

"I personally think that when people hear the words skin cancer they think of it as the lowest form, most common, and oh it's nothing anyway, you know they don't think of it as serious as it can be. Like it wasn't until I read my diagnosis and sat down with my doctor that I started get lumps in my throat and hearing up and thinking this isn't just a mark on my body that needs to be taken off, this is something can kill me, and I don't think that this message is out there as some of the other forms like breast, lung, or colon."

- Focus Group Participant

BACKGROUND

The rapid development in melanoma treatment options has significantly improved overall survival, changing the prognosis from an average of 6-9 months to a potential cure in 20-30% of patients.¹ Unfortunately, patient education has lagged behind. While the medical community has been excited at the rapidly changing treatment landscape from single agent chemotherapy to immunotherapy and targeted therapy, we have not kept pace with informing patients about these treatment options. Patients have expressed frustration at not having any local support groups or information sessions, and an environmental scan also confirmed a lack of proper educational programs and support groups for melanoma patients in the Durham region.

OBJECTIVES

1. To assess the supportive care needs of melanoma patients and survivors attending an outpatient clinic.
2. To develop an intervention program to address the educational gap and support needs for melanoma patients.
3. To seek feedback and gather opinions about the intervention program from melanoma patients and survivors.

METHODS

Design: Cross-sectional mixed method

Prospective Participants: Melanoma patients currently attending an Oshawa outpatient clinic.

Retrospective Participants: Melanoma patients who attended the outpatient clinic in Oshawa within the last two years.

Procedure

Quantitative

A sociodemographic questionnaire was completed and a short form Supportive Care Needs Survey (SCNS-SF34) with two supplementary sections: 1) additional information and screening behaviour and 2) melanoma specific, was used to measure the needs of patients.² This tool contained five constructs: psychological, health system and information, patient care and support, physical and daily living, and sexuality^{3,4} and is measured on a five-point scale: 1 = no need/not applicable; 2 = no need, satisfied; 3 = low need; 4 = moderate need; 5 = high need. The data was statistically analyzed to identify the highest reported needs and to determine any relationships with sociodemographic information.

Qualitative

The participants who consented to the focus group attended and expressed their opinions and feedback about the intervention program. The focus group data was thematically analyzed.

Table 1. Frequency (and percentage) of supportive care needs responses for top twelve reported needs

In the last month, what was your level of need for help with:	No Need	Low Need	Moderate Need	High Need
Psychological Construct				
1. Fears about the cancer spreading (n=74)	29 (39.2)	21 (28.4)	14 (18.9)	10 (13.5)
2. Uncertainty about the future (n=75)	38 (50.7)	18 (24.0)	10 (13.3)	9 (12.0)
4. Worry that the results of treatment are beyond your control (n=72)	45 (62.5)	15 (20.8)	6 (8.3)	6 (8.3)
5. Concerns about the worries of those close to you (n=74)	49 (66.2)	10 (13.5)	10 (13.5)	5 (6.8)
6. Anxiety (n=75)	50 (66.7)	10 (13.3)	10 (13.3)	5 (6.7)
7. Feelings about death and dying (n=75)	47 (62.7)	16 (21.3)	8 (10.7)	4 (5.3)
Health System and Information Items Construct				
8. Being informed about your test results as soon as feasible (n=75)	57 (76.0)	2 (2.7)	6 (8.0)	10 (13.3)
10. Being informed about things you can do to help yourself to get well (n=75)	58 (77.3)	2 (2.7)	5 (6.7)	10 (13.3)
Melanoma Specific Construct				
3. More information about the risk of recurrence of melanoma (n=75)	41 (54.7)	15 (20.0)	9 (12.0)	10 (13.3)
9. More information about possible outcomes when melanoma has spread from the skin (n=75)	53 (70.7)	8 (10.7)	6 (8.0)	8 (10.7)
11. More information about non-surgical treatment of melanoma (chemotherapy, immunotherapy) (n=75)	52 (69.3)	10 (13.3)	7 (9.3)	6 (8.0)
12. To be informed about things you can do for skin protection (n=75)	55 (73.3)	9 (12.0)	2 (2.7)	9 (12.0)

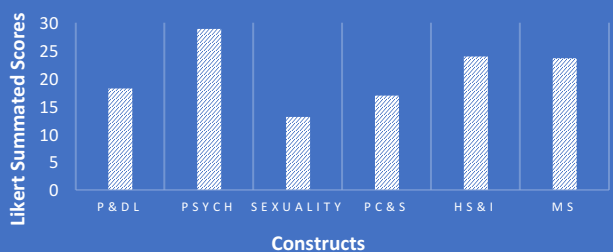
Note. Some participants did not answer every question so n=72-75 for each question.

Table 2. Frequency (and percentage) of additional informational needs and screening behaviour responses

	Yes	No
47. When you were first diagnosed with melanoma, were you provided with any informational tools to assist you in understanding your diagnosis?	49	22
48. Throughout your treatment, do you feel you received sufficient information regarding your diagnosis and prognosis?	60	11
49. Throughout your treatment, do you feel you received sufficient information regarding the full range of treatment options?	58	11
50. Do you feel comfortable enough to ask your medical team/doctor questions concerning your diagnosis or treatment?	72	1
51. Do you conduct regular self-checks to screen for melanoma, skin cancers, or a recurrence?	65	7
52. Have you attended any information sessions or support groups for melanoma?	5	68

Note. Some participants did not answer every question so n=69-73 for each question.

FIGURE 1. LIKERT SUMMATED SCORES FOR QUESTIONNAIRE CONSTRUCTS



RESULTS

General Trends

- 75 of 225 offered surveys, were returned; a response rate of 33.5%.
- Majority male (61.3%) participants (Table 1).
- Participant average age was 63 and average diagnosis age was 60.
- Highest reported constructs were psychological, health system and information items (HS&I), and melanoma specific (MS). Top twelve reported needs fell into one of these three identified constructs (Figure 1).
- The majority of participants were given sufficient (85.9%) information but sometimes (31%) this was not done timely upon diagnosis (Table 2).
- Participants felt comfortable communicating with their healthcare providers (98.6%), and performed regular skin self-checks (90.3%), (Table 2).
- Most participants (93.2%) haven't previously attended a support group or informational session for melanoma (Table 2).

Other Trends

- Participants aged < 63 had greater needs than those who were ≥ 63, for almost every question. Significantly (p < 0.05) higher needs were observed in 14 questions which were primarily from psychological (8), sexuality (2), or MS (2) constructs
- Females had higher needs than males in almost every question, with significantly (p < 0.05) higher needs in four questions: work around the home (F=2.47, p=0.019), anxiety (F=2.26, p=0.029), being given information about sexual relationships (F=2.22, p=0.035), to be informed about the need for surgical removal of lymph nodes (F=2.46, p=0.020).
- Participants who lived alone or were unmarried had significantly (p < 0.05) higher needs than their respective counterparts in the psychological and P&DL constructs.

DISCUSSION

- While majority of participants indicated they had no supportive care needs, a substantial number indicated the need for support in three constructs: psychological, HS&I, and MS.
- HS&I questions are information needs about cancer diagnosis/prognosis, treatment/tests, family, and financial issues. Melanoma specific questions are informational needs specifically about melanoma. The needs that stem from both these constructs are focused on receiving comprehensive information about the disease and the healthcare system.
- The psychological questions focused on fears of cancer spreading and uncertainty about the future. Both psychological and informational needs are the prominent areas that require support.
- Psychological needs can be resolved through supportive care⁵, and have been proven to improve the psychosocial outcomes of patients⁶. Informational needs can be resolved through valid and comprehensible educational resources⁷ and have been proven to improve adherence to preventative behaviours.

To address this issue there are multiple forms of intervention that fall into one of four categories: educational techniques (reduce helplessness, uncertainty, and anxiety), behavioral techniques (reduce adverse events from treatment), individual psychotherapy (enhanced psychological coping and quality of life), and group interventions⁸. The outcomes from the results of this study and other literature were used to develop an intervention program (Table 3).

Table 3. Proposed Intervention Program

Major Construct	Evidence-Based Options
Psychological	Telephone based social support (Behavioral and Individual psychotherapy) Support group (Behavioral, Group interventions, and Individual psychotherapy) 6-week structured psychotherapy (Behavioral, Group interventions, and Individual psychotherapy)
Health System and Information	Infographic on the patient journey, cancer care resources and the changing role of health care providers (Educational) Booklet containing details regarding roles/responsibilities of healthcare providers and patients during each stage of melanoma (Educational, Behavioral)
Melanoma Specific	Disease related information booklet (Educational) 12-minute educational slide presentation (Educational) 30-90 minute psychoeducational sessions (Educational, Behavioral, Group intervention, and Individual psychotherapy)

FOCUS GROUP AND CONCLUSION

The key concepts kept in mind during the development of this intervention program were to first maximize education, because patients who are more educated about the disease and the resources available to them will endure lower psychological stress. Secondly, the program was intended to offer support for patients with different lifestyles.

Major focus group themes on the proposed intervention program:

- All the informational tools would be useful tools and should be offered by physicians to patients; they must be comprehensive, consistent with each other, and accessible from home
- Telephone based social support had overwhelming approval and the fact that this is offered by the MNC should be stated by physicians to patients
- A melanoma specific support group would be useful for not only patients but also their family members
- Public perception of melanoma needs to change

This study provided an in depth analysis of the supportive care needs of melanoma patients in Oshawa, and used the results to develop a framework for educating and supporting melanoma patients. However, a major limitation was the 3 year difference between current age and age at diagnosis; needs of patients change over time. Currently the intervention program is in the process of implementation and the intent is to complete a one-year post evaluation.

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