

Unexpected survivorship:

Problems and supportive care needs of advanced melanoma survivors.

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Abstract

Title: Unexpected survivorship: Problems and supportive care needs of advanced melanoma survivors.

Background: Of the advanced melanoma patients 22% can now become a survivor because of the approval of the treatment with ipilimumab in 2011. This unexpected survivorship encompasses managing the long-term consequences of the disease and/or treatment. Providing supportive care can be helpful in managing these consequences and can improve the quality of life (QoL). Despite these insights no research has been done to examine the supportive care needs of the unexpected advanced melanoma survivor.

Research Question: What are the problems and supportive care needs of advanced melanoma survivors who have been treated with ipilimumab and have survived their disease for at least two years?

Method: This was an explorative and qualitative study among survivors and caregivers. Unstructured interviews were conducted with 11 individuals and one focus group consisting of four professionals was held.

Results: The following four main themes were identified from data: Psychosocial domain (anxiety about the future, mental health problems, coping), social support (reactions of others, trust in caregivers), daily life (continuing daily life, problems with daily life, physical problems) and communication (experienced threshold in communication with caregivers, absence of follow-up by caregivers, need for a contact person during follow-up).

Conclusion: The outcome describes a unique perspective on follow-up care within a newly formed group of melanoma survivors. The majority continued life as it was before the diagnosis. Each individual survivor, however, had their own problems which need a custom, person-centered approach of primarily non-medical supportive care.

Recommendations: It is recommended to conduct research specifying which of the caregivers can provide the best supportive care and aimed at developing a person-centered model of supportive care that meets the needs of the survivors to improve their health related QoL.

Keywords: Melanoma; survivors; quality of life; supportive care

Samenvatting

Titel: Onverwachte overleving: Problemen en ondersteunende zorgbehoeften van overlevenden van een gemetastaseerd melanoom.

Achtergrond: Door het middel ipilimumab, welke in 2011 werd geregistreerd, ontstaat voor 22% van alle patiënten met een gemetastaseerd melanoom de kans om deze dodelijke ziekte te overleven. Deze onverwachte overleving maakt dat zij moeten leren omgaan met de lange termijn effecten van deze ziekte en/of de behandeling. Het verlenen van ondersteunende zorg kan van belang zijn om met deze effecten om te leren gaan en kan daarbij de kwaliteit van leven verbeteren. Ondanks deze inzichten is er nooit onderzoek gedaan naar de ondersteunende zorgbehoeften van deze specifieke groep.

Onderzoeksvraag: Wat zijn de problemen en ondersteunende zorg behoeften van overlevenden van een gemetastaseerd melanoom die behandeld zijn met ipilimumab en de ziekte minimaal twee jaar hebben overleefd?

Methode: Een verkennende, kwalitatieve studie is uitgevoerd onder overlevenden en zorgverleners. Er zijn 11 ongestructureerde interviews afgenomen en er is één focusgroep met vier zorgverleners gehouden.

Resultaten: De volgende vier hoofdthema's werden geïdentificeerd: psychosociaal domein (angst over de toekomst, psychische problemen, coping), sociale ondersteuning (reacties omgeving, vertrouwen in zorgprofessionals), dagelijks leven (oppakken dagelijkse routine, problemen met het dagelijks leven, lichamelijke problemen) en communicatie (drempel in communicatie richting zorgverleners, gemis in nazorg zorgverleners, behoefte aan vast contactpersoon in nazorg).

Conclusie: Deze resultaten bieden een uniek perspectief op nazorg binnen een nieuwe groep gemetastaseerd melanoom overlevenden. Ondanks dat bij de meeste overlevenden het dagelijkse leven weer hervat is als voor de diagnose, kan elk individu andere problemen en behoeften ervaren waardoor er nazorg op maat nodig is. Deze nazorg is primair niet-medisch georiënteerd.

Aanbevelingen: Vervolgonderzoek moet aantonen welke zorgverlener het meest geschikt is om deze zorg op maat te gaan verlenen. Daarbij is vervolg onderzoek aanbevolen om een nazorg model op maat te ontwikkelen.

Keywords: Melanoom; overleving; kwaliteit van leven; ondersteunende zorg.

Introduction

In 2014, 826 people in the Netherlands died as a result of an advanced melanoma (1) and this number is steadily increasing (1,2). For a patient diagnosed with an advanced melanoma (unresectable Tumor Node Metastasis (TNM) - stage III or IV (3)) the prognosis is poor with a median overall survival of eight to ten months (2,4,5) and with a five-years survival rate of approximately 10% (3,6). With the approval of the novel immunotherapy treatment with ipilimumab (Yervoy®) in 2011 (2), a chance to survive an advanced melanoma has emerged for 22% of the patients (5). After a survival time of circa three years, the patient can assume that they are an unexpected survivor (5).

This unexpected survivorship encompasses managing the long-term consequences of the disease and/or treatment (7). Providing supportive care can be helpful in managing these consequences. Supportive care comprehends the optimal well-being of cancer patients in all stages of their disease (8). It is a person-centered approach which provides the necessary service and, for those living with or affected by cancer, meets their spiritual, emotional, social, physical or informational needs (9,10). Cancer survivors have reported a lower health related quality of life (QoL) (11). Providing information about disease specific supportive care needs has been shown to lower distress and have a positive effect on QoL (12,13). Furthermore the satisfaction with this information has shown to be an important predictor of the QoL components: physical, emotional, social, and functional well-being (13).

Even though this is known, advanced melanoma survivors are still being left without the resources, knowledge or skills to fulfil their supportive care needs (7). Research conducted among patients diagnosed with a TNM-stage I-III melanoma shows that unmet supportive care needs are particularly experienced in the areas of melanoma-specific information and psychological concerns like the uncertainty about the future or the fear of cancer recurrence (14-16). These study results also show that anxiety and depression were significantly associated with unmet supportive care needs (14). Despite these insights no research has been done to examine the needs of the unexpected advanced melanoma survivor. Ipilimumab is the only treatment as of yet which has a follow-up long enough (>2years) to speak about survivors. Although the surviving population of this disease is modest identifying the specific supportive care needs is important to decide which service is necessary to fulfil the unmet needs of this new, surviving population (14). As patients and professional caregivers can have different ideas about what issues and needs are the most important (17), both perspectives are included in this study.

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Objectives

The main research question of this study is: What are the problems and supportive care needs of advanced melanoma (unresectable TNM-stage III or IV) survivors who have been treated with ipilimumab and have survived their disease for at least two years? To answer this research question the following research aims will be addressed:

- To explore problems and supportive care needs of patients who have been diagnosed with an advanced melanoma (unresectable TNM-stage III or IV) and who have survived ≥ 2 years after treatment with ipilimumab.
- To explore the perspective of caregivers on problems and supportive care needs of patients who have been diagnosed with an advanced melanoma (unresectable TNM-stage III or IV) and who have survived ≥ 2 years after treatment with ipilimumab.

Methods

Design

This study is explorative and qualitative in nature. This design is chosen because of the lack of knowledge about these specific supportive care needs and to ensure that the survivors and caregivers could give their own definition of reality as experienced from their own perspective (18).

Population

Participants eligible for the interviews were survivors (≥ 18 years of age), who had been diagnosed with an advanced melanoma, were treated with monotherapy ipilimumab in the Netherlands Cancer Institute and had survived at least two-years after completion of ipilimumab treatment.

Caregivers eligible for participation were patient navigators, oncologists and advanced practice nurses (Bachelor nurses with the Master of Advanced Nursing degree) who are tasked with the care for this specific population within the Netherlands Cancer institute.

Data collection

Data collection was completed from January 2017 until May 2017. To have the flexibility to follow the experiences and thoughts of the participants, the interviews and the focus group were unstructured (18). A predetermined topic list (Appendix 1) was used by researcher A.K. to keep the research aim in mind during the interview and to

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investigate certain issues (18). These topics were based on literature about supportive care needs of melanoma survivors in other stages of the disease (14-16), literature about supportive care in general (19) and the short-form supportive care needs survey (SCNS-SF34) (20). Each interview and the focus group started with an introduction followed by the open question: How are you, in this moment, in relation to the melanoma and the treatment? / How do you think melanoma survivors are doing in relation to their disease and treatment? Fixed questions or assumptions were not used as this does not contribute to flexibility. The interviews and the focus group were recorded on audiotape and transcribed verbatim by researcher A.K..

The audio recording of the first interview was evaluated by A.K. and researcher E.B. by listening to the recording and discussing the interview techniques, the topics and the collected data.

Procedures

Through medical file research, performed by a medical doctor of the Netherlands Cancer Institute, 21 eligible survivors were identified. All of these survivors received information on this study which was added to the invitation letter for the ongoing larger study "*Prospective multicenter cohort study of late physical, psychological and social effects in patients treated with ipilimumab for advanced melanoma*". Those who did not respond to the letter within six weeks received a reminder letter. After written informed consent participants were contacted via telephone by A.K. to schedule the interview. As participants feel more at ease in their intimate environment, which can lead to the researcher gaining richer data (21), the location of the interview was in accordance with the participants' choice. Interviews and the focus group among the caregivers took place in the Netherlands Cancer Institute. The caregivers were invited to participate by e-mail. The oncologists were interviewed and the patient navigators and advanced practice nurses were asked to participate in a focus group.

Data analysis

An inductive approach was used during the six phases of thematic analysis of Braun and Clark (22). Getting familiar with the data during phase one was done by A.K. using the process of transcriptions and by (re)reading the transcripts. The coding of the data during phase two was carried out by A.K. and A.B. Coding was done independently and intercoder agreement between A.K and A.B. was reached during the process of analysis by discussing their findings and interpretations. This intercoder agreement ensured that every fragment

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was labeled with the 'correct' code and that labels were not placed arbitrarily (21). Searching, reviewing and defining themes out of the different codes during phase three, four and five was also done by A.K and A.B., supported by the software program NVivo11 (QSR International; Victoria, Australia). As before findings and interpretations were subject to discussion. Due to the recursive process of the study, the researchers went back and forth between different phases as needed.

Ethical issues

The medical ethics review committee of the Netherlands Cancer Institute in Amsterdam deemed that the study does not require ethical approval in accordance with the Medical Research Involving Human Subjects Act (WMO). This study was conducted in accordance to applicable regulatory requirements and the principles of the Declaration of Helsinki (2013).

Results

Participants characteristics

Thirteen survivors of the, before mentioned, larger study, responded to our invitation. Eight agreed to participate in this study. It is unknown why the other survivors refused to participate or did not respond. Seven of the interviews were held at the participants' home and one was held at the hospital. The partner also participated in three of the interviews. The survivors had a mean age of 63 years (range 33-82), six of them were male, five were married / cohabiting, one had a relationship and there were two single survivors. The mean time since the last dose of ipilimumab was 4,55 years with a range of 1,92-9,75.

Out of the seven participating caregivers, all three oncologists, one of the three patient navigators and three out of four advanced practice nurse agreed to participate in the study. Reasons of non-participation were absence because of holiday (n=2) and no time (n=1). Four of the caregivers were male. The years of experience in the care of advanced melanoma patients varied between one and half year and 18 years with a mean of 8,7.

Problems and needs

Four main themes were identified from data: Psychosocial domain (anxiety about the future, mental health problems, coping), social support (reactions of others, trust in caregivers), daily life (continuing daily life, problems with daily life, physical problems) and communication (experienced threshold in communication with caregivers, absence of follow-up by caregivers, need for a contact person during follow-up).

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Psychosocial Domain

Anxiety about the future

Anxiety and uncertainty about the future played a very important role within this domain. The intensity of this anxiety and its influence on the daily life differed for each survivor. In an extreme case it led to anxiety attacks. The feeling that trust is gone in one's own body was a shared experience by almost every survivor and recognized by all the caregivers.

“S3: Whenever I feel something, I think the cancer is back”.

“O3: Most, 60-70% I estimate eventually has a trust issue with their own body.”

The regular doctors' visits slowly help to recover the confidence in one's own body and gave the assurance that recovery was indeed going well. Besides this confirmation however, these visits can evoke fear and tension due to the uncertainty of the outcome.

“S2: The last scan always leads to nervous moments, but it is less tense now than in the beginning. It is longer ago now, and you gain confidence in a good outcome.

“O2: Patients are, of course, very nervous for the results of the scans and that is the first thing I tell them, ‘The scan was good and the lab results were good’.”

Mental health problems

In addition to anxiety and depression, loneliness and a negative self-image were also problems which could occur during the process of transition from the status of terminal cancer patient to the status of cancer survivor. These problems however only seem to be present in a minority of survivors.

“S1: I look into my eyes and I see that, I don't see them sparkling anymore.”.

Coping

Coping behavior to deal with psychosocial problems differs for each survivor and varies from writing in a diary, overeating or alcohol abuse.

“S8: It is, as you can say psychological, that it gives a numbing effect and that I feel better because of it. [...] that is, I have been drinking more.

Some survivors needed help from a professional, such as a psychologist to deal with these problems.

“O3: I always offer support services, and especially social workers, to patients to aid in psychosocial support.

Most of the survivors however can handle these problems by themselves because of, the social support or their own down-to-earth character.

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“S5: And if it comes back, than it comes back and maybe there’s something else [treatment]. Well that’s nice, and if there is nothing, well then I’ve been giving a nice amount of years.”

Social support

Reactions of others

Survivors and one oncologist indicated that the social network of the survivor plays an important overall role in processing the entire period from diagnosis until survivorship. One, or more, relative(s) or friend(s), close to the survivor, can help the survivor experience life more positively again, and help them through difficult times and even prevent loneliness.

“S5: and then I thought, alright, and I then I came home and thought; well, now it’s over. So I went upstairs, didn’t say anything, grabbed a plastic bag, opened the closet, and all my clothes: gone, gone, gone [...] Well brought the bag with my clothes away [...] Well he said at least you can buy new ones. Well that’s a little positivity at least.”

Next to the support of relatives or friends, the response from employers also contributes to the processing of the survivor. A positive response offered the opportunity to resume work at an own pace in the best possible way. One of the oncologists mentioned the potential positive contribution of the company doctor during the reintegration process which was confirmed by a patient.

“S2: It was built up very slowly. I spoke to the company doctor and that actually went pretty good. [...] You increase work when you think you are up for it, and when you aren’t you don’t do it.

Trust in caregivers

The support of the caregivers was considered valuable by most survivors. Through an intensive period of treatment, recovering and surviving, survivors can experience a special relation, based on trust, with caregivers like their oncologist and advance practice nurse.

“O2: There are all kinds of things, not related to the disease, but I hear them as a doctor because I have helped them so well in their eyes. They tend to involve us in all kinds of issues.”

Daily life

Continuing daily life

Most survivors said they had resumed daily life as before which was confirmed by the oncologists. The survivors work and engage in daily activities such as shopping, exercise and household chores.

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“S7: I just work. Four days in the week but I would have done the same without ipilimumab”

The encouragement of the oncologist helped some to resume certain activities.

“S3: He said, than you come back, you don’t use any medication, just restart cycling. And that is what I did, and just biked 60 kilometers and I could do it as well as before”

Problems with daily life

Problems which hindered everyday life as desired were discussed in the minority of survivors. These problems were in the area of finance, insurance, mortgage or finding work as a result of psychological problems or low-energy.

“S8: Yes this is a rental home. That is a strange thing. Because we investigated that, but of course I cannot get a mortgage.”

One of the survivors and most of the caregivers discussed problems when the survivor had quit work due to the poor prognosis of the melanoma. When they did survive, the lack of job structure made it more difficult to continue life as before.

“C1: and she had quit her job because she was ill. [...] But then she reacted well to ipilimumab and all of a sudden she was discharged from treatment and she had didn’t know what to do with her live.”

Physical problems

Physical issues that were discussed included problems with sexuality, weight change or long term consequences of a complication of treatment. Almost all issues concerned only the individual survivor. Only fatigue was a problem mentioned by a small number of survivors and also by one of the oncologists. This fatigue caused them to take rest periods during the day, in effect influencing daily activities.

“S1: and then I stopped laying down in the afternoon but I could not stay up anymore in the evenings”.

The oncologists also discussed medical problems like hypothyroidism, the need for steroids and skin problems like vitiligo. However none of these problems were mentioned by the interviewed survivors.

Communication

Experienced threshold in communication with caregivers

The most important topic of the visit to the outpatient department is the scan made prior to the visit. Good news about the results can contribute to the survivor wanting to go home instead of talking about other less positive issues.

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“S8: You enter and you just want to know the results. And when the result is good you don’t talk about how bad things are going.”

“C4: and then it is complicated to address a subject like sexuality with the oncologist. You have good results and are set for the near future”

In addition to this, survivors mentioned that a threshold to discuss problems with the oncologist may be caused by the duration of the consultation hour. While waiting in the waiting room, some of the survivors think that the doctor is too busy for their non-medical problems.

“S2: He doesn’t have a lot of time, they are usually short conversations.”

Finally the gender of the caregiver, especially when that is someone from the other sex, is experienced as a threshold as it was less comfortable to discuss sensitive problems.

“O2: a woman would perhaps have an easier time talking with a female advanced practice nurse where as a male would have an easier time talking to me”

Absence of follow-up by caregivers

Survivors’ experiences of conversations in the outpatient visits are that they are mainly medical oriented. This is recognized by the caregivers. Some survivors need more non-medical follow-up care because of the nature of the current problems.

“S1: I never get called by the advanced practice nurse about how I am doing and if there is anything else. I don’t want to call them myself; I am not their only patient”.

This kind of follow-up care can be given by someone like the social worker or the advanced practice nurse.

Oncologists on the other hand are sincerely interested in how things are going with the survivor, but they can’t help or refer them to other professionals if the survivors don not talk about their current problems.

“O2: If they let me know they have complaints, then they always get the opportunity to do something about it. But I have to know about it. If I don’t know, I don’t do anything about it.

Need for a contact person during follow-up

While dealing with certain problems, survivors do not know which person they have to contact. They are confident that everyone will be willing to help them, but they doubt between contacting their oncologist, general practitioner or the advanced practice nurse.

“S4: I got telephone numbers from everyone, like if anything is up, that I can always fall back on one of them.”

“O1: Usually they call the nurse practitioner or the oncologist”.

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“C1: I do not know for sure, but I think the oncologist is their contact person for the follow-ups.”

Discussion

The main finding of this study is that most of the survivors have continued life without many problems and supportive care needs. The problems that were found are mainly in the psychosocial domain, most commonly dealing with the anxiety for recurrence of the melanoma. Besides this overall problem, many kinds' problems and needs were discussed but almost all concerned only individual survivors. Next to the, mainly medical-oriented, outpatient visits with the oncologist, there is a need for supportive care to deal with non-medical problems which can differ for every single survivor. This supportive care can be given by other professionals than an oncologist. Furthermore the network of the survivor has an important role in processing the encountered problems as they can provide positivity and the structure to which a survivor can cling to.

The outcome of this study is in line with an article written by Stanton et al. (23). She described that cancer-related problems are improved or resolved during the first years after treatment. However, she also described that a minority of survivors can have long-term problems. One of these problems, described by Weaver et al. (24), shows that significant more cancer survivors report a poor physical and mental health related QoL. Fear of cancer recurrence is also described by Ghazali et al. (25). This fear is seen as an unfilled need of the survivor because this is challenging to manage (26). Van de Wal et al. (27) described a regular doctor's visit being one of the triggers to reactivate this fear.

One other result of our study indicated that other professionals, besides the oncologists, need to be involved during follow-up because of non-medical problems and needs. Stanton et al. (23) recognized that other professionals, such as psychologists, nurses, patient navigator or social workers, are needed for the psychosocial assessments and referrals. The opposite is described by Huibertse et al. (28). She found that most of the survivors reported a preference for the medical specialist for follow-up care and that the survivors prefer to discuss psychosocial cancer-related problems with a general practitioner.

To increase the validity of the results, data triangulation was done by including the different perspectives of survivors and caregivers. Coding carried out by A.K. and A.B. independently of each other also contributed to the validity (18). Findings and interpretation were discussed which led to an agreement about different findings. This intercoder agreement contributed to the reliability of the data (21). The reliability was also enhanced by using a good quality tape for recording and by transcribing the recorded interviews (21).

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Another strength is that during the data collection saturation of data appears. Besides these strengths, there are also a few limitations in this study. The sample consisted of survivors and caregivers of one comprehensive cancer center. This could have influence the results, as the follow-ups can be different in other hospitals. This can cause different problems or needs. Also the low response rate of survivors can have an effect on the outcome of this study. The included survivors did show a wide variation in age and duration of survival which can contribute to the representativeness of the results. Another limitation may be the presence of the partner in three of the interviews. This interaction may have had an impact on the problems and needs discussed.

The perspective of the caregivers corresponded for a great deal with the issues discussed by the survivors. However it must be said that the focus group was less valuable than expected because the participated caregivers had little to no experience with the follow up of this population.

Concluding we can say that these outcomes, based on the literature and our results, describe a unique perspective on follow-up care within a newly formed group of melanoma survivors. The majority continued life as it was before the diagnosis. Each individual survivor, however, had their own problems which need a custom, person-centered approach of non-medical supportive care. It is recommended to do research which of the caregivers can provide the best supportive care as literature and our results aren't conclusive. It is also recommended to compare these outcomes with the results of the ongoing, quantitative study, "*Prospective multicenter cohort study of late physical, psychological and social effects in patients treated with ipilimumab for advanced melanoma*". These outcomes can then be used in the development of a person-centered model of supportive care that meets the needs of the survivors to improve their health related QoL.

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Appendix 1 : Topic list

Algemene introductie:

Ten eerste hartelijk dank voor uw deelname aan dit onderzoek. Met dit onderzoek willen wij de supportive care behoefte/ Zorgbehoefte onderzoeken die er is onder mensen waarbij de behandeling met ipilimumab bij een gemetastaseerd melanoom goed is aangeslagen.

Dit interview gaat over uw ervaringen in de periode die start na de laatste behandeling tot aan vandaag, maar kan ook gaan over behoefte waar u in de toekomst behoefte aan denkt te gaan krijgen met betrekking tot deze behandelingen.

Openingsvraag:

Hoe gaat het op dit moment met u in relatie tot het melanoom en behandeltraject?

Topics:

- Lichamelijke conditie
- Algemene dagelijkse levensverrichtingen
 - Voeding
- Psychisch
 - Psychische zorgen
 - Angst
 - Depressie
 - Onzekerheid toekomst
- Spiritueel
- Relaties / naasten / mantelzorgers
- Seksualiteit
- Gezondheidsinstelling / Behandelcentrum
- Informatievoorziening
- Ervaren Gezondheid gerelateerde kwaliteit van leven

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