Exploring the melanoma survivorship experience: a qualitative study

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Dear Editor,

Cutaneous melanomas are the fifth most common cancer in the United States and the United Kingdom, with a 5-year relative survival of 87–93%.\textsuperscript{1,2} Targeted and immune checkpoint therapies have further expanded the number of advanced melanoma survivors. Cancer survivorship recommendations have been published by Macmillan Cancer Support; yet programs for melanoma survivors in the US are still in their infancy.\textsuperscript{3} We aimed to explore experiences and challenges that US patients diagnosed with melanoma experienced in a tertiary cancer centre using in-depth interviews.

This study was approved by the Emory University Institutional Review Board. We interviewed 30 patients equally distributed between Stage I-II and Stage III-IV melanoma. Patients were consecutively enrolled from pigmented lesion and medical oncology clinics at the Emory Clinic and Winship Cancer Institute, a tertiary referral centre. Research was conducted from 12/9/2019 to 2/26/2020. Eligible patients had a histologically confirmed diagnosis of cutaneous melanoma and completed either surgical treatment with no plans of initiating systemic treatment or at least 12 months of systemic treatment with no evidence of residual disease or stable disease. Exclusion criteria were age below 18 years and impaired decision-making capacity. A semi-structured interview guide was developed to characterize physical, psychosocial, practical, spiritual, communication, and information needs in melanoma survivors based on literature review. The guide was further refined with interview simulations (Z.W. and S.R.) and pilot interviews (N.F.). Interviews were conducted in clinic and over telephone and ranged from 10 to 33 minutes (Z.W. and N.F.). Data collection was stopped when data saturation was reached. A qualitative content analysis approach was used to develop the codebook. Each interview was transcribed verbatim from audio recordings and coded independently by 2 researchers (Z.W. and N.F); discrepancy in coding was jointly reviewed and consensus was reached by discussion. Codes were organized into relevant...
themes and subthemes. Qualitative analyses were performed using MAXQDA, version 20.0 (VERBI GmbH). Consolidated criteria for reporting qualitative research guidelines were followed.4

Among 30 interviewees, 14 (47%) were female. Thirteen (43%) patients had Stage IA, 1 (3%) had Stage IB, 1 (3%) had Stage IIA, 5 (17%) had Stage III, and 10 (33%) had Stage IV melanoma. Themes surrounding physical, psychosocial, practical, spiritual, and information challenges were identified (Table 1). Some participants reported significant stress, sometimes characterized as traumatic, surrounding the initial diagnosis and diagnostic or prognostic tests. Most but not all participants report decreased stress over the long term. When a patient was first diagnosed with melanoma, participants would have liked educational resources such as a pamphlet with commonly asked questions or a list of recommended online resources.

Beyond the initial diagnosis, there were also long-term physical, behavioural, and emotional impacts. Limitations in physical activity appeared particularly important. Participants restricted or completely stopped outdoor activities they had enjoyed to avoid ultraviolet radiation. Others noted surgical complications or immunotherapy side-effects limiting their day-to-day function. The reliance on others eroded their sense of independence. Patients also cited the uncertainty surrounding appointments with their physicians as a significant source of stress but ultimately found providers and staff to be reassuring. Spirituality and a spiritual community were identified as important pillars of support in addition to their family and providers. Furthermore, labels such as “cancer survivor,” or medical history questions could be stigmatizing. Finally, participants were interested in virtual care to expeditiously address new lesions of concern, answer questions, and as an educational resource.

Quality of life for melanoma patients can be most affected at initial diagnosis, highlighting the importance of early intervention and early enrolment of patients in a survivorship program.5 In addition to counselling, patients desired additional resources about their diagnosis or treatment options. Electronic or hard copy educational material continue to provide value.6 Survivorship programs or institutions can curate a list of approved resources to provide to patients. Patients on immunotherapy can have impaired physical function from treatment complications7 or from ultraviolet radiation avoidance. A focus on personalized physical therapy and photoprotection would be an important resource in survivorship programs to preserve and regain physical function. Psychoeducational intervention helped to reduce the impact of fear of cancer recurrence in melanoma patients.8 We found that the unknowns surrounding upcoming appointments or test results are sources of significant stress and anxiety for patients. This should be accounted for in the design of psychoeducation interventions in survivorship programs. Deeper understanding of melanoma survivors’ experiences can inform the development of survivorship programs and patient care.

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References


### Table 1

Core themes surrounding diagnosis and treatment of melanoma

<table>
<thead>
<tr>
<th>Theme</th>
<th>Selected quotations</th>
</tr>
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<tbody>
<tr>
<td>Status quo</td>
<td>It [melanoma] was a, even now, well now it is not a big deal. I come once a year, or before that it was not that long ago. It was every six months … And you know, since I was fortunate, the results were, constantly improving … (Stage IV. Participant 02).</td>
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<tr>
<td>Patient Education</td>
<td>Being more informed if I had had access to more reading material. Perhaps that would have helped … If we had a library of, here is the situation, here is the cycle of what is going to happen. Here are the implications. Those kinds of things. (Stage IV. Participant 09).</td>
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<tr>
<td>Virtual methods</td>
<td>And then these little stupid age spots pop up because we've damaged our skin in the sun. And then, you know, then you get nervous. So that would be of interest if they could work it out … to submit … pictures or have it, you know, more education online. (Stage IIIA. Participant 11).</td>
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<td>Physical Activity</td>
<td>But truthfully as a result of the melanoma, I really don’t like the sun … I almost quit playing tennis outside because of my melanoma. (Stage IA. Patient 29).</td>
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<td>Uncertainty</td>
<td>You are so on edge when you come to the doctor here if you have cancer, active cancer, or even if you don’t because you’re waiting for that shoe to drop. (Stage IV. Participant 01).</td>
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<tr>
<td>Stigma</td>
<td>I am a ‘cancer survivor,’ I am a ‘this survivor,’ and I think that creates … artificial expectations on the part of the patient, you’re never cancer free. (Stage IV. Participant 01).</td>
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<td>Spirituality</td>
<td>… I turned to some elders in the church and other friends who I could count on to pray for me … (Stage IA. Participant 21).</td>
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