



THE AFFECTS OF MELANOMA ON THE MENTAL WELLNESS OF PATIENTS, AND THE LANDSCAPE OF MENTAL HEALTH SUPPORT IN THE CANADIAN MELANOMA COMMUNITY

Taylor Tomko B.A.¹, Kathleen Barnard ECCE¹, Natalie Richardson¹

¹ Save Your Skin Foundation, Vancouver, Canada



INTRODUCTION

Between 1992 and 2013, incidence rates for melanoma in Canada have increased by 2.1% per year in males, and 2.0% per year in females; in 2017, there were 4,000 new cases of melanoma in males and 3,300 in females, totalling approximately 7,200 new cases of melanoma in Canada (CCS 26, 38). It is projected that in 2017, 1,250 Canadians will die from causes related to melanoma (47). This project aims to look beyond these statistics by considering the mental wellness of English (Eng) and French (Fr) Canadians that have received a melanoma diagnosis or treatment, or are living beyond their melanoma journey.

OBJECTIVE

The aim of Save Your Skin Foundation was to contribute to the knowledge gap surrounding what affects the experiences of melanoma diagnosis, treatment, and survivorship have on mental wellness. We hoped that by asking patients questions related to their mental wellness during their melanoma journey, the survey would be able to offer insight as to which emotions patients most frequently experience, the methods patients use to improve their mental wellness, and how mental wellbeing shifts from diagnosis, to treatment, to survivorship. Additionally, the survey contained questions regarding the demand for institutional (medical facility and patient groups) mental wellness support, the existing accessibility of said support, and potential opportunities for improvement within medical institutions and patient groups.

METHOD

Save Your Skin Foundation ran a survey among melanoma patients and survivors to examine how diagnosis and treatment of the disease has affected survey participants. The survey was conducted in English using the SurveyMonkey online platform. It was also made available in French for Quebec residents. The survey consisted of a mix of yes/no questions, multi-option multiple choice questions, and paragraph answers. Every question provided participants the opportunity to comment if they did not feel the provided options were reflective of their experience.

The English survey was open from August 21, 2017 to September 25, 2017; the French survey was open from August 28, 2017 to September 25, 2017. There were 28 participants in the English survey, and 19 in the French survey. French to English translations were largely performed by our in-house translator, Danika Garneau. The English and French results are combined for the purpose of this project. The poster will provide an overview of the survey results; for access to the complete survey responses or summarizing report, please contact Save Your Skin Foundation.

REFERENCES

Save Your Skin Foundation. "Save Your Skin Foundation Mental Health Survey 2017". Open 21 August, 2017 to 25 September, 2017. SurveyMonkey.
Save Your Skin Foundation. "Sondage sur la Santé Mentale de la Fondation Sauve Ta Peau 2017". Open 28 August, 2017 to 25 September, 2017. SurveyMonkey.
Government of Canada and the Canadian Cancer Society et al. Canadian Cancer Statistics 2017: Special Topic: Painless Cancers. Government of Canada and the Canadian Cancer Society, 2017. Web. Access: <http://www.cancer.ca/~media/cancer.ca/CW/cancer%20information/cancer%20101/Canadian%20cancer%20statistics/Canadian-Cancer-Statistics-2017-CN.pdf?file=

ON THE MINDS OF MELANOMA PATIENTS

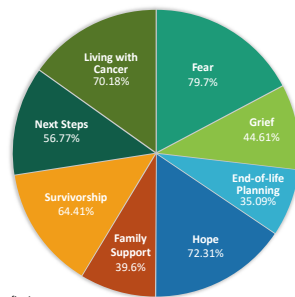


fig. 1

In response to the question "What kinds of subjects would you like to discuss in an emotional support setting? Check all that apply," (fig.1) twenty-one participants in the English survey answered, and nineteen in the French survey. From these responses we created this image which is a depiction of the combined percentage totals. Comments on this question largely concerned patient self-perception and quality of life, including: "self-esteem, difficulty accepting ugly scars," "permanent medical history and prescriptions, no more sun or tanning, permanent life change," and, "sometimes feel like I have PTSD (post-traumatic stress disorder) from the whole experience." Commenters also alluded to uncertainty and posed questions about survivorship and future planning, specifically whether or not they could/should think about becoming pregnant, or seeking advice for keeping life as 'normal' as possible. Responses to this survey uphold the growing importance for addressing the needs of the growing population of melanoma survivors, or those who have finished treatments.

HOW PATIENTS VIEW THEIR SITUATION

At what point in your treatment process do you seek emotional support? Upon diagnosis, during treatment, post-treatment; check all that apply. (fig.2)



fig. 2

There were thirty-nine comments (Eng: 23, Fr: 16) in response to the questions "How would you describe your feelings throughout or after your cancer experience? Are these emotions ongoing, recurring, or occasional?" Twelve of these comments stated that their negative emotions are constant; nine said they were recurring, usually before scans or medical appointments; five said they were occasional; and seven commenters noted feeling more positive after their treatments had ended. Frequently cited emotions include:

fear anxiety grief shame depression vulnerability frustration hope

There were thirty comments (Eng: 17, Fr: 13) in response to the question "Are there any other comments you would like to make about your cancer experience, and the affect it has had on you and/or your family's mental health?". Of these comments, ten mentioned that their cancer experience had changed their relationships with their family. Of these, three comments stated that their family had become closer through their experience, while five mentioned that it has damaged their familial relationships. Two of these comments mentioned the importance of being honest with your family, including children, about your experience. Three comments mentioned that they were more grateful for their life and optimistic for the future after their treatments ended, while six mentioned that they were still having difficulties feeling physically or emotionally as well as they had before their melanoma diagnosis. One comment mentioned difficulty navigating the medical system. Five comments expressed gratitude for assistance they received: one for their psychiatrist, two for their medical teams, and two for support groups like Save Your Skin Foundation.

What would your ideal support system look like? Check all that apply. (fig.3)

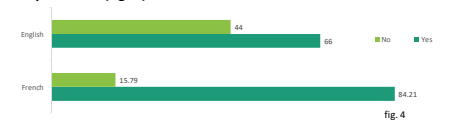


fig. 3

In response to the question "What would your ideal support system look like?", one commenter demonstrated interest in finding an online support system, one would seek out a supportive family doctor, and the final commenter would ideally continue to have access to patient organizations such as Save Your Skin Foundation. There were twenty three comments (Eng: 17, Fr: 6) in response to the question "If you were participating in an online support system, what kind of resources would you like to see?". Of these comments, eight mentioned they would like their online support systems to provide educational resources, including information about the medical system, treatments and treatment access, and ways to maintain their overall health. Four comments sought outlets for stress and support for their mental health. Specificity in demographic, including age, gender, and cancer type, were mentioned four times.

SUPPORT VS. NO SUPPORT

Do you seek emotional support to help you through your cancer experience? (fig. 4)

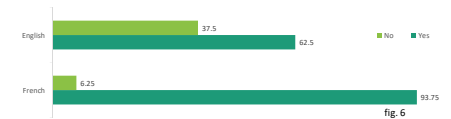


If you have not sought emotional support, why not? Check all that apply. (fig. 5)



There were twelve comments (Eng: 9, Fr: 3) in response to the question "Do you find that support is available to you in your location?". Four of these commenters suggested that they were not made aware of any support services. Three comments cited geographical distance as a barrier to receiving support, while two commenters mentioned that while support was available for them, it was through cancer types other than melanoma.

If you have not been able to receive emotional support, do you wish you could have? (fig. 6)



CONCLUSIONS

The first conclusion to be drawn from the survey results is that the majority of patients (Eng: 66%, F: 84.21%) (fig. 4) seek emotional support during their cancer journey (question 1). This need for support does not appear to be satisfied, especially for those in the French-speaking provinces; reasons for this discrepancy include lack of mental wellness resources provided by cancer centres (Eng: 29.17%, Fr: 64.71%), financial restrictions (Eng: 14.29%, Fr: 62.50%), and lack of availability of support in their geographic locations (Eng: 32%, Fr: 70.59%)(7; 3; 6) (fig. 5). Survey responses suggest that emotional support is seen to be of relatively equal importance at every stage: after melanoma diagnosis, during treatment, and once treatments have finished (9) (fig. 2). Based on comments to question 15, which discussed when patients felt the need for mental wellness support, the need for wellness resources appears to be recurring or ongoing, often alongside the patterns of the disease itself.

It would appear that there are improvements to be made to overcome barriers of access to mental wellness support for melanoma patients in Canada. A greater emphasis on awareness of existing resources, an increase in mental wellness programs in cancer centres, and more options for patients in remote areas could be helpful steps in supporting the emotional wellbeing of Canadians living with melanoma.