

# Experiences of resuming life after immunotherapy and associated survivorship care needs: a qualitative study among patients with metastatic melanoma\*

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## Abstract

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**Background** Immune checkpoint inhibitors (ICIs) have significantly improved the overall survival of patients with metastatic melanoma. It is unclear how the growing group of metastatic melanoma survivors resume their lives after treatment, and which needs they have regarding survivorship care (SSC).

**Objectives** To gain an in-depth understanding of metastatic melanoma survivors' experiences of resuming life after ICIs and their associated SSC needs.

**Methods** A qualitative study was conducted among 20 patients with metastatic melanoma in whom ICIs had been discontinued after ongoing tumour response. One focus group (n = 9) was held, which was complemented by 11 individual interviews. Purposive sampling was used to select a variable sample in terms of sex, age, time since discontinuation of ICIs, and perceived impact of the disease. A topic guide was used to structure the (group) interviews, which were transcribed verbatim and analysed in a thematic content analysis, using several phases of coding.

**Results** In resuming life after ICIs, the prognosis switch often caused mixed feelings among patients, mainly because of the uncertainty about the future. Demands and expectations from self and others, persistent complaints and new problems in different life domains often make it challenging to proceed with life as it was prior to metastatic cancer. Patients indicated they needed to find a new balance, which included learning to cope with uncertainty and a changed perspective on life and close relationships. In terms of SSC needs, patients particularly stressed the need for more tailored patient information, available at one location. In addition, they emphasized the need to know who to turn to in case of questions and indicated the need for psychosocial support, also for their close relatives.

**Conclusions** Metastatic melanoma survivors face various challenges in resuming life after ICIs and are left with several unmet SSC needs. Efforts should be focused on offering psychosocial supportive care in addition to medical care, from diagnosis onwards, taking into account the patient's close relatives. A single point of contact and personalized survivorship care plan (SCP) could be of added value in guiding them through the patient journey, which is, given its multidisciplinary nature, particularly important in melanoma care.

**What is already known about this topic?**

- Since the introduction of immune checkpoint inhibitors (ICIs) the overall survival of patients with metastatic melanoma has improved significantly, leading to a growing group of melanoma survivors.
- Melanoma survivors may face various problems and challenges in resuming life after treatment, which may be associated with unmet survivorship care (SSC) needs.
- An in-depth understanding of their experiences with resuming life and the associated SSC needs is currently lacking.

**What does this study add?**

- Metastatic melanoma survivors experience various challenges after immunotherapy, from the uncertain prognosis switch to the struggle of finding a new balance in life.
- Besides negative aspects, such as complaints in different life domains, the patient journey is often accompanied by positive outcomes, for example a changed perspective on life.
- They stress the need for tailored patient information and broader supportive care, also for their close relatives.

**What are the clinical implications of this work?**

- In addition to medical care, efforts should be focused on offering psychosocial supportive care, including return-to-work issues, from diagnosis onwards, ideally taking into account the patient's close relatives.
- To guide them through the patient journey, a single point of contact and a personalized survivorship care plan (SCP) could be of added value.
- The latter is particularly important in melanoma care, given its multidisciplinary nature.

Worldwide, nearly 300 000 patients are newly diagnosed with cutaneous melanoma each year.<sup>1</sup> In metastatic melanoma, multiple advances in treatment options have led to improved overall survival, especially immune checkpoint inhibitors (ICIs).<sup>2–5</sup> Consequently, ICIs have converted a historically incurable cancer with a very poor prognosis into a potentially curable disease.<sup>6</sup>

Therefore, an increasing number of patients with metastatic melanoma face the challenge of resuming life after successful treatment, which is potentially associated with severe and long-term consequences of treatment-related adverse events.<sup>7</sup> Research among patients with other types of cancer has shown that returning to normal life after treatment may be difficult; they may face persistent or recurring physical symptoms, as well as emotional, psychosocial and work-related complaints.<sup>8–11</sup> Moreover, the often unexpected switch in prognosis (i.e. expected death vs. recovery) could be difficult to cope with.<sup>12</sup>

To deal with the challenges and long-term consequences of both disease and treatment, the American Institute of Medicine recommends providing survivorship care (SSC) to all cancer survivors after completing primary treatment.<sup>13</sup> SSC aims at informing and supporting patients, ensuring access to effective interventions and improving their quality of life.<sup>13,14</sup> While research on SSC among melanoma survivors – in this study

defined as patients with metastatic melanoma with durable tumour responses following treatment with ICIs – is still lacking, research in other types of metastatic and nonmetastatic cancer has shown that patients are often left with numerous unmet needs when it comes to SSC.<sup>15,16</sup>

Previous quantitative studies among patients with melanoma have shown they may also face physical and emotional problems after treatment,<sup>17,18</sup> and a first qualitative exploration of experiences of patients who have recovered from stage I–IV melanoma showed multiple challenges.<sup>19</sup> However, qualitative in-depth research focusing on this topic is currently lacking. Therefore, the aim of this study was to gain an in-depth understanding of metastatic melanoma survivors' experiences of resuming life after ICIs, and their associated SSC needs.

**Patients and methods****Study design and methodological considerations**

A qualitative design was considered most suitable to gain an in-depth understanding of patients' experiences and needs.<sup>20,21</sup> We initially planned to organize focus groups because of the expected positive effect of group interaction.<sup>22</sup> However, due to the COVID-19 pandemic, which started after

the first focus group, we decided to organize additional individual interviews by telephone. The main strength of interviews over focus groups is the closer setting, in which it is acceptable to ask relatively personal questions.<sup>23</sup>

The reporting of this study followed the Standards for Reporting Qualitative Research.<sup>24</sup> The medical ethics committee of Erasmus MC concluded after review of the study design that the rules laid down in the Medical Research Involving Human Subjects Act (Dutch abbreviation: WMO) did not apply to this study (MEC-2019-0558 and MEC-2020-0197).

### Selection of participants

Eligible participants for (group) interviews were patients diagnosed with stage IV melanoma, who achieved a tumour response to treatment with ICIs at the Erasmus MC in Rotterdam, the Netherlands. A purposive sampling method was used,<sup>25,26</sup> striving for a variable sample in terms of sex, age and time since discontinuation of treatment. Potential participants received an invitation letter and informational leaflet with further details about the study and how to participate by contacting the researchers. All patients signed an informed consent form. Focus group and interview participants were respectively offered a €40 or €25 voucher as incentive. Eventually, nine patients participated in the focus group. After 11 additional interviews, saturation was reached and recruitment of patients ended (see Data analysis).

### Data collection

Prior to the (group) interviews, all participants completed a short self-administered questionnaire to collect demographic information. The face-to-face focus group was held at the Erasmus MC, Rotterdam, and took approximately 120 minutes; the interviews lasted 50–80 minutes. The focus group was led by two experienced focus group moderators (M.L., psychologist, female, age 41; and M.C.W.J., health scientist, female, age 38) and the individual semistructured interviews were conducted by a researcher (N.C.W.K., medical doctor, female, age 25), none of whom were directly involved in the care of patients with melanoma. To structure the focus group discussion, a topic guide was used based on relevant literature<sup>27–29</sup> and the experiences of the research team (Appendix S1; see Supporting Information). Three main topics were addressed: impact of disease and treatment, experiences with discontinuation of treatment and resuming life, and SSC experiences and needs. For the interviews, a topic guide based on the focus group was used. Adjustments to the interview guide were made after analysing the first four interviews, to put more emphasis on the switch in prognosis. All (group) interviews were audiotaped.

### Data analysis

All recordings were transcribed verbatim in anonymized form and analysed using NVivo version 12 (QSR International, Doncaster, Australia). A thorough thematic content analysis was

performed, using elements from grounded theory (i.e. several phases of coding, constant comparison and sampling until saturation),<sup>30–33</sup> embedded in a constructivist methodology.<sup>34</sup>

Analysis started with (re)reading and summarizing the interviews.<sup>31</sup> Subsequently, four transcripts were openly coded by one researcher (N.C.W.K.) and were checked and complemented by a second (M.L.), resulting in a preliminary unstructured list of open codes. In the second phase of axial coding, relations between codes were identified and categories and subcategories were created by one researcher (N.C.W.K.). The resulting hierarchical coding scheme was discussed with a second researcher (M.L.). The remaining eight interviews were axially coded by two researchers (N.C.W.K. and a medical student), using this coding scheme, and were checked by a third (M.L. or a medical student). During this process, the coding scheme was constantly refined. Data saturation was reached when no new (sub)categories were identified,<sup>35</sup> which occurred after one focus group and 10 interviews. In the last phase of selective coding, links were established between the categories, and main themes and subthemes were identified.<sup>32</sup> These were further refined in discussions within the multidisciplinary research team (N.C.W.K., M.L., A.A.M.V. and K.J.). Throughout the whole process, constant comparison was applied by comparing each interpretation and finding with new data.<sup>33</sup> A draft version of the results was reviewed and approved by one of the patients.

## Results

The patients' characteristics are displayed in Table 1.

The analysis resulted in five main themes and 12 subthemes (Table 2). These are discussed below, all from the patient's perspective.

### Dealing with a switch in prognosis

The first main theme identified was 'dealing with a switch in prognosis', which was subdivided into two subthemes. Illustrative quotes are presented in Table 3.

#### Mixed feelings and emotions regarding prognosis switch

The mostly unexpected switch in prognosis evoked various feelings and thoughts among patients. Patients indicated being grateful for the immunotherapy and for still being alive. Being able to go places they thought they would never see again was sometimes experienced as very emotional.

However, some patients indicated having difficulties understanding and/or believing their improved prognosis, which was therefore experienced as difficult to enjoy. Some even felt angry, feeling misinformed by their doctor; they were going to die, and suddenly everything turned out to be all right again. However, other patients had never been aware of being in a palliative course. They stated that their doctor – and therefore also the patient – had confidence in the efficacy of immunotherapy, causing the positive prognosis not to be perceived as a switch.

Table 1 Participants' characteristics

Participant	Sex	Age (years)	Performance status <sup>a,b</sup>	LDH <sup>a</sup>	Brain metastases <sup>a</sup>	Treatment	Start of ICIs (year)	Best tumour response <sup>c</sup>	Treatment duration of ICIs (months)	Reason for discontinuation of ICIs
Interview participants										
1	F	32	WHO 0	125	No	Nivolumab	2018	PR	6	OR
2	M	78	WHO 0	206	Unknown	Nivolumab	2017	PR	20	OR
3	F	45	WHO 0	345	Unknown	Pembrolizumab	2016	CR	7	OR
4	M	72	WHO 0	228	Unknown	Pembrolizumab	2016	PR	16	OR
5	F	38	WHO 0	147	Unknown	Nivolumab	2018	PR	5	AE, OR
6	F	61	WHO 0	151	No	Nivolumab	2017	CR	3	AE, OR
7	F	59	WHO 1	440	Yes	Nivolumab	2019	PR	5	OR
8	M	48	WHO 2	278	Yes	Ipilimumab, nivolumab	2019	PR	–	–
9	M	51	WHO 1	1197	No	Ipilimumab, nivolumab	2018	PR	24	OR
10	F	40	WHO 1	771	Yes	Ipilimumab, nivolumab	2020	PR	–	–
11	M	43	WHO 0	184	Unknown	Nivolumab	2016	CR	12	OR
Focus group participants										
12	F	50	WHO 0	147	Yes	Pembrolizumab	2014	CR	24	OR
13	M	46	WHO 0	158	No	Nivolumab	2017	CR	12	OR
14	F	51	WHO 0	148	No	Nivolumab	2018	PR	6	AE, OR
15	M	37	WHO 0	220	Yes	Ipilimumab, nivolumab	2017	PR	24	OR
16	M	56	WHO 0	187	Unknown	Nivolumab	2017	CR	12	OR
17	M	53	WHO 0	221	Unknown	Pembrolizumab	2016	CR	24	OR
18	F	42	WHO 0	200	Unknown	Pembrolizumab	2016	CR	24	OR
19	M	83	WHO 0	332	Unknown	Nivolumab	2016	PR	12	AE, OR
20	M	52	WHO 1	264	No	Ipilimumab, nivolumab	2018	PR	2	AE, OR

AE, adverse event; CR, complete response; F, female; ICI, immune checkpoint inhibitor; LDH, lactate dehydrogenase in U L<sup>-1</sup>; M, male; OR, ongoing tumour response; PR, partial response. <sup>a</sup>At the start of ICIs. <sup>b</sup>Assessed using World Health Organization Performance Status criteria. <sup>c</sup>According to the Response Evaluation In Solid Tumors (RECIST) 1.1 criteria.<sup>57</sup>

### Facing an uncertain future

Although patients generally appreciated their life extension, the uncertain future was considered difficult to face. This uncertainty, how they would come through and the realization that they could still die of the disease, often caused chronic stress among patients. This was also fed by the loss of trust in their body, which they had developed since the (unexpected) diagnosis of metastatic melanoma. Some never expected, or even knew, melanoma could have such an impact on their entire body. Sometimes, these uncertainties led to a (constant) fear of recurrence and also fear of dying. Patients claimed their uncertain future was not always well understood by close relatives, as they, according to the patients, did not understand the risk of disease recurrence or progression and expected them to be cured and healthy, and act accordingly.

### Challenges to proceed with life as prior to metastatic cancer

The second main theme identified concerned 'challenges to proceed with life as prior to metastatic cancer', reflected

in two subthemes. Illustrative quotes are presented in Table 4.

### Demands and expectations to resume life again

Patients indicated that life started to ask a lot of them again and they had to deal with often very high demands in several life domains. While trying to get their own lives back on track, they could not focus only on themselves but also needed to focus on their families again. For example, their children were growing up and needed guidance and some felt they needed to fight for their marriage again.

Furthermore, patients indicated that they considered themselves cured, making (too) high demands on themselves, while also having to deal with expectations of others. On the one hand, they felt others expected too much of them and assumed the patients would proceed with their lives as before, because they considered them 'cured'. On the other hand, low expectations were felt while being declared (partly) unfit for work by the Public Employee Insurance Agency (PEIA) and when colleagues were surprised they were already back at work, as they had not expected to see them again so soon.

Table 2 Overview of themes on experiences and needs of survivorship care

Main themes	Subthemes	Categories
1 Dealing with a switch in prognosis	1.1 Mixed feelings and emotions regarding prognosis switch	Feelings of gratitude Difficult to understand and/or believe Feelings of anger
	1.2 Facing an uncertain future	Stress caused by uncertain future Loss of trust in body Fear of recurrence and dying Lack of understanding by close relatives
2 Challenges to proceed with life as prior to metastatic cancer	2.1 Demands and expectations to resume life again	High demands in several life domains High expectations of oneself Assumptions about being 'cured' by surroundings
	2.2 Persistent complaints and new problems in different life domains	Persistent physical and psychological complaints Late effects of treatment Issues in returning to work Negative influence on social life Problems felt by close relatives
3 Finding a new balance	3.1 Coping with uncertainty	Concerns about living with limitations Trust in body needs to be regained Staying hopeful and optimistic
	3.2 Changed perspective on life, re-evaluation of close relationships and changed personality	Enjoy life more fully Stronger connection with religion Re-evaluating the importance of close relationships Friendlier and less worried about little things in life More easily irritated
	3.3 Towards no longer being a patient	Not knowing who you are Continued feeling of being a patient Being 'the one with cancer'
4 Needs regarding (medical) information and care	4.1 Need for tailored patient information, available at one location	Information tailored to individual's situation Information tailored to individual's needs Information in understandable language
	4.2 Need for periodic and additionally flexible follow-up	Periodic follow-up checks provide reassurance Additional flexible follow-up when needed
5 Falling between two stools: need for broader supportive care	5.1 Need to know where to go and whom to turn to	Information about available care options Information about whom to turn to with questions and problems
	5.2 Need for psychosocial support	Practical and personal information Psychological information and support Access to peer support Work-related information and support
	5.3 Need for support for close relatives	Support in dealing with consequences of disease

### Persistent complaints and new problems in different life domains

Patients experienced a range of negative outcomes after discontinuation of treatment. Firstly, persistent complaints and late adverse events, such as persistent fatigue, itching and concentration problems, were experienced as burdensome. For example, patients experiencing vitiligo mentioned their altered appearance as difficult to accept. They sometimes did not recognize themselves in the mirror, nor did other people. Furthermore, psychological complaints – not being able to enjoy their positive prognosis, uncertainty and fear of recurrence – hampered patients' lives.

These complaints often made it challenging to resume their lives, which was manifested in problems in various life

domains. This was especially so for work and return to work: while some could resume their work as before, others experienced return to work as more challenging. While they generally received understanding from both their employer and colleagues, they noticed that the word 'cancer' in their files resulted in problems with the PEIA: they had been declared (partly) unfit for work, which would limit their ability to work at the same level as before, and also complicate finding a new job.

In line with this, patients sometimes felt a negative influence on their social lives too. They had lost friends during this process, who, according to patients, could not handle the pain and consequences of the disease, which made them feel sad and made them re-evaluate friendships (see also Subtheme 3.2). Furthermore, patients indicated sometimes skipping

Table 3 Dealing with a switch in prognosis

Subthemes	Quotes
1.1 Mixed feelings and emotions regarding prognosis switch	'Well, first you're told that you might make it to Christmas this year. Then a month later, you're told you might survive 10 or 15 years. I just can't understand it. That's what's on my mind these days...that I uh, cannot understand that I'll live longer. I don't understand. I can't have fun anymore.' – Individual interview, male, 48 (patient 8)
1.2 Facing an uncertain future	When I feel pain or something...I'll think oh no, it better not be...and it'll stay that way for a while, but that's something I hear from all people who have had cancer. With every pain you think, oh no, it's not back, is it? And yeah, I can relate, that that's the way you think. – Individual interview, female, 59 (patient 7)

Table 4 Challenges to proceed with life as prior to metastatic cancer

Subthemes	Quotes
2.1 Demands and expectations to resume life again	'Life demands so much of you again. Your children grow up and need guidance. And, marriage isn't as easy as you would like and yeah, you just have to move on. You have to fight for yourself again, and for your family, and your marriage, and you can no longer think only of yourself. You just can't.' – Individual interview, female, 45 (patient 3)
2.2 Persistent complaints and new problems in different life domains	'Well, dramatic. They [PEIA] see the file, "cancer"; yep, you're declared unfit for work.' – Focus group, male, 53 (patient 17)

PEIA, Public Employee Insurance Agency.

social activities (like birthdays) to avoid having to talk about their disease all the time.

Finally, patients indicated that their partners and close relatives sometimes faced problems too as they also had to deal with the impairments of the patient and associated uncertainty. Furthermore, partners often take care of the patient at home and accompany them to all appointments, and therefore sometimes have to cut back or stop working for a while too. As such, it sometimes felt that not only the patient but the whole family was sick.

Nevertheless, some patients indicated their life was back to normal, which they experienced as pleasant. They had resumed their work and were, for example, able to play sports at the same level as before the onset of their disease.

### Finding a new balance

The third main theme identified was 'finding a new balance', which was reflected in three subthemes. Illustrative quotes are presented in Table 5.

#### Coping with uncertainty

In finding a new balance, patients often find it hard to cope with uncertainty. They, especially the younger patients, worried about having to deal with the experienced impairments for the rest of their lives. Patients felt like their bodies had abandoned them and were having trouble with being on their own again, without immunotherapy. They first needed to regain trust in their body, a process that takes time and is, according to patients, facilitated by receiving increasingly good results at checkups.

However, feelings of hope were also felt, and for some this was the main focus. They indicated staying optimistic and only focusing on things they can control, such as paying better attention to their bodies and seeking help sooner when having concerns about their health. Furthermore, they indicated living in the moment rather than thinking about the future, also because they did not yet dare to make plans for their future.

Table 5 Finding a new balance

Subthemes	Quotes
3.1 Coping with uncertainty	'You have to start trusting your own body again. Because, it's gone wrong so many times, in the beginning it's like, oh I feel something, if I still feel it tomorrow, then I have to call someone. Things like that. There's no safety line anymore. Suddenly you're on your own again. It's quite strange.' – Individual interview, female, 38 (patient 5)
3.2 Changed perspective on life, reevaluation of close relationships and changed personality	'You enjoy completely different things! I started to walk a lot and sometimes it happens it suddenly starts to rain. I used to hate walking and now I walk in the rain while smiling.' – Individual interview, male, 51 (patient 9)
3.3 Towards no longer being a patient	'When it comes to cancer, I don't feel like a patient anymore because I'm no longer receiving treatments. Except for the day I have to get a [computed tomography] scan. Then I think yes, that was because of the cancer, and then the next week when I visit the oncologist. Yes, I WAS a cancer patient. That's how I think about it at the moment.' – Individual interview, female, 59 (patient 7)

## Changed perspective on life, re-evaluation of close relationships and changed personality

Patients explained that the disease often changed their perspective on life. They now deal with life more consciously, undertake more activities and try to enjoy life more fully. Patients mentioned having learned about the transience of things, and the vulnerability of people. They can put things into perspective more easily and enjoy the little things more. New religious beliefs, or starting to think there must be something more after death, were also mentioned. For those already having a religion, this connection grew stronger and they felt more strengthened by their faith.

With respect to patients' social lives, everything they had been through made them re-evaluate the importance of the people around them. Although some friends were lost, other connections, especially those who stood by them during their treatment, were strengthened, leading to a higher appreciation of close relationships.

Also, the personality of some patients changed. Some became friendlier and mentioned they were less likely to worry about minor matters. Conversely, others felt more easily irritated and less able to tolerate stimuli. For some, their personality changed so drastically they no longer knew who they were, which made it even harder for them to proceed with life as before.

## Towards no longer being a patient

Discontinuation of treatment was generally the moment the perception of being a patient stopped. In contrast, the persistence of complaints and prescribed medication caused them to continue to feel like a patient. In particular, being back in the hospital for a checkup was mentioned as a moment when this feeling returned or was accentuated. Other patients mentioned that the reaction of and stigmatization by people around them prolonged this feeling. To them, they remain 'the one with cancer', which hinders them in their daily activities, for instance by avoiding social activities in order not to be patronized (see also Subtheme 2.2).

## Needs regarding (medical) information and care

The fourth main theme identified concerned 'needs regarding (medical) information and care', reflected in two subthemes, of which illustrative quotes are presented in Table 6.

### Need for tailored patient information, available at one location

Patients expressed the need for tailored information, preferably all available at the same location, for instance a (digital) file. Instead of receiving general information, they indicated preferring information that specifically applies to their (medical) situation, adjusted to their individual needs. According to patients, information needs differ among

Table 6 Survivorship care needs

Subthemes	Quotes
4.1 Need for tailored patient information, available at one location	'I'd like the information to be provided from my – the patients' – perspective. Sometimes it can be too clinical from the doctors' perspective.' – Individual interview, female, 38 (patient 5)
4.2 Need for periodic and additionally flexible follow-up	'Every three months, that's fine by me. That is, yes, I might think in the future when they say come back in six months' time, that six months might be too long. But, of course, there's also a certain trust that you have to rebuild within yourself.' – Individual interview, male, 51 (patient 9)
5.1 Need to know where to go and whom to turn to (contact person)	'Well, I think when I look at myself, because for me the survivorship care has not always been optimal. But then I went looking for information myself. I wish there would be something where, if you do have issues with nutrition for example, where you could just find solutions for these problems.' – Individual interview, female, 38 (patient 5)
5.2 Need for psychosocial support	'Yes, I think. . .yes, I think that um. . .psychologist, that's an important one with survivorship care, knowing myself (laughs), or at least, someone you can talk to. I know that in difficult situations, or just. . .uh. . .yes, I just carry on and everything goes well, and then afterwards, when the stress subsides, so to speak, when everything is resolved and in a calm state of affairs, only then do the emotions surface with me. Then it hits me.' – Individual interview, female, 40 (patient 10)
5.3 Need for support for close relatives	Patient: 'Your family also needs help.' Interviewer: 'Okay, you're saying that the family should be offered help as well?' Patient: 'Yes, my husband got no explanation and every time people asked him "How is your wife?". Not once: "How are you?".' – Focus group, female, 42 (patient 18)

patients, as both coping mechanisms and patient journeys (i.e. disease trajectories) differ. Moreover, patients claimed that information was often given on a doctors' level of education, whereas they preferred doctors to take the patient's perspective.

### Need for periodic and additionally flexible follow-up

During this rather uncertain period, patients often experienced periodic follow-up checks as reassuring. However, at the same

time, they were often experienced as very stressful. Whereas patients were overall satisfied with the current frequency of the checkups, some questioned whether it was being reduced too quickly. Being able to adjust the frequency to individual needs would be experienced as pleasant.

### Falling between two stools: need for broader supportive care

The last main theme concerned 'Falling between two stools: need for broader supportive care', which was reflected in three subthemes, with illustrative quotes presented in Table 6.

#### Need to know where to go and whom to turn to

According to patients, the fact that they initially were expected to die, and SSC being mainly medically oriented, resulted in a so-called 'SSC gap'. As patients currently often do not know where to go and what their options are in case of questions and complaints, they considered a referral guide throughout their whole disease trajectory as potentially useful, but especially after completion of immunotherapy. Having these options during this uncertain period would feel comforting and reassuring.

#### Need for psychosocial support

Although the received medical care was generally experienced as good and sufficient, some, especially those who suffered the most, expressed the need for (getting the option of) psychosocial information and support before, during and after treatment. This includes personal and practical information (i.e. direct contact numbers and appointment reminders) as well as psychological information and support (i.e. more attention to the possible mental impact). Patients also stated that they would benefit from hearing or reading stories of other patients or from peer contact, to learn from the situation of others and compare it with their own. Furthermore, they stressed the need for more work-related information and support, such as explanations of their diagnosis and therapy for their employers and more attention to their (dis)ability to work.

#### Need for support for close relatives

Finally, patients believed that besides support for themselves, their close relatives (i.e. partners and other family members) should be offered support too, as they often also have a hard time dealing with the consequences of the patient's disease. Currently, the patients' wellbeing is constantly being evaluated, but their close relatives are being overlooked.

## Discussion

This in-depth qualitative study shows that metastatic melanoma survivors experience various challenges in resuming life

after treatment with ICIs, from the experienced uncertain switch in prognosis to the continued struggle of finding a new balance in life. These experiences are translated into several unmet SSC needs along the patient journey.

The identified challenges extend the complaints (e.g. fatigue, depression) commonly reported in quantitative quality-of-life studies.<sup>8,9,36,37</sup> Despite the favourable switch in prognosis, patients experienced difficulties dealing with this, mainly because of their uncertain future. This is in line with previous research showing that patients with cancer often experience difficulties and uncertainties with their generally unexpected changed prognosis.<sup>12</sup> Uncertainty is a common theme for these patients during the whole patient journey<sup>38–41</sup> and is hence important to focus on in SSC.

Another important finding is that melanoma survivors, trying to resume life, often experience too high demands and expectations from themselves and others. Patients indicated that melanoma is often seen as 'just a mole'. This may be related to their often healthy outward appearance until late in the course of illness, whereby the severity and thereby the impact of melanoma, or skin cancer in general, may often be underestimated. Besides persistent complaints, patients reported experiencing new problems in various life domains, among which work-related problems in particular made resuming life challenging. In line with this, previous studies showed that cancer survivors have a higher risk of loss of paid employment,<sup>42,43</sup> especially those with a more advanced cancer stage.<sup>42</sup> As being partly or fully work disabled increases the risk of impaired cognitive functioning,<sup>44</sup> it is important to pay more attention to (support in) return to work.

In this era of patient-centred care,<sup>45,46</sup> offering adequate, tailored SSC to patients should be the standard of care.<sup>13</sup> In the current study patients were generally satisfied with their medical care and experienced follow-up as a core component to alleviate fear and uncertainty. However, they expressed several unmet SSC needs, for instance the need to know who to contact in case of questions and complaints. In multidisciplinary melanoma care (often divided over multiple centres because of the centralization of immunotherapy in the Netherlands), a single point of contact for patients, for example support of a nurse specialist, could be of added value. Patients also emphasized the importance of tailoring information to their specific situation and needs, and indicated this would preferably be available at one location. To guide patients through the patient journey, by providing them with the right information, a SCP could also be a solution. SCPs are care plans for cancer survivors, consisting of critical information needed for the survivors' long-term care, ensuring survivors receive appropriate SSC as recommended by the Institute of Medicine.<sup>13</sup> Although the use of SCPs has been recommended for a long time,<sup>13</sup> there are signs that implementation in practice is low.<sup>47</sup> Our results indicate that melanoma survivors consider SCPs useful and provide directions on how to design tailored SCPs.

Moreover, patients stressed the need for a wider offer of psychosocial care, in addition to medical care. This need



includes psychological support, and also the previously mentioned work-related information and support. According to patients, psychological information and support should be offered from the initial diagnosis onwards and should include both themselves and their close relatives.<sup>48</sup> Patients in our study considered peer support a valuable type of psychosocial support, and previous research has shown it could improve patients' psychological empowerment (e.g. increased self-efficacy and positive coping)<sup>49</sup> and enable social reintegration<sup>50</sup> and return to work.<sup>51</sup> Current melanoma SSC does not include psychosocial supportive care and is mainly medically oriented. This is in contrast to the large amount of SSC offered to people who have had other cancers (e.g. breast, colorectal, metastatic testicular, and adolescent and young adult cancer), for whom numerous forms of SSC exist, which also focus on the patients' families.<sup>52,53</sup>

Our conclusions should be interpreted in the light of several limitations. Firstly, as this was a regional project, patients were included from only one academic hospital treating patients within this region. By choosing patients with varying characteristics relevant to this topic, to which we added cases until we reached saturation, we aimed to reach a sample with maximum variation. Moreover, as the organization of melanoma care is comparable throughout the Netherlands, we assume that themes will be similar outside our region. Even though cultural differences may play a role, it is likely that most of the identified themes will also be applicable outside the Netherlands and perhaps worldwide. Secondly, we focused only on patients in whom ICIs had been discontinued after ongoing tumour response. We chose this specific patient group as we were interested in describing the challenges faced in resuming life after treatment, for which a tumour response is, of course, necessary. Nevertheless, we found that SSC needs already arise at diagnosis. Thus, exploring the experiences and needs of patients without treatment response and earlier in the treatment process would yield valuable additional information for designing optimal patient-centred melanoma SSC.

Due to the COVID-19 pandemic, we chose to move from face-to-face focus groups to individual telephone interviews. Although this prevented us from being able to see patients' nonverbal reactions and body language, and they were not able to see ours,<sup>54</sup> it ensured patients were in their trusted home setting, which may have facilitated patients in being candid, giving less socially desirable answers.<sup>54,55</sup> Consistently with this, we obtained valuable information and received positive feedback from patients. Moreover, by complementing our focus group with individual interviews, the advantages of both methods were used, while potential limitations were minimized.<sup>22,23</sup> Lastly, we conducted a thorough thematic content analysis, drawing on elements from grounded theory.<sup>30,32,56</sup> The multiple phases of coding, which started with inductive open coding,<sup>56</sup> together with sampling until saturation<sup>35</sup> and the technique of constant comparison,<sup>30</sup> contributed strongly to the robustness of our results.

In conclusion, to our knowledge this study provides the first qualitative in-depth account of the experiences of patients

with metastatic melanoma resuming life and their associated SSC needs. To tailor melanoma SSC more to patients' needs, efforts should be focused on offering psychosocial supportive care, in addition to medical care, from the moment of diagnosis, also taking into account the patient's close relatives and with particular attention to return-to-work issues. Providing them with a single point of contact, a personalized SCP, or both, could guide patients through the patient journey, which, given its multidisciplinary nature, is particularly important in melanoma care. This may foster a smoother transition of melanoma survivors into mainstream life.

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## Conflicts of interest

A.A.M.V. has undertaken advisory or consultancy work (paid to the institute) for BMS, Eisai, Ipsen, MSD, Merck, Novartis, Pfizer, Pierre Fabre, Roche and Sanofi.

## Data availability

The data are available on request due to privacy and ethical restrictions.

## Ethics statement

The medical ethics committee of Erasmus MC concluded after review of the study design that the rules laid down in the Medical Research Involving Human Subjects Act (Dutch abbreviation: WMO) did not apply to this study (MEC-2019-0558 and MEC-2020-0197). All patients signed an informed consent form.

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## Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's website:

**Appendix S1** Predefined topic guides.

**Video S1** Author video.