

# Unmet supportive care needs and desire for assistance in patients receiving radiation treatment: Implications for oncology nursing

by Margaret I. Fitch and John Maamoun

## ABSTRACT

*Unmet supportive care needs can contribute to emotional distress and reduced quality of life for cancer patients. We undertook a supportive care needs assessment for patients undergoing radiation therapy to provide a basis for program planning. A self-report supportive care needs survey was completed by a convenience sample of 115 patients on days five, seven and 16 during their course of radiation. The most frequently identified physical unmet needs at all three times were fatigue (33%–49%), dry and itchy skin (24%–37%), and sleep difficulties (23%–30%). The number of patients citing these unmet needs increased significantly over the study time period. Within the emotional domain, worry (34.5%) was cited most frequently on day five. The number of individuals expressing worry did not decrease significantly by day 16. Across all domains and individual items, there was wide variation in the percentage of individuals who had an unmet need and also indicated they wanted help with that unmet need. This pattern remained consistent over time. This study emphasizes the need for a defined or intentional process to assess supportive care needs and patient desire for assistance or help with unmet needs.*

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## INTRODUCTION

Cancer and its treatment have more than a physical impact. There are psychosocial, emotional, spiritual, and practical consequences for individuals who have been diagnosed with this disease (Fitch, Page, & Porter, 2008). These consequences result in a variety of patient needs that can change over time (Chen, Lai, Liao, Lin, & Chang, 2010) and differ by disease site, stage (Kim et al., 2009) and treatment modality (Hack et al., 2010; Shun et al., 2008). While some individuals mobilize their own resources and cope effectively with the consequences, others experience on-going distress and challenge.

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Unmet supportive care needs can contribute to heightened emotional distress, ineffective coping, and reduced quality of life (Hack, et al., 2010; Raupach & Hiller, 2002). Distress from physical symptoms alone can range between 10% and 80% (Bradley, Davis, & Chow, 2005). The distress can be high enough that approximately 35% of cancer patients would benefit from referral to a supportive care expert (Zabora, Loscalzo, & Weber, 2003). In particular, symptom distress is a predictor of psychosocial adjustment (Mazanec, Daly, Douglas, & Musil, 2011) and overall symptom severity is significantly associated with changes in quality of life (Shun, et al., 2008). Not only do patients living with unmet supportive care needs experience an increased burden of illness and suffering, but it is likely they will require additional resources (i.e., calls to cancer centre, visits to emergency departments, visits to physicians) (Kennard et al., 2004; Von Essen, Larsson, Obeng, & Sjoden, 2002).

There is a growing recognition that the full range of supportive care needs ought to be assessed and that early identification of unmet needs could mitigate issues that patients face (Turner et al., 2011). As a result, various approaches have been used to identify supportive care needs including assessment and intervention in physical, psychosocial, and practical domains (CPAC, 2012). These approaches are producing evidence to support the multidimensional impact of cancer and its treatment on individuals (Shun et al., 2008; Mazanec et al., 2011). But they are also contributing to a growing appreciation about the importance of understanding the patterns and magnitude of unmet supportive care needs for different patient populations. These type of data help to clarify the demand for supportive care services and form an important basis for program planning and human resource allocation to different patient groups.

There are two major drawbacks in many supportive care needs studies. One of the drawbacks is the use of single measure cross-sectional design rather than longitudinal designs (Hack et al., 2010). Although cross-sectional efforts provide an understanding of the prevalence of supportive care needs at a point in time, they do not allow us to understand changes in the pattern of needs over time. Following patients from the beginning of their course of treatment is required to capture a picture of the change in patterns of needs.

The second drawback is that few supportive care needs studies have incorporated a question about the patient's desire or wish for assistance with a need. This is a critical aspect in understanding the demand for service, planning program approaches, and allocating resources. Steele and Fitch (2008) reported that all patients with unmet supportive care

needs will not necessarily desire help for the difficulties they are experiencing, despite feeling high levels of distress. It is important to interact with patients and assess their specific desire for assistance. Once the patient's desire for help is clear, care can be tailored accordingly (Turner et al., 2011).

In our desire to understand more about the specific supportive care needs of the patients undergoing radiation treatment attending our cancer centre, and overcome the two significant drawbacks in previous supportive care need studies, we undertook a longitudinal study. We anticipated this study would assist us in understanding the type and level of demand for supportive care services for this patient population and would provide a foundation for future program planning both within the cancer centre and with our community partners.

## PURPOSE

The purpose of our work was twofold: to describe 1) the unmet supportive care needs of patients undergoing radiation treatment for cancer, and 2) their desire for assistance in meeting those needs. We anticipated this work would increase our understanding about the pattern of supportive care needs over the course of radiation treatment and the magnitude of the demand for supportive care services, as well as reveal gaps in service delivery and be a foundation for future program planning and resource allocation.

## METHODS

This study used a descriptive longitudinal design to assess unmet supportive care needs in a convenience sample of individuals receiving radiation treatment in a large urban tertiary cancer centre. A self-report survey was utilized at three points in time to gather the data. Ethical approval was obtained from the Research Ethics Board of the hospital prior to implementing the study.

### Patient accrual and participation

Patients were accrued in the reception area of the radiation treatment department. All patients were beginning an active course of radiation treatment at the time of accrual, able to speak and read English, and over the age of 18 years. Patients were approached by the research assistant who explained the purpose of the study and expectations for participation. Those who consented to participate completed the study instrument (i.e., Supportive Care Screening Tool) on day five, day seven, and day 16. These time periods were selected because they reflected specific times in the course of treatment when supportive care needs might be of significance. At day five, patients would be expected to have some familiarity with the cancer treatment modality and the cancer centre, as they had undergone patient orientation and education related to their treatment. Some of their initial concerns may have been reduced by these standard care interventions. Any remaining needs would likely need specific intervention. Day seven was selected to determine if there had been change during the 48-hour interval when they were most likely to have had a check-up appointment with a radiation oncologist and oncology nurse, thus

an opportunity to have their needs identified and managed. Finally, day 16 was selected because the side effects of radiation treatment would be emerging and we would expect to see change in the types of items that were endorsed (i.e., thus see new items endorsed on day 16 that would require intervention as the end of treatment approached). Participants completed the supportive care tool in the waiting room of the radiation clinic.

### Data collection

The Supportive Care Screening Tool is a self-report checklist measure (Maamoun, Fitch, & DiProspero, 2013) and takes approximately five minutes to complete. The items are based on the Supportive Care Conceptual Framework (Fitch, Page & Porter, 2008) and covered seven domains (physical = 23 items, emotional = 9 items, informational = 5 items, practical = 7 items, family = 2 items, and spiritual/religious = 1 item). Each item allows the respondent the opportunity to indicate if the item has been a concern (response options: yes/no) during the past week including that day, and whether the person wants help with the concern (response options: no, yes, I am already getting help). The two-page instrument contains the entire set of items, as well as a Distress Thermometer (National Comprehensive Cancer Network, n.d.) and a section for the clinician to add pertinent information after having a conversation with the patient. The clinician section contains the space to add the following information: disease site, radiation treatment start date, treatment status, follow-up plans, from whom patients were receiving any help, and additional comments deemed noteworthy by the clinician. The psychometric analysis showed the instrument was reliable (test-retest at 24 hours), sensitive to change over a week, and valid (comparison with EORTC QLQ-30) in a sample of newly diagnosed cancer patients receiving radiation therapy (Maamoun, Fitch, & DiProspero, 2013).

### Data analysis

Descriptive data analysis was conducted including the frequency and distribution of the various needs identified by the patients for each of the three times the supportive care tool was completed, and the concerns for which patients would like assistance. Chi-square calculations were used to determine if there had been significant changes in the number of individuals who were experiencing a particular unmet need over time (comparison of time one versus time three).

## RESULTS

### Selected demographics

A total of 123 new cancer patients to the radiation department were accrued to the study and 115 individuals completed all three assessment time periods. The data from the eight individuals who did not complete the supportive care screening tool on all three occasions was dropped from the final analysis on the advice of our statistician.

The sample reflected a mixed group of disease sites (see Table 1). Sixty-four per cent of the participants were female and the average age was 63.2 (standard deviation 13.4) years. The majority had completed college or university.

Demographic Characteristics	Male (N=41)	Female (N=74)
Age (in years)		
Mean	68.3	60.3
Standard Deviation	10.9	13.9
Range	35–87	28–88
Education (highest level achieved)		
Primary 1	9	12
Secondary 2	14	34
College/university 3	14	20
Post university 4	4	8
Disease Site		
Breast/Chest Wall	1	58
Genitourinary	22	5
Gyne/Pelvis	1	7
Head and Neck	8	1
Other (Lung, GI, CNS, Scalp)	9	3

### Supportive care needs

Of the 23 items in the physical domain, fatigue, dry and itchy skin, sleep difficulties, and pain were the most frequently identified unmet needs at all three points in time (days 5, 7 and 16) (see Table 2). Thirty-three percent of the sample reported fatigue on day five and by day 16, this percent had risen to 48.7% of the sample (Chi-square=5.83, P=0.02). On day five, 24.3% experienced dry and itchy skin and 22.6% experienced sleep difficulties. These percentages rose to 36.5 and 29.6 respectively by day 16. For five other symptoms (sleep, pain, diarrhea, eating, change in urination, and constipation) the percentage of individuals experiencing each symptom also increased. Statistically significant differences were noted only for dry and itchy skin (Chi-square=4.03, P=0.04), pain (Chi-square=5.38, P=0.02), and changes in urination (Chi-square=4.33, P=0.04).

In the information domain, between 22.6% and 25.2% of the sample had unmet needs on day five (see Table 3). These percentages had decreased somewhat by day 16. The decreases in concerns about information concerning treatment (Chi-square=5.51, P=0.02), medical procedures (Chi-square=4.36, P=0.04), and available services (Chi-square=5.22, P=0.02) were statistically significant.

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Item	Time 1		Time 2		Time 3	
	% Patients with Concerns in Sample (N=115)	% Patients with Concern Who Desire Assistance	% Patients with Concerns in Sample (N=115)	% Patients with Concern Who Desire Assistance	% Patients with Concerns in Sample (N=115)	% Patients with Concern Who Desire Assistance
Fatigue	33.0	26.3	33.0	18.4	48.7	12.5
Skin dry and itchy	24.3	28.6	20.9	16.7	36.5	16.7
Sleep difficulties	22.6	34.6	23.5	44.4	29.6	26.7
Pain	17.4	40.0	19.1	59.1	30.4	31.4
Nose dry and congested	16.5	36.8	13.9	37.5	16.5	10.5
Nausea	13.0	33.3	13.0	26.7	6.95	12.5
Tingling in hands/feet	13.0	40.0	13.0	26.7	6.95	12.5
Lack of appetite	11.3	23.1	13.0	6.7	13.9	25.0
Indigestion	10.4	58.3	9.6	9.1	13.9	25.0
Diarrhea	10.4	50.0	11.3	53.8	19.1	22.7
Feeling swollen	10.4	50.0	7.8	55.6	6.95	50.0
Getting around	6.95	37.5	6.1	14.3	6.1	14.3
Eating	6.95	50.0	6.1	14.3	8.7	30.0
Weight loss	6.95	50.0	8.7	30.0	7.8	11.1
Change in urination	6.95	50.0	8.7	40.0	15.7	27.8
Breathing	5.2	50.0	7.8	22.2	5.2	33.3
Constipation	5.2	66.7	6.1	28.6	12.2	7.1

\* Items with less than 5% of patients indicating current unmet needs: Vomiting, bathing, dressing, mouth sores, fever and sexual.

**Table 3: Patient Unmet Needs and Desire for Assistance - Information**

Item	Time 1		Time 2		Time 3	
	% Patients with Concerns in Sample (N=115)	% Patients with Concerns Who Desire Assistance	% Patients with Concerns in Sample (N=115)	% Patients with Concerns Who Desire Assistance	% Patients with Concerns in Sample (N=115)	% Patients with Concerns Who Desire Assistance
Your disease	25.2	75.9	24.2	72.4	20.0	56.5
Your treatment	25.2	79.3	21.7	76.0	13.0	60.0
Your symptoms	23.5	74.1	25.2	68.96	17.4	55.0
Your medical procedures	22.6	76.9	18.3	71.4	12.7	64.3
Available services	22.6	80.8	15.7	66.7	11.3	61.5

**Table 4: Patient Unmet Needs and Desire for Assistance - Practical \***

Item	Time 1		Time 2		Time 3	
	% Patients with Concerns in Sample (N=115)	% Patients with Concerns Who Desire Assistance	% Patients with Concerns in Sample (N=115)	% Patients with Concerns Who Desire Assistance	% Patients with Concerns in Sample (N=115)	% Patients with Concerns Who Desire Assistance
Insurance/ Finances	6.95	50.0	6.1	57.1	5.2	50.0
Transportation	19.1	45.0	13.0	26.7	13.9	50.0

\* Practical items for which less than 5% of patients endorsed as an unmet need: Housing, housekeeping, legal advice, work/school and child care. Family items (dealing with parents and dealing with children) and spiritual items - less than 5% of patients cited as an unmet need.

**Table 5: Patient Unmet Needs and Desire for Assistance - Emotional**

Item	Time 1		Time 2		Time 3	
	% Patients with Concerns in Sample (N=115)	% Patients with Concerns Who Desire Assistance	% Patients with Concerns in Sample (N=115)	% Patients with Concerns Who Desire Assistance	% Patients with Concerns in Sample (N=115)	% Patients with Concerns Who Desire Assistance
Worry	34.8	32.5	30.4	34.3	30.4	25.7
Nervousness	24.3	25.0	18.3	33.3	17.4	30.0
Sadness	22.6	34.6	20.0	30.4	20.9	12.5
Fears	20.0	43.4	15.6	38.9	12.3	28.6
Appearance/Body image	16.5	36.8	10.4	41.7	10.4	33.3
Depression	14.8	35.3	17.4	25.0	15.7	5.6
Loss of interest in activities	11.3	38.5	10.4	58.3	10.4	58.3
Feeling hopeless	9.6	45.5	6.95	37.5	7.8	33.3

The most frequently identified practical unmet need on day five was about transportation (19.1%) (see Table 4). On day 16, this topic was still a concern for 13.9% of the sample.

Within the emotional domain, worry (34.8%) was cited most frequently on day five followed by nervousness (24.3%), sadness (22.6%), and fears (20%) (see Table 5). Although these percentages all decreased by day 16, the decreases were not statistically significant.

### Desire for assistance

Across all domains and individual items there was wide variation in the percentage of individuals who had an unmet need and also indicated they wanted help with that unmet need. For fatigue, 26.3% wanted help from the cancer centre staff, while 50% of those with unmet needs related to diarrhea, eating, weight loss or change in urination wanted help (See Table 2). In the information domain, across all items, 75% or more of those with unmet needs wanted help (see Table 3). Almost half of those with transportation concerns wanted help, as did 50% of those with financial concerns (see Table 4). Across the items in the emotional domain, between 25% and 45.5% wanted help with their concerns (see Table 5). These patterns in the proportion of individuals with unmet needs who wanted assistance were consistent over time.

## DISCUSSION

This study was undertaken to provide a foundation for program development to meet the supportive care needs of patient receiving radiation treatment. The use of an inception cohort facilitated the longitudinal assessment of needs. Following newly diagnosed cancer patients over time allowed us to see the pattern of symptoms or the changes in the nature and magnitude of symptoms during the course of the treatment. Understanding which symptoms are present at the start of treatment and how they change over time gives us a baseline picture and helps to set the stage for priorities within our program. However, it is important to note that the true determination of service demand on a day-by-day basis would also require measurement of unmet needs for the total patient population (i.e., daily prevalence of unmet needs including all patients receiving treatment at that time).

The identification of fatigue as the most frequently occurring symptom mirrors reports by other investigators (Krishnasamy, Wilkie, & Haviland, 2001; Sarna et al., 2004). It is a symptom that can have a profound impact on quality of life (Olson, Krawchuk, & Qudussi, 2007). Evidence is growing that patient education and exercise are effective interventions (CCO, 2011) for this symptom and ought to be offered as early as possible during the course of treatment.

The prevalence of other physical symptoms, and the observed changes over time, emphasizes the need for on-going assessment of patient experience with symptoms and tailoring of management interventions. The significant change noted in the symptoms over time (by day 16) illustrates the

expected emergence of side effects as the course of treatment proceeds and emphasizes the importance of taking steps to prevent the side effects, as much as possible, and reduce their impact on quality of life. Consideration also must be given to which symptoms are clustered or apt to occur together. The experience of symptoms from a patient point of view is one of living with all symptoms simultaneously, not necessarily living with an isolated symptom (Kiteley & Fitch, 2006; Kim et al., 2009). It would be useful if interventions were designed to be appropriate for combinations of symptoms and not directed to isolated or single symptoms. For example, an exercise intervention to counteract fatigue would need to take into account other patient symptoms of pain and shortness of breath.

Informational needs existed for approximately a quarter of the sample. Although there was an observed reduction in the number of participants who reported unmet informational needs as their treatment experience unfolded, there were still between 11% and 20% of the sample who were experiencing unmet information needs at the end of treatment. This raises questions about whether these individuals require different patient education resources and communication approaches than those in current use. Not all individuals learn in the same way and some require additional detail and emotional support for their learning to be effective (Zeguers et al., 2012).

The observation that emotional issues were prevalent throughout the course of the treatment and did not substantially decrease is concerning. This observation raises questions about what attention is being paid to emotional issues throughout the course of radiation treatment. The department has radiation therapists and designated oncology nurses. Despite the daily interaction with patients and, thus, the opportunity to establish an individualized supportive relationship, it is surprising that so many patients continued to experience emotional concerns. In the future, it would be important to determine the nature of the concerns and the relationships between patients and staff. It is important to know if adequate attention was being given to cultivating a supportive therapeutic relationship during the course of the treatment or if there were barriers for staff in assessing emotional needs, discussing these concerns with patients, or referring the individuals who wanted additional assistance.

The observation that there were no changes in the level of need related to transportation raises questions about whether this topic was discussed with patients, or if patients knew about the transportation service provided by the Canadian Cancer Society. Particularly with radiation patients, who have to travel to the cancer centre on a daily basis for several weeks, transportation ought to be discussed before treatment begins and appropriate interventions offered.

This study gathered perspectives about the supportive care needs of patients from their point of view. We did not investigate the actual assessment process or interventions that were offered. Therefore we do not know if the increase in the prevalence of unmet needs is a result of no intervention being offered or if the intervention that was provided was ineffective.

We know from the questionnaire that some patients declined our assistance because they felt they were already receiving sufficient assistance for particular needs through other routes. Future research ought to focus on understanding the actual care that was delivered to patients in light of ongoing unmet needs.

Finally, the number of individuals with unmet needs who indicated they wanted assistance for those needs presents an initial picture of the demand for immediate service from cancer centre staff. The frequency with which individuals indicated a desire for assistance is in line with what has been reported previously (Steele & Fitch, 2008). The observation emphasizes that there is variation in what patients want and that all patients are not ready for help at a particular point. However, providers will not be aware of the individual patient preference for assistance without an individualized conversation regarding that person's perspectives about needs and desire for assistance.

## IMPLICATIONS FOR PRACTICE AND FUTURE RESEARCH

The results of this study have implications for both practice and future research. Above all, there is a need to have a consistent and concrete process to assess supportive care needs of patients undergoing radiation treatment. This process ought to include the use of a standardized, reliable and valid tool, as well as a follow-up conversation about the responses indicated by the patient on that tool (Fitch, Howell, McLeod, & Green, 2012). The follow-up conversation needs to focus on the patients' perspectives about the depth of their concern and their desire for assistance. Subsequent assessment and intervention then ought to focus on what is concerning the individual and be based on evidence about what intervention is effective. Additionally, the process ought to be repeated throughout the course of the treatment and not only at the beginning.

The findings from this work present a picture of unmet needs in both physical and psychosocial domains. Not only must oncology nurses be able to assess supportive care needs across all domains, but they also must be knowledgeable about the interventions and care pathways that could be used for effective resolution of unmet need. Some cancer centres have provided education about evidence-based practice guidelines

regarding symptoms and care pathway algorithms (including referral criteria) for staff members to follow in clinical situations. Examples of such tools are posted on [www.cancerview.ca](http://www.cancerview.ca); [www.cancercare.on.ca/toolbox/symptools](http://www.cancercare.on.ca/toolbox/symptools).

Building appropriate care pathways will require interaction and negotiation with all other members of the inter-professional team, as well as community-based agencies. Not all supportive care can be provided in the cancer centre. The care pathways describe when referral is required and the routes for timely access to other disciplines and services. Sorting out the care pathway approaches provides an excellent opportunity to explore partnerships with other departments or disciplines, as well as community-based agencies that can offer supportive care programs. Nursing can play a leadership role in building inter-professional care pathways.

An important area for future research is understanding the actual link between unmet supportive care needs and actual care delivery. It is encouraging to see that efforts to study this issue are beginning to emerge (Carey, Lambert, Smits, Paul, Sanson-Fisher, & Clinton-McHarg, 2012). Additionally, it would be helpful to isolate effective interventions and best practice approaches that require professional attention versus those that could be provided by volunteers or peers. Future efforts are also needed to find interventions that are easily administered in a busy clinical setting to effectively reduce unmet needs in the various domains. In particular, approaches to reduce emotional distress are needed. Ideally, a menu or range of effective interventions needs to be available because the sources of distress can be so varied. Some individuals will require pharmacological physical symptom management, while others will benefit from a cognitive behavioural approach (Turner et al., 2011; Beard et al., 2011). Some individuals will require an information-based intervention, while others would benefit more from a supportive or emotional-based approach. Understanding which supportive care needs require brief interventions and which ones require longer term approaches would also be helpful. Subsequently, designing and testing brief interventions for use by frontline oncology nurses in a busy ambulatory setting would be beneficial. It would also be useful to know when effective interventions require delivery by another provider (i.e., Advanced Practice Nurse, other discipline) or in another setting (i.e., office, classroom, community centre, home).

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