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The death of a loved one. A proposal to prevent complicated grief in palliative home care when assistance

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ABSTRACT

Background: past studies have investigated the relationship between mourning and the quality of life in caregivers who care for terminally ill patients. Recently, complicated pain has been recognized as a risk factor for mental and physical health and severe suffering can interfere with individual functioning and social relationships. Every day, home-based palliative care workers confront health professionals who may develop complicated pain after the patient's death.
Methods: the aim is to identify family members who take care of a high risk of complicated pain and to do this the SISIFO Consortium has developed a psychological intervention program to prevent complicated pain in family caregivers of terminally ill patients.
Results: the common features of the psychological intervention and the future directions of the research were discussed.
Conclusions: the purpose of this document is to illustrate the detailed procedure of the palliative home care service. Furthermore, the results of the psychological intervention program adopted by the service were briefly summarized.

Keywords: *palliative care; caregiver; mourning; complicated grief; psychological intervention*

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Introduction

Each of us lives the experience of the death of a relative or a loved one throughout our lives. The manifestations of suffering that characterize mourning, however painful, should be considered as a physiological reaction to loss. Through resilience most people manage to recover from the loss and do not experience psychic and / or physical symptoms over time (Bonanno, 2004). However, for some psychic symptoms or complications may arise in the so-called mourning process defined as "complicated mourning".

Complicated mourning is essentially characterized by the presence of feelings of sadness and nostalgia, continuous evocation of the deceased, memories and intrusive images that can persist even for years after death. The interest of the scientific literature for this disorder is given by the associated consequences, including an increase in mortality risk, especially in the period immediately following the loss (Stroebe, Schut, & Stroebe, 2007).

A lot of research has been done to assess the prevalence of complicated grief in people who have suffered a loss by obtaining different results. For example, according to the DSM-5 (American Psychiatric Association, 2014) the percentage of subjects who live in a condition of "complicated mourning" would be around 7-10%; another study found a percentage of around 20% (Mason, Tofthagen, 2018). Recently, a meta-analysis has identified a prevalence of approximately 10%, even if a high heterogeneity of the included studies is observed (Lundorff, Holmgren, Zachariae, et al., 2017).

At the same time, researchers' attention turned to identifying risk factors for the development of complicated grief in order to identify the caregivers most at risk and implement targeted psychological support interventions (Nielsen, Neergaard, Jensen, et al., 2017).

However, there is currently a gap between clinical practice and empirical research regarding the identification of subjects at risk. An effective prevention method is to screen caregivers when the patient enters palliative care (Thomas, Hudson, Trauer, et al., 2014). In the sphere of palliative care, bereavement takes on a central role since the charge by the multidisciplinary team (Rugnone, Traina, Lenzo, et al., 2017). For example, the so-called "early mourning" requires a psychological intervention because it hinders the path of accompanying the patient and the family. Furthermore, it is an established fact that the presence of "early mourning" increases the use of medical services in the spouse after the patient's death, especially in the case of chronic diseases (Gerber, Rusalem, Harmon, et al., 1975).

Mourning is a risk factor for the development of both physical and mental disorders (Wittouck, Van Autreve, De Jaegere, et al., 2011), so prevention and treatment are a fundamental part of all palliative care services. Although the scientific literature and the clinical experience of palliative care workers agree on these needs, there are also critical issues that can increase the risk of complicated grief. One of the main critical points concerns the assistance modalities in the sphere of home palliative care. Over the years, many caregivers have taken care of palliative care patients who had been caregivers of other patients assisted in the past. This information, which emerged usually during the meetings of case discussion teams, caused mixed emotions in the operators. Astonishment, anger, guilt along with a strong personal involvement are just some of the reactions of the operators who found themselves in the same house to assist a patient who had previously been the caregiver of another patient. This has prompted us to ask ourselves what happens to families when assistance ends. Over time, the need has also arisen to implement an intervention method aimed at preventing complicated mourning conditions in caregivers.

In this perspective we started by examining the legislative reference on palliative care in Sicily and specifically what is sanctioned with respect to mourning. In this regard, the Decree of the Sicily Region of 2 December 2015 "Organization and development of the local palliative care network" (Decreto della Regione Sicilia, 2015) identifies support for mourning as a distinctive element of palliative care. The Decree also highlights the role of the treating team in carrying out a visit of condolences as an integral part of the care pathway after death. The local palliative care network as established by the Decree "must therefore guarantee support programs for the relatives of patients cared for in the case of pathological mourning (page 33)".

However, critical issues are still observed by the local network in ensuring adequate psychological support to family members, at least from reports of some family members. In fact, there has been a lack of awareness of the moment of strong instability that the family experiences in conjunction with mourning.

The personal and family reorganization phase for some members can be particularly difficult. To increase the risk of the onset of complicated mourning conditions can contribute to the provision of assistance. The last part of the accompanying path of the patient and the family is generally linked to an increased care intensity on the part of the multidisciplinary team. A greater presence of the home team is related to a greater need for families to be supported. The requests are not only of a care and health nature, but also emotional, psychological and relational. The loss of the family member is sometimes added to the loss of a relationship with the care team that over time had also become an emotional point of reference.

The patient's death and the end of home care can therefore determine a hiatus that if not "thought" by the care team helps to hinder the physiological process of mourning. In other words, the end of health care cannot coincide with the end of the relationship since the latter must follow parallel but different passages.

In this perspective, the procedure outlined by the SISIFO Consortium implemented with all the families of patients in home-based palliative care will be described below. The SISIFO Consortium is a consortium of social cooperatives that has been providing home-based palliative care since 2003 in the territory of Messina and its province. It is currently one of the bodies accredited by the Sicily Region and operates in the provinces of Agrigento, Caltanissetta and Messina.

By way of example and without any claim to completeness, three cases will be presented here followed within this project. These cases are very different from each other and can help illustrate some elements inherent to the complexity of the path.

Method

Procedure and Measures

The interviews were carried out at the headquarters of the operations center in a specially dedicated room. Before the beginning of the interview process at the operations center, in the cases 2 and 3, four post-mourning home meetings were held.

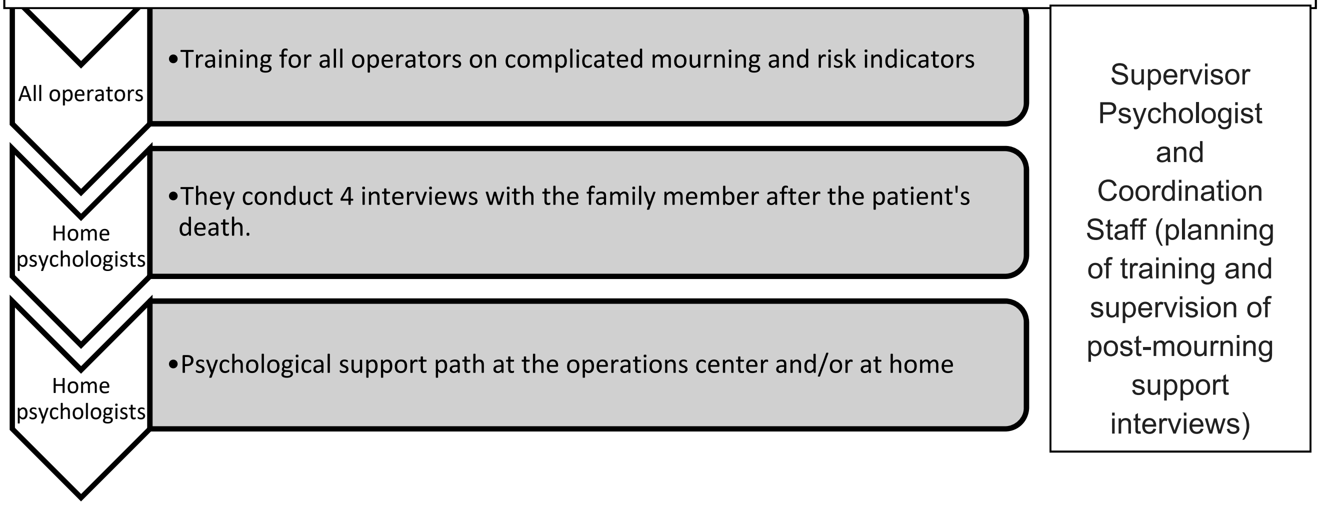
Steps of the project

The project was developed in steps below summarized starting from December 2015:

1) **Training.** The training course was aimed at all operators focusing on complicated mourning and on which are the risk indicators. In addition, for home-based service psychologists, training focused on the early identification of risk factors and on monitoring them during psychological intervention.
2) **Ad hoc creation of a course of four interviews.** During the bereavement visit, the psychologist, in consultation with the team, can propose interviews to the family member, usually carried out at the family's home. The decision to carry out these further meetings stems from the observation made during home care and from the needs identified during the bereavement visit. At the end of these interviews, the home psychologist draws up a report on the case with the indication or not to a path of psychological support. Post-mourning talks generally have goals to analyze the caregiver's demand.
3) **Path of psychological support for complicated mourning.** Family members at risk of developing complicated mourning can begin a path of psychological support at the operations center and / or home at the end of the four interviews. The interviews are generally weekly and last one year. On a regular basis and at the end, the psychologist draws up a report on the progress of the course and the objectives achieved. There is also an evaluation of the mourning at the beginning and every 6 months through standardized tools.

The entire route is coordinated by the supervisor psychologist. The entire path is financed by the Consortium and follows a funnel structure, as can be seen from Figure 1.

Figure 1. Step of the complicated mourning prevention project



Participants

The participants are all the families of patients in palliative care at home belonging to the Consorzio SISIFO.

The SISIFO Consortium is a consortium of social cooperatives that provides palliative care at home since 2003 in the territory of Messina and its province and is currently one of the bodies accredited by the Sicily Region operating in the provinces of Agrigento, Caltanissetta and Messina.

Case 1

Mrs. S. are the parents of a 24-year-old patient who came into care following the sudden onset of severe leukemia. Sometime after the death of his son, on the advice of the home palliative medicine doctor, Mr. S. presented himself at the first interview with the psychologist showing a strong need to reconstruct the meaning of what happened to them. The son is described as a model boy, loved by all, with an excellent schooling and always ready to help others. From the moment of diagnosis, everything that happened was experienced by the parents as if it were not true, as if it were a nightmare with open eyes, a complete derealization. However, they have daily been involved in taking care of their child, so much so that after the patient's death they experience a series of difficulties. One of the main concerns is to be able to talk about the death of the child, to share what happened to them without arousing only glances of compassion in others.

During the initial meetings they suddenly realize that this difficulty also lives between them. The mourning support process lasted six months and had as its first objective the expression of emotions, often conflicting, linked to the memory of the child. Given the strong and often discordant emotions present in the aftermath of mourning, the meetings were aimed at making explicit and understanding the emotions experienced. The central phase of the journey focused on the families of origin of the couple and on their being parents. The presence of feelings of guilt and thoughts that oscillate between impotence and omnipotence emerges in this phase. Messrs. S. are wondering what they could have done to save their child if, for example, they had noticed before the illness. It should be pointed out that the disease was diagnostic already in the terminal phase and up until then had not given specific signals. The last part of the path to support bereavement is characterized by another crucial question, summarizing how to continue living without the child. Despite the difficulties and the suffering connected to this question, there is an evolution in the processing of the loss. Until then the S. gentlemen had repeatedly claimed that their life was completely over. The mourning support path closes for Easter (a holiday that symbolically contains death and resurrection) with the awareness of the difficulty of a life without the child but also of the effort to continue living for him.

Case 2

A. and S. are two sisters in their 50s whose eighty-year-old mother was treated in home care. The assistance lasted a couple of months and was characterized by the strong difficulties of the two caregivers to accept the termination of the mother's illness. The two ladies, unmarried and unoccupied, have always lived with their mother since their father had suddenly passed away about 25 years ago. From the first interviews, it emerges that they had never imagined themselves living without their mother, especially after the death of their father. Before their mother's illness, they spent their days together, often remembering the past with great nostalgia, when "there was still a father". During palliative care assistance at home, they were constantly and progressively informed about the patient's prognosis, but as they say now they never wanted to "really believe it". So now, they find themselves in an unexpected and new condition that is, living alone and having to think about the future. In the first interviews, there are also strong feelings of guilt that revolve around the conviction of not having done everything that was possible for the mother. The most obvious difficulty at the beginning of the path therefore concerns the failure to accept the loss of the mother. However, this loss is part of a broader criticality linked to relations with others and more generally with the outside world. The family world is, in fact, described as a secure base, a protected context where it is possible to find satisfaction for their needs. In contrast, the outside world is considered full of dangers of various types and excessively frustrating. This dysfunctional thought that has characterized the whole childhood of the two ladies, now risks forcing them into a condition of isolation. The psychological intervention on mourning must therefore be inserted within a wider objective, aimed at a change in the internal and external relations of the two sisters. The psychological support path lasted one year with weekly meetings. At the end of the meetings there are no longer strong feelings of guilt that characterized the beginning together with a greater openness to the outside world.

Case 3

Ms. T. is the wife of a 50-year-old patient who entered home-based palliative care following a sudden worsening of conditions. A few years earlier he had received a diagnosis of late-stage cancer so that no therapy could be undertaken. During the talks, the lady tells of having lived the last months of her husband's life trying not to think about the termination of the illness. The death of her husband was therefore experienced as something unexpected and unjust. Despite the notable deterioration of the patient's condition, the lady continued to believe that her husband "would have made it". Now after a long time he says that at that moment he could not accept this cruel truth, nor could he accept that her husband knew that there was nothing left to do now. The lady is also afraid of forgetting about him and for this he surrounds himself with objects that help her to remember him. Almost all the initial interviews focused on the often-intrusive memories of her husband's last days. Every moment is lived vividly and is accompanied by intense feelings of sadness. In the first months after mourning, the lady expressed the need to think that her husband was only temporarily absent. The lady repeatedly dwells on the fact that her life coincided entirely with that of her husband. Now that her husband is gone, her life has lost all meaning, there is an empty space that cannot be filled. The work of processing the loss seems inextricably linked to the need to reconceive itself. The only way to avoid being overwhelmed by the loss of a husband is through an individual change and a new social opening. Only in this way will it be possible for the lady to live with this absence. After the initial phase, the path of psychological intervention focused on the lady's dysfunctional thoughts and on the "need to look to the future at an age when one is no longer young, but not even elderly". A year later the lady no longer complains of intrusive thoughts or feelings of guilt, despite the sadness and nostalgia for the loss of her husband. At the same time, the woman reports that she has made many friends and discovered personal resources she didn't think she had.

Results

From the quantitative data in our possession for the years 2016, 2017 and 2018, the prevalence of cases in which further meetings with caregiver were held after the bereavement visit is around 10%. From the reports made by the psychologists, the needs and critical issues that emerged during these meetings are heterogeneous. A brief description of the followed cases has shown the clinical efficacy of the psychological intervention to reduce anxiety and depression and to improve quality of life.

However, the different characteristics, as length of treatment and diversification of caregivers' symptomology, should be carefully considered by psychologists. A deeper discussion of results and clinical implications is argued below.

Discussion

Clinical experience and scientific literature have led us over the years to question what happens to our patients' families when home care ends. The end of medical interventions is accompanied by relational needs on the part of the family and in particular of the caregiver who in some cases need a real care taken by the psychologist. Mourning is indeed a real critical moment from which significant psychopathological conditions can also arise. In this perspective the psychological intervention on mourning is considered an integral part of the palliative care approach. However, in daily clinical practice there are critical issues in the ability of local palliative care networks to provide timely and appropriate responses to caregivers. For this reason, at the end of 2015 the SISIFO Consortium implemented an intervention procedure with the aim of reducing the risk of complicated grief for all caregivers of patients assisted in home care. As stated, from the first data in our possession relating to the three-year period 2016-2018 it would seem that the need for further post-mourning talks is around 10% of the total number of cases followed. This data appears to be in line with some studies that show a medium-low prevalence of development risk of complicated grief. At the same time, we observe a high complexity in the needs of caregivers who have undertaken a path of psychological support after bereavement. In this regard, three very different cases have been briefly presented and highlight the need to include the intervention of the psychologist within a broader horizon. Another element that contributes to making interventions on mourning complex concerns the time variable. Conventionally, the time necessary for what is termed "mourning" is identified in a year (Freud, 1915). Nevertheless, from clinical practice it emerges that interventions on caregivers at risk of complicated grief can vary in duration depending on the initial objectives. The analysis of the demand, together with the shared definition of the objectives seem to assume a fundamental role in the effectiveness of the psychological intervention.

This is also important to prevent the psychological intervention from becoming iatrogenic, for example reinforcing the caregiver in the role of "victim" or "sick". For this reason, it is important that the psychologist not only work on the symptoms but also on the resources of the caregiver. Another common element that emerges from the cases followed is the emotional confusion experienced by the caregiver in the period immediately following mourning. Different and often conflicting emotions and feelings may be present. Together with sadness and anger, it can also be present to relief for the end of an unsustainable suffering in the last period of life of the family member. Increasing limitations together with the irreversibility of the disease can in fact lead the caregiver to hope that this situation will end soon. In addition, there may be a strong sense of guilt in not being able to do more to help your family member. These are just some of the facets present in the caregiver's internal world, of which he is often not fully aware. In the early stages of the mourning support pathway, it is therefore important for the psychologist to help the caregiver express and understand these emotions.

Attention to mourning and to everything associated with it is not just for the psychologist, but for the whole multidisciplinary team. Each operator must have specific skills to be able to manage the relationship with the family even after the patient's death. In addition, each member of the multidisciplinary team must be able to assess the risk of complicated grief by actively collaborating with the psychologist to promptly report critical situations.

Ultimately it is important to highlight the need for complicated mourning prevention to receive greater attention from the palliative care network nodes. The creation of shared procedures that can provide targeted, timely and effective responses to patients' families appears to be desirable. Nevertheless, it is important that research into the prevalence of complicated mourning and above all risk factors increase in the sphere of palliative care. Currently underway there is a research that sees the SISIFO Consortium as the leader of a project aimed at investigating the prevalence and risk factors of complicated grief. The results obtained will serve to improve the complicated mourning prevention procedure described in this paper.

Conclusion

Mourning is a critical moment from which significant psychopathological conditions can arise. In this perspective the psychological intervention on mourning is considered an integral part of the palliative care approach. However, in daily clinical practice there are critical issues in the ability of local palliative care networks to provide timely and appropriate responses to caregivers.

Since 2015, the SISIFO Consortium has set itself the goal of implementing an intervention procedure to reduce the risk of complicated grief for all caregivers of patients assisted in home care. From the data in our possession, a high complexity has been observed in the needs of caregivers who have undertaken a path of psychological support after bereavement. Another element that contributes to complex interventions on mourning concerns the time variable. However, clinical practice shows that interventions on caregivers at risk of complicated pain can vary in duration depending on the initial objectives. Furthermore, it is of considerable importance that the psychologist not only work on the symptoms but also on the resources of the caregiver. Furthermore, there may be a strong sense of guilt in not being able to do more to help your family member. These are just some of the facets present in the caregiver's internal world, of which he is often not fully aware. It is also essential that every member of the multidisciplinary team is able to assess the risk of complicated pain by actively collaborating with the psychologist to promptly report critical situations.

It is important that research on the prevalence of complicated grief and above all risk factors increases in palliative care.

Limit of the research and future prospective

This study has some limitations. First, our sample size was small and the absence of a control sample limits our knowledge about the clinical efficacy of the proposal psychological intervention. In fact, it is not possible to generalize the study results to the clinical practice. Second, the results are mainly based on a qualitative point of view and the use of well-established measures to evaluated the risk of complicated grief is needed.

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Declaration of Interest statement

Declarations of interest: none.

Authors' contribution

Vittorio Lenzo, Carmen Isgrò, Antonino Germanà, Micol Mazzei, Caterina Testaì, Valeria Verrastro e Maria Catena Quattropani have contributed in equal measure to the realization of the concept, to the analysis of the data, to the preparation of the manuscript and to the modification of the manuscript. All authors contributed to and have approved the final manuscript.

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