European Journal of Oncology Nursing 28 (2017) 47–55

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

# The importance of self-care for fatigue amongst patients undergoing chemotherapy for primary cancer

Patricia O' Regan*, Josephine Hegarty

*School of Nursing and Midwifery, University College Cork, Ireland*

A R T I C L E I N F O

*Article history:*
Received 7 July 2016
Received in revised form
3 February 2017
Accepted 20 February 2017

*Keywords:*
Cancer related fatigue
Fatigue self-care strategies

A B S T R A C T

*Purpose:* To measure Cancer Related Fatigue (CRF), and explore fatigue self-care strategies used to ameliorate CRF amongst patients undergoing chemotherapy for primary cancer.
*Methods:* A consecutive sample of patients (n = 362) undergoing chemotherapy with a primary diagnosis of breast, colorectal, Hodgkin's and non-Hodgkin's lymphoma cancers were recruited. A mixed methods design was utilised. The study questionnaires included: the Piper Fatigue Scale-Revised and a researcher developed fatigue Self-Care Survey.
*Results:* The mean total fatigue score was 4.9 (SD = 2.2); the highest mean subscale score occurred in the affective meaning dimension (M = 5.4, SD = 2.9).
The mean number of strategies used at least “occasionally” was 14.8, (SD = 3.42, range = 5–24). The most frequently used self-care strategies were: *“Receiving support from family and friends”* (66.6%); *“having a healthy diet”* (57.1%); *“taking part in hobbies or distraction activities”* (42.9%); *“spending time chatting with friends”(37.3%); “adjusting mood and being more positive”* (36.3%) and *“resting and taking it easy”* (33.8%). The self-care strategies of socializing (OR = 0.66, 95% CI = 0.47–0.930, p = 0.016) and exercise (OR = 0.73, 95% CI = 0.57–0.93, p = 0.012) were associated with decreased odds of developing CRF. Four categories emerged following analysis of qualitative data, these included: rest and relaxation, physical activity, psychological well-being, and supportive care.
*Conclusions:* CRF is a debilitating, complex phenomenon, therefore multiple CRF strategies should be used for the optimum management of CRF including exercise and socializing. Health care professionals have an important role in promoting the use of evidence based fatigue management strategies.

## 1. Background

Cancer related fatigue (CRF) is consistently reported as one of the most frequent and distressing symptoms associated with cancer and its treatment (Berger et al., 2012; Peters et al., 2014; Weis and Horneber, 2015). It is reported that 82–96% of patients receiving chemotherapy experience cancer related fatigue (Campos et al., 2011; Horneber et al., 2012; Andersen et al., 2013). CRF is a very significant problem encountered by the vast majority of patients who receive chemotherapy and often occurs for a period of time post completion of treatment (Berger et al., 2009; Horneber et al., 2012; Andersen et al., 2013). Fatigue is an undertreated symptom that has been shown to contribute to: impaired physical and cognitive functioning, significant socioeconomic costs, shorter survival and increased mortality rates (Piper et al., 2008; Howell et al., 2013; Jones et al., 2015; Weis and Horneber, 2015).

In recent years there has been a move away from the paternalistic delivery of health care to the promotion of patient involvement and autonomy in managing health care needs (Hubbard et al., 2008; Brander et al., 2012). The introduction of self-care to patients with cancer improves quality of life, symptom management, and patient satisfaction (Johnston et al., 2009; Faithfull et al., 2011). Johnson et al. (2009), in a systematic review highlighted the benefits of self-care in the control of symptoms, these included: improved health status, being more informed and reduced symptom distress. Despite there being a greater emphasis in health care today on patient involvement in self-care, little is known about cancer patients own experiences of being actively involved in their self-care (Kidd et al., 2008).

A number of structured interventions and individualised strategies such as exercise, education, and complementary therapies have been tested either in isolation or in combination for the

---

* Corresponding author.
*E-mail addresses:* p.oregan@ucc.ie (P. O' Regan), j.hegarty@ucc.ie (J. Hegarty).

http://dx.doi.org/10.1016/j.ejon.2017.02.005
1462-3889/

treatment of CRF. The use of exercise in the treatment of fatigue has the most supporting evidence of effectiveness to date (Al-Majid and Gray, 2009; Cramp and Byron- Daniel, 2012; Cheville et al., 2013; NCCN, 2016). Data from several empirical studies also support the role of educational and psychosocial interventions for the management of CRF in assisting patients self-manage and reduce CRF (Jacobsen et al., 2007; Reif et al., 2013; Minton et al., 2015). The National Comprehensive Cancer Network (NCCN) guidelines (2016) using graded evidence recommend a number of interventions for patients on active treatment for their cancer. These are broadly categorised as: patient/family education and counselling; general strategies for management of fatigue; non-pharmacological and pharmacological interventions.

Overall, the empirical literature has indicated moderate effectiveness of various self-care strategies to date including, resting, various complementary therapies, work, social activities enhancing psychological well-being and social support (Dodd, 1988; Richardson and Ream, 1997; Borthwick et al., 2003; Ream et al., 2006; Lee et al., 2008; Williams et al., 2010). Further research is necessary to gain insight into what patients personally instigate to reduce or ameliorate CRF and what they actually deem as effective, which this study aimed to achieve.

### 1.1. *Study aims*

The primary aim of this study was to measure CRF; to describe the frequency and perceived effectiveness of individual self-care strategies; and to explore the use of self-care strategies in the management of fatigue among a sample of patients with a diagnosis of different cancer groups (breast cancer, colorectal cancer, Hodgkin's and non-Hodgkin's lymphoma) receiving chemotherapy. Fatigue levels across these four cancer groups were also compared.

## 2. Methods

### 2.1. *Study design*

This mixed methods study incorporated a quantitative, descriptive, comparative and correlation survey with an additional qualitative descriptive component. The study was underpinned by a study framework which involved a combination of elements of the Piper Integrated Fatigue model (Piper et al., 1987), Orem's Self-Care Deficit Theory (Orem, 1985) and the National Comprehensive Cancer Network (NCCN) (2016) Practice Guidelines framework on the management of cancer-related fatigue.

Piper's et al. (1987) Integrated Fatigue model (IFM) offers a comprehensive framework for explaining fatigue which encompasses four of the dimensions of subjective fatigue (Piper, 2003). Self-care was defined as “the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being” (Orem, 2001; pg.104). Fatigue self-care strategies are the strategies that patients use to manage their symptom experience (Dodd et al., 2001).

## 3. Measures

Fatigue was measured using the Piper Fatigue 27 item Scale–Revised (PFS-R) (Piper et al., 1998) and associated subscales of: behaviour (6 items), affect (5 items), sensory (5 items) and cognition/mood (6 items). All items were coded on a 0–10 Likert scale. The remaining five questions were open-ended, offering patients the opportunity to qualify their fatigue experience. Fatigue scores of 1–3 indicated mild fatigue, 4–6 indicated moderate fatigue and 7–10 indicated severe fatigue levels. Fatigue was also measured in terms of a cut off score of four, with scores $<4$ indicating “not clinically significant fatigue”, and scores of $\geq 4$ indicating significant, or moderate/severe fatigue (Ma et al., 2011; Kluthcovsky et al., 2012). Reliability of the PFS-R in terms of internal scale structure, was determined with a sample of breast cancer survivors (Cronbach's alpha of 0.97), and factor analysis was used to establish validity of the dimensional structure, revealing four dimensions of subjective fatigue (Piper et al., 1998). Reliability of the PFS-R scale was high in this study with a Cronbach's alpha of 0.964.

The researcher developed fatigue self-care survey (FSCS) ($n = 26$ items) was created based upon a review of the NCCN guidelines and associated empirical research. Individual self-care strategies (i.e. items on the FSCS) were not grouped into subscales or scales given the discrete nature of each item. In relation to each self-care strategy participants were asked about the frequency of engagement in the activity, and the associated level of perceived effectiveness using a five point Likert scale, ranging from never to very often. A range of open ended questions were also included to ascertain patient's experiences relating to the use of fatigue self-care strategies. The FSCS was reviewed by a panel of experts ($n = 16$) who rated each fatigue self-care strategy question on a four part content validity index (CVI). Those items with a CVI greater than 0.75 remained within the FSCS (Yaghmale, 2009). No summative scale score was calculated for the FSCS questionnaire as each item was individual, therefore summative scale scores were thought not to be appropriate.

In addition participants were also asked a range of questions relating to demographics (age, gender, marital status, employment status, education levels, and living arrangements) and clinical (cancer type and length of time since commencement of chemotherapy) factors.

### 3.1. *Participants*

The study included a consecutive sample of patients with a primary diagnosis of breast, colorectal, Hodgkin's and non-Hodgkin's lymphoma cancers. For the purpose of sample size and for this study it was not possible to measure CRF in all cancer population groups, thus a sample of 4 cancer groups was purposively chosen. Breast and Colorectal cancers were explored as these are major cancer groups and Hodgkin's and non-Hodgkin's as little is known about the fatigue levels of these cancer groups. The literature previously highlighted that the vast majority of research on CRF involving chemotherapy was ascertained from patients with a breast cancer diagnosis, with a dearth of studies noted from the other cancer population groups. This study attempted to bridge this gap while studying other cancer population groups. In addition, patients with breast cancer were recruited to enable comparisons with previous studies. All participants had to be receiving chemotherapy for a minimum duration of six weeks to meet the inclusion criteria and were recruited over a nine month period from the four oncology units based in one City in Southern Ireland. A consecutive sample of eligible patients was accessed thus, ensuring maximum recruitment to the study and limiting bias. To ensure maximum homogeneity within the sample, the recruitment of patients receiving the same chemotherapy regime was initially considered, however, a review of the patient lists in all sites prior to the commencement of data collection showed there were insufficient numbers of patients receiving any one chemotherapy regime to allow recruitment of a sufficient sample size within a realistic time frame. Patients receiving other concurrent treatments (surgery, radiotherapy or immunotherapy) were excluded. Patients were excluded from the study if they had previously received chemotherapy, as it was anticipated that their previous experiences of CRF, including how they managed the symptom, would impact on their present circumstances. The literature also indicates how past