure to the elements previously identified as stressors. The clinical rationale behind this approach is to “inoculate” the stressor in person’s experience, in combination with the acquisition of effective coping skills, so that people could be prepared when they will encounter similar situations in daily life.

In fact, people experience stress when perception of their own skills does not balance the perception of difficulty of the environmental requirements. According to Cohen and colleagues [20], psychological stress occurs when people perceive that potential situational threats exceed their adaptive capacity.

SIT has been already validated in clinical contexts, to help patients in facing particularly strenuous conditions [21]. It has also been applied to cancer patients and post-treatment observations indicated that the stress inoculation techniques were beneficial in altering anxiety-related behaviors [22].

The general objectives of SIT are threefold and are related to the three phases of the protocol:

(1) SIT aims to change the maladaptive stress response of the individual, thanks to the acquisition of knowledge and the understanding of stress process. Thus, the first phase, named conceptualization, aims at making individual aware of the transactional nature of psychological stress [23] by giving general information about the main stress’ effects and symptoms that could appear in specific stressful situations.

(2) SIT aims to develop an activity of self-regulation. Thus, the second phase, named skill acquisition and rehearsal, aims at teaching individual to manage emotions and maladaptive behaviors as well as learn new active coping skills. In accordance with Murphy [24], the combination of different strategies may yield better stress management than single-strategy programs. Specifically, relaxation practices [25] and breathing techniques, and mindfulness meditation programs [26] can be easily integrated in this phase.

(3) SIT aims to explore and modify dysfunctional cognitive appraisal related to stressful events. Thus, the last phase, named application and follow-through, aims at increasing self-efficacy [27] by helping individual to use the acquired coping skills in real contexts. The acquisition of specific skills of stress management during the mediated experience can promote the sense of personal self-efficacy and prepare people to cope with real stressful situations. According to Bandura's [28] theory, once established, self-efficacy tends to generalize to other situations. Indeed, once acquired, these competencies assigned to internal factors become a means to the management of stressful situations and they can be transferred and applied to other contexts.

2 Integrating Technologies in Psychological Interventions to Cope with Chemotherapy

The emerging convergence of technology and health care is offering new methods and tools to help people cope with stressful upcoming events. According to Botella and colleagues [29] computer assisted therapy [30] and Web 2.0 [31] have demonstrated their potentiality in supporting psychological interventions. More, as claimed by the Positive Technology approach, advanced technology offers several affordances for improving the quality of our personal experience to promote well-being [32]. Thus, the main objectives and the three stages of SIT have been recently implemented in cyber-interventions based on SIT methodology (cyber-SIT), which utilize advanced technologies to create simulations to teach individual how effectively cope with psychological stress [33].

Specifically, the use of advanced technology may efficiently support all the three phases of SIT. As far as the conceptualization phase, the multimedia presentations where information is enriched and distributed through images, animations, sound, voice, and written text can enhance the understanding of the transactional nature of stress, and its main causes and effects [34]. With respect to the skill acquisition and rehearsal phase, advanced technologies could guarantee participants meaningful experience in interactive environments and can help individuals in acquiring effective coping skills. Relaxation practices and meditation programs could be effectively integrated in mediated experiences characterized by natural and restorative settings where participants can do specific exercises [33, 35]. Finally, as far as the application and follow-through phase, digital environments can be used for patients' exposure to stressful stimuli with often equal therapeutic benefits to in vivo exposure [36] and/or superior to other methods such as guided imagery [37].

According to the results of a recent systematic review [38], cyber-SIT appears to be a promising clinical approach, and there are interesting researches that effectively combined traditional SIT clinical protocol within advanced technologies. Villani and colleagues tested the effectiveness of a cyber-SIT delivered through mobile phones by comparing it with a control group (neutral video through mobile phones) in a sample of oncology nurses [39]. Results showed psychological improvement of the experimental group in terms of anxiety state, anxiety trait reduction, and coping skills acquisition.

Computer-based approaches and imagery interventions, as well as patient education, have been found to be effective for a number of conditions suggesting the

potential benefits of similar applications for alopecia [40–42]. Recently, the process of preparing patients for hair loss has been supported through a computerized hair imaging software which allowed women to see themselves with a new hairstyle/without hair prior to change has been tested [43]. Based on concepts related to guided imagery and anticipatory grief, this intervention aimed to aid women in coping with anticipated treatment-related alopecia and promote self-acceptance. The HAAIR (Help with Adjustment to Alopecia by Image Recovery) system was assessed as a useful educational resource creating a realistic experience of hair loss and confrontation with baldness.

Integrating technologies in psychological interventions focusing both on the physical side effects and on the emotional and psychological aspects related to chemotherapy could represent a promising approach to facilitate coping and adjustment in breast cancer patients.

3 The e-SIT Protocol

In an effort to address the distress of chemotherapy and of alopecia in particular, and to facilitate anticipatory coping, we developed e-health protocol based on Meichenbaum’s SIT intervention [19] for helping women undergoing chemotherapy to cope with impending hair loss.

The e-SIT protocol last two weeks and details are presented in Table 1.

Table 1. e-SIT protocol: phases, objectives and proposed experiences

SIT phase	Objective	Proposed experience
Conceptualization phase (session 1)	The aim of this phase is to increase knowledge about the upcoming situation and its psychological impact.	At this stage breast cancer women are invited by the psychologist to reflect on the nature of the psychological stress due to disease and upcoming treatment in order to achieve a greater consciousness about its main components. Furthermore, in this session patients experience a live-video simulation of a chemotherapy session that they will receive within a few weeks. Patients are encouraged to pay attention to perceived threats, concerns and provocations as problems-to-be-solved and to identify which aspects of the situations and of their reactions are potentially changeable.

(Continued)

Table 1. (Continued)

SIT phase	Objective	Proposed experience
<p>Skills acquisition and rehearsal phase (sessions 1–7)</p>	<p>The aim of this phase is to provide the opportunity to learn psychophysical coping strategies.</p>	<p>At this stage women start the online experience. The multimedia experience includes seven 25 min sessions to see once a day. Each session includes two parts. In the first one, patients can watch live-video interviews with women who have gone through breast cancer experience, with particular attention to their expectations and emotions, to chemotherapy side effects and to strategies to cope with changes. Specifically, interviews are focused on these areas:</p> <p>Expectations: the video investigates women’ expectations and knowledge before starting chemotherapy;</p> <p>Emotions: the video explores women’ emotional experiences related to disease and how women have managed them;</p> <p>Chemotherapy side effects: the video investigates the side effects women have to deal with after treatment;</p> <p>Hair-loss: the video explores the meaning of hair loss and related changes in the appearance perception;</p> <p>Change: the video explores the impact of illness and therapies on several aspects of women’ life (physical, psychological, social, and working);</p> <p>Activity: the video focuses on the potential activities that women can do during the treatment;</p> <p>Suggestions: the video aims to offer a new perspective, highlighting that some women</p>

(Continued)

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SIT phase	Objective	Proposed experience
		<p>recognize also positive aspects related to disease experience. In the second part, a relaxation and meditation experience is proposed. Specifically, a natural relaxing video is integrated with narrative audio. Exercises are based on muscle progressive relaxation (focusing on legs, arms, abdome, shoulders, face, front, etc.) [25] and breathing. More, the narrative includes Mindfulness inspired strategies [26], such as thought contemplation and detached mindfulness, useful to be aware of one's thoughts and emotions associated with them, and to look at the problem from a different perspective.</p>
<p>Application and follow - through phase (sessions 8–10)</p>	<p>The aim of this phase is to expose women to the effects of the imminent chemotherapy and to verify their acquisition of coping skills to effectively manage the stressful upcoming event.</p>	<p>Women continue the online experience. Also in this case, each session includes two parts. First, video-live of breast cancer patients' interviews currently undergoing chemoterapic treatments - both with and without wigs - are presented. In this way women directly deal with changes due to illness, chemotherapy and related side effects. In addition, suggestions proposed by other patients offer the chance of anticipate possible solutions to problems they will have to cope with. Second, supported by a natural relaxing video integrated with narrative audio, women are encouraged to apply relaxation and meditation strategies acquired in the previous phase sessions.</p>

The e-SIT protocol will be delivered by using a website (www.conilsenodipoi.it). Participants will be given access to the intervention for a period of 14 days. Upon log-in, a welcome page will appear, providing information on what to expect within the online intervention. The psychologist researchers' personal contact will be provided for coping both with technical and psychological difficulties. Thanks to Internet, women can follow the intervention in their own comfortable, familiar surroundings [44].

Figure 1 shows the protocol flow.

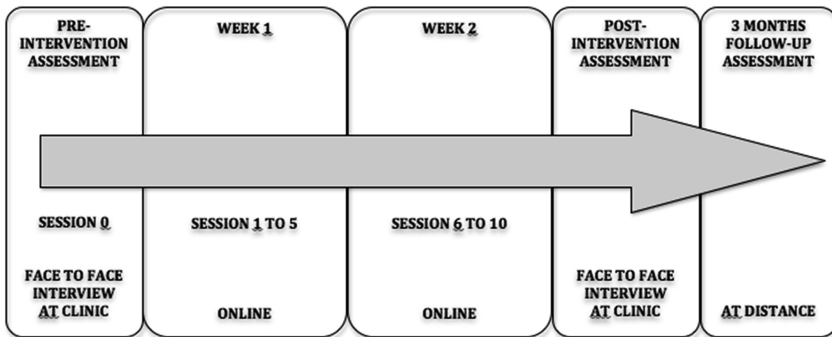


Fig. 1. E-SIT Protocol flow

Oncologists will propose the research to all breast cancer patients, which is offered chemotherapy, fulfilling the following inclusion criteria: diagnosis of breast cancer radically operated; negative staging for distant metastases; suitability for adjuvant chemotherapy with anthracyclines and taxanes. The trial will include fifty women with age between 30 and 70 years that will be randomized to two groups. The experimental group will follow the e-sit protocol as an adjunct to treatment as usual for two weeks. The control group will receive the usual care for two weeks.

The assessment will be realized in two moments. Before and after each online session, the emotional state of patients will be evaluated online through a Visual Analogue Scale (VAS). At the begin and at the end of the protocol the pre-intervention and post-intervention assessment will be performed. The psychologist will meet patients and will propose them several questionnaires aiming to assess their psychological well-being, adjustment to disease, emotion regulation skills and satisfaction about their body.

To conclude, the e-SIT protocol represents a promising approach to help women to cope with the stressful experience of chemotherapy and specifically with hair loss.

Nevertheless, controlled studies should test the effectiveness of the approach and compare it with treatment as usual.

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References

1. Lemieux, J., Maunsell, E., Provencher, L.: Chemotherapy-induced alopecia and effects on quality of life among women with breast cancer: a literature review. *Psycho-Oncol.* **17**(4), 317–328 (2008)
2. Carelle, N., Piotto, E., Bellanger, A., Germanaud, J., Thuillier, A., Khayat, D.: Changing patient perceptions of the side effects of cancer chemotherapy. *Cancer* **95**(1), 155–163 (2002)
3. Duric, V.M., Stockler, M.R., Heritier, S., et al.: Patients' preferences for adjuvant chemotherapy in early breast cancer: what makes AC and CMF worthwhile now? *Ann. Oncol.* **16**(11), 1786–1794 (2005)
4. Griffin, A.M., Butow, P.N., Coates, A.S., Childs, A.M., Ellis, P.M., Dunn, S.M., et al.: On the receiving end V: patient perceptions of the side effects of cancer chemotherapy in 1993. *Ann. Oncol.* **7**, 189–195 (1996)
5. Lindley, C., McCune, J.S., Thomason, T.E., Lauder, D., Sauls, A., Adkins, S., Sawyer, W. T.: Perception of chemotherapy side effects: cancer versus noncancer patients. *Cancer Pract.* **7**(2), 59–65 (1999)
6. Williams, J., Wood, C., Cunningham-Warburton, P.: A narrative study of chemotherapy-induced alopecia. *Oncol. Nurs. Forum* **26**(9), 1463–1468 (1999)
7. Richer, M.C., Ezer, H.: Living in it, living with it, and moving on: dimensions of meaning during chemotherapy. *Oncol. Nurs. Forum* **29**(1), 113–119 (2002)
8. Luoma, M., Hakamies-Blomqvist, L.: The meaning of quality of life in patients being treated for advanced breast cancer: a qualitative study. *Psycho-Oncol.* **13**(10), 729–739 (2004)
9. Rosman, S.: Cancer and stigma: experience of patients with chemotherapy-induced alopecia. *Patient Educ. Couns.* **52**(3), 333–339 (2004)
10. Browall, M., Gaston-Johansson, F., Danielson, E.: Post- menopausal women with breast cancer: their experiences of the chemotherapy treatment period. *Cancer Nurs.* **29**(1), 34–42 (2006)
11. Harcourt, D., Frith, H., Fussell, A.: "Chemo sucks": anticipating the impact of an altered appearance during cancer treatment on self and others. In: *Appearance Matters Conference*, Bath, UK (2006)
12. Fobair, P., Stewart, S.L., Chang, S., D'Onofrio, C., Banks, P.J., Bloom, J.R.: Body image and sexual problems in young women with breast cancer. *Psycho-Oncol.* **15**(7), 579–594 (2006)
13. Frith, H., Harcourt, D., Fussell, A.: Anticipating an altered appearance: women undergoing chemotherapy treatment for breast cancer. *Eur. J. Oncol. Nurs.* **11**(5), 385–391 (2007)
14. Lindley, C., McCune, J.S., Thomason, T.E., Lauder, D., Sauls, A., Adkins, S., Sawyer, W.T.: Perception of chemotherapy side effects: cancer versus noncancer patients. *Cancer Practice* **7**(2), 59–65 (1999)
15. Tierney, A., Taylor, J., Closs, S.J.: Knowledge expectations and experiences of patients receiving chemotherapy for breast cancer. *Scand. J. Caring Sci.* **6**(2), 75–80 (1992)
16. Aspinwall, L.G., Taylor, S.E.: A stitch in time: self-regulation and proactive coping. *Psychol. Bull.* **121**(3), 417–436 (1997)
17. Walker, J.: *Control and the Psychology of Health*. Open University Press, Buckingham (2001)
18. Meichenbaum, D.: *Cognitive-Behavioral Modification: An Integrative Approach*. Plenum Press, New York (1977)
19. Meichenbaum, D.: *Stress inoculation training*. Pergamon Press, New York (1985)

20. Cohen, S., Janicki-Deverts, D., Miller, G.E.: Psychological stress and disease. *J. Am. Med. Assoc.* **298**(14), 1685–1687 (2007)
21. Foley, F.W., Bedell, J.R., Larocca, N.G., Scheinberg, L.C., Reznikoff, M.: Efficacy of stress-inoculation training in coping with multiple-sclerosis. *J. Consult. Clin. Psychol.* **55**(6), 919–922 (1987)
22. Moore, K., Altmaier, E.M.: Stress inoculation training with cancer patients. *Cancer Nurs.* **4**(5), 389–394 (1981)
23. Lazarus, R.S., Folkman, S.: Transactional theory and research on emotions and coping. *Eur. J. Pers.* **1**, 141–169 (1987)
24. Murphy, L.R.: Stress management in work settings: a critical review of the health effects. *Am. J. Health Promot.* **11**(2), 112–135 (1996)
25. Jacobson, E.: *Progressive Relaxation*. University of Chicago Press, Chicago (1938)
26. Kabat-Zinn, J.: Mindfulness-based interventions in context: past, present, and future. *Clin. Psychol. Sci. Pract.* **10**(2), 144–156 (2003)
27. Bandura, A.: Health promotion from the perspective of social cognitive theory. *Psychol. Health.* **13**(4), 623–649 (1998)
28. Bandura, A.: Health promotion by social cognitive means. *Health Educ. Behav.* **31**(2), 143–164 (2004)
29. Botella, C., Riva, G., Gaggioli, A., Wiederhold, B.K., Alcaniz, M., Banos, R.M.: The present and future of positive technologies. *Cyberpsychol. Behav. Soc. Netw.* **15**(2), 78–84 (2012)
30. Proudfoot, J., Ryden, C., Everitt, B., Shapiro, D.A., Goldberg, D., Mann, A., Gray, J.A.: Clinical efficacy of computerised cognitive-behavioural therapy for anxiety and depression in primary care: randomised controlled trial. *Br. J. Psychiatry* **185**(1), 46–54 (2004)
31. Andersson, G.: Using the Internet to provide cognitive behaviour therapy. *Behav. Res. Ther.* **47**(3), 175–180 (2009)
32. Riva, G., Banos, R.M., Botella, C., Wiederhold, B.K., Gaggioli, A.: Positive technology: using interactive technologies to promote positive functioning. *Cyberpsychol. Behav. Soc. Netw.* **15**(2), 69–77 (2012)
33. Villani, D., Riva, G.: Does interactive media enhance the management of stress? Suggestions from a controlled study. *Cyberpsychol. Behav. Soc. Netw.* **15**(1), 24–30 (2012)
34. Mayer, R.: *Multimedia learning*. Cambridge University Press, New York (2009)
35. Villani, D., Riva, F., Riva, G.: New technologies for relaxation: the role of presence. *Int. J. Stress Manage.* **14**, 260–274 (2007)
36. Emmelkamp, P.M.G., Krijn, M., Hulsbosch, A.M., de Vries, S., Schuemie, M.J., van der Mast, C.A.P.G.: Virtual reality treatment versus exposure in vivo: a comparative evaluation in acrophobia. *Behav. Res. Ther.* **40**(5), 509–516 (2002)
37. Riva, G.: Virtual reality in psychotherapy: review. *Cyberpsychol. Behav.* **8**(3), 220–230 (2005)
38. Serino, S., Triberti, S., Villani, D., Cipresso, P., Gaggioli, A., Riva, G.: Toward a validation of cyber-interventions for stress disorders based on stress inoculation training: a systematic review. *Virtual Reality* **18**(1), 73–87 (2014)
39. Villani, D., Grassi, A., Cognetta, C., Toniolo, D., Cipresso, P., Riva, G.: Self-help stress management training through mobile phones: an experience with oncology nurses. *Psychol. Serv.* **10**(3), 315 (2013)
40. Freeman, L., Cohen, L., Stewart, M., et al.: Imagery intervention for recovering breast cancer patients: Clinical trial of safety and efficacy. *J. Soc. Integr. Oncol. Spring.* **6**(2), 67–75 (2008)
41. Lewis, D.: Computer-based approaches to patient education: A review of the literature. *J. Am. Med. Inform. Assoc.* **6**(4), 82–272 (1999)

42. Wofford, J.L., Smith, E.D., Miller, D.P.: The multimedia computer for office-based patient education: a systematic review. *Patient Educ. Couns.* **59**(2), 57–148 (2005)
43. McGarvey, E.L., Leon-Verdin, M., Baum, L.D., Bloomfield, K., Brenin, D.R., Koopman, C., Parker, B.E.: An evaluation of a computer-imaging program to prepare women for chemotherapy-related alopecia. *Psycho-Oncol.* **19**(7), 756–766 (2010)
44. Powell, J., Hamborg, T., Stallard, N., Burls, A., McSorley, J., Bennett, K., Christensen, H.: Effectiveness of a web-based cognitive-behavioral tool to improve mental well-being in the general population: randomized controlled trial. *J. Med. Internet Res.* **15**(1), e2 (2013)