

Priority Supportive Care Needs of Patients Living with and Beyond Cancer: A Systematic Review

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ABSTRACT

Introduction: Supportive care needs are felt needs expressed by the patients and family members of cancer patients. Cancer disease itself cause many kinds of problems in cancer patients. The identification and management of supportive care needs is essential to provide most priority care expressed by people with cancer. Detail information about the supportive care need can help service planning/redesign of each individual cancer patients. This study aims to identify different kinds of supportive care needs with priority among cancer patients of different country.

Methods: This systematic review study included only English published articles between 1995 Jan to 2020 from PubMed, Scopus, Web of Science and Science direct, Google Scholar and JSTOR. The extraction of data was done by two independent authors and a third independent author checked the data extraction. The PRISMA statement was adopted.

Results: Total eleven studies(cross sectional descriptive- 7, qualitative-1 prospective cohort design-1, design not mentioned) were included in this review. Psychological supportive care need was the first priority supportive care needs among most of the respondents and SCNS-SF 34 was the most frequently used scale in the studies.

Conclusions: Different methodologies used in different studies hinder the analysis of types of supportive care needs among patients living with cancer and minimize the quality of generalization. Estimation of sample size was lacking in ninety percent of studies. Identification of support as per type of cancer is also essential to prioritize their problem.

Keywords: Anxiety, fatigue, neoplasm, pain, sexuality, supportive care needs

INTRODUCTION

Supportive care is the informational, emotional, spiritual, social, psychological, physical needs follow-up services planned to help patients, their families, and caregivers with their experiences during diagnosis, treatment, follow-up, and palliative stages of cancer.¹

Supportive care Needs (SCNs) are the felt and expressed necessities of individual patient related to their dealing with disease itself, sign, symptoms, side-effects of medicine, acceptance of disease, decision-making and minimization of hazards to self and their family members.²

Cancer is a major public health problem worldwide³ and it is one of the most fatal diseases

that causes several deaths every year.⁴ It was reported that more than 19.3 million (19,300,000) new cancer cases were diagnosed leading to approximately 10 million deaths in 2020.⁵

Seventy percent of cancer patients experience many kinds of SCNs including physical symptoms, social isolation, spiritual suffering, informational and most of those were psychological needs.⁶

This study aims to critically evaluate the body of evidence about cancer patients' SCNs and to identify gaps in the literature. Specifically, the review tries to find to (1) ascertain the prevalence of SCNs in cancer patients according to time point of the cancer illness; (2) examine differences in unmet need for different tumor groups and different stages of disease; (3) identify clinical and personal characteristics of cancer patients; (4) identify the frequently used design, sampling, instrument, data analysis technique (5) and identify the most frequent SCNs among cancer patients.

Significance of the Study

This study will help researchers to plan for intervention for cancer patients and also help to conduct research for the assessment of SCNs by identifying gap in methodology.

METHODS

Study Selection Criteria and Search Strategy

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines^{7,8} and the recommendations of the Cochrane Collaboration⁹ were applied to conduct this review. Six electronic databases (PubMed, Scopus, Web of science, Science Direct, Google Scholar, and JSTOR) were searched through a two-step systematic search strategy that was planned to identify studies employing qualitative and/or quantitative methods. A wide range of keywords and free text terms were used to increase inclusiveness and sensitivity of the searches. Pre-specified selection criteria were applied to all records identified. Reference lists of all full-text articles were also examined for any studies that

might have been overlooked. Electronic searches were beginning on 20th December 2020 and concluded on 30th December 2020. We searched the specified databases since 1995 Jan to 2020 April. English published articles qualitative, quantitative and cohort studies were included in the study. Search terms were cancer, supportive care, needs, assessment, pain, fatigue, anxiety, information, sexuality.

Inclusion criteria

Descriptive cross sectional, qualitative and cohort studies conducted among cancer for the assessment of SCNs and full text articles in English language were included in the study.

Exclusion criteria

Review studies, experimental studies, commentaries, letters, pilot study and study protocols were excluded from the study. If the content of the selected article was not match the inclusion criteria after through reading, those articles were not included in the study. Studies were excluded if full text papers could not be found.

Intervention, Comparator(s)/Control

Cancer patients that had received any form of treatment included in this study. As this review was not assessing the effectiveness of an intervention program, there was no appropriate comparator or control group.

Outcome Measures

The primary outcome was the identification of any SCNs, categorized into physical, psychological, informational, sexual, social, or other. Needs could be specifically identified, or could be inferred from reported distress, for example patients reporting fatigue would be categorized as having physical need.

Study selection and data extraction procedures

Two authors (KD and JFM) independently screened the titles and discrepancies around inclusion were resolved by discussion with the third author

(BA) following a two-stage process. The initial screening stage resulted in a shortlist of articles including titles and abstracts. In the second stage, the screening process involved retrieval of articles in full-text, whereby the two co-authors independently assessed all articles for eligibility against selection criteria until consensus was reached. Data extraction tables were specifically developed for this review, pilot-tested on three randomly selected studies of the final sample, and refined accordingly. After eliminating the duplicates, two authors (KD, BA) independently extracted data from each of the eligible reviews into a purpose-built, standard data extraction form and CC checked the data extraction.¹⁰ Data extracted from each paper were as follows: title, year of publication, country of study setting, study design, population studied, methods of data collection and analysis and results. The needs identified in each paper were classified as physical, psychological, informational, sexual, supportive or other. For quantitative data, scores or rankings for each need were recorded, along with whether needs differed between sub-groups. For qualitative data, overarching themes, sub-themes and illustrative quotes were extracted.

DATA ANALYSIS

A systematic review was conducted due to the heterogeneity nature of the data. After initial screening, the full texts relevant to the topic were reviewed independently by 2 authors (JFM and KD). Extraction of data was performed and entered in a data charting form in Microsoft Excel. Any emerged disagreement concerning inclusion and exclusion from the final review, the third author (BA) got involved. After the data were entered into a data charting form, the authors (JFM and KD) reviewed the data to identify the review's key focus areas. The results of the review are reported according to the PRISMA Statement.^{8,11} The studies included in the revision were first examined for descriptions of the supportive care needs and qualitative synthesis. Narrative synthesis was done after listing down the supportive care needs. Narrative synthesis and analysis are process of expressing

and producing the findings of studies collected together for review are needed. The findings were described and combined into the text of the review by examining the similarities and the differences between the findings of different studies. The exploration of patterns in data and grouping of studies based on characteristics of sample, methodology used and findings of the study. Exploring relationship in the data within and between the studies were also carried out.

RESULTS

Study Characteristics

The extensive review of literatures on this issue shows that there has been no study in Nepal related to the assessment of the SCNs of cancer or cervical cancer (CC) patients. This claim was further proved by our search of six different databases PubMed, Scopus, Web of science, Science Direct, Google Scholar, and JSTOR on 30th December 2020. The researcher used five key search terms namely CC, cancer, SC, SCNs and assessment to search the articles from 1995 to 2020.

On the first electronic literature search a total of 1290 record were identified through five different data bases (PubMed, Scopus, Web of science, Science Direct and JSTOR) and it was reduced to 1274 after duplicate removed and records marked as ineligible by automation tools. After screened titles and abstracts, the records further reduced to 16 for full text eligibility while 1258 records were excluded because their titles and abstracts did not conform to the topic or the study designs. After thorough and detail readings of illegible full text article, 11 article were included in this review. Out of these, 5 articles were excluded because 3 articles had tool development studies, 2 articles had no explicit discussion of needs but not specific to Nepal, and 11 articles were related to the studies conducted in other countries namely Canada, Iran, China, India, Australia, Malaysia, Indonesia, California and UK. (Refer to figure 1)

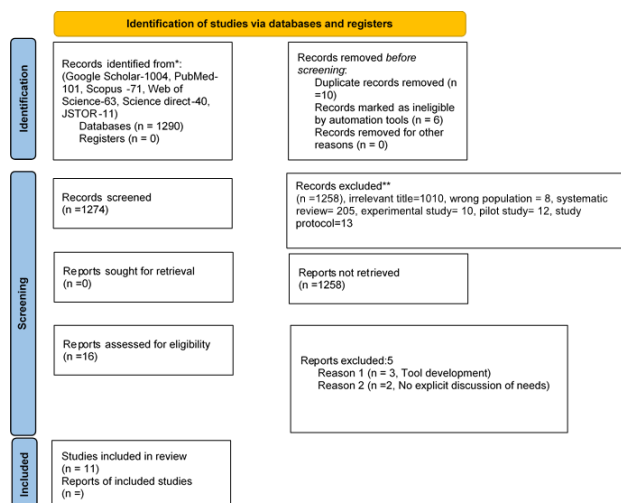


Fig. 1 Study flow diagram

Total participants, mean age, stage of cancer, design and country

Among eleven studies included in this review, seven studies were cross sectional descriptive¹²⁻¹⁸, one study was prospective cohort¹⁹, one study was qualitative²⁰ and two study did not mentioned design^{21,22} with 2156 different cancer patients from 9 different countries (Canada, China, India, Australia, Indonesia, Iran, Malaysia, USA and UK). Three studies among cancer^{12,13,21}, two studies gynecological cancer^{16,18}, one ovarian cancer¹⁵, one cervical cancer²⁰, one lungs cancer²², one breast cancer¹⁷ and one colorectal¹⁹ were conducted. All studies were conducted in hospital. The mean age of the respondents was mentioned by three studies²⁰⁻²² which was found between 43.45 ± 12.08 to 68.5 ± 10.1 and other remaining eight studies did not mention the mean age of the respondents. The stage of cancer was only mentioned in six studies.^{14,17,18,20-22} Among them the respondents of four studies were in stage I-IV^{18,20-22}, one study in stage 0- IV¹⁷ and one study in primary-tertiary stage of cancer.¹⁴ (Refer to table 1)

Study size estimation, sampling, data collection technique

The sample size estimation was done by only one study on the basis of population size of 2880, a 50% response rate, 95% confidence level and 5% margin of error, assuming a normally distributed

population.¹⁶ Convenience sampling was used in three studies^{16,17,23}, consecutive sampling in two studies^{15,22}, random in one¹², purposive in one²⁰ as a sampling technique and remaining four studies did not mention about it.^{13,14,19,21} Self-administered data collection technique was used in seven studies^{13,15,16,19,21-23} whereas interview (interviewer administered) was used in four studies.^{12,14,17,20} (Refer to table 1)

Scale used in study

The mostly used scale for the assessment of SCNs was Supportive Care Need Survey Short Form 34 (SCNS-SF34) which was used in five studies.^{16,17,19,21,23} European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C30 (EORTC QLQ-C30) was used in three studies^{17,21,23} Symptom Distress Scale (SDS) was used in one study.¹² Supportive Care Needs Survey (SCNS-59) was used in one study.¹³ The Center for Epidemiologic Studies Depression Scale (CES-D) was used in two studies.^{19,22} Memorial Symptom Assessment Scale—Short Form (MSAS-SF) was used in one study.²² Karnofsky's Performance Status (KPS) Index was used in one study.¹⁴ Cancer Needs Questionnaire Short Form (CNQ-SF) was used in one study.¹⁴ Positive and Negative Affect Scale (PANAS) was used in one study.¹⁹ (Refer to table 1)

DATA ANALYSIS

Regarding software for data analysis, SPSS in four studies^{13,14,17,23}; R environment in one study¹⁶; Mplus in one study²¹; NVivo in one study²⁰ was used and remaining other four studies did not mention about it.^{12,15,19,22} Descriptive and inferential statistics was used in seven studies^{14,16,17,19,21-23}, only descriptive statistics was used in three studies^{12,13,15} and content analysis was used in one study.²⁰ (Refer to table 1)

Outcomes

Psychological supportive care need was the first priority among the respondents of six studies^{14,15,17,19,21,23}, physical supportive care need was the first priority among the respondents of two

studies^{12,22}, health system information need was the first priority among the respondents of two studies^{13,16} and symptom management strategies was the first priority among the respondents of one studies.²⁰ (Refer to table 1)

DISCUSSION

This systematic review identified 11 articles that have reported the SCNs of patients with cancer during their illness. These studies pinpoint that people affected by cancer have a range of SCNs. As per the findings of this study psychological SCNs was the first priority SCNs among the respondents of six studies. Anxiety and fears about the cancer spreading to other body parts were the most commonly identified psychosocial needs in a review study among cancer patients.² The SCNs of patients with cancer were associated with their physical symptoms, anxiety and quality of life.²⁴

This study also found health system information and physical daily living SCNs was the first priority SCNs among respondent of two studies. Sufficient information about side effects management of treatment were also important areas SCNs. Assistant during cooking, shopping and cleaning were identified SCNs among cancer patients during treatment and post-treatment phase.²

As per the findings of this review the most commonly used instrument was SCNS-SF 34 in five studies with cross sectional descriptive design in seven studies. The most commonly used instruments for needs assessment among patients with advanced cancer were the SCNS (N=8) through cross sectional design.²⁴

Sexuality SCNs was not the priority SCNs among the respondents of eleven studies of this review which is in line with the findings of review studies among cancer patients.^{24,25}

This study found that all most all of the studies did not mention about sample size measurement technique. Sample size calculation is essential to determine the number of samples needed to

detect significant changes in clinical parameters, treatment effects or associations after data collection.²⁶

STRENGTH AND LIMITATION

This study has its inclusive nature, looking across all populations and all types of cancer. It has included the cancer population from Asian and European countries. Financial SCNs of the cancer patient was not explored by this study. The majority of studies used convenience sampling so may not accurately capture the needs of the general cancer population. Most included studies were cross-sectional therefore could not analyses how patients' concerns changed over time.

CONCLUSION

Cancer patients reported a wide range of context bound SCNs. Examining their needs on the basis of viewing patients as a whole unit will be highly optimal. Care needs should be comprehensively evaluated by using rigorously designed mixed methods research and longitudinal studies within a given context. Inclusion of measurement of sample size in methodology will improve the quality of data analysis. Study with mixed method longitudinal design will aids to identify the exact SCNs of cancer patient in different phase of cancer. Inclusion of interview technique as a data collection method may include illiterate respondents.

Study characteristics

Eleven studies were included in this review and their details are provided in the characteristics of the studies included in the study.

Table 1 Characteristics of included studies

AN	Authors, year, country	Mean age, Cancer Type	Sample size Cancer Stage	Design, Sampling Data collection technique Sample size estimation	Software Data analysis	Instrument	Outcomes
1	Canada ¹²	-NM -Cancer	-132 -NM	-Cross-sectional -Random -Face to face interview -NM	-NM -Descriptive statistics	-SDS - General Health Questionnaire	-96% reported current symptoms (fatigue (66%), worried outlook (61%), difficulty sleeping (48%), and pain (42%)). -Psychologically distressed-33% -Informational needs-(85%) social concerns -66%, need for assistance with day-to-day living- 41%.
2.	Iran ¹³	-NM -Cancer	-274 -NM	-Descriptive study -NM -SA NM	-SPSS- version 13, Descriptive statistics (frequency, percentage, mean, and standard)	-SCNS -59	More than 50% of the participants reported unmet needs. Unmet needs were related to the health system information and physical daily living
3.	China ²⁰	-46.40 (9.80) (With reported cognitive) -43.45 (12.08) (Without reported cognitive) -Cervical cancer	-31 -Stage IA- Stage IIB-IVA	-Qualitative -Purposive -Semi-structured interviews -NM	-NVivo 11 -Qualitative content analysis	-Semi-structured interview with interview guide -Interviews were conducted face to face in ward's meeting room -Each interview lasted 30–45 min	64.5% reported cognitive complaints. - - Most common complaint was loss of concentration (n=17, 85.0%). - Chemotherapy related cognitive complaints (n=15, 75.0%) and ageing (n=8, 40.0%). - Common SCNs: symptom management (55.0%) and counselling services (40.0%).
4.	India ¹⁴	-NM -Oral cancer	-120 -Primary- Tertiary	-Descriptive cross-sectional -NM -Interview -NM	-SPSS version 21 -Descriptive statistics -Regression analysis	- KPS Index - CNQ-SF	Highest priority SCNs in Psychological, followed by communication , patient support , health information , and physical needs. Factors significantly related SCNs were stage of the cancer, past treatment , occupation, location of the cancer, duration of the treatment, and undergoing problems during the treatment (P <0.05)
5.	Canada ¹⁵	-NM -Ovarian cancer	-50 -NM	-Descriptive cross-sectional -Consecutive sampling -SA -NM	-NM -Descriptive statistics	- SCNS	- Eight of the top 10 reported needs were psychosocial, such as fears of cancer returning or spreading. -The women expressed a range of difficulty in managing their needs. -Significant numbers of women indicated they did not wish to have assistance from the clinic staff with some needs.

6.	Australia ¹⁶	-NM -Gynecological cancer	-343 -NM	-Cross-sectional -Convenience sampling -SA -Based on a population size of 2880, a 50% response rate, 95% confidence level and 5% margin of error, assuming a normally distributed population.	-R environment -Exploratory factor analysis -Descriptive & inferential statistics	(SCNS-SF34)	-83% identified one moderate or high level supportive care need. -The five highest ranked needs were, 'being informed about your test results as soon as feasible' (54.8%), 'fears about cancer spreading' (53.7%), 'being treated like a person not just another case' (51.9%), 'being informed about cancer which is under control (50.7%), and 'being adequately informed about the benefits and side-effects of treatments before you choose to have them' (49.9%). Eight of the top ten needs were from the 'health system information' domain.
7.	Malaysia ¹⁷	-NM -Breast cancer	-117 -Stage 0-IV	-Cross-sectional -Convenience sample -Interviewer-administered questionnaire -NM	-SPSS version 20.0 -Descriptive (Mean, median scores and standard deviation) -Inferential (independent t-test, one-way analysis of variance (ANOVA) and Pearson correlation coefficient)	-SCNS-SF 34 - EORTC QLQ-C30	The highest unmet SCNs were observed in the psychological domain (Mean 53.31; SD ± 21.79), followed by physical domain (Mean 38.16; SD ± 27.15).
8.	Indonesia ²³	-NM -Gynecological cancer	-153 -Stage I-IV	-Cross sectional -Convenience sampling -SA -NM	-SPSS version 22.0 -Descriptive (frequency distribution and percentages) -Inferential (Linear regression)	SCNS-SF34 EORTC-QLQ-30	-Unmet SCNs predict poorer quality of life -96% of respondents stated SCNs -Concerns about the worries of those close to the patients" (89.5%) was the most frequently identified SCNs in the psychological domain
9.	China ²¹	-50.07 (13.09) -Cancer	-301 -Stage I-IV	-NM -NM -SA -NM	-Mplus 7.3 -Latent class analysis (Bayesian information criterion, Akaike information criterion, entropy, bootstrapped likelihood ratio test, and Vuong-Lo-Mendell-Rubin likelihood ratio test -SPSS version 22.0 -Chi-square tests and ANOVAs (Descriptive & Inferential)	SCNS-SF34 EORTC-QLQ-C30	-Four patterns of needs were identified. -Respondents in class 1 (47%) reported few unmet needs, in class 2 (15%) had moderate levels of needs, in class 3 (25%) and class 4 (13%) reported similarly high levels of SCNs

10.	California ²²	-68.5 (10.1) -Lungs	-109 -Stage I-IV	-NM -Consecutive sampling -SA -NM	-NM -Descriptive (frequency, percentage, mean and SD) -Inferential (independent samples t-tests and w2 tests, paired-samples t-tests, Pearson product-moment correlations, multivariate hierarchical regression)	-Supportive Care Needs Survey, Short Form-29 -The Impact of Events Scale—Revised - CES-DS -The COPE -Distress thermometer - MSAS-SF -Medical Outcomes Study Short Form	- Greatest need in physical daily living followed by psychological, health system information and patient care support needs. -The most common unmet need was a lack of energy and tiredness (75%). -Higher levels of SCNs were associated with worse physical functioning, greater symptom bother, lower satisfaction with health care, and higher levels of intrusive thoughts about cancer.
11.	UK ¹⁹	-NM -Colorectal	-526 -NM	-Prospective cohort -NM -SA -NM	-NM -Descriptive (frequency, percentage) -Inferential (chi-squared test, multivariable logistic regression, linear regression)	-SCNS SF-34 -The EuroQoL 3-level version -The Quality of Life of Adult Cancer Survivors Scale Part 1 -QLQ-CR29 -Personal Wellbeing Index-Adult -State-Trait Anxiety Inventory - CES-DS - PANAS -The MOS Social Support Survey -The Self-efficacy for Managing Chronic Disease Scale	-SCNS SF-34 was completed by 526 patients at 15 months and 510 patients at 24 months. - One-quarter of respondents had at least one moderate or severe unmet need at both time points. -Psychological and physical unmet needs were most common and did not improve over time. -Over 60% of patients who reported 5 or more moderate or severe unmet needs at 15 months experienced the same level of unmet need at 24 months. -HRQoL at beginning of treatment predicted unmet needs at the end of treatment. -Unmet physical, psychological, health system information needs were associated with poorer health and HRQoL at the end of treatment.

NM =Not mentioned, SCNs= Supportive care needs, SA=Self-administered

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