



October 10, 2017

To commemorate World Mental Health Day, 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 using the SurveyMonkey online platform, and was available in both english and french. The survey consisted of a mix of yes/no questions, multi-option multiple choice question, and paragraph answers. Every question provided the 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 responses to the english survey, and 19 responses to the french survey. French to english translations were largely performed by our in-house translator, Danika Garneau. The following report will narrativize the results of the survey by question in consecutive order, pointing out trends in the responses. The english and french results will be combined for the purpose of this report. For access to the original survey results, please [contact Save Your Skin Foundation](#). For more information about World Mental Health Day, [visit their website](#).

Question 1: “do you seek emotional support to help you work through your cancer experience?”

English survey (answered: 25, skipped: 3):

Yes: 66% (14)

No: 44% (11)

French survey (answered: 19, skipped: 0): Yes: 84.21% (16)

No: 15.79% (3)

Between the english (5 comments) and french (3 comments) surveys, there were eight comments in response to question 1, “do you seek emotional support to help you work through your cancer experience?”. Of these comments, two highlighted the importance of friends, coworkers, and family for counselling. One comment noted that their nurse set them up with a ‘chemo buddy’ for mutual support during their treatments. Two commenters stated that emotional support did not seem to be available to them, one suggesting that the psychologist available at the hospital was not helpful, as it reminded them of their condition.



Question 2: “what kind of support do you seek? Check all that apply.”

English survey (answered: 25, skipped: 3): melanoma support group: 44% (11)
One-on-one therapy: 52% (13)
Friends and/or family: 76% (19)
Online therapist: 0% (0)
Exercise: 48% (12)

French survey (answered: 19, skipped: 0): melanoma support group: 68.42% (13)
One-on-one therapy: 31.58% (6)
Friends and/or family: 63.16% (12)
Online therapist: 10.53% (2)
Exercise: 26.32% (5)

There were seven comments (english: 6, french: 1) in response to question 2, “what kind of support do you seek? Check all that apply”. Two of these comments specified the support groups they participated in (Gilda’s Club and Médication), and another specified that they looked for blogs online. Regarding physicality, one comment specified taking long walks, and one expressed interest in meditation and energy care.

Question 3: “if you have not sought emotional support, why not? Check all that apply”

English survey (answered: 14, skipped: 14): not interested: 35.71% (5)
Nervous: 21.43% (3)
Hasn’t worked for me in the past: 0% (0)
Financial difficulties: 14.29% (2)
Difficult to access: 21.43% (3)
Physical limitations: 0% (0)
Didn’t know it was available: 35.71% (5)

French survey (answered: 8, skipped: 11): not interested: 12.50% (1)
Nervous: 25% (2)
Hasn’t worked for me in the past: 0% (0)
Financial difficulties: 62.50% (5)
Difficult to access: 12.50% (1)
Physical limitations: 12.50% (1)
Didn’t know it was available: 0% (0)

There were nine comments (english: 7, french: 2) in response to question 3, “if you have not sought emotional support, why not? Check all that apply”. One of these suggested that the responder did not realize that emotional support was a possibility for them other than through patient organizations like



Save Your Skin. In two of the comments, the participant did not feel that they needed professional support, one because they were comfortable enough with their treatment plan that they were not concerned about their future, and the other felt sufficiently supported by their family and friends; another comment suggested that professional therapy would not be the kind of support that they required. One comment noted that they were unable to afford professional therapy, but were a part of online support groups and looked to other melanoma patients for support.

Question 4: “if you have not been able to receive emotional support, do you wish you could have?”

English survey (answered: 16, skipped: 12): Yes: 62.50% (10)
No: 37.50% (6)

French survey (answered: 16, skipped: 3): Yes: 93.75% (15)
No: 6.25% (1)

There were six comments (english: 6, french: 0) in response to question 4, “if you have not been able to receive emotional support, do you wish you could have?”. Three of these suggested that the question was not applicable to the survey participant, and one commenter stated that they were completely satisfied with the support they received from friends, family, and patient organizations, such as Save Your Skin.

Question 5: “what kinds of subjects would you like to discuss in an emotional support setting? Check all that apply.”

English survey (answered: 21, skipped: 7): fear: 85.71% (18)
Grief: 52.38% (11)
End-of-life planning: 33.33% (7)
Family support: 47.62% (10)
Survivorship: 76.19% (16)
Hope: 76.19% (16)
Next steps: 71.43% (15)
Living with cancer: 66.67% (14)

French survey (answered: 19, skipped: 0): fear: 73.68% (14)
Grief: 36.84% (7)
End-of-life planning: 36.84% (7)
Family support: 31.58% (6)
Survivorship: 52.63% (10)



Hope: 68.42% (13)

Next steps: 42.11% (8)

Living with cancer: 73.68% (14)

There were seven comments (english: 6, french: 1) in response to question 5, “what kinds of subjects would you like to discuss in an emotional support setting? Check all that apply”. Additions to the list of subjects that could be discussed in a therapeutic setting included family planning, advice for keeping life as ‘normal’ as possible (the commenter specifically cited outdoor recreation activities), and one commenter suggested “self-esteem, difficulty accepting ugly scars, drastic changes in life patterns, permanent medical history and prescriptions. Quality of life, ie. no more sun or tanning,” also mentioning that they “sometimes feel like I have PTSD from the whole experience, and it is a permanent life change” (English survey, question 5 comments).

Question 6: “do you find that support is available to you in your location?”

English survey (answered: 25, skipped: 3): yes: 68% (17)

No: 32% (8)

French survey (answered: 17, skipped: 2): yes: 29.41% (5)

No: 70.59% (12)

There were twelve comments (english: 9, french: 3) in response to question 6, “do you find that support is available to you in your location?”. Four of these comments suggested that they were not made aware of any support services. Three comments cited geographical distance as a barrier to receiving support, while two comments mentioned that while support was available for them, it was through cancer types other than melanoma.

Question 7: “do you feel that your cancer care centre provides/promotes access to support services?”

English survey (answered: 24, skipped: 4): yes: 70.83% (17)

No: 29.17% (7)

French survey (answered: 17, skipped: 2): yes: 35.29% (6)

No: 64.71% (11)

There were seven comments (english: 4, french: 3) in response to question 7, “do you feel that your cancer care centre provides/promotes access to support services?”. Five commenters were never made aware of emotional support resources by their cancer care centre, and one commenter believed that



their cancer care centre did not offer any forms of mental health support. One additional commenter said that they were told of emotional support services by an independent Dermatologist.

Question 8: “does your insurance provider cover costs for therapy?”

English survey (answers: 25, skipped: 3): yes: 60% (15)
No: 40% (10)

French survey (answered: 17, skipped: 2): yes: 64.71% (11)
No: 35.29% (6)

There were eight comments (english: 4, french: 4) in response to question 8, “does your insurance provider cover costs for therapy?”. One commenter did not have insurance, three were unsure whether therapy was covered by their insurance provider, and three did not have sufficient coverage from their insurance for therapy costs.

Question 9: “at what point in your treatment process do you seek emotional support? Check all that apply.”

English survey (answered: 26, skipped: 2): diagnosis: 80.77% (21)
Treatment: 73.08% (19)
Post-treatment: 57.69% (15)

French survey (answered: 19, skipped: 0): diagnosis: 52.63% (10)
Treatment: 52.63% (10)
Post-treatment: 63.16% (12)

There were no comments in response to question 9.

Question 10: “if you stop pursuing emotional support after you finish treatments, why? Check all that apply.”

English survey (answered: 16, skipped: 12): financial difficulties: 18.75% (3)
Difficult to access: 31.25% (5)
Didn't seem necessary: 68.75% (11)

French survey (answered: 10, skipped: 9): financial difficulties: 40% (4)
Difficult to access: 40% (4)



Didn't seem necessary: 20% (2)

There were ten comments (english: 7, french: 3) in response to question ten, "if you stop pursuing emotional support after you finish treatments, why? Check all that apply". Three of these comments suggested that the patient continued therapy after the end of their treatments. One person stopped because they could not afford to continue, one was not sure where to find treatment for survivors, and one felt that therapy would no longer be helpful.

Question 11: "do any members of your family seek emotional support?"

English survey (answered: 26, skipped: 2): yes: 26.92% (7)
No: 73.08% (19)

French survey (answered: 19, skipped: 0): yes: 21.05% (4)
No: 78.95% (15)

There were no comments regarding question 11.

Question 12: "have you ever gone to counselling in a family setting?"

English survey (answered: 27, skipped: 1): yes: 18.52% (5)
No: 81.48% (22)

French survey (answered: 18, skipped: 1): yes: 27.78% (5)
No: 72.22% (13)

There were no comments regarding question 12.

Question 13: "what would your ideal support system look like? Check all that apply."

English survey (answered: 28, skipped: 0): one-on-one therapy: 67.86% (19)
Group therapy: 53.57% (15)
Online therapy: 21.43% (6)
Friends and/or family: 60.71% (17)

French survey (answered: 19, skipped: 0): one-on-one therapy: 73.68% (14)
Group therapy: 52.63% (10)
Online therapy: 26.32% (5)



Friends and/or family: 47.37% (9)

There were three comments (english: 3, french: 0) in response to question 13, “what would your ideal support system look like? Check all that apply”. One commenter demonstrated interest in finding an online support system, one would seek out a supportive family doctor, and the final comment would ideally continue to have access to patient organizations like Save Your Skin Foundation.

Question 14: “if you were participating in an online support system, what kind of resources would you like to see?”

English survey: answered: 17, skipped: 11

French survey: answered: 6, skipped: 13

There were twenty-three comments (english: 17, french: 6) in response to question 14, “if you were participating in an online support system, what kind of resources would you like to see?” We felt that this question was important, as online therapy and support systems are becoming increasingly popular. Of these comments, eight mentioned that 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 somewhere that they could find outlets for stress and support for their mental health. Specificity in demographic, including age, gender, and cancer type, were mentioned four times.

Question 15: “how would you describe your feelings throughout or after your cancer experience? Are these emotions ongoing, recurring, or occasional?”

English survey: answered: 23, skipped: 5

French survey: answered: 16, skipped: 3

There were thirty-nine comments (english: 23, french: 16) in response to question 15, “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, and hope.



Question 16: “are there any other comments you would like to make about your cancer experience, and the affect it has had on your and/or your family’s mental health?”

English survey: answered: 17, skipped: 11

French survey: answered: 13, skipped: 6

There were thirty comments (english: 17, french: 13) in response to question 16, “are there any other comments you would like to make about your cancer experience, and the affect it has had on your 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 cancer diagnosis. Notably, the latter six comments were all made on the french survey. 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.

Conclusions

Several conclusions may be drawn from the results of this survey. The first, which may be derived from question 1, is that the majority of patients seek emotional support during their cancer journey (english: 66%, french: 84.21%). Of the patients who were unable to receive this emotional support, the results for question 4 suggests that a large population of them wished that they were able to do so (english: 62.50%, french: 93.75%). The need for emotional support appears to be present and is not entirely satisfied, especially in the french-speaking provinces.

In the english survey, 35.71% attributed their not receiving emotional support to a lack of interest, or not realizing any was available. A majority of french survey participants (62.50%) did not receive therapy due to financial difficulties. 70.59% of french survey participants did not feel that support was available in their location, while 32% of english survey participants felt the same way. This may be related to the fact that only 35.29% of french survey participants feel that support was provided to them by their cancer centres, while 70.83% of english survey participants felt that it was. A similar percentage across both surveys (english: 60%, french: 64.71%) reported that their insurance providers covered therapy costs. Despite the relatively equal insurance coverage and presumably equal opportunities for therapy, these percentages suggest that the ways mental health assistance is advertised could be improved, especially in the french-speaking provinces.



The responses to question 9 suggest that emotional support is seen to be of relatively equal importance at every stage: after diagnosis, during treatment, and once their treatments have finished. Furthermore, question 5 suggests that survivorship is a subject survey participants wanted to address in their emotional therapy practices (english: 76.19%, french: 52.63%). This upholds the growing importance for addressing the needs of melanoma survivors, or those who have finished treatments, as this population continues to grow.

While a relatively small number of survey participants reported seeking counselling in a family setting (english: 18.52%, french: 27.78%), or that any of their family members sought emotional support (english: 26.92%, french: 21.05%), many of the comments on question 16 (“are there any other comments you would like to make about your cancer experience, and the affect it has had on your and/or your family’s mental health?”) mentioned negative changes to the family dynamic, and the importance of being honest about your experience with your family. These results suggest that a heavier emphasis could be placed on the family unit in the therapy setting, and that cancer patients should be encouraged to attend family counselling.

Save Your Skin Foundation appreciates the time and efforts of those who participated in these surveys, and all who have read this report. We hope that this information highlights areas in the emotional support provided to melanoma patients, and cancer patients more generally, that could be improved. Together, we can lessen the burden of those recently diagnosed with melanoma, those undergoing treatment, and survivors.

Works Cited

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.