

The Impact of Advanced Melanoma on the Relational Sphere, Body and Quality of Life: A Phenomenological-Hermeneutic Study

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Abstract

Background: Cutaneous melanoma represents one of the most frequent cancers in the adult population and accounts for more than 80% of skin cancer deaths. Due to pharmacological innovations, there is an increased chronicization of the disease, so the concept of quality of life becomes increasingly important. The purpose of this study was to assess the psychological and social impact of advanced melanoma, thus the influence of the disease in the relationship with one's body, on the relational sphere, on ways of coping with the event, and on the perceived quality of life.

Method: Four semi structured interviews were administered to a sample of 22 patients with advanced melanoma (stage III and IV) to explore in depth participants' subjective experiences regarding the impact of the disease. The interviews were transcribed and subjected to content analysis using the phenomenological-hermeneutic method.

Results: From the analysis of the interviews, many patients experienced fear, anxiety and shock at the time of diagnosis, feelings of isolation and reduced social support during the oncology process. Medical and family support was found to be crucial for adjustment to the disease, while body image was negatively affected by the disease. However, some patients showed resilience and positive adaptation to cancer, trying to maintain their quality of life.

Conclusion: This study highlighted the importance of considering the psychological and social impact of advanced melanoma in patients. Understanding their experiences is essential to provide appropriate support and develop interventions aimed at improving their quality of life.

Keywords: Malignant Melanoma, Psycho-oncology, Phenomenological-Hermeneutic method, Qualitative research

Abbreviations: MM: Malignant Melanoma, WHO: World Health Organisation



Introduction

Malignant melanoma (MM) is a skin cancer arising from melanocytes, its incidence is increasing worldwide and represents a significant public health challenge. According to the World Health Organisation (WHO), cutaneous melanoma is the sixth most common cancer globally, with more than one million new cases diagnosed each year, and despite constituting only 1% of skin cancers, it accounts for more than 80% of skin cancer deaths [1]. The incidence of melanoma varies widely in different geographical areas of the world, with countries such as Australia, New Zealand and North America having the highest incidences [2-4]. The incidence of melanoma has increased in recent decades, especially among younger adults [5,6]. Although the incidence of melanoma is increasing dramatically and the mortality rate remains high, the use of immunotherapy and target therapies has allowed a significantly more favourable survival rate and in most cases a chronicisation of the disease at an advanced stage [7-9]. The possibility of living a long life despite the advanced stage of the disease has shed light on the psychological correlates of melanoma, both in the patient and the family member, and numerous studies in the literature have highlighted the impact that the oncological disease has on the emotional and psychological sphere. Dunn [10], in a review of the literature, found that between 20 and 28% of patients with MM show anxiety, while between 16 and 19% show depression, and the trend worsens as the stage increases. Thus, the prevalence of anxiety and depression in the cancer population is significantly higher than in the healthy population [11], reaching 23% and 17% respectively [12,13]. [14] highlighted that approximately 30% of patients with MM present clinically significant distress, where a worsening is evidenced by female gender, early age, low schooling, visibility of the disease site and lack of social support. Due to its visibility and scarring outcomes, MM often results in impaired body image, which correlates with increased distress, anxiety and depression [15,16]. The impact of melanoma therefore reverberates at a distance from diagnosis in social, physical, behavioural and emotional concerns. The main experiences indicate a reaction of shock and disbelief at the moment of diagnosis, fear and anxiety related to check-

ups, and a feeling of being isolated in the experience of the disease; while in the behavioural field, the main changes involve lifestyle, eating habits and sun exposure [17]. An experience that often accompanies the cancer patient is the fear of recurrence and uncertainty about the future [18], while there is often a process of reorganisation of relationships according to new needs [19].

Regarding coping strategies, avoidance strategies, having a positive mindset, an approach focused on hope and the present, spending more time with family members, seeking positive meaning from experiences and having spirituality were found to be more frequent [20-22].

In the literature, many quantitative scientific studies have examined the impact of melanoma on the emotional, psychological and social sphere, but little qualitative research has explored in depth the experience of patients with advanced melanoma on this issue.

The aim of the present article is to investigate, using the phenomenological-hermeneutic method, the experiences of the illness in a group of patients with MM, specifically investigating the impact of MM on quality of life, the relationship with one's body, the relational context and the ways of coping with the event. To our current knowledge this is the first study to investigate these dimensions with phenomenological-hermeneutic methodology.

Materials and Methods

A total of 22 patients with advanced melanoma (stage III,IV) were recruited in the present study, n=8 at stage III, n=14 at stage IV, aged between 29 and 84 years with a mean of 58 and median of 61. At the time of the study, 10 patients were undergoing target therapy, 12 immunotherapy. The study was conducted at the regional reference centre for melanoma (melanoma and skin cancer unit), Santa Maria Annunziata Hospital, ASL Toscana Centro, Italy.

Four open-ended questions (**tab.1**) were created in order to give participants room to deepen their experiences regarding the topics analysed. Then the patients were led to a room where, following informed consent, the semi-structured interview was handed over.

The reasons for choosing to use the phenomenological-hermeneutic method to analyse the contents that emerged can



be traced back to the very object of the work: to give space to the participants' emotions, to encourage the reporting of an experience considered unique and independent from

institutional training schemes and placed on a side closer to the world of life and personal experience.

Table 1

Question 1	"What impact has the tumour had on your quality of life?"
Question 2	"How has the disease affected your relationship with your body?"
Question 3	"How did you try to cope with the illness?"
Question 4	"What influence did the illness have on your relationships?"

The processing of the results was carried out by means of the inductive method characteristic of the hermeneutic phenomenological approach. The narrative units that emerged from the reports were organised into a series of phenomenological categories [23-25]. The categories were structured on the basis of an analysis of the unravelling and meaning-making processes of the participants' experiences [26]. The written narratives were read several times individually by the research team. The differential and peculiar aspects reported by the individual participants were traced and were proposed to the other researchers in order to identify the elements common to all reports, thus bringing them together within conceptual categories. In this way, the

contents relating to the same themes were systematised into a series of containers. The categories into which the writings were divided (**tab.2**), according to the standards defined by the COREQ (Consolidated Criteria for Reporting Qualitative Research) Check List [27], have a phenomenological character in that they emerge through the criterion of evidence [28]. The divergent points within the researchers' group view during the analysis and category construction phase were addressed and resolved consensually in a comprehensive approach to the different readings. The researchers then selected and reported in the text the most significant accounts within each phenomenological category.

Table 2

Questions	General categories	Specific categories
What impact has cancer had on quality of life	A hurricane	Shock Impotence Acceptance phase Doctor's support The strength of family members
	Lifestyle change	Reorganising everyday life The difficulty of cancer care
	Resilience	Willpower/confidence Faith in God
	The deterioration	The limitations of the disease Comorbidities



	Fear	Fear of relapse
How he tried to cope with the disease	Relying on one's own strength	A test to be faced Relying on one's own resources Maintaining interests
	Relying on doctors	Confidence in science The relationship with the doctor Having a point of reference
	The strength of family ties	Family support Seeking new resources
	Trying to distract oneself	Avoidance
	Awareness	Fatalism
How the disease has affected his relationship with his body	Inhabiting a body that does not belong to us	Physical limitations Health precautions Weight gain Having additional pathologies
	Sense of fear	Beware of symptoms Showing one's body
	The teachings	The importance of life
What influence did the illness have on your relationships	Nothing has changed	Everything remained the same
	The impact	The additional burden of the pandemic The duration of the oncological pathway Social media as a means of sharing
	The power of authentic relationships	The selection process Sharing
	Loneliness	Feeling lonely
	Isolating oneself	The pain that isolates
	Accommodation strategies	Compensate

Main specific and general phenomenological categories



Results

What impact has the tumour had on your quality of life?

A hurricane

Some interviewees highlighted the destructive force of the tumour, well represented by the image of the hurricane:

It was like a hurricane, it came suddenly (...). Pz11

A hurricane that in some cases turned their lives upside down: *It upset me, conditioned me, sense of helplessness, almost non-existent quality of life, for a period of time depression and total darkness.* Pz14

This was followed by a phase of cohabitation:

Initially it was very hard, but as the years go by I try to live with it as best I can, although I alternate between good and bad periods. Pz18

Among the factors that helped patients to accept themselves was the support of their doctor:

The impact in 2012 was devastating, with time, prioritising, I learnt to live with it, the support of my professor was crucial (...). Pz12

And family ties:

Very big impact, initially scared I tried to do the things I used to do before, maybe with less pleasure. My family gave me strength and courage and I cried a lot at the beginning. Then I started facing the situation and I also started accepting the limitations (...). Pz15

Lifestyle change

The disease has severely undermined patients' functioning, and this process can be aggravated by the burden and duration of treatment:

I have been dealing with melanoma since 2007, I did all the check-ups up to 2017 with negative results, so I had an almost normal life. In 2017 and 2019 secondary tumours came out in the spine and lungs, then in the head. I had two rounds of radiotherapy to the spine and head. First I did drug therapy (chemotherapy) for more than a year, then since 2018 immunological therapy and the situation seems under control. Pz16

Resilience

Despite the strong commitment in terms of adherence to the time-consuming courses of treatment, some respondents pointed out that they managed to maintain a good quality of life:

I changed my schedule, my habits, my look and tried to incorporate other things into my daily actions that would allow me to beat the melanoma without losing my optimism and maintain the quality of my (beautiful) life. Pz10

And not to be conditioned by the changes brought about by cancer treatment:

(...) since I started therapy, I have obligations (the pills) to remind me what I have, but I try not to let it affect me. Pz17

In some cases, then, the will to live seems stronger than the disease:

In my case, a positive impact, always look forward and be joyful always, I want to live, I rely on God. Pz3

The deterioration

For some patients, on the other hand, the tumour has led to a marked deterioration in their quality of life:

Certainly the quality of life has deteriorated, I used to be able to do everything, now I can't; I can't walk much because I get tired, I can't sunbathe any more because with melanoma you can't, I have to be careful with my diet, etc... Pz20

Especially for those patients who were already suffering from other diseases:

Premising that I am a renal transplant recipient and have been fighting with nephropathy since birth, the tumour has marked a marked deterioration in my quality of life with constant thoughts of death. Pz2

Fear

The quality of life seems to be threatened by a pervasive fear for the present and the future:

As I have tended to be depressed all my life, I feel even sadder and worry about the future and the possible aggravation of the current situation, for me and my family. Pz7

Marking an existential fracture with the fear of reoffending:

I am afraid for the future, afraid of not getting well or getting worse. Pz8

How did you try to cope with the disease?

Relying on one's own strength

Relying, once again, on its own resources:

I went from having a disabled son who needed mum's care, to finding myself taking care of myself...I rolled up my sleeves as always. Pz5

It is also important to be able to accept oneself while trying to preserve one's own interests as much as possible:



Trying to do what I have always done, although with difficulty, especially physically, because I often feel tired, sleepy and very listless. Pz18

Relying on doctors

For some respondents, being able to rely on doctors was of great help:

I always rely on the care and advice of the doctors who have been with me for 20 years now (...). Pz20

It then becomes less burdensome to be able to follow the therapies if they fit within a doctor-patient relationship of trust:

I accepted its existence right from the start, I always told myself that what needed to be done I would do it, I trusted the doctors and what was proposed to me from the start, trying to fully understand each step. Pz17

The strength of family ties

The support of family members proves to be an extremely valuable element in facing the new challenges:

Apart from an initial moment where I sought as many positive answers as possible to any (severe) questions I was asking myself, I continued doing the usual things, helped a lot by my family, who were never absent. Pz4

The family can be a source of lifeblood:

I attach myself with all my strength to life, trying to think of the positive things. My source of life is my family, especially my two children. Pz12

Thinking of loved ones can activate additional resources:

(...) I live looking upwards, also because I know that from up there my father watches and gives me strength, I think he is proud of me. I firmly believe this, we are a very united family, we put up with each other, and this I believe is the trump card to face this very complicated new path. Pz13

Trying to distract oneself

Some patients coped with the disease by feeling the need for distraction:

I try not to think about it too much, to be optimistic and chase away my anxieties. Pz8

And normalising it in their lives:

Trying to make friends and giving me an explanation of the progressions. Informing myself (but not too much) and distracting myself just enough. Pz19

Awareness

The answers of some respondents focus on their awareness of their health status and the risks they face:

I do not cope in any way. I wait and hope that the therapy works, with the knowledge that this might not even happen. Pz7

How has the disease affected your relationship with your body?

living a body that does not belong to us

In some cases, the disease has severely affected the perception of one's own body. Emblematic are the words of this interviewee:

Still not quite clear, the feeling is that of inhabiting a body that no longer belongs to me totally. Pz19

And forced to respect the timing of one's own body:

Obviously I found myself having to do a lot to...make it a little less, not so much because of the tumour itself, but the surgery damaged one of my limbs, so I was slower and went back to work after 6 months! Pz5

Those who have to live with a multiplicity of physical problems and a consequent deterioration in their quality of life:

The disease has severely affected me physically, slowing down, tiredness, sexual problems and I have totally lost my salivation, so nights are a nightmare because of having to go to the bathroom, both to urinate and to moisten my mouth. Pz16

Who had to take precautions:

Somehow it has affected me a bit, I can't sunbathe anymore and I really wanted to, I also have skin problems (vitiligo) so especially in summer I am always covered up to avoid making it worse. Pz20

Who with the changes in body weight as reported by these patients:

Until the time of the last treatment in no way, after the treatment due to weight gain, it had a negative influence. Pz18

And those already suffering from previous illnesses have seen the perception of devastation exacerbated:

Having undergone other surgeries in the past, my relationship with my body was already compromised, the tumour exacerbated the sense of ugly, different, sick that I felt. Pz2



Sense of fear

One emotion that finds space when dealing with one's body in the aftermath of cancer is fear. Fear of seeing new signs of the disease in one's body:

Some concern about certain focal pains in the breast. Sometimes I wonder if they will be related to an expanding tumour or if they are insignificant. Pz12

Fear of the physical changes that treatment might entail, fear of showing scars:

One of the biggest fears was hair loss, when I was told that with immunotherapy my hair would stay that way, I felt more relieved. As mine is a very conspicuous scar at elbow height, mine has become a 'long sleeve' life, both in winter and summer of course. This is stronger than me, I cannot show my bare arm. Pz13

The Teachings

And if, as we have seen, for some people scars are a source of shame, for others they can become a source of teaching, as this valuable testimony highlights:

Scars have no emotional impact, they just remind me every day of how important it is to live and think healthily and carefully. Pz6

What influence did the illness have on your relationships?

Nothing has changed

If nothing has changed for anyone

It did not disturb me at all, everything around me remained the same. Pz11

The impact

For others, the impact of the disease on relationships was strong, amplified by the pandemic:

It was impactful, although we tried to carry on as normally as possible. Clearly I am immensely sorry for my wife who is paying the highest price and for my son, then the covid did the rest, with lockdowns of very long months... Pz16

Technological means (telephone, PC, etc.) help patients cushion the impact and keep communication with their loved ones alive:

High from a physical point of view, also due to the suspension of the driving licence, from an audio/video point of view the time spent on the phone or PC has increased. Pz19

The strength of relationships

From the answers of the interviewees, it is possible to

understand how the illness has affected relationships.

Patients report having had the opportunity to recognise and cultivate meaningful connections:

It gave me the opportunity to select and understand close friends and relatives. Pz8

Remembering how important emotional closeness is:

It reminds me how lucky I am to have people who love me beside me every day. Pz6

Loneliness

In some cases, however, the closeness of relatives and friends failed to stem scenarios of loneliness:

Some people were close to me, while others did not care at all. In short, I felt very lonely, and found myself having to deal with most things myself. Pz5

Everyone tries to stand by me, but I am realising that I am left alone to fight, alone against evil. Pz21

It sometimes leads to keeping the burden of the disease to oneself:

I am already a very isolated person, only to a few close friends have I communicated my state. Sometimes I don't feel understood by my closest relatives, but then I think they are as afraid as I am, because of the possible consequences. We keep this terrible secret to ourselves now. Pz7

Isolating oneself

Neoplasia often marks a break with the life lived up to that point.

The patient may experience both physical and mental pain that may lead them to isolate themselves:

The therapy I am following makes me more lazy and sore. Pz 3

And periodically avoid contact with others:

At times I don't feel well, so I don't feel like doing anything or going anywhere, I avoid contacting friends and relatives. Pz18

In others, however, the quality of relationships led to isolation:

I have decreased my social life, partly out of fear of questions, partly because I don't feel like hearing futile talk or seeing people whose company I find superficial. Pz 2

Accommodation strategies

Some patients have come to terms with the new needs brought about by the disease, in order to continue with their daily



routine:

At first, I thought the illness was a burden on my family and friends, and I tried hard to make everything go as before, especially at work. Then I realised that it was still OK if I needed an extra hour of rest, I became less nervous and my relationships with others improved as a result, especially at work. Pz17

Discussions

The analysis of experiences shows how the disease has impacted on various domains of the person, forcing a necessary readjustment to the new situation.

Many patients described the initial phase as a hurricane, confirming how the diagnosis has a traumatic impact on the patient [29,30].

The disease has affected everyday life, leading to a reorganisation of it, due to the treatment plan to be adhered to, side effects and precautions to be followed [31]. In the cancer patient, an important theme is the fear and uncertainty of the future [32], including not knowing whether the therapy will have an effect, whether there will be relapses and how life will change in the near future, in fact, as emerged in the present study, fear and uncertainty for the future can also be manifested in a more implicit way through the continuous monitoring of skin and symptoms. Fear of recurrence is a factor to be taken into account especially in light of the higher rate of chronicity of the disease [33-35].

One need that emerged was to find a balance between illness and normality in order to rebuild a present and re-initiate activities that the person used to do before, this process requires resilience and adaptability.

In the present study, among the factors favouring this were the support of the doctor and contact with health personnel: being able to rely on doctors represents a great need for the patient, where it remains an unmet need there is a worse adaptation to the disease [36].

Another factor that was found to be facilitating was the possibility of experiencing a sense of belonging and closeness to the family context, which in the literature correlates with greater emotional and physical well-being, a reduction in variables such as anxiety and depression, and greater adaptation to illness [37-39].

Melanoma, precisely because of its visibility, can affect the patient's body image, weighing on the quality of life [15,16,40], in the present study it also had a profound impact in the relationship with one's own body, creating a sense of estrangement. Body image was also influenced by weight gain given by medical treatment, these data have also been reported in other studies as strongly impacting events in the relationship with one's body [17].

Finally, MM affected social relationships: tiredness, nausea, pain and fear of burdening the other can lead to isolation of the person from the social context [41], as was the case in some participants.

As the results showed, it is common for social relationships to be difficult to interact with the sick person, which led to a process of readjustment of social relationships through a selection of friendships [18,19].

However, some patients have reported that they have successfully adapted to the disease with the help of family members and close friends, for example, by compensating for physical deficits or using alternative means of communication in order to maintain a normal quality of life.

Limits

The first limitation of this study is that it only considered the population of patients with advanced melanoma undergoing target therapy and immunotherapy, and did not examine patients undergoing other types of treatment (e.g. chemotherapy), which could lead to different experiences due to the different impact of treatment and side effects.

Conclusions

The aim of this study was to explore the experiences of patients with advanced melanoma and to develop an understanding of their experiences during the oncological process. The phenomenological-hermeneutic approach allowed participants to reflect on their experiences regarding their relationship with their bodies, the influence of the disease on their relationships and perceived quality of life, and how they cope with melanoma, bringing out their deepest experiences.

The experiences shared by the participants in this study confirm the traumatic nature of melanoma diagnosis and the



need to implement interventions that take into account the many facets of the dimensions examined in order to improve the health and quality of life of these patients.

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