

Research and malignant mesothelioma: lines of action for clinical psychology

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Abstract

The purpose of this paper is to present two studies. Study 1 is a literature review on psychological needs of malignant mesothelioma (MM) patients. Study 2 is aimed at assessing how patients and caregiver experience the diagnosis. In study 1 we performed a systematic literature review; while in study 2 we performed a thematic analysis of semi-structured interviews. Study 1 detected 5 psychological constructs (i.e. 1. Psychological impact of MM diagnosis; 2. Emotional aspects connected to the occupational context; 3. Coping strategies; 4. Treatment experiences; 5. Quality of life). Study 2 identified 4 themes (i.e. 1. Physical symptoms, affects, and defenses; 2. Living in or near a National Priority Contaminated Site; 3. "Nothing is like it was"; 4. "What will become of us?"). The literature review suggests a specific profile of suffering for MM, a result strengthened by the qualitative study on semi-structured interviews. The present paper highlights the lack of specific measures and clinical interventions for this distinctive population.

Key words

- clinical research
- malignant mesothelioma
- emotional distress
- clinical psychology
- qualitative research

INTRODUCTION

Psychological research on malignant mesothelioma (MM) has shown that its diagnosis has high psychic costs for both patients and caregivers. After the diagnosis, in fact, both patients and families undergo significant changes, and their mental life seems to narrow and to focus only on the disease, acknowledgement of it, and its negative consequences [1, 2], with significant impairment of their quality of life [3-5]. Their mental life seems to be characterized by the severe presence of anxiety and depression, together with overwhelming negative affect (i.e., fears, helplessness, guilt, and rage) [3, 4, 6-8].

Moreover, research has also stressed the impact of MM in social interactions. One of the major consequences MM patients and their families have to face is the redefinition of internal and external roles, taking on responsibilities that would previously have been unusual, and changing plans because of reduced time left to live together and the substantial costs of treatments and legal fees [9]. Again, patients and caregivers seem to experience intense feelings of exclusion, which may compromise their sense of belonging to the community and impair social ties, leading to withdrawal [3, 8, 10-12].

Several national and international guidelines and operational recommendations [13-16] underline the importance of evaluating the psychological and socio-relational impact of MM in order to better understand the needs of MM patients, to offer appropriate support

services, and to improve the quality of care worldwide. Despite the growing interest in the psychological and relational facets of the disease, MM still requires further psychological research, and our knowledge on psychological processes connected to MM is still poor. Specifically, the limited number of studies and the heterogeneity of nonspecific measures already used in previous research do not enable collection of homogenous data and prevent comparisons among different studies' results. Moreover, the majority of the available studies have been conducted using a quantitative approach, while the subjective experience of living with this kind of work-related fatal disease seem to be rarely taken into account in the literature (for a qualitative literature review, see [17]).

In line with the previous considerations, in this paper, we would like to present the results of two research lines of the Research-Intervention Group of the Department of Psychology, University of Turin, "Psychological assessment and whole patient care for malignant mesothelioma patients and their caregivers" (for the whole research program, see www.dippsicologia.unito.it/dogruppi.pl/Show?id=4ax2):

development of specific measures to detect psychological distress and needs related to MM;

assessment of the psychological impact of MM diagnosis on patients and families.

In the first study, we will present the results of a systematic literature review aimed at identifying the main areas of psychological distress in MM patients, which

will constitute the theoretical basis for the development of a specific questionnaire for the assessment of the psychological impact of the disease.

In the second study, we will investigate the impact of the MM diagnosis through a qualitative bottom-up approach applied to the *verbatim* transcriptions of audio-recorded interviews conducted with MM patients and their first-degree caregivers.

STUDY 1: DEVELOPMENT OF SPECIFIC TOOLS FOR THE ASSESSMENT OF THE PSYCHOLOGICAL IMPACT OF MM

MATERIAL AND METHODS

This study is part of the agreement between the Department of Translational Medicine, University of the Oriental Piedmont, and the Department of Psychology, University of Turin, for the realization of the project "Access to care, psychological support and epidemiological surveillance of asbestos-related pathologies in Italy: an integrated project," research program 9, "Special Program for Asbestos," ID 59/2016, Call for research in cooperation – Plan of research activities 2016-2018.

Search strategies

A systematic search strategy was used to identify relevant studies. Research included studies published in the last 36 years (January 1980-October 2016). Studies were identified by searching the following the electronic databases: Cochrane Library, Psychology Behavioral Sciences Collection, PsychINFO, PubMed, PubGet, PubPsych, and Scopus. We used a combination of the keywords "mesothelioma" or "asbestos + surveillance" or "asbestos + exposed" with "patient", "experience", "psychological", "support", "quality of life", "stress", "counseling/counselling", "palliative care", "psycho-oncology", "depression", or "anxiety".

Any discrepancy regarding the inclusion/exclusion of articles was discussed within the research group until an agreement was reached. Each potentially relevant study selected was obtained in full text and assessed for inclusion in the review independently by four judges. In case of disagreement, a fifth judge was consulted.

A standardized data extraction form was used to collect data from each relevant study. Extracted information included:

1. general study details (authors, year of publication, type of study);
2. setting (country, industry subsector, and trade and job);
3. participant details (sociodemographic characteristics);
4. type of asbestos exposure (occupational, environmental, familial, leisure activities);
5. psychometric tools used;
6. major outcomes.

Selection criteria

The systematic review was conducted in accordance with the PRISMA – Preferred Reporting Items for Systematic Reviews and Meta-Analyses – guidelines for

search, systematization, and report of systematic reviews [18].

Inclusion criteria were:

1. quantitative (cohort, case-control, cross-sectional) or qualitative (case crossover, case report) studies;
2. a population consisting of or including MM patients or asbestos-exposed subjects (i.e. people living in asbestos contaminated sites) ($n > 5$);
3. focus on the psychological aspects;
4. only Italian, English, French, or Spanish language;
5. publication within the given time interval (January 1980-October 2016).

Exclusion criteria were:

1. studies conducted on animals or environmental matrices;
2. studies not reporting original results (reviews, letters, editorials, and comments).

The entire procedure is displayed in *Figure 1*.

RESULTS

The selection procedure resulted in an outcome of 20 articles, 12 on patients and 8 on exposure. Because the main aim of the present study is to investigate MM patients' experience, we will consider only the 12 identified papers on MM patients (for the whole process and results, including the ones on exposure to asbestos, see [19]).

Areas investigated by the 12 articles detected are summarized below (*Table 1*).

1. Psychological impact of MM diagnosis on individuals

Several studies focused on the onset of psychological reactions to the severe physical conditions of the disease. The diagnosis seems to produce a "shock reaction" [6, 20, 21], leading to the development of anxiety, depression, apathy, discomfort, difficulties in concentration, and social dysfunctions in the first subsequent months [3, 4, 6, 21-23]. The uncertainty about the disease, along with the awareness of its rapid progression and its incurable nature, generate intense anxiety [6], compromising social roles and mental well-being [3, 4, 21].

2. Emotional aspects related to the occupational context

The main emotional aspects related to the occupational context are feelings of being unlucky and disbelief. The long latency period between the exposure and the onset of the disease, the sense of belonging to the company, the feelings of loyalty toward employers, and the legal matters seem to convey intense anger toward the family and the physicians [3, 20, 22, 24]. Finally, the fear of indirect household exposure and therefore of being responsible for unintentional familial contamination arises [6].

3. Coping strategies

The main coping mechanisms adopted by patients to deal with the negative feelings arising after the MM diagnosis are avoidance and denial [6, 22, 24]. Some patients seem to adopt optimistic behaviors aimed at

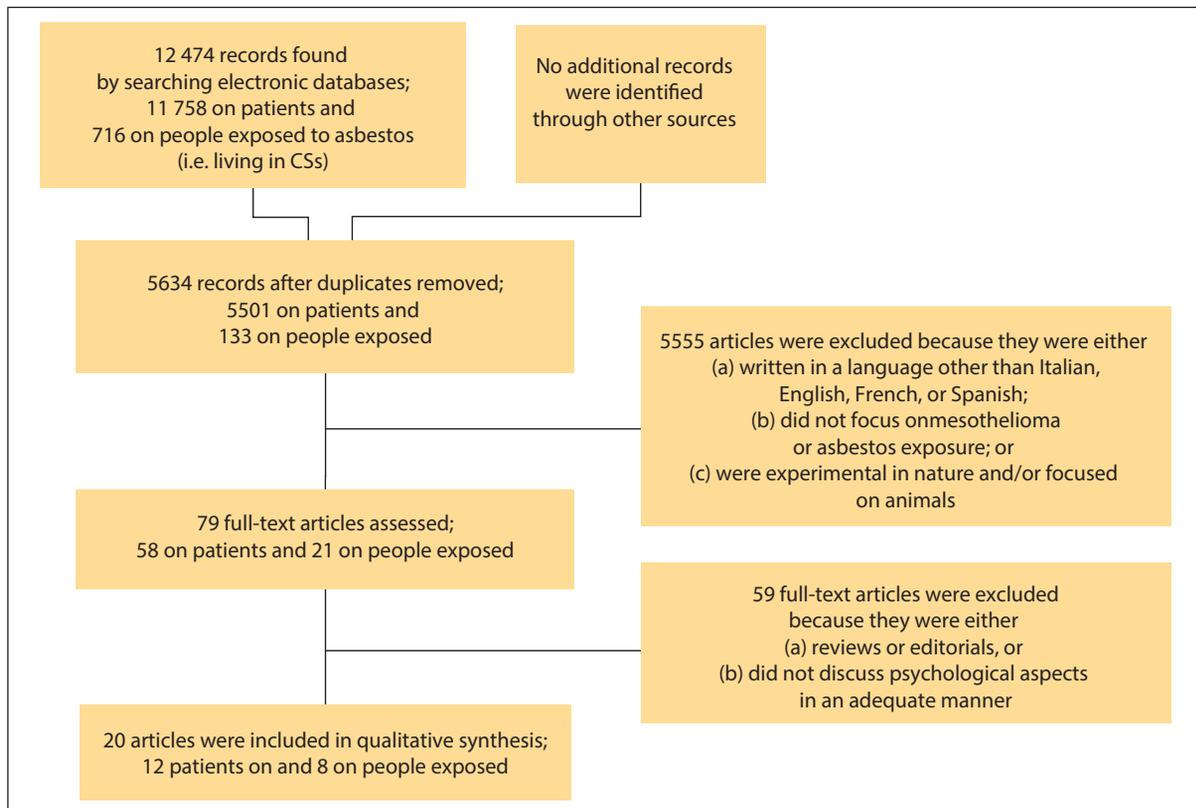


Figure 1 Flow chart of the search strategy and selection procedure.

Table 1 Areas investigated by the 12 articles detected by the systematic review

| Areas of investigation for the patients | N. articles |
|---|-------------|
| Psychological impact of MM diagnosis | 7 |
| Emotional aspects connected to the occupational context | 5 |
| Coping strategies | 5 |
| Treatment experiences | 3 |
| Quality of life | 3 |

1. Psychological impact of MM diagnosis = psychological symptoms and emotional responses related with MM physical conditions; 2. Emotional aspects connected to the occupational context = emotional distress and employer's psychological reactions related with diagnosis, and occupational context; 3. Coping strategies = mechanisms adopted by patients to cope with the negative affectivity and emotional distress subsequent to MM diagnosis; 4. Treatment experiences = subjective experience and emotions related with medical treatments; 5. Quality of life = factors affecting the quality of MM patient's life.

restoring a sense of self-efficacy and regaining an active role in the management of the disease [20]. Kao and colleagues [5] explained the phenomenon of "sickness behavior," used to describe a constellation of nonspecific symptoms such as fatigue, anorexia, fever, depression, cognitive impairment, and exaggerated response to pain, as a maladaptive coping strategy to face the impact of the disease.

4. Treatment experiences

Although subjective experience of treatment varies according to the individual physical and psychological conditions, the most frequently reported reactions are pain and discomfort. Medical treatments (i.e., chemotherapy, surgery, radiotherapy) are experienced with acute emotional distress, and patients seem to consider themselves unable to deal with them [6, 20, 25]. Moreover, health care protocols seem to be linked with feelings of uncertainty and distrust [6].

5. Factors affecting the quality of life

Complementary and alternative medicine, palliative and physiotherapy care, and the observance of a specific diet may increase patients' sense of control over the disease, fostering the idea of having a positive impact on it. Furthermore, correct information regarding legal aspects of possible compensation seem to increase patients' feelings of agency [6, 26]. Finally, support groups could play a pivotal role in helping patients manage negative emotions and reactions connected with MM [27].

STUDY 2: ASSESSMENT OF THE PSYCHOLOGICAL IMPACT OF MM ON PATIENTS AND FAMILIES

MATERIAL AND METHODS

This study is part of the AVPM Project (Assessment delle Variabili Psicologiche nei casi di Mesotelioma – Assessing Psychological Variables in Mesothelioma),

which involves the National Health Center for Asbestos, the Interdepartmental Functional Unit for Malignant Mesothelioma (UFIM) of the SS. Antonio e Biagio e Cesare Arrigo and Santo Spirito Hospitals, and the Post-Graduate School in Clinical Psychology (SSPC) of the University of Turin (CCM protocol number J19E12001060001).

To investigate the subjective impact of MM diagnosis on both patients and caregivers, we used a qualitative thematic analysis of audio-recorded interviews. Semi-structured interviews have already been used in previous research with MM patients [6, 20, 22, 24, 26, 28] and allow a more in-depth investigation of the subjective way of experiencing the disease.

Patients and their first-degree caregivers were administered semi-structured interviews on specific areas of MM experience:

1. asbestos exposure and work history;
2. treatment history;
3. subjective impact of the disease on the individuals and on their relationships, particularly family ones;
4. strategies to deal with end of life, death, and survival.

Interviews were carried out by two trained clinical psychologists, audio recorded, and then independently coded following Braun and Clarke's six-step method [29] by three of the authors (IGF, FG, and MB). In line with the original method, we decided not to quantify qualitative data. An inductive data-driven form of thematic analysis was adopted: a bottom-up approach in which collected data informed theoretical considerations [30].

Participants were recruited and interviewed between October 2014 and January 2015, and November 2016 and October 2017 at the UFIM, as a preliminary step for the recruitment of participants for the brief psychodynamic group interventions structured by our Research-Intervention Group. The recruitment process is still ongoing, and the next interviews will be carried out between February and March 2018.

Inclusion criteria were:

1. having a diagnosis of MM in any localization or being a family member/caregiver;
2. MM diagnosis < 6 months;
3. signing an informed written consent form.

Exclusion criteria were:

1. having poor knowledge of the Italian language;
2. having a certified psychiatric diagnosis;
3. having a certified diagnosis of a neurodegenerative disease (e.g., Alzheimer's disease, Parkinson's disease, etc.).

All subjects participated anonymously in the study and gave their informed written consent. The AVPM Project, including the present study, was approved by the local Institutional Review Board (IRB) and the Hospital Ethical Committee (AVPM-14/11/2014) and was conducted in accordance with the Declaration of Helsinki. All participants' names have been disguised to protect confidentiality.

Participants

During the recruitment period, 131 new diagnoses of MM occurred, consistent with the epidemiological data of Casale Monferrato [31]. Eleven (8.40%) subjects

were excluded because of their critical clinical conditions, 36 (27.48%) only had their first visit at the UFIM, 36 (27.48%) stated that they were not interested in the interviews, 11 (8.40%) decided not to participate in the interviews because they lived far from the UFIM, and 4 (3.05%) were excluded because of their psychological/psychiatric conditions.

The final sample (N = 61) is composed of 33 MM patients (54.09%) and 28 caregivers (45.90%). Table 2 shows the sociodemographic and clinical characteristics of the sample, differentiated for clinical condition (patients/caregivers).

RESULTS

The thematic analysis identified four different themes:

1. physical symptoms, affects, and defenses;
2. living in or near a National Priority Contaminated Site (NPCS);
3. "Nothing is like it was";
4. "What will become of us?" (Figure 2).

1. Physical symptoms, affects, and defenses

1a. Facing new limitations/needs

The impact of the disease leads to invalidating symptoms and a new physical condition that require both patients and caregivers to come to terms with emerging needs connected to a sick body, undergoing severe medical treatments – even experimental ones.

Fabrizia (caregiver): In ten days, let's say, our lives, and most of all her [her mother, who has MM] life, turned upside down.

Kate (patient): I'm very, very angry. But not...not because of the disease in itself, because I was used to doing everything, all alone.

Giusy (caregiver): She [her mother-in-law, who has MM] used to be autonomous, completely, to help the others. [...] This has been really hamstringing for her.

During the interview process, a large number of patients (26/33) were involved in clinical trials at the UFIM, causing them to feel like "guinea pigs".

Clara (patient): Let's see, we'll see. We'll get to see where those treatments will take us. I'm like a guinea pig, we'll see. Maybe, well, we'll carry this on, I don't know, because it's a clinical trial.

At the same time, for some patients and caregivers, clinical trials seemed to be the only and best way to be treated for MM.

Adriana (patient): The doctor wanted to suspend his [another patient's] experimental treatment, interrupt it, but he doesn't agree, because he thinks that he will not be followed anymore for his disease and his treatments.

1b. Affects connected to the disease

Thinking about the disease gives rise to many painful consequences, such as rage and depressive symptoms, linked with the perception of one's own finitude and mortality.

Luigi (patient): There are times when you just, uh, you just mope around up.

**Table 2**

Sociodemographic and clinical characteristics of the sample

| | Full sample (N = 61) | | | Patients (N = 33) | | Caregivers (N = 28) | | t-test | p-value |
|----------------------------------|----------------------|-------|-------|-------------------|------|---------------------|----------|--------|---------|
| | M | SD | Range | M | SD | M | SD | | |
| Age | 60.08 | 12.10 | 22-77 | 64.76 | 8.16 | 54.57 | 13.73 | -3.585 | 0.001 |
| | N | % | n | % | n | % | χ^2 | gdl | p-value |
| Gender | | | | | | | 10.94 | 1 | 0.001 |
| Males | 27 | 44.30 | 21 | 63.64 | 6 | 21.43 | | | |
| Females | 34 | 55.70 | 12 | 36.36 | 22 | 78.57 | | | |
| Educational Level | | | | | | | 6.22 | 4 | 0.183 |
| Elementary School | 7 | 11.50 | 5 | 15.15 | 2 | 7.14 | | | |
| Middle School | 20 | 32.80 | 14 | 42.42 | 6 | 21.42 | | | |
| High School | 25 | 41.00 | 9 | 27.27 | 16 | 57.12 | | | |
| Degree | 7 | 11.50 | 4 | 12.12 | 3 | 10.71 | | | |
| Post-Degree | 2 | 3.30 | 1 | 3.03 | 1 | 3.57 | | | |
| Work | | | | | | | 7.75 | 8 | 0.458 |
| Employee | 18 | 29.50 | 9 | 27.27 | 9 | 32.13 | | | |
| Teachers | 4 | 6.60 | 2 | 6.06 | 2 | 7.14 | | | |
| Laborer | 7 | 11.50 | 4 | 12.12 | 3 | 10.71 | | | |
| Freelance professional | 8 | 13.10 | 5 | 15.15 | 3 | 10.71 | | | |
| Health professional | 1 | 1.60 | 0 | 0 | 1 | 3.57 | | | |
| Legal professional | 5 | 8.20 | 2 | 6.06 | 3 | 10.71 | | | |
| Artist | 1 | 1.60 | 0 | 0 | 1 | 3.57 | | | |
| Housewife | 2 | 3.30 | 0 | 0 | 2 | 7.14 | | | |
| Retired | 15 | 24.60 | 11 | 33.33 | 4 | 14.28 | | | |
| Family Status | | | | | | | 4.47 | 5 | 0.484 |
| Single | 1 | 1.60 | 0 | 0 | 1 | 3.57 | | | |
| Cohabitants | 2 | 3.30 | 1 | 3.03 | 1 | 3.57 | | | |
| Married | 49 | 80.30 | 26 | 78.78 | 23 | 82.11 | | | |
| Separated | 3 | 4.90 | 2 | 6.06 | 1 | 3.57 | | | |
| Divorced | 3 | 4.90 | 3 | 9.09 | 0 | 0 | | | |
| Widow | 3 | 4.90 | 1 | 3.03 | 2 | 7.14 | | | |
| Diagnosis | | | | | | | | | |
| epithelioid pleural mesothelioma | | | 23 | 69.69 | | | | | |
| sarcomatoid pleural mesothelioma | | | 1 | 3.03 | | | | | |
| biphasic pleural mesothelioma | | | 8 | 24.24 | | | | | |
| peritoneal mesothelioma | | | 1 | 3.03 | | | | | |

Antonio (caregiver): We're all upset.

Maria Pia (patient): My whole world has fallen apart. [...] When the ultimate diagnosis arrived, it killed me, in a moment. [...] I've been killed that day.

Giuliana (patient): I am afraid of blowing up.

Silvia (caregiver): I thought she [her mother, who has MM] was immortal.

1c. Death and aerial contagion phantasies

The fear of an "aerial contagion" of the disease could be traced in many participants' words, as well as ubiquitous death anxieties and a sort of "phantom of death" that could strike everybody, even the strongest ones.

Mirella (caregiver): I mean, he [her husband, who has MM] doesn't have the leprosy.

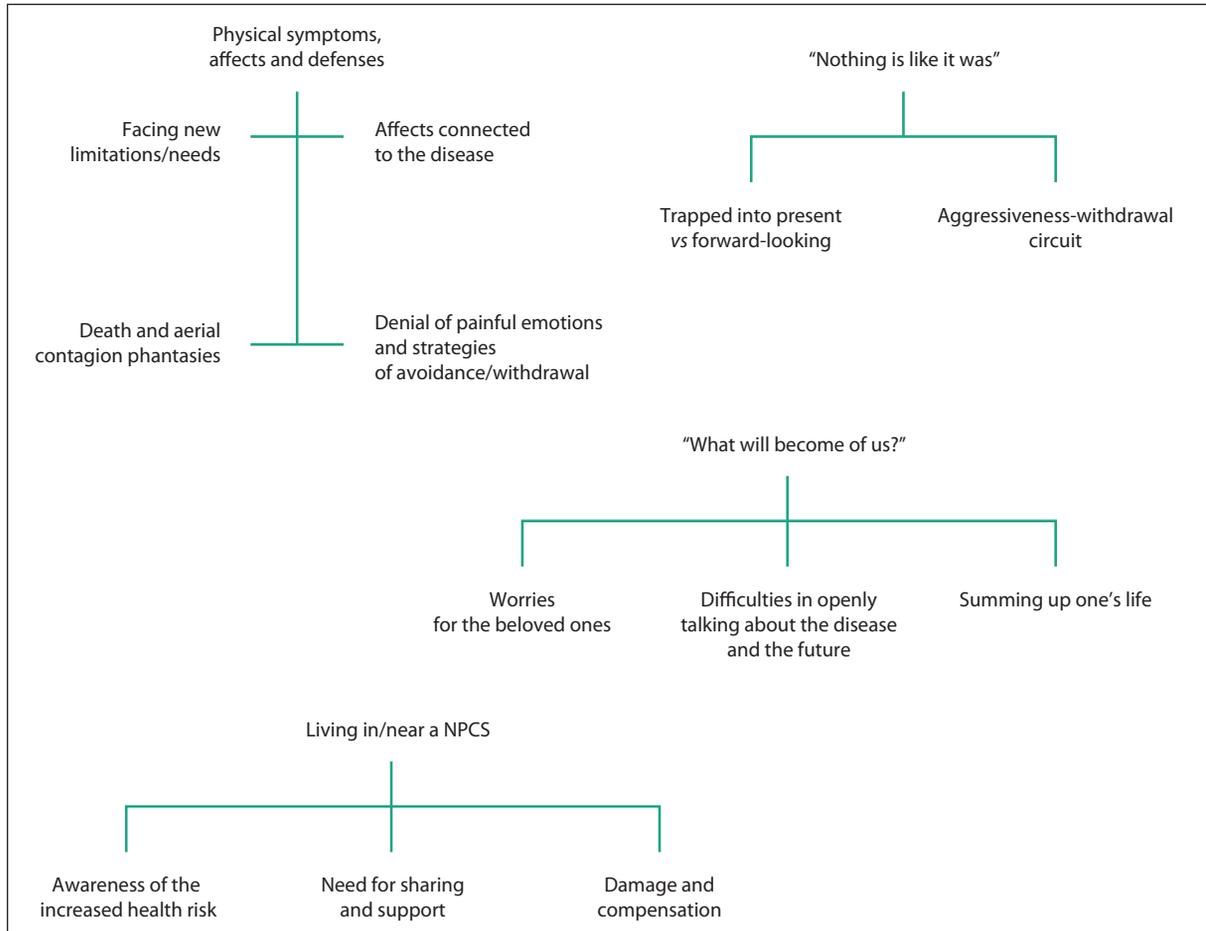


Figure 2
Thematic map.

Gabriella (caregiver): And there was a lady back in those days, in that very week when I went there, there was a lady who passed away that very morning. [...] She was a lady I knew, she had the strongest body that lady.

1d. Denial of painful emotions and strategies of avoidance/withdrawal

From the participants' narratives arose avoidant attitudes toward the emotional burden connected to the MM prognosis, showing the internalization of an internal logic based on not thinking/not seeing.

Mauro (caregiver): You try not to think about it. The less I think about it, the better I feel.

Bruno (patient): [another patient] told me: "Why are you so low? You don't have to think about that. I never think about that."

Laura (caregiver): I don't know if you really want to be aware of it, because you see her [her mother, who has MM] feeling good in this moment and you try to do what you've always done.

Many patients and caregivers seem to fight against feelings of guilt and shame connected to their illness. Gazes and questions activate intense feelings difficult to metabolize, which the patients seem to face with a withdrawal attitude.

Anna Rita (caregiver): There's nothing to be ashamed of, huh. I think. Because there are people who really [...] don't talk about that, you know. [...] What do you want to hide anyway?

Rino (patient): [and they ask you]: "How are you doing?" How do you think I'm doing? Don't be a pain in the ass!

Luca (patient): I've started thinking [...] "Now I'll go around, they'll see soon that I have mesothelioma, that I have a disease." And then I've asked to myself: "But why they have to see it? I don't have it written on my face."

Elvira (caregiver): It's like living as rats hiding in the hole.

2. Living in or near an NPCS

2a. Awareness of the increased health risk

During the interviews, all the subjects talked about the etiology of MM, connecting it with the geographical area in which they used to reside. They were all aware that living in or near Casale Monferrato represented a high risk for developing MM since their childhood and that it could still represent a risk for their health and the health of their loved ones.

Clara (patient): It's something that just happened, it happens to anyone [here], it could happen to anyone.



Matteo (patient): It happened to me, but it could happen to anybody here, after all, look. This not to be fatalistic, but how many ones we have left behind, even younger than me.

2b. *Need for support and sharing*

Some patients and caregivers put into words their need for affective closeness, containment, and the possibility to share the painful facets of the disease. In the narratives, the struggle to make sense of the diagnosis and its consequences with the loved ones strongly emerged.

Marta (caregiver): I count very much on [...] the possibility that he [the husband, who has MM] can compare himself to others with the same disease. So that he can stop feeling as he was marked by God. Because he says very often: "Why is this happening to me?"

Salvatore (patient): I don't have a companion. At night, I find myself all alone. You cannot say: "I have someone to whom I can talk about that". Yea, there is my son and my ex-wife, perhaps they will ask me how am I doing.

Filippo (patient): The point is always this: all you need is having the guts to say the first line, to talk, to communicate with the others, rightly, because if you stay in silence it's obvious that it's always hard to communicate.

Vittorio (caregiver): She was on the ground, but that day, let's say, talking with [another patient] she is reborn. They cheered her up, in a word, with their words.

2c. *Damage and compensation*

More than half of the sample talked about the trial against the Eternit factory and expressed a strong feeling of injustice, together with retaliation for the suffered damage.

Rino (patient): To attest that it is an occupational disease, I had to go to the INAIL and take some witnesses. They went there and answer all their questions [...]. They make it harder so that they don't have to pay: after all, it's mesothelioma. You should have the right and stop.

Loredana (patient): A lot of people really feel these feelings of shame, but in my opinion it's not mine, the shame. The shame is in the social world, that has not promptly intervened to stop some these things. Namely, I am the victim, there is no reason to be ashamed of being a victim.

3. *"Nothing is like it was"*

3a. *Trapped in the present vs forward-looking*

Patients focused on how their lives had changed because of MM, sometimes minimizing the impact of the diagnosis, sometimes putting emphasis on making the best use of the time left, sometimes talking about small goals they desired to reach and things they would like to do. Narratives show a constant tension between being stuck in a present worsened by the disease and the possibility of having a forward gaze to the future.

Fabio (patient): Well, nothing is like it was. You

have to think about your situation and make it go on in another way.

Sofia (patient): Indeed, these are the things that give you the chance to see the world not all black, but pale rose.

Camilla (patient): Sometimes I think about it, I even start crying alone. Others, I try not to think about that, I try to find ways to get distracted in any way, to give space to the things that I love, to the dreams that I still have. Dreams are not forbidden.

3b. *Aggressiveness-withdrawal circuit*

Caregivers showed a tendency to aggressively underline that their relatives changed after the MM diagnosis, grumbling against them and complaining that they were no longer as they used to be (desire vs reality).

Elvira (caregiver): [...] Why isn't he playing [the saxophone] anymore? Why is he behaving like that? Why doesn't he have these things [he used to do]?

Luisa (caregiver): They have always told him that he can live a normal life. He is the one who refuses to do so. [...] He could live a very normal life, but he doesn't, because he knows he is sick. [...] It makes me even madder that I cannot convince him to have a normal life.

Sometimes the patients themselves underline their changes and try to ward off their loved ones so that they cannot see how they have changed and will change because of the disease.

Maria Pia (patient): He wants to stay close to me, but it's hard, very hard for me, because I've changed. I'm angry, mean, I do not bear anybody anymore, I don't want to see anybody. And I feel, I don't know, a nullity. [...] I've told him: "Let's finish here our relationship". But he does not want to.

Such communications create a big emotional distance, triggering a circuit of aggressiveness and withdrawal that strongly impairs the quality of family exchanges.

Bruno (patient): She hurts herself and she becomes annoying with me.

Rosangela (patient): It's not that I don't want to fight or that they bother me. Well, but I'm saying that they always poke me.

4. *"What will become of us?"*

4a. *Worries for the loved ones*

Patients more often than caregivers expressed worries about the impact of MM on their families and about the fate of their loved ones.

Elisa (patient): Well, I think I can handle it, but what about him [the husband, MM patient]?

Domenico (patient): When I discovered it, there was a week, ten days, when I said: "Oh, jeez, what do I do? What will become of my future?" This is the first thing you start thinking of, not so much for me and for my fear, but for my children.

Angelo (patient): At first I was the one who supported her [the wife] and not she who supported me. Oh, well, I told her: "Take it easy. I do not give up".

4b. Difficulties in openly talking about the disease and the future

Participants' narratives show a certain difficulty in openly talking about the illness, their/their loved one's death, and the future, combined with an implicit demand to find new ways to talk about that in their families.

Rosangela (patient): He [the husband, MM patient] doesn't want to talk about my disease. [...] He doesn't talk with anybody.

Mirella (caregiver): Maybe [talking] in one way or another you can exchange views and ways to manage all of these, that could be completely different.

4c. Summing up one's life

For many patients, the diagnosis became a way to start thinking about their lives and how they have lived them.

Rosalinda (patient): This does not worry us, at all. We have worked, we have worked the entire life and then we have also built things. We are happy about that.

Loredana (patient): Look, it's a work you have to do. I hope I've walked well in my life, to have spent it well and that's it. If [the treatments] will go well, I am really happy, because I still have some ambitions to realize. If it will go bad, it doesn't matter.

DISCUSSION

The main aim of the present paper was to offer an overview of two research lines of the Research-Intervention Group of the Department of Psychology, University of Turin, "Psychological assessment and whole patient care for malignant mesothelioma patients and their caregivers".

Because there are no homogenous data and due to the absence of specific tools for the assessment of the psychological impact of MM, at the beginning of the paper, we presented the results of a systematic literature review (study 1: Development of specific questionnaires to detect the psychological distress and needs connected with MM). The review process led to the identification of 5 main areas of psychological distress connected with MM (psychological impact of MM diagnosis; emotional aspects connected to the occupational context; coping strategies; feeling connected to the treatment experience; quality of life), which will constitute the theoretical basis for the construction of a brief self-reported specific questionnaire.

The systematic review highlights that MM diagnosis is a traumatic event strictly connected with the occupational milieu of the disease, the reduced efficacy of medical treatments, and the poor prognosis. It has been suggested that the lack of effective treatments and defined guidelines may lead MM patients to experience feelings of confusion and uncertainty with respect to what is going to happen in their treatments and in their whole lives [20, 28]. Moreover, the awareness of the work-related etiology of the disease leads to specific forms of emotional distress, including rage and shame due to the unfair fate (i.e., becoming ill because of their work), along with feelings of guilt and a sense of responsibility for the onset of the disease and for having

exposed their loved ones to increased health risk [29, 32]. These negative emotions are painful and difficult to elaborate on, and MM patients may experience an internal conflict related with their sense of belonging and loyalty to the company/factory and their occupational identity. To face negative affectivity, patients often activate avoidance and denial strategies, which allow them to survive the catastrophic impact of the diagnosis by splitting the emotions connected to the disease and minimizing its impact [10].

One important result emerging from the review is the patients' subjective view of treatments, which seem to be experienced with a certain lack of trust and discomfort, probably because of the uncertainty of their effectiveness. Arber and Spencer [6] underlined that the unpredictable and rapid onset of MM may generate acute emotional distress in patients and compromise their efforts to deal with it, shaking down their faith in the health care protocols they are involved with. Moreover, patients enrolled in experimental clinical trials may experience intense conflicting emotions about the treatments: the fear of having a placebo may lead them to develop an aggressive attitude toward the health institutions that use them as "guinea pigs" and cannot prevent them from dying [28].

Finally, the review shed light on the importance of complementary and alternative medicine (e.g., palliative care, kinesiotherapy, diet) as well as of the legal and psychological facets of the disease, suggesting they should also be taken into account in the management of MM. Indeed, fostering these aspects may increase the active role of patients, increasing their agency and fostering the idea of having a positive impact on their medical journey and their whole life [33]. Asbestos support groups play a pivotal role in the process giving correct information about legal issues and the compensation process, as well as helping families affected by this work-related cancer to explore and elaborate on the negative effects linked with MM. As we suggested elsewhere, mesothelioma patient care and treatment should include an inter-disciplinary approach, which implies a highly specialized medical staff, advising caregivers on the correct management of symptoms, providing emotional support to the whole family, and exploring treatment options, as well as legal and financial options [34].

The main themes that emerged from the literature review are supported by the results of the thematic analysis presented in the second part of the paper (study 2: Assessment of the psychological impact of MM in patients and families). In line with previous studies [31], patients are more often males, while caregivers are more often females and younger. In fact, the majority of our sample had occupational exposure to asbestos, and a large amount of them worked at the Eternit factory.

The thematic analysis identified four different themes: 1. physical symptoms, affects, and defenses; 2. living in or near an NPCCS; 3. "Nothing is like it was"; and 4. "What will become of us?"

The interviews show that MM deeply compromises the body and the mind of those affected: indeed, a large amount of participants talk about fragilities and physical limits, new emerging needs for concrete help,



closeness, and affective involvement in such a painful time of their life. Guilt, helplessness, anger, and shame seem to destabilize both patients and caregivers, and to be often hidden in the family communications. The suffering connected to the illness seems to be actively denied: a sort of “out of sight, out of mind” attitude [20] seems to emerge, which prevents complete elaboration of the disease and the grief. Straker [35] pointed out that often cancer patients find themselves alone in front of the disease and overwhelming death anxieties they try to cope with through the activation of primitive defenses (i.e., denial, splitting, omnipotence). The activation of these defenses may lead to a sort of “you don’t have to think about that” attitude, revealing the tendency for denying mortality and avoiding a harmful reality [6, 24].

Dealing with MM could be too harsh of a reality to face, in particular in an NPCS, characterized by an increased health risk for the whole population. Some patients feel like some sort of “plague spreaders,” revealing the fear of infecting and being infected. The community has undertaken a lot of concrete actions to oppose asbestos (i.e., the creation of a park called Eternot in the place where the factory used to be as a symbol of memory and witness). Nevertheless, the community still has a strong idea of a contagion that can affect and kill anybody, even long after the factory’s closure and the asbestos ban [33, 36]. There is a sort of taboo for some of them, as if not talking about MM would mean getting away from the idea of separation and death [37]. It seems easier for them to speak about the damage they have suffered and ask for concrete compensation for what was unfairly taken away from them [38].

Patients describe caregivers as powerless witnesses of their illness. It seems very difficult for the caregivers to accept the gap between the mental and physical conditions of their loved ones as they were and as they are now, between the life they desire to live together and what they can do because of their new limitations (desire vs reality). It could be possible that the frustration and the hopelessness connected to the impossibility to modify this situation cause the caregivers to aggressively react to the limitations and the needs of the patients in an attempt to push them to actively react to the disease. However, this communicative strategy gives rise

in the patients to the feeling of not being recognized in their condition and leads to affective and relational withdrawal.

Finally, patients and caregivers wonder about their future: They seem to be worried more for their loved ones than for their own fate. They express difficulty in openly talking one to others about what is happening to them and what they are feeling [38-40]. This tendency could possibly be connected to a sort of unconscious attempt to protect others from the devastating impact of the disease. The request for new and more adaptive communicative modalities between patients and their families subtly emerges, which can help find new ways to talk about the disease in a sharing and close climate.

CONCLUSIONS

Psychological research on MM has important clinical implications for the management of both patients and their caregivers. It should be aimed at investigating the emotional features of the disease in order to increase the understanding of the psychological and relational facets of MM. Moreover, we strongly suggest the importance of building bridges between psychological research and interventions so that scholars can define shared international guidelines and evidence-based health care protocols including different disciplines. In our opinion, considering the occupational etiology of the disease, protocols should also include a strong link with unions, associations, and institutions (public or private) involved in the legal procedures for the compensation.

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Conflict of interest statement

There are no potential conflicts of interest or any financial or personal relationships with other people or organizations that could inappropriately bias conduct and findings of this study.

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REFERENCES

1. Bolis T, Masneri S, Punzi S. Il caregiver in oncologia: Tra ruolo e bisogni. *G Ital Med Lav Ergon*. 2008;30(3 Suppl. B):B32-B36.
2. Hashemi M, Irajpour A, Taleghani F. Caregivers needing care: the unmet needs of the family caregivers of end-of-life cancer patients. *Support Care Cancer*. 2018;26(3):759-66. DOI: 10.1007/s00520-017-3886-2
3. Granieri A, Tamburello S, Tamburello A, Casale S, Cont C, Guglielmucci F, Innamorati M. Quality of life and personality traits in patients with malignant pleural mesothelioma and their first-degree caregivers. *Neuropsychiatr Dis Treat*. 2013;9:1193-202. DOI: 10.2147/NDT.S48965
4. Nowak AK, Stockler MR, Byrne MJ. Assessing quality of life during chemotherapy for pleural mesothelioma: feasibility, validity, and results of using the European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire and Lung Cancer Module. *J Clin Oncol*. 2004;22(15):3172-80. DOI: 10.1200/JCO.2004.09.147
5. Kao SC, Vardy J, Harvie R, Chatfield M, van Zandwijk N, Clarke S, Pavlakis N. Health-related quality of life and inflammatory markers in malignant pleural mesothelioma. *Support Care Cancer*. 2013;21(3):697-705. DOI: 10.1007/s00520-012-1569-6

6. Arber A, Spencer L. It's all bad news': The first 3 months following a diagnosis of malignant pleural mesothelioma. *Psychooncology*. 2013;22(7):1528-33. DOI: 10.1002/pon.3162
7. Hughes N, Arber A. The lived experience of patients with pleural mesothelioma. *Int J Palliat Nurs*. 2008;14(2):66-71. DOI: 10.12968/ijpn.2008.14.2.28597
8. O'Brien ME, Watkins D, Ryan C, Priest K, Corbishley C, Norton A, Ashley S, Rowell N, Sayer R. A randomised trial in malignant mesothelioma (M) of early (E) versus delayed (D) chemotherapy in symptomatically stable patients: the MED trial. *Ann Oncol*. 2006;17(2):270-5. DOI: 10.1093/annonc/mdj073
9. Guglielmucci F, Franzoi IG, Zuffranieri M, Granieri A. Living in contaminated sites: Which cost for psychic health? *Mediterr J Soc Sci*. 2015;6(4 S3):207-214. DOI: 10.5901/mjss.2015.v6n4s3p207
10. Borgogno FV, Franzoi IG, Barbasio CP, Guglielmucci F, Granieri A. Massive trauma in a community exposed to asbestos: Thinking and dissociation in the population of Casale Monferrato. *British Journal of Psychotherapy*. 2015;31(4):419-32. DOI: 10.1111/bjp.12170
11. Granieri A. Amianto, risorsa e dramma di Casale. *Risvolti psicologici nelle persone affette da mesotelioma e nei loro familiari*. Genova: Fratelli Frilli; 2008.
12. Granieri A. L'amianto, la double peine. Casale Monferrato: atteintes physiques, traumatismes psychologiques, résistances. Fréjus: Sudarenes; 2013.
13. Baas P, Fennell D, Kerr KM, Van Schil PE, Haas RL, Peters S. Malignant pleural mesothelioma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Ann Oncol*. 2015;26(Suppl 5):v31-v39. DOI: 10.1093/annonc/mdv199
14. Novello S, Pinto C, Torri V, Porcu L, Di Maio M, Tiseo M, Ceresoli G, Magnani C, Silvestri S, Veltri A, Papotti M, Rossi G, Ricardi U, Trodella L, Rea F, Facciolo F, Granieri A, Zagonel V, Scagliotti G. The Third Italian Consensus Conference for Malignant Pleural Mesothelioma: State of the art and recommendations. *Crit Rev Oncol Hematol*. 2016;104:9-20. DOI: 10.1016/j.critrevonc.2016.05.004
15. Scherpereel A, Astoul P, Baas P, Berghmans T, Clayson H, de Vuyst P, Dienemann H, Galateau-Salle F, Hennequin C, Hillerdal G, Le Péchoux C, Mutti L, Pignon JC, Stahel R, van Houtte P, van Meerbeeck J, Waller D, Weder W; European Respiratory Society/European Society of Thoracic Surgeons Task Force. Guidelines of the European Respiratory Society and the European Society of Thoracic Surgeons for management of malignant pleural mesothelioma. *Eur Respir J*. 2010;35(3):479-95. DOI: 10.1183/09031936.00063109
16. Stahel RA, Weder W, Felip E, ESMO Guidelines Working Group. (2008). Malignant pleural mesothelioma: ESMO clinical recommendations for diagnosis, treatment and follow-up. *Ann Oncol*. 2008;9(Suppl.2):ii43-44. DOI: 10.1093/annonc/mdp134
17. Ball H, Moore S, Leray A. A systematic literature review comparing the psychological care needs of patients with mesothelioma and advanced lung cancer. *Eur J Oncol Nurs*. 2016;25:62-7. DOI: 10.1016/j.ejon.2016.09.007
18. Moher D, Liberati A, Tetzlaff J, Altman DG; PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med*. 2009;6(7):e1000097. DOI: 10.1371/journal.pmed.1000097
19. Bonafede M, Ghelli M, Corfiati M, Rosa V, Guglielmucci F, Granieri A, Branchi C, Iavicoli S, Marinaccio A. The psychological distress and care needs of mesothelioma patients and asbestos-exposed subjects: a systematic review of published studies. *Am J Ind Med*. 2018;1-13. DOI: 10.1002/ajim.22831
20. Clayson H, Seymour J, Noble B. Mesothelioma from the patient's perspective. *Hematol Oncol Clin North Am*. 2005;19(6):1175-90. DOI: 10.1016/j.hoc.2005.09.003
21. Dooley JJ, Wilson JP, Anderson VA. Stress and depression of facing death: Investigation of psychological symptoms in patients with mesothelioma. *Aust J Psychol*. 2010;62(3):160-8. DOI: 10.1080/00049530903510757
22. Lebovits AH, Chahinian AP, Gorzynski JG, Holland JC. Psychological aspects of asbestos-related mesothelioma and knowledge of high risk for cancer. *Cancer Detect Prev*. 1981;4(1-4):181-4.
23. Ugalde A, Aranda S, Krishnasamy M, Ball D, Schofield P. Unmet needs and distress in people with inoperable lung cancer at the commencement of treatment. *Support Care Cancer*. 2012;20(2):419-23. DOI: 10.1007/s00520-011-1296-4
24. Lebovits AH, Chahinian AP, Holland JC. Exposure to asbestos: psychological responses of mesothelioma patients. *Am J Ind Med*. 1983;4(3):459-66. DOI: 10.1002/ajim.4700040306
25. Ribi K, Bernhard J, Schuller JC, Weder W, Bodis S, Jörger M, Betticher D, Schmid RA, Stupp R, Ris HB, Stahel RA; Swiss Group for Clinical Cancer Research SAKK. Individual versus standard quality of life assessment in a phase II clinical trial in mesothelioma patients: feasibility and responsiveness to clinical changes. *Lung Cancer*. 2008;61(3):398-404. DOI: 10.1016/j.lungcan.2008.01.013
26. Wood H, Connors S, Dogan S, Peel T. Individual experiences and impacts of a physiotherapist-led, non-pharmacological breathlessness programme for patients with intrathoracic malignancy: a qualitative study. *Palliat Med*. 2013;27(6):499-507. DOI: 10.1177/0269216312464093
27. Moore S, Darlison L, Tod AM. Living with mesothelioma. A literature review. *Eur J Cancer Care*. 2010;19(4):458-68. DOI: 10.1111/j.1365-2354.2009.01162.x
28. Guglielmucci F, Franzoi IG, Bonafede M, Borgogno FV, Grosso F, Granieri A. "The less I think about it, the better I feel": a thematic analysis of the subjective experience of malignant mesothelioma patients and their caregivers. *Front Psychol*. 2018;9:205. DOI: 10.3389/fpsyg.2018.00205
29. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77-101. DOI: 10.1191/1478088706qp063oa
30. Charmaz C. *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage; 2006.
31. Ministero della Salute. Stato dell'arte e prospettive in materia di contrasto alle patologie asbesto-correlate. *Quaderni del Ministero della Salute*. 2012;15.
32. Guglielmucci F, Franzoi IG, Barbasio CP, Borgogno FV, Granieri A. Helping traumatized people survive: a psychoanalytic intervention in a contaminated site. *Front Psychol*. 2014;5:1419. DOI: 10.3389/fpsyg.2014.01419
33. Granieri A. The Drive for Self Assertion and the reality principle in a patient with mesothelioma: the History of Giulia. *Am J Psychoanal*. 2017;77(3):285-94. DOI: 10.1057/S11231-017-9099-0
34. Granieri A. Community exposure to asbestos in Casale Monferrato: From research on psychological impact to a community needs-centered healthcare organization. *Ann Ist Super Sanità*. 2015;51(4):336-41. DOI: 10.4415/ANN_15_04_14
35. Straker N. Psychodynamic psychotherapy for cancer patients. *J Psychother Pract Res*. 1998;7(1):1-9.

36. Granieri A, Borgogno FV. Pensabilità e dissociazione in una popolazione colpita da trauma massivo: Una ricerca intervento di matrice psicoanalitica. *Il Vaso di Pandora. Dialoghi in psichiatria e scienze umane*. 2014;22(2):83-102.
37. Guglielmucci F. Vita, morte e lotta nel sito contaminato di Casale Monferrato. Alcune riflessioni tra clinica e ricerca. Genova: Fratelli Frilli; 2016.
38. Granieri A. Extreme Trauma in a Polluted Area: Bonds and Relational Transformations in an Italian Community. *International Forum of Psychoanalysis*. 2016;25(2):94-103. DOI: 10.1080/0803706X.2015.1101488
39. Franzoi IG, Guglielmucci F, Borgogno FV, Granieri A. Il caso Giulia. *Psicoterapia e Scienze Umane*. 2015;XLIX(4):656-64. DOI: 10.3280/PU2015-004007
40. Granieri A. La comunità contaminata di Casale Monferrato: aspetti corruttivi della governance e sopravvivenza psichica. In: Ambrosiano L, Sarno M (Eds.). *Corrottori e corrotti. Ipotesi psicoanalitiche*. Milano: Mimesis; 2016.

