Evaluation and prevention of maladaptive reactions in patients with gynaecological cancer: an experimental study of the expression of emotional experience

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Abstract

Introduction: the prevention and the early diagnosis in the treatment of breast cancer represents the main type of intervention able to change the course of the disease. The aim of the study is to highlight the peculiarities of the experience of cancer diagnosed inpatients.

Materials and methods: through the content analysis the authors have examined, by performing chi-square test, 25 free content verbal reports of patients suffering from gynaecological cancer and 25 reports of patients with non-tumour disease, all in-patients in the same specialised department.

Results: in the oncological patients group the results have showed the greatest frequency on emotional disorder and specific behaviour read as an expression of extended defensiveness and frequent references to the family members, in particular to the spouse and children (p<0.05). The two studied groups have in common the feelings of insecurity and the desire to obtain information about the disease.

Shortly, the behaviours found in oncological patients can be traced back to the initial reaction of rejection and isolation, accompanied by an indirect request for contact with the family members. The content analysis has not disclosed the differences in the two groups about the perception of the treatment and health facilities ought to welcome the ill person.

Discussion: the evaluation of the verbal reports can be the starting point to highlight and operate in any emotional disorder and maladjusted reactions which can further reduce the subjective well-being of the patient, compromising the adherence to the therapy and further debilitating, reducing the physical reaction against the neoplasia.

KEY WORDS: cancer, content analysis, emotional experience.

Background

The prevention and the early diagnosis in cancer care is the main type of intervention able to change the course of the disease. In Italy the total number of prevailing cases has increased and it grows at a rate of about +3% per year (1).

Assuming a stability of these increase rates, it is possible to quantify that about 2,900,000 Italian citizens in 2014 were alive after the diagnosis of tumour. To carry out a periodic screening of the population at risk, however, may not be sufficient to contain the phenomenon of the delays in the diagnosis.

Even after initial adherence to the first investigation, in the second cycle of screening, if the results strongly suggest presence of neoplastic formations, sometimes the patient does not undergo further diagnostic exams to confirm or exclude the presence of the disease stopping the necessary course for an early diagnosis.

Some of the reasons mentioned by the patients for not having contacted the doctor earlier can be grouped into the following general categories: ignorance of the meaning of symptoms, hope that the symptoms disappear “as by magic”, socio-economic and family problems, lack of pain, fear about cancer.

In addition, the insufficient information, the lack of homogeneity in the prevention campaigns, the lack of involvement of professionals from the field can all influence the adherence to these initiatives. In a statement of the Ministry of Health on the cancer screening Greco (2) says: “disoriented, uninformed, and a sceptical citizen no longer considers screening as an act of responsibility toward their own health”.

In case of more specific diagnostic tests it should not be underestimated, the onset of emotional factors such as anxiety, fear, loss of self-esteem, sadness, uncertainty on what to do and (for someone) even depression, which trigger denial or sceptic behaviour, put the patient away from the possibility of having a certain diagnosis and eventual treatment.

If the diagnosis is confirmed it could be desirable to establish tools that act as a psychological support to people called to a subsequent check up. It is important to remember that the communication of the diagnosis of a
chronic disease such as cancer leads to the radical change in the life-style of the subject. The awareness of being a cancer patient causes a variety of reactions such as confusion, anxiety, fear and desperation. In some types of tumour, such as female tumours; uterine cervix, breast and colorectal the early diagnosis, through adherence to the screening cancer, can make a difference in the course of the disease. The intervening psychological factors are crucial. In the case of the confirmed gynaecological cancer, the experience of diagnosis and treatment has been described as a physical and psychological trauma that reduces the patient to the condition of passive acceptance and increase the vulnerability (3).

After having overcome the impact of the diagnosis the patient must face the treatment which consists, almost always, in surgery: this represents, for the majority, a traumatic experience accompanied by hopeless feelings (4, 5). The diagnosis and possible surgery would be the greatest stress factors. The emotional disorder caused by the stressful event, is associated with the urgent need to put in place, as soon as possible, specific strategies to the new situation. One research carried out on women with a breast cancer diagnosis, has detected the greater sensitivity to the psychological adjustment in the period between diagnosis and surgery (6). It is desirable to provide care and attention during this period, because an active acceptance of the diagnosis is a good predictor of adjustment one year after the surgery (7).

This data has been confirmed in several studies which have shown a wide range of demands for psychosocial support and for information expressed by recovered patients with female cancer. In particular, the healthcare professionals from this field have shown need for emotional support (8-11).

It is also important not to underestimate the subjective aspects related to the entity of the emotional-physiological reaction manifested in the stressful conditions. Some events are experienced as stressful depending on whether they are perceived as such and in which measure. A stimulus may trigger a reaction of distress or not depending on how the circumstances are interpreted and evaluated (12). Therefore, the importance of diagnosis communication is crucial. Some researchers have pointed out that the doctor’s empathy and communication skills are the basic elements involved in the reduction of the emotional disorder. These skills can increase self-efficacy of the patient in the acceptance of the diagnosis (13).

As confirmation of this data a recent study shows the importance of communication style used by the physician with the patient. Speak clearly about the disease, its course and the subsequent treatment, has a positive impact on the representation of the disease, which in turn would seem to be related to the physical improvement and the adaptive skills of the patient. The quality of the doctor-patient relationship instead does not appear to play a decisive role in the initial stages, but rather during the treatment (14). This data has been reflected in a study of the quality of life before and after the rehabilitation of patients with breast cancer. The results showed that the degree of satisfaction of the doctor-patient relationship can improve the quality of patients life in the period following the rehabilitation treatment (15).

Despite an increasing number of women recovered from cancer and adjusted to the changes, for some of them the negative psychosocial consequences have been persistent and interfering with the quality of life. This data highlights real need for a therapeutic support (16, 17). The different ways in which the process of adjustment starts to the stressful situation are defined coping strategies. Gonzales et al. (18) found there are different styles of coping in patients diagnosed with breast cancer: the defensive avoidance, the fragility and the hopelessness feelings mixed with pessimism, passive acceptance and resignation. All these factors predict a poor psychological adjustment in the first three years after the surgery. The defensive strategies adopted seem to reduce the stress in three months, but increase the fear of the relapse during the first year.

In relation to what has been said some studies have explored the role of social support in stress relief for the patients with gynaecological cancer, confirming the importance of being able to escape the isolation with the support of the family, in particular of the spouse (19, 20).

The social activities where is possible to speak about physical and psychical suffering may be complementary to any type of therapy, and in some cases improve its effectiveness. During the hospitalization a functional adjustment to this disease seems to be conditioned by two fundamental psychological factors. The first, predominantly cognitive, includes use of attention and judgement processes, embodied by cultural contributions, in particular, education and employment. The second, mainly affective, seems to be composed primarily of acceptance and adherence to the medical procedures and toward the healthcare personnel (21). Negative experiences for the above aspects were connected with the development of emotional distress, both with the deterioration of the life quality. Sometimes healthcare practitioner may not grasp the patient relational or psychological condition. For this reason it is crucial that healthcare practitioners who work with cancer patients listen to and carefully observe everything that the person carries with, trying to catch up with all the verbal and non-verbal signs useful to provide the necessary support for the right adjustment.

During the period between the diagnosis and surgery the need for a psychological support and for being listened to with the possible impact on the outcome of clinical treatments has created the conditions for further study of this subject. The goal of our study is to highlight the peculiarities of the experience of cancer diagnosed inpatients. For this purpose, free topic reports of the inpatients received surgical treatment for genital carcinoma were examined and compared with reports produced by inpatients from the same ward, but tumour free and less seriously ill and with less dramatic physical and psy-
We have adopted this technique to analyse the recorded reports provided by patients in our sample. The analysis makes possible to measure objectively expressions to emotional content, thereby providing data on the extent of emotional adjustment of the subject. The proliferation of techniques based on the transcript of the verbal content and/or on voice recognition has highlighted the need of scientifically valid methods where obtained data could provide relevant information for the analysis of psychic processes (23).

The software for the content analysis may be divided into two groups:

a) CAQDAS (Computer-aided qualitative data analysis software) software allows to label manually portions of text with alphanumerical codes related to the concepts that the researchers wish to stress (the best known are Atlas, The Ethnograph, Nvivo, etc.);

b) The software for the semi-automatic analysis through statistical and lexical techniques (the best known are SPAD, Alceste, Lexico, etc.).

The softwares of the first group are also very useful for browsing the text but with increase of the text size of the coding process they become very expensive. The software of the second group instead is based upon the words and their relationships within the text analysis and are particularly useful for the systematic analysis of large texts.

For our work we have chosen the first group of software in order to perform a qualitative analysis of text built on the patients reports. Therefore Atlas software was initially used to collect the significant vocabularies according to the patient’s reports, then through SPSS 22.0 chi-square test was performed to highlight any differences between the interviews of the different sample patients.

Results

After the collection and transcription of the interviews we proceeded to the examination in order to identify trends that characterize the communications of the patients, choosing the single word as the unit of analysis. Based on this preliminary examination 9 words were defined. These categories have emerged from the frequency analysis of the words related to issues of particular interest in the light of our previous experiences (18) and the recent acquisitions in the literature outlined above:

- emotional disorder
- time perception
- references to the family
- reflective activity
- uncertainty
- emphasis on information
- somatic diseases
- references to health services and healthcare practitioners
- references to diagnostic treatments and therapies.

These categories were defined as mutually exclusive and independent: the value of one category does not influence the value of another.
The data collected from the cancer patients group were subjected to the statistical analysis and compared with those of the control group by the chi-square test. The first category of words defined as “an emotional disorder”, isolated and studied, includes all expressions of considerable degree of emotional involvement of the interviewed subjects (Tab. 1).

Table 1 - Results of comparison of the content analysis between the group of oncological patients and the control group (*p<0.05; **p<0.01).

<table>
<thead>
<tr>
<th>Category</th>
<th>Words</th>
<th>Patients</th>
<th>Frequency</th>
<th>X²</th>
</tr>
</thead>
<tbody>
<tr>
<td>I: Emotional Disorder</td>
<td>fear, problems, alone, shame, anxiety, dead, cry, die</td>
<td>Oncological</td>
<td>83</td>
<td>10.04**</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Control</td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>II: Time Perception</td>
<td>now, now, years, months, already yesterday, wait, week, time/i, now, urgency</td>
<td>Oncological</td>
<td>135</td>
<td>20.06**</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Control</td>
<td>214</td>
<td></td>
</tr>
<tr>
<td>III: Reference to the family environment</td>
<td>home, family, child, husband, brother, sister</td>
<td>Oncological</td>
<td>118</td>
<td>20.18**</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Control</td>
<td>56</td>
<td></td>
</tr>
<tr>
<td>IV: Reflective activity</td>
<td>thought, I think, I thought, thought</td>
<td>Oncological</td>
<td>21</td>
<td>3.91*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Control</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td>V: Uncertainty</td>
<td>maybe, I can, instead, seems, we can</td>
<td>Oncological</td>
<td>71</td>
<td>n.s.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Control</td>
<td>52</td>
<td></td>
</tr>
<tr>
<td>VI: Emphasis on information</td>
<td>truth, true, normal, really, know, answer, I knew, the result</td>
<td>Oncological</td>
<td>56</td>
<td>n.s.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Control</td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>VII: Somatic Disease</td>
<td>blood, hemorrhage, plague, pain, inflammation, nodule, losses, cysts, sterility, distress</td>
<td>Oncological</td>
<td>86</td>
<td>n.s.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Control</td>
<td>70</td>
<td></td>
</tr>
<tr>
<td>VII: Health services and practitioners</td>
<td>doctor, professor, phd, practitioner, gynaecologist, clinical, counselling, department, policlinic</td>
<td>Oncological</td>
<td>135</td>
<td>n.s.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Control</td>
<td>139</td>
<td></td>
</tr>
<tr>
<td>IX: Diagnostic and therapeutic interventions</td>
<td>pap tests, visit, ultrasonography, investigations, inspections, monitoring, hospitalization, surgery, scraping, care, therapy, lavages, surgery, seeding</td>
<td>Oncological</td>
<td>138</td>
<td>n.s.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Control</td>
<td>140</td>
<td></td>
</tr>
</tbody>
</table>
In 25 reports of oncological patients in fact were found 74 words, such as: fear, problems, alone, shame, anxiety, dead, crying and dying. The control group has used such terms only 38 times; the difference was statistically significant (chi² 10.04; p < 0.01).

The frequency in the second category called “time perception” has shown a lower value of 135 with a lower use of idioms of time, such as; now, immediately, year, months, yesterday or similar, among the seriously ill patients against the 214 from the control group.

The difference between groups was statistically significant with a chi-square value equal to 20.06 with p<0.001. That could indicate how the admission to the hospital is likely to become a confused and negative parenthesis of patient’s past and future.

There is a significant difference in the third category of words obtained by isolating terms referred to the family “reference to the family”, such as: home, family, husband, son, daughter. The greater frequency in the cancer patients (118 against 5; chi² 20.18; p<0.01) seems to indicate a considerable need for family support; especially referred to the husband and daughter.

Lower frequency in subjects suffering from carcinoma, also in the fourth category of words that indicate “reflective activity” (thought, I think, I thought). The difference between 21 and 36 units in this case is also statistically significant (chi² 3.91; p<0.05).

Both of latest two categories seemed to be the expression of the extensive work of defensive mechanisms. No significant difference was found between the two groups for the other isolated categories defined in terms of “uncertainty” (words such as: perhaps, on the other hand, it seems, can, etc.), “emphasis on the information” (words as: an answer, result, truth, knows, etc.) even if expressed with greater frequency from patients with carcinoma.

They were also isolated terms indicating the “somatic disease”, which were equally frequent in the two groups, without significant differences between patients with tumour and control patients. It is important to emphasize the bigger gravity and drama of physical symptoms for oncological patients.

In fact the most used words were: blood (26 times for oncological group against 6 times for the control group), haemorrhage (9 against 1), pain (16 against 10) and so on. In the control group the most frequently used terms were cysts (25 against 5), pain (5 against 0).

Equally present in both groups the references to “health services and healthcare practitioners” and “diagnosis and therapy”. The last two examined categories of words, as was expected were equal because the interviews were run in an inpatient hospital environment.

Outside of the terms included in the categories it appears however that the presence of words such as “I hope” and “life” in control group appears to be suggestive absent from the stories of cancer patients that contain 9 times the word “God” that is absent in the group of reference (Tab. 1).

Discussion

In the light of the results obtained from the analysis of the frequencies of the words emerged from reports of patients there seem to be some evident considerations to be made.

In the category defined as “emotional disorder” it is possible to suppose that the experience of low mood or depression is significantly more evident in the oncological patients than in the control patients. There is trend to withdraw and to develop the anxiety symptoms characterized by recurrent concerns for health conditions, probably justified by the illness.

The data of “time perception” category might indicate how the hospitalization would tend to become a confused and negative parenthesis between past and future. The perception of time would be particularly more evident for the control patients who seem to keep alive a hope for the future and for the remission of their disease. Differently, the perception of time in oncological patients would be frozen in a suspended moment without time frame.

The “family” environment becomes particularly relevant in this context as a physical and mental place where patient is welcome and supported in the difficult time of illness. The “reflective activity” is even more evident in control patients than in those oncological perhaps because the former are able to think about their own disease while maintaining a good contact with the reality and the ability to manage the illness that would become more adaptive. The oncological patients deal with the disease by letting themselves be overwhelmed by the symptoms and by the problems related to the tumour without having a full control of themselves and of their capacity to deal with the circumstances.

Terms related to the “uncertainty” and the “emphasis on information” did not appear to be expressed differently between the patients with carcinoma and those from control group: both groups of patients would benefit from a clear guide to tackle the disease and its outcome.

No significant differences were found between two groups of patients in following categories: “somatic disease” and “reference to health services and healthcare practitioners”.

In conclusion, the serious illness is a dramatic event that has a devastating impact on the psychological state, family and social life. Cancer disease requires to cope with difficult aspects and has an impact on every person involved, including healthcare practitioners who are in contact with the most painful aspects of existence: the suffering, disability, loss, death.

Usually it happens that the patient after the painful and troubled diagnostic iter, contacts the healthcare service with the symptoms detached from the disease. One’s own body is experienced as something that does not belong to this oneself, as an unknown, violent, and unexplained punishment. On the other hand the practitioners are worried about the patient’s body and act on the body in a desperate attempt to uproot the evil and defy the death.

If the disease cannot be cured everything seems useless and without purpose: powerless the patient refuses the support and cure while waiting for death.
Evaluation and prevention of maladaptive reactions in patients with gynaecological cancer: an experimental study of the expression of emotional experience

In the light of this picture it is necessary first of all that the healthcare practitioners are aware of their limits and then acquire the technical and cultural tools to be able to deal with the illness. The confrontation with death is the missed point for healthcare practitioners because of the death defensive tactics is widespread and supported by our society. In fact, the death is unpopular and not discussed very often so it is not processed until there is a sharp contact with death but often there it is not enough time available to do so. Therefore it is important to think out proper concept of death and of how death should be managed in the hospital and supported by the healthcare practitioners. Inspired by the observations of Elisabeth Kübler-Ross (24) about the psychological reactions of patients in a terminal phase, we can find in the model of stages of the process of acceptance of death the strategy to cope with the disease and its outcome. These stages start from shock, followed by negation, isolation, anger, bargaining, depression, and then finally acceptance. To reach the stage of acceptance and live up to the end, without desperation, it would be necessary, second Kübler-Ross, to come through and overcome all the former stages. Following this model the reports of patients with cancer could be extremely useful to know and to deal together with them the different stages of the disease. The attention and care, however, would already be done through the actively listening practitioner, who remains an important reference figure for both the patient and his or her family.

The practitioner is a credible and empathic resource because they can provide information, support, advice and adequate treatment, both in pre-op and post-operative stages. However, there is a need to increase health practitioners’ awareness in order to avoid underestimation of symptoms of psychological difficulties a facilitate access to the specific training to improve communication skills. It is important to pay more attention to the representation of the disease closely linked to the amount of information received, but especially to the manner in which it is communicated. The emotional state of the cancer patient could be evaluated and monitored through in-depth interviews and questionnaires done periodically (25), providing valuable information to the practitioner so that they are able to intervene quickly at the first manifestations of maladapted reactions with the intention to improve the quality of life.

References


