

The impact of a “narrative interview” intervention in oncology. A study protocol for a feasibility study

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Abstract. *Background and aim of the work.* Oncological diagnosis determines a biographical breakdown and requires the person to adapt to the disease. If patients, after diagnosis, ask professionals for ‘compassionate care’, research on these issues is still underdeveloped. There are currently no studies that use the narrative interview as an intervention tool. The objectives of the study are to evaluate: (1) the feasibility of the narrative interview intervention on cancer patients in the first diagnosis; (2) the impact of the narrative medicine intervention on the patient’s self-perception, his psychological distress and adaptation to the disease. *Methods.* It is a mixed-method study, with an intervention (narrative interview) and quantitative evaluation before/after intervention and qualitative evaluation post-intervention (reflective writing). The analysis will use the Psychological Distress Inventory scale for the assessment of psychological distress and the Mini-Mental Adjustment to Cancer Scale for the assessment of disease adaptation. Adult patients, with oncological pathology will be recruited one month after the communication of the diagnosis, regardless of the type of tumor. The Wilcoxon test for paired data will be used to verify pre-post-intervention differences. The ‘reflective writings’ will be subjected to thematic analysis. *Discussion and conclusion.* The study evaluates the feasibility of the narrative interview intervention as a primary outcome. Secondly, the impact of the intervention is assessed in relation to: a) identification of risk or protective factors on psychological distress and adaptation to the disease; b) re-elaboration of the patient’s experiences and experiences related to his/her own illness. (www.actabiomedica.it)

Key words: oncological patient, narrative interview, study protocol, intervention, psychological distress, adjustment to cancer

Background

Narrative Medicine is a clinical-care intervention methodology based on specific communication skills. Interventions that exploit the appreciation and interpretation of a narrative (e.g. poetry, film, storytelling) fall within the sphere of narrative medicine (1). Its use encourages patients to see themselves at the center of their stories and this can help the person in an attempt to find a balance between self-concept, disease

and therapeutic treatment (2, 3): people thus, become protagonists of the treatment process (4).

One of the instruments of narrative medicine is the narrative interview that studies phenomena through people’s experience. It is not based on a generalized and decontextualized study of a given phenomenon but it analyzes and defines it through the stories of individuals. In the narrative interview, the interviewer asks questions to interpret and understand the participant’s words rather than trying to explain or

predict them: in fact, those who tell their health and disease history do so to convey a specific perspective of an event (5). Researchers who use this investigation technique tend to let the interviewee guide the content and pace of the interview itself (6). On average, each interview has a total duration of about 60 minutes (7). The narrative interview also allows you to better understand the different problems of assistance for the person and his family (8, 9).

The narrative interview, often used as an educational and sociological methodology (10), was intended by the authors (11, 12) in an innovative way: specifically structured and used by healthcare professionals (suitably trained), aimed at promoting listening active and the empathic relationship that is created between the practitioner and the patient during the interaction and favors ‘compassionate care’ (13). Indeed, ‘compassion’ was born as an empathic response to the suffering of the sick person, as a rational process that pursues the well-being of patients: this should be part of the daily work of health professionals (14). It is therefore essential to give primacy to the patient’s voice, to provide the patient with a relationship of care appropriate to the evolution of their history (15). Active listening participates in eradicating patients from that condition of solitude and suffering that implies disease by allowing them to live with dignity (16). Providing holistic care according to this model will help meet patients’ physical and psychosocial needs (17).

In this perspective, healthcare professionals can help patients make sense of the disease by helping them recognize it as part of their life path and as a challenge to be faced rather than being overwhelmed by it (18). Helping to reflect on the disease can represent a modality of nursing care with a significant wellness potential supported both by narrative theory and by the theoretical and philosophical heritage of nursing care (15).

The need to have explicit conversations with patients on their mental state and understanding of their suffering is highlighted. A patient-centered approach enhances the patient’s conceptualization of their problem and narrative to understand the disease, this can improve the care relationship (19).

It is very important to use effective communication strategies during the interview as they lay the foundations for the creation of a good empathic rela-

tionship (20): it is also necessary to find what is important from the patient’s point of view to optimize assistance (21). The narrative interview is curative (18, 22), as it allows you to talk about yourself and the new condition that you are experiencing, recalling its experience and trying to give meaning to the disease (15).

At the time of cancer diagnosis, the communication of bad news represents the fundamental starting point of the individual’s path of illness. The diagnosis of cancer involves a substantial increase in anxiety and this emotional response is mediated by the communication style used by the professional (23). The disease affects not only the body but also the psyche and the whole system of social and family relationships that revolves around the patient (24, 25). Cancer is a disease that often leads to stress, anxiety and potential exhaustion in family members, (26). The individual must learn to live with a chronic disease between the promise of treatment and the threat of disease progression: this produces complex and paradoxical experiences that do not easily adapt to familiar mental patterns (27).

In a narrative perspective, the diagnosis of cancer, in fact, determines a biographical breakdown of one’s life history; In this perspective the communication of bad news to the person requires an adaptation to the disease itself, trying to reconstruct the history of interrupted life that becomes history of the disease.

People who receive a cancer diagnosis and a negative prognosis are significantly more likely to develop psychological distress (28, 29).

The ‘compassionate care’ are required by patients, but research on this is still underdeveloped (13) and patients during the disease course, want to meet the professionals who listen to them showing compassion and competence in dealing with the pain (16).

The scientific literature concerning medicine and the narrative interview turns out to be quite wide thanks to the considerable interest that this narrative tool has aroused in researchers and scholars, however there is no focus on the application of the narrative interview as intended by the authors of this study, or carried out by health professionals, in the post-diagnostic phase and which helps the professional to understand the possible effects of the disease on the person.

This feasibility study aims to assess what impact the narrative interview, carried out by health profes-

sionals, could have on the person who has recently received a tumor diagnosis and, in particular, on two outcomes: psychological distress and adaptation to disease.

Aims

The study has the primary objective of evaluating the feasibility of the narrative interview intervention carried out by health professionals on cancer patients in the first diagnosis.

The secondary objective is to evaluate the impact of the narrative intervention on the patient's self-perception, psychological distress and adaptation to the disease.

Method and procedure

Study design

This study is a mixed method study, which provides a quantitative assessment before / after intervention (narrative interview) and a qualitative assessment of post-intervention (reflective writing).

The intervention consists in performing two narrative interviews, after fifteen days of each other.

The qualitative evaluation will be addressed to patients recruited and subjected to a narrative interview and will use the tool of reflective writing, after the first interview (T1) and after the second interview (T2).

The quantitative analysis will use the scale Psychological Distress Inventory (PDI) for the assessment of psychological distress and the Mini-MAC scale for the assessment of adaptation to the disease. The two scales will be administered before (T0) and after the first narrative interview (T1) and will be administered again after

the second narrative interview (T2), scheduled two weeks after the first (Table 1).

Study population: sample recruitment

The study population concerns patients in the first cancer diagnosis. Patients with oncologic pathology in first diagnosis will be included, regardless of the type of the tumor and will undergo narrative interview a month before the communication of the diagnosis. This period of time is foreseen in respect of the patient's emotionality.

Inclusion criteria are taken into consideration:

- Speaking well in the Italian language;
- Having expressed willingness to participate in the study and have given written informed consent;
- Cancer patients in the first diagnosis of cancer;
- Be over 18 years old

The experimenters will illustrate the study, explaining the objective that it aims to analyze. Participants will be asked to read the information sheet, sign the consent and be informed explaining the possibility of stopping the trial at any time.

Training of professionals

To conduct a narrative interview, various skills are required that help the professional to create a context of relationship and participation suitable for data collection. For the purpose of the good performance of the interview, in fact, the interviewer should create a climate based on non-judgmental listening and mutual trust. For these reasons, the interviews will have to be conducted by members of the research team who have received special training in this regard. Nursing professionals who attended the I Level Master in "Case / care management in hospital and on the territory for

Table 1. Study design

	Pre-Intervention		Post-Intervention		Post-Intervention
	T0		T1		T2
PDI (Psychological Distress Inventory)	X	Narrative Interview1	X	Narrative Interview 2	X
Mini-MAC (Mini-Mental Adjustment to Cancer)	X		X		X
Reflective writing			X		X

the health professions” received this training during their training course. Before carrying out the interview, researchers will be aware of how to conduct a narrative interview that will help understand the complexity of the person, what moves them, what determines their manifestations, what are their responses to internal and external changes and where it is oriented. Particular attention will be paid to the ability to identify the appropriate setting, the use of effective communication, the use of communication facilitation strategies, the ability to actively listen, the development empathy and the ability to know how to be in a difficult relationship. The preparation of the individual researchers will be integrated with an afternoon of interactive training where the contents learned will be put into practice through role-playing activities and narrative interview simulations.

Variables studied: pre-test

Before the narrative interview, the study participants will complete the following questionnaires validated in Italian for the evaluation of the outcomes parameters: Psychological Distress Inventory (PDI) for the evaluation of psychological distress; Mini-MAC for the assessment of disease adaptation.

The PDI (Psychological Distress Inventory; (30): is a self-administered tool developed by a group of Italian researchers that measures the impact of disease and therapies in terms of psychological distress, in particular adaptation disorders such as reactive anxiety to cancer and its therapies such as inner tension and worry; reactive depression like displeasure, decreased energy, loss of self-esteem and loss of interest and, finally, emotional reactions to changes in body image and disturbances in interpersonal and sexual behaviors. The PDI consists in 13 questions, the answers of which use a 5-point Likert scale for assessing the intensity of distress (from 1 = “not at all” to 5 = “very much”). The PDI has been developed and validated for use in patients with tumor in different stages of disease and uses the 7 days prior to the compilation as time reference. The overall score is calculated by adding the score of single items: a high score indicates a high distress in all items except 2 and 6; in these two items it is necessary to invert the score before being able to sum. The

overall score varies from a minimum of 13 points to a maximum of 65 points. The Mini-MAC (Mini-Mental Adjustment to Cancer (31, 32): is a test consisting of 29 items that examine patients’ cognitive and behavioral responses to the tumor using a 4-point Likert scale (from 1 = “completely disagree, it is not my case at all” to 4 = “completely agree, it is exactly my case”). The items define 5 types of psychological reactions to the pathology and have been formulated to evaluate the coping style most frequently chosen to tackle the problems and not the quantity of the reaction or the symptoms. The results therefore show which of these styles tend to be most used. The 5 typologies are, specifically, Fatalism (5 items): the idea of the subject is that successes and failures depend on a life plan already set which cannot be escaped; the Combative Spirit (4 items): the individual believes in his own ability to improve the uneasy situation he is experiencing through commitment, the right act attitude and collaboration with healthcare staff; Desperation / Depression (8 items): the subject refuses to evaluate positive alternatives and has an approach towards depressive events; Anxious Concern (8 items): the person experiences emotions such as anger, fear, anxieties tends to agitate himself/herself and makes him/her live the path of treatment with greater concern; Avoidance / Minimization (4 items): the person avoids thinking about disease and treatment, trying as much as possible to distract himself/herself so as not to think about the situation he/she is experiencing.

Intervention

The intervention is based on the administration of two narrative interviews to the participants, the first one month from the diagnosis of the disease and the second with a time interval of two weeks.

Narrative interview: the tool is used by specially trained health professionals and has the purpose of understand how the person experiences the communication of the diagnosis of disease, in particular, in terms of stress and adaptation, using as a tool of ‘cure’ the relationship between the patient and the health professional, that will analyze the following three topics: the communication of the diagnosis as an element that causes stress, the adaptation of the person to the

disease and the impact of the disease on the person's lifestyle history.

The interviewer will be trained to create a positive relationship with the sick person, to use some communication facilitation strategies, to maintain the relationship even in difficult situations (such as the silence or hesitation of the participant) to create an atmosphere of active listening and empathic understanding. The interviewer will also collect some socio-personal data of the participants. In addition, an observer is expected to be present. The observer collects and notes information on the participant's verbal and non-verbal communication and supports the interviewer so that the dialogue remains relevant to the objectives of the meeting and to the stimulus questions proposed. In the context of this study, the interview will have a duration between 30 and 40 minutes and will be audio-recorded.

Two weeks after the first interview will be done the second narrative interview that will be based on the topics of the first one detecting any changes on the main covered topics.

The topic of the first narrative interview is reported in Table 2, the topic of the second narrative interview is reported in Table 3.

Variables studied: post-test

In relation to the quantitative assessment, at the end of the second interview, the participants will be given the same tools as in phase 2.

About the qualitative assessment, to verify the impact of the narrative interview carried out by health professionals on the person who received a diagnosis of cancer and on the two outcomes of psychological distress and adaptation to the disease, the sample will be asked to write a reflective text in which to expose one's emotions and reflections with respect to the narrative interview previously carried out and describe the aspects appreciated and criticized. This will allow to understand the patient's declared perception of a narrative medicine intervention carried out by health professionals, in the first cancer diagnosis. The Reflective Writing is a tool of evaluation of person's life experience (33, 34). Reflective writing promotes the use of critical thinking, meta-cognition (35), self-awareness

(36), mental processes that promote flexibility and adaptation (37) allowing individuals to analyze life events and situations of disease (38) in an objective way depending, above all, on those clinical events considered critical or adverse (39). Reflective writing gives concrete meaning to one's inner processes, to one's anxieties and worries that, otherwise, would remain disjointed and worthless (36, 40).

The trace of reflective writing is shown in Table 4.

Data analysis

Statistical analysis

As outcome parameters the scores reported by the participants in the questionnaires of the pre / post narrative interview sessions will be analyzed. The statistical analysis of the data will be descriptive: average, median, minimum, maximum, significant percentiles, central tendency index, standard deviation. Non-parametric analyzes will be performed on the collected data and in particular the Wilcoxon test for paired data to verify the pre-post-intervention differences.

Qualitative analysis

The 'reflective writings' written on paper format then computerized will be subjected to thematic analysis (44). The method requires two researchers to independently analyze the transcripts by repeatedly reading the text, extrapolating the emerging themes, grouping them and / or dividing them into content categories. During the analysis, the researchers verify that, from time to time, the main themes and the categories of content that compose them are consistent with the transcription data, identify significant sentences that condense and represent the meaning of the themes and categories identified. The methodological rigor of the analysis process will be further guaranteed through the supervision of a third researcher outside the study. Once the categories have been extrapolated, any change in meaning (meaning shift) will be highlighted in relation to what the professionals express before and after the training intervention.

Table 2. Trace of conduction of the first narrative interview

The narrative interview, as an intervention tool for patients who have received the diagnosis of oncological disease, includes 3 fundamental sections:

- a) The communication of the diagnosis as an element of stress;
- b) The adaptation of the person to the disease;
- c) The impact of the disease on the person’s life and relationships

For each area some example questions are reported.

Introduction to the interview

At this stage it is useful to try to put the interviewee at ease as much as possible, thanking him/her for having accepted the invitation and willingness to provide clarifications.

Examples of questions:

Thanks for being here. Compared to the information you received, is there something that is not clear to you?

Opening question of the interview

For the sick person

Examples of questions:

Do you feel like telling how the disease diagnosis was communicated?

(try to understand where the communication took place, with what style of communication, in what terms, who was present ...)

1. The communication of the diagnosis as stress element

These questions are a guide to starting an interview about communicating the diagnosis of cancer disease.

The questions focus on how the diagnosis relates to distress and personal difficulties.

Examples of questions:

Do you want to tell us what your experiences were when communicating the diagnosis?

(investigate thoughts, emotions, concerns, expectations...)

2. The adaptation of the person to the disease

These questions can help understand how and if the sick person uses internal or external strategies to cope with the disease.

The answers to these questions can help identify coping strategies that could be more or less helpful in the process of adaptation to the disease.

Examples of questions:

Would you like to tell us how your life has changed since the diagnosis?

(attention is paid to highlighting internal and/or external elements that may have been obstacles or favorable to change)

To date, do you want to tell us what you are experiencing?

(we investigate changes in thoughts, emotions, concerns, expectations ...)

3. The impact of the disease on life and relationships

These questions help to understand how and if the person’s life changed after the diagnosis and in which crucial domains: physical well-being (symptoms related to pathology and/or therapy), psychological well-being (emotional and cognitive aspects), social well-being (social relationship and emotional life), finally spirituality, religion and personal beliefs.

Examples of questions:

Would you like to tell us how the quality of your life has changed?

(pay attention to physical aspects, aspects related to concerns, social and family relationships, self-image and social role, work...)

Would you like to tell us what possible changes there are in your family and social relationship life?

Final question:

Example:

For today we are almost done, do you think of anything else you would like to add? Would you like to meet us again in 15 days?

Closing of the interview

At this stage the interview ends, thanks and requests for the second interview are available

Example:

Thank you very much for your availability

Now I would close the interview, but I would like to ask you if I can possibly hear you again if, re-reading what we said, there are points to be explored.

So, do I have your availability?

Table 3. Trace of conduction of the second narrative interview

The second narrative interview takes up the tracks of the first interview and includes the same 3 fundamental sections. For each area, also in this case, some example questions are reported.

Introduction to the interview

At this stage it is useful to try to make the interviewee as comfortable as possible, thanking him/her for having accepted the invitation and willingness to provide clarifications.

Examples of questions:

Thanks for being here again. Compared to the information you received in the last interview, is there something that is not clear to you? Can we proceed?

Opening question of the interview

For the sick person

Examples of questions:

Compared to the last time we met, how do you feel today?

1. The communication of the diagnosis as stress element

These questions are a guide to highlight if there have been changes in relation to experiences of distress and personal difficulties related to the communication of the diagnosis.

Example of questions:

To date, compared to the communication of the diagnosis, what are your experiences?

(explore if something has changed from the first to the second interview with respect to thoughts, emotions, concerns, expectations)

2. The adaptation of the person to the disease

These questions can help understand whether the person has changed his internal or external strategies to cope with the disease.

Example of questions:

To date, do you want to tell us how you are facing your illness? Do you feel that your life has changed? If so, in what?

(explore changes in thoughts and emotions, about how to deal with the disease and adaptation to it)

3. The impact of the disease on life and relationships

These questions help to understand how and if the person's life has changed since the last meeting and if there have been changes in the related domains: physical well-being (symptoms related to pathology and / or therapy), psychological well-being (emotional and cognitive aspects), social well-being (social relationships and emotional life), finally spirituality, religion and personal beliefs.

Examples of questions:

In your opinion, what changes have occurred in your life?

(physical aspects, aspects related to concerns, social and family relationships, self-image and social role, work)

What eventual changes did you have in your relationship life (with family, with friends ...)?

Final question:Example:

We are almost done; do you think of anything else you would like to add?

Closure of the interview

At this stage the interview ends, we thank the participant for participating in the study

Thank you very much for your availability

Table 4. Form for filling in reflective writing

Dear participant, the following questions are intended to understand how you lived the experience of the narrative interview previously carried out. There is no right answer, feel free to express any kind of opinion, emotion and reflection, aspects appreciated or criticized referring to the interview itself. This will make it possible to understand, through your opinion, if a narrative interview intervention proves to be advantageous applied in the present clinical context. Thank you for your cooperation.

1. Would you like to try to describe how you felt during the previous interview?

2. What did the interview stimulate in you?

3. Were there any particular moments that you appreciated, or moments of difficulty or unease?

4. Do you feel any need that could allow you to live this interview better?

5. Is there anything else you want to add and feel that you are reporting?

Ethical considerations

The study will be conducted in accordance with this protocol, any amendments introduced and authorized, the ethical principles of the Helsinki Declaration (<http://www.wma.net/e/policy/b3.htm>). The participants in the study will be informed in detail by the investigator on the aims and objectives of the study and must sign specific informed consent to the study and to the processing of personal data which will be archived together with the study documentation. The informed consent including the information note clarifies how the study is voluntary, with the possibility of withdrawing at any time, and through the specific information note, the information on the study that will be carried out is complete. Participants can at any time modify or delete the collected data. The document also declares that the interview will be audio-recorded and that the data collected and studied will be disclosed in strictly anonymous form. The study obtained a favorable opinion from the Ethical Committee of Area Vasta Emilia Nord (Protocol N. 2019/0111884).

Discussion

The primary objective will be assessed by trained professionals who carry out their work outside the clinical setting of the study and who will not have contact with the patients involved in the study, to protect the confidentiality of data collection. For the feasibility of the study, the number of patients who, once recruited, offer their consent to participate in the study and the number of patients who, once the informed consent has been signed, will complete the intervention. The study will be considered feasible if $\geq 50\%$ compliance is found in both cases.

About the evaluation of the secondary objective, the fallout of the intervention will be evaluated on:

- Self-perception by the patient: reflective writing
- Psychological distress: PDI (Psychological Distress Inventory);
- Adaptation to the disease through the identification of the types of psychological reactions to the disease: Mini-MAC (Mini-Mental Adjustment to Cancer).

To date, there are no studies using the narrative interview as an intervention tool on cancer patients on their first diagnosis. For this reason, it was decided to proceed with a feasibility study of the intervention, estimating its effect. This will help to structure a subsequent multicentric study on efficacy assessment. The intervention should act on three elements: a) identify risk factors or protective factors on psychological distress and on settling with the disease, which medicine does not adequately consider; b) taking into consideration the person in a holistic dimension, which focuses not only on the bio-clinical aspects, but also on the psychological, relational, spiritual aspects; c) helping the reworking of their life journey and experiences related to the disease, in which the patient becomes an active part of the treatment process, with repercussions on the therapeutic adherence and on the quality of life of the person. It is therefore hypothesized that the narrative interview intervention will help patients to achieve a greater awareness of the psychological and social aspects, not only of the strictly clinical aspects of the disease, as underlined in the study by Murphy and Coll. (2). In addition, the narrative interview is expected to be helpful to the patients to rework their experiences of life and of the illness, their relationship with family members and health personnel. This intervention would therefore improve compliance and therapeutic adherence linked to the development of the disease (41). The narrative interview should therefore help to increase the understanding of the disease in subjects interviewed, reducing their psychological distress

Previous international studies underline the importance of the narrative interview as a tool to help the patient find a meaning and a personal sense of the disease and to overcome suffering (42). Fortuna (43), in the Italian context, also substantiates the evidence that the narrative helps the patient to feel heard and to participate more actively in their health and in their care process. The expected results are also in line with what Sakalys said (15), that reflexive writing and storytelling help to give meaning to the disease with the aim of supporting the patient in organizing the stories and providing a report that allows the evolution of the disease history. By developing the ability to understand and interpret events, experiences could take on

a profound meaning which, once integrated and assimilated, will guide future behaviors (44, 45). The act of transforming thoughts into words creates new ideas, since the memory of experience allows, in addition to the analysis and understanding of it, to be able to alter its original perception, giving rise to new ideas and reflections (46)

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