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Original article

Italian nurses knowledge and attitudes towards fatigue in pediatric onco-hematology: A cross-sectional nationwide survey

Elena Rostagno [a], Anna Bergadano [b], Michela Piredda [c, *], Maria Grazia De Marinis [d]

[a] Pediatric Oncology and Hematology Unit, S.Orsola-Malpighi Hospital, Via Massarenti, 40138, Bologna, Italy
[b] Pediatric Onco-Hematology Stem Cell Transplantation and Cellular Therapy Division, Regina Margherita Children's Hospital, Piazza Polonia, 94 – 10100, Torino, Italy
[c] Research Unit Nursing Science, Campus Bio-Medico di Roma University, Via Alvaro del Portillo, 21 - 00128, Roma, Italy
[d] Research Unit Nursing Science, Campus Bio-Medico di Roma University, Via Alvaro del Portillo, 21 - 00128, Roma, Italy

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ABSTRACT

Background and Objective: Fatigue is one of the most debilitating and prevalent symptoms in pediatric cancer patients and it is important to know if nurses are able to recognize and manage it. The aim of this study was to investigate the knowledge and attitudes towards fatigue of nurses working in Italian pediatric onco-hematology centers.
Methods: Cross-sectional online survey. An existing questionnaire was adapted to the Italian context, extended with a section on attitudes, and psychometrically tested. The questionnaire was sent to all nurses working in Italian pediatric onco-hematology centers.
Results: Respondents (n = 189), who were working in 37/53 (~70%) centers, reported 42% of children and 68% of adolescents experiencing fatigue, with intensity increasing with age. Contributing factors were treatments and co-morbidities; frequent symptoms were mood changes and lack of energy. Among respondents who did not assess fatigue, 36.2% did not know an appropriate tool. Nurses recognized fatigue as an important problem and their knowledge and attitudes towards fatigue seemed satisfactory.
Conclusion: This study provides nurses with an instrument to investigate their knowledge and attitudes about fatigue. Nurses' awareness of the significance of fatigue is a fundamental step towards improving its management and offering strategies that can help both the child and their family.

1. Introduction

Cancer-related fatigue (CRF) is one of the most debilitating and prevalent symptoms in pediatric cancer patients. Depending on patients' age, cancer diagnosis, and illness stage, the prevalence of fatigue varies from 35.6% [1] to 93% [2], especially among hospitalized children [3]. Fatigue is related to cancer, chemotherapy, and other conditions such as depression, sleep deprivation, or pain [4]. It is a multidimensional phenomenon that develops over time, is often already present at the time of diagnosis, and persists throughout the therapeutic path [5]. CRF reduces energy levels and negatively affects patients' psychological states, ways of thinking and feeling, abilities to concentrate, and interpersonal relationships. Pediatric patients with a high fatigue level report a lower quality of life [6] and of sleep [7]. Many patients therefore experience great suffering due to fatigue.

Cancer-related fatigue is defined differently by children and adolescents. While the adolescents highlight a changing sense of physical and mental exhaustion, the children underline being physically weak or tired [8].

With the exception of the last decades, CRF in the pediatric field has received little attention from health professionals. This may be due to aggressive treatments aimed at obtaining child healing and survival absorbing the main consideration of clinicians. In this perspective, side effects such as fatigue are seen as inevitable and not as a priority [9,10]. As a consequence, the effects caused by

* Corresponding author. Research Unit Nursing Science, Campus Bio-Medico di Roma University, Via Alvaro del Portillo, 21 - 00128, Roma, Italy.
E-mail addresses: elena.rostagno@aosp.bo.it (E. Rostagno), anna.bergadano@unito.it (A. Bergadano), m.piredda@unicampus.it (M. Piredda), m.demarinis@unicampus.it (M.G. De Marinis).
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fatigue on the children could be under-assessed and underestimated.

Lack of symptom detection can make an illness even more stressful [11]. Instead, in particular, effective assessment and treatment of the fatigue symptom can improve both the quality of the care provided and the quality of patient's life which are one of the primary goals one of the primary goals of care [12,13]. For health professionals to be able to assess and manage fatigue effectively, they need specific knowledge and positive attitudes. Knowledge and attitudes are key components of professional competences and should be assessed in conjunction [14].

To our knowledge, only three surveys were conducted to assess health professionals' knowledge of CRF in children with cancer. These surveys used an adapted version of a questionnaire previously developed by Magnusson et al. [15] and modified by Knowles et al. [16] The questionnaire mainly investigated the knowledge of professionals regarding risk factors, mechanisms, and prevalence of fatigue, and the interventions implemented to reduce the symptom. Health professionals' attitudes, identified as ability to pay attention to the issue, were not investigated. The most recent survey [17] including nurses and physicians working in four pediatric clinics in Turkey, found that those health professionals who regard CRF as a problem know the causes of fatigue and use different interventions to improve the symptom. The other two surveys conducted in the UK reported that health professionals perceived fatigue to be a significant problem, but its mechanisms, risk factors, prevalence, and duration were poorly understood [9,18]. Moreover, they reported a different perception between children and adolescents of the experience of fatigue.

In summary, current literature is limited to a few studies on health professionals' knowledge about fatigue, while data on attitudes is lacking. Among health professionals caring for pediatric patients with cancer, nurses are in a key position to manage symptoms such as fatigue and, when symptoms are controlled, patient's quality of life improves and costs are reduced [19]. The knowledge and attitudes of oncology clinical nurse specialists have a positive impact on cancer patients' outcomes such as fatigue, pain, and health-related quality of life [20]. However, no instrument was found able to investigate both nurses' knowledge and attitudes toward CRF in pediatric patients and, in particular, no study was conducted in Italy on the subject. Therefore, the aims of this study are: 1) to modify the questionnaire used in previous studies by inserting a section on attitudes and testing its psychometric properties; 2) to investigate knowledge of and attitudes regarding fatigue among nurses working in Italian centers of pediatric onco-hematology.

2. Methods

2.1. Research design and instrument

The study was a cross-sectional online survey. The questionnaire was based on those used by Gibson et al. [9,18] and Yilmaz et al. [17] and adapted following the guidelines by Brancato et al. [21] A panel of four clinical nurses expert in pediatric oncology, two of whom had advanced competence in English, met to translate and adapt the above questionnaire to the Italian context. Moreover, after two meetings, the panel developed four indicators of nurses' attitudes on pediatric CRF. The resulting instrument consisted of three sections: 1) knowledge about fatigue in pediatric oncology; 2) assessment and management of fatigue; and 3) nurses' attitudes towards fatigue. The knowledge section included four questions (two closed and two open-ended); the assessment and management section included three closed questions; the attitudes section included four statements with which respondents had to express their agreement using a 5-point Likert scale (from 1 = complete agreement to 5 = complete disagreement). Socio-demographic data was also collected. The questionnaire was developed as an on-line form, allowing data to be automatically recorded on an Excel spreadsheet.

Content validity of the instrument was assessed in a pilot study involving twenty nurses working in a pediatric oncology centre. It included the relevance and wording of the questions, the functionality of the online form, and the acceptability of the questionnaire. No changes were needed as a result of this pilot test.

2.2. Setting and population

All nurses working in any of the 53 pediatric onco-hematology centers existing in Italy were invited to participate. At the time the study was conducted, there were 956 nurses working in pediatric oncology in Italy.

2.3. Data collection

Data was collected from October 1, 2017 to November 30, 2017. The 53 nursing referees of the centers were sent an e-mail invitation to participate containing the link to the survey with the request to forward it to all nurses in their centers. An invitation e-mail was also sent directly to all nurses registered for the newsletter of the nursing working group of the Italian Association of Pediatric Hematology and Oncology. Three e-mail reminders were sent to those who had not answered a couple of weeks apart.

2.4. Data analysis

Descriptive analysis was conducted as percentages and frequencies of respondent demographics and questionnaire scores. The differences between scores of knowledge, attitudes, fatigue assessment, and management as dependent variables were compared with univariate analysis of variance (ANOVA) with nurses' demographics as independent variables. Internal consistency of the items investigating nurses' attitudes was assessed by computing the Cronbach's alpha coefficient.

2.5. Ethics

The study was conducted in accordance with current Italian legislation concerning the protection of human subjects and the processing of personal data (Law n.675, December 31, 1996). The completion and submission of the questionnaire were considered as an expression of consent to participate in the study and authorization to process data for the purposes and in the manner indicated in the e-mail invitation.

3. Results

One hundred and eighty-nine nurses out of 956 answered the questionnaire (19.8% response rate) from 37/53 (~70%) different Italian pediatric oncology and hematology centers. A hundred and seventy (79.9%) were female, with mean age of 42 years (range 24–62, SD 9.3) and mean work experience in pediatric oncology of 12.2 years (range 0.25–35, SD 9.2). In particular, 84.2% of nurses had worked in this setting for at least 3 years and 46.6% for at least 10 years. Sixty-seven (35.4%) respondents reported possessing a degree in Pediatric Nursing and one hundred and twenty-two (64.6%) a degree in Nursing, while 54 (28.5%) had obtained one or more post-registration qualifications. Sample demographics are detailed in Table 1.

During undergraduate and post-registration education, 46.6%

Table 1
Sample demographics.

	Respondents (N = 189)		
	N	%	Mean (range)
Gender			
M	19	10.1	
F	170	89.9	
Age			
24-30	38	20.1	40.2 (24–62)
31-40	58	30.7	
41-50	67	35.4	
>50	26	13.8	
Work experience in pediatric oncology			
≤2	30	15.9	12.2 (3m-35 y)
3-10	71	37.6	
>10	88	46.6	
Qualification			
Nurse	122	64.6	
Pediatric Nurse	67	35.4	
Post-registration qualification (n = 73)			
Master in oncology and palliative care	10	13.7	
Other Master	50	68.5	
Master in Science of Nursing	12	16.6	
PhD	1	1.4	

Note: m= months; y= years

(n = 88) had received some training on fatigue in the pediatric patient, including university lectures (35.2%) or participation in conferences (31.8%) lasting 1–4 h (72.7%). Almost all nurses (98.9%) believed it would be useful to receive more training on the subject.

3.1. Knowledge about pediatric fatigue

The first set of questions assess the perceived intensity of the symptom of fatigue on an 11-point Likert scale (from 0 = "not at all intense" to 10 = "extremely intense") in four groups of age: 2–4, 5–7, 8–12, and 13–18 years. Fatigue intensity increases with age in nurses' reports. In particular, mean intensity is 5.9 for children aged 2–4 years, 7 for children aged 5–7 years, 8 for the age group 8–12 years, and 9 for adolescents (13–18 years).

Knowledge about fatigue prevalence was assessed specifically for children and adolescents. Nurse respondents reported 42% children and 68% adolescents experiencing fatigue. Respondents were asked to list five contributing factors to fatigue. They provided 828 answers, which were grouped into ten categories (Table 2). Treatments (including chemotherapy, radiotherapy, surgery, and corticosteroids) and their side effects were the most frequent contributing factors (26.6%), followed by co-morbidities such as anemia, infections, and pain (17.8%), frequent or prolonged hospitalizations (14.8%), and psychological problems including depression, anxiety, anger, stress, sadness, anguish, and loneliness (12.3%). Less reported categories were life disruption (isolation from friends and school), physical problems (decrease of physical activities, lack of energy, difficulty in accepting the new physical appearance), nutritional problems, cancer, sleep disturbances, and parental/family support. Nurses were asked to also list five signs and symptoms of fatigue. The most frequently reported signs/symptoms were mood changes (26.6%), lack of energy (26%), sleepiness (14%), change in appetite (9.1%), lack of interest in socialization (9%), decreased ability to concentrate (5.3%), and lack of interest in play (3.1%).

Table 2
Contributing factors.

	Answers (N = 828)	
	N	%
Treatment and side effects	220	26.6
Comorbidities	148	17.8
Hospitalization	123	14.8
Psychological problems	102	12.3
Nutritional problems	38	4.6
Cancer	34	4.1
Sleep problems	19	2.3
Parental/family support	18	2.2
Others	36	4.5

Table 3
Interventions.

	Answers (N = 250)	
	N	%
Psychological support	71	28.4
Stimulating and encouraging play and recreational activities	46	18.4
Encouraging physical activity	36	14.4
Pharmacological therapy	27	10.8
Nutritional support	19	7.6
Guaranteeing sleep/rest	13	5.2
Complementary therapies	12	4.8
Communication/information	8	3.2
Transfusion support	5	2.0
Other	13	5.2

The study was conducted in accordance with current Italian legislation concerning the protection of persons and other subjects regarding the processing of personal data (Law n.675, December 31, 1996).

3.2. Fatigue assessment and management

Eighty-one (42.8%) respondents declared that they evaluated fatigue. The methods used to assess fatigue were direct patient observation (n = 64, 79%), an unspecified structured questionnaire (n = 7, 8.6%), the Fatigue Scale (Adolescent) (n = 1, 1.2%), the Fatigue Diary (n = 1, 1.2%), and directly asking the patient (n = 1, 1.2%). Seven respondents reported evaluating fatigue but did not specify in what way.

Among the 108 nurses who reported not evaluating fatigue, the reasons for the lack of evaluation were investigated. Thirty-four (36.2%) reported that they did not know a measuring instrument, 29 (30.9%) reported not having adequate training, and 11 (11.7%) that the centre where they work does not provide for it. The remaining 34 nurses did not specify the reason for the lack of evaluation. One hundred and sixty-six nurses (87.8%) believe useful interventions to reduce fatigue do exist (Table 3), and 108 (65%) report having proposed them to their patients and obtaining apparently positive results, but without conducting studies to evaluate their effectiveness.

3.3. Attitudes

The Cronbach's alpha coefficient for this section was 0.695 and did not improve with removal of any item. Respondents had to express the extent of agreement with the following statements: 1) Fatigue evaluation is a nursing competence; 2) Fatigue affects the quality of life of the patient and the family; 3) Fatigue cannot be evaluated because it is too subjective; and 4) Fatigue does not affect treatment compliance. The two latter items had negative wording and their responses were reverse coded. The lowest scores (range 1–5) meant more positive attitudes towards fatigue assessment and management. Nurses' agreement with the above statements was shown respectively by the following scores: 1.97 (SD 1.08), 1.67 (SD 1.21), 2.28 (SD 1.05), and 1.81 (SD 1.03).

3.4. Nurse demographic characteristics associated with knowledge and attitudes

The differences between scores of knowledge, attitudes, fatigue assessment, and management as dependent variables were compared with univariate analysis of variance (ANOVA) with nurses' demographics as independent variables. Gender, age, undergraduate training, and work experience in pediatric onco-hematology do not significantly affect the perception nurses have of the intensity and prevalence of the symptom for patients, or of their attitudes, assessment, and management of fatigue.

4. Discussion

The primary aim of this study was to investigate the knowledge of and attitudes towards fatigue reported by nurses working in Italian centers of pediatric onco-hematology. To this end, a pre-existing questionnaire was modified with the addition of a special section on attitudes. The internal consistency of this section was very close to the value of 0.7, which is considered adequate [22]. Although nurses' response rate was low (19.8%), which was the main limitation of this study, 70% of pediatric onco-hematologic centers were represented in the survey.

The attitudes towards fatigue assessment and management of nurse respondents were positive, suggesting their readiness to pay attention to the issue. However, it was not possible to compare these results with previous studies, because this was the first survey investigating this aspect. In agreement with health professionals in the surveys conducted by Gibson et al. [9,18] and by Yilmaz el al. [17], Italian nurses also believe that fatigue is a major problem, and, in particular, more for adolescents than for children. These results are confirmed by various studies that have assessed the importance of fatigue in pediatric patients with cancer [11,23,24].

For Italian nurses, the symptom fatigue seems less prevalent in children (42%) than in adolescents (68%). Enskär and von Essen [2,25] in their studies showed that the problem of fatigue was reported with higher prevalence by children and adolescents receiving treatment (65% of the children, 93% of the adolescents) than by those who had completed treatment (43% of the children, 67% of the adolescents). However, it is very difficult to estimate precisely the intensity and prevalence of fatigue as they vary over time and treatment [26,27], and there are numerous differences in measurement [28].

In this study, in agreement with previous literature [9,17,18], the main factors related to fatigue were treatments and side effects, comorbidities, and psychological problems. Unlike the professionals who participated in the surveys by Yilmaz et al. [17] and Gibson et al. [18], Italian nurses identified hospitalization, life disruption, and parental/family support as some of the factors related to fatigue. The need for frequent and sometimes prolonged admissions and changes in living habits are two interlinked factors. In the study by Hinds et al. [8], the environment of the hospital was identified as a factor related with fatigue by patients, parents, and health personnel. The emotional state of the parents was not identified as a related factor in any of the previous surveys. However, parents' distress has been found to mediate between children' symptoms and distress [29–31]. Moreover, no differences with the previous surveys were identified regarding the signs and symptoms [9,17,18].

Most nurses who did not assess fatigue reported that they did not know an appropriate measurement tool, and those who assessed it did so mainly by using observation as a measurement method. The most commonly used tools [32,33] to assess the fatigue in pediatric oncology are the Peds Quality of Life Multidimensional Fatigue Scale [34] and the Fatigue Scale [35,36]. There are no Italian versions of these psychometrically tested tools and this is probably the reason why Italian nurses do not know and do not use them.

Most of the nurse respondents believed there were interventions that were useful to reduce fatigue and many proposed them to their patients. Research has not yet produced significant evidence about effective interventions to reduce fatigue in this context [37]. Therefore, nurses must be cautious when using available non-pharmacological interventions.

5. Conclusion

Fatigue is the most prevalent and debilitating symptom in pediatric cancer patients and the survey revealed that nurses recognized it as a problem. Nurse participants showed satisfactory knowledge about fatigue intensity, prevalence, and related factors. Nurses' attitudes toward fatigue were also good, showing their readiness to pay attention to this symptom. The lack of validated Italian instruments to assess cancer-related pediatric fatigue and of effective interventions hinders its assessment and treatment. This study provides pediatric oncology nurses with an instrument to investigate their knowledge and attitudes about fatigue. However, more research should further test its psychometric properties.

The study involved nurses coming from most Italian pediatric oncology centers and its results can be considered representative of the current situation in Italy. This may be particularly true for aspects that, although disclosed by a number of respondents, are likely to be part of the routine behavior of the whole nursing team, such as assessment and treatment of fatigue. In contrast, knowledge and attitudes could be more influenced by individual variability. Further research with bigger samples should confirm the results from this study.

Regardless of the results obtained, the greatest strength of this research has been that of making Italian nurses aware of the importance of the assessment of fatigue and of the active role they can play in its management and treatment. Nurses' awareness of the significance of this symptom is a fundamental step towards improving its management and offering strategies that can help both the child and the family.

Declaration of competing interest

None.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jclepro.2020.000000.

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