Original article: nursing

Meeting the needs of cancer patients: is there a need for an organizational change?

Chiara Foà[1], *Tiziana Mancini*[2], *Rossella Prandi*[3], *Lida Ghirardi*[1], *Franca De Vincenzi*[4], *Maria Cristina Cornelli*[1], *Patrizia Copelli*[5], *Giovanna Artioli*[5]

[1] University Teaching Hospital, Parma, Italy; [2] Department of Literature, Arts, History and Society, Parma University, Italy; [3] Primary Care Trust, Modena, Italy; [4] Primary Care Trust, Parma, Italy; [5] Hospital of Santa Maria Nuova (Reggio Emilia), Italy

Abstract. As stated in the literature the most important needs of cancer patients are not adequately meet. Improving information, communication and education provided have not led to incisive changes in the organizational model of the oncology departments. The study contributes to this direction, by planning an "Integrated Operating Point" (I.O.P.) dedicated to cancer patients and their relatives in Italy. 42 Some professionals, patients and relatives were involved and 42 of them participated in focus group/or interviews. Results of thematic content analysis allow us to sketch out some key elements that I.O.P. should have in order to support cancer patients and their families. Integration of services, continuity of care, and cooperation between professionals involved are key elements that might qualify such organizational development.

Key words: needs, cancer, patient, relative, professional, focus group, interview

Introduction

As stated in the literature the most important needs of cancer patients are not adequately meet (1-6). In particular, the continuity of care (7-10) and psychological support (11-14) are missing from clinical agendas. Improving information, communication and education provided to patients and their families, even if it is necessary, have not led to incisive changes in the organizational model of the oncology departments (15-16). Indeed the integration of several services for people with cancer needs to be enhanced, in order to integrate resources and meet to patients and family needs (1, 3).

The need of a strong integration of services at all levels clearly emerged from some previous experiences of a Single Point of Access (S.P.A.) realized in 8 Italian Regions and dedicated to people with frailty, chronic illness, addiction (17). S.P.A. has the following functions: access reception, collection of recommendations, guidance and management of demand, direct activation of services in response to simple needs and integration with local offices and hospital services network. The most important activities are: needs analysis, recording of access, informative answers and guidance, signalling complex cases with the transmission at a Multidimensional Assessment Unit. The integration "of all that is behind the single door access system" is considered one of the biggest advantages of the experience conducted (17).

Moreover a randomized Italian clinical trial (18) showed that the establishment of Points of Information and Support (P.I.S.) can reduce the psychological distress of patients and increase their satisfaction. The P.I.S. offers a library for patients, relatives and friends with internet access. It is managed by a nurse specializing in oncology, specifically trained to respond to requests from patients or to address them, if necessary, to the psychologist or oncologist. Even activity data of the National Foundation G. Ghirotti (19) confirm value and importance assigned to the Points of Counselling for cancer patients. It helps the person and family to get out of loneliness and disorientation. There are many international internet sites providing information and services related to cancer cure and counselling. Among those some have institutional roles or are public healthcare programs or projects as World Health Organization (WHO, 20), and National Cancer Institute's Cancer Information Service (NCI's CIS, 21). Others are risen by initiative of patients and their families, as People Living With Cancer supporting the Cancer Call Centre (PLWC, 22).

More are funded and supported by multidisciplinary associations of professionals and organizations, as American Psychosocial Oncology Society (APOS, 23) or private funds, as PLWC (22).

Some of them are worldwide, such as the American Society of Clinical Oncology (ASCO, 24) a world be known oncological society, and the WHO (20), that provide full and detailed information about prevention worldwide. Programs and initiatives about tobacco risks, physical training, diet, expositions to infections and radiations are included.

Others are European, such as Telematic Services in Cancer (Telescan, 25) that is among the first European internet services about cancer research, treatment and widespread of information completely online for patients, families, professionals and researchers. Others important Services and society are national, such as APOS (23), the Cancer Call Centre (22) and the NCI's CIS (21). For more than 35 years NCI's CIS has been providing scientific information to patients, families, friends, and healthcare professionals about risk factors, symptoms, diagnosis and other topics.

The APOS (23) is the only multidisciplinary organization in the United States researching psychological, social and behavioral aspects of cancer. Il has the goal of increasing the level of attention for health professionals and for public engagement about cancer patient's care, for innovative methods for diagnosis and treatment. The main aim is to create a network of patients and caregivers including psychiatrists, psychologists, nurses, social assistants and experts in managing all problems related to cancer.

The study presented here attempts to make a contribution in this direction, planning the opportunity to open an "Integrated Operating Point" (I.O.P.) dedicated to cancer patients and their relatives. Through a qualitative research conducted in a region of North of Italy this study has analyzed the representations of patients, relatives, social and health professionals and volunteers about an hypothetical Integrated Operating Point (I.O.P).

Accordingly to action-research perspective (26), the goal of the qualitative research was to improve the participation of who directly involved, identifying the problems and the possible solutions in collaboration with the researchers (27).

Methods

Participants

The research has been conducted in a region of the center of Italy. Heath Cancer Services' professionals, members of Cancer Associations, cancer patients and relatives took part in this study, for a total of 42 participants (76.2% women). All of them gave their informed consent.

Four of the patients were women and among them 3 had breast cancer and 1 had a sarcoma. The relatives were 5 (3 women), the oncologists were 10 (6 women), the nurses were 7 (3 women), the volunteers of Cancer Associations were 8 (7 women) and the social care assistants were 6 women. One psychologist (woman), one social worker (woman) and one general practitioner (man) took also part in the survey.

Instrument and data analysis

Patients, relatives, physicians, nurses, social care assistants and volunteers participated in 6 focus groups. To outgo the numerical inadequacy for focus group criteria, three face to face in-depth interviews were conducted with the psychologist, social worker and general practitioner.

Focus group/ interview sessions were conducted by researchers in order to explore:

a) the r*epresentation of the integrated operating point* (I.O.P) for information and orientation of the people affected by cancer and their families. In particular aims, functions and needs that the I.O.P. could meet and its organization/location were identified;

b) the *representation of patients/relatives* who could benefit from the I.O.P;

c) the representation *of ideals operators* of the I.O.P;

d) the *evaluation* in term of *advantages and disadvantages* of I.O.P.

In order to boost the effective pooling of resources from patients, families, social and health professionals and volunteers, it was examined whether and how I.O.P. could be able to improve health and community services skills to answer cancer patients and their family needs as to guarantee the continuity of care.

The average time span of focus groups/interviews was 60 minutes. All focus group/interview sessions were audio-recorded, transcribed verbatim and processed through an analysis of thematic content. The analysis consisted in decomposing the text into sentences and in their classification in synthetic cores or sub-categories (27). Five trained assistants independently coded the needs and the solutions to meet them into different dimensions. The inter-rater agreement was 96%. Quotations offered by participants are provided in order to illustrate the emerged theme that has been then connected in order to synthesize participants' representation of I.O.P.

Results

1. Identity of the Integrated Operational Point (I.O.P.) for the reception and orientation of the people affected by cancer and their families

1.1 Aims, functions and the needs that I.O.P. could meet

All participants imagine the I.O.P. as a well organized and coordinated context, in which both patients and their families can find answers to a variety of problems that accompany cancer disease. Among them, there are both supportive and informative functions. For example, the general practitioner underlined the importance to give a waste range of information: *"patients often ask me who should go to get answers to some problems that are often trivial for us, but an insurmountable obstacle for them [...]. Often they are not aware of economic support, or waive the requirement to obtain it, because the path is not properly explained" (General practitioner).*

For other professionals and relatives the I.O.P. has to be aimed to offer:

"*Help, guidance and support to develop and maintain skills and contact with the family, providing palliative care at home and addressing the issue of death and of mourning*" *(Health and social care assistant 6). "Surely this must be a center point of listening for emergencies. If the center does not have a doctor, for the medical emergency, the connection with the hospital could offers […] a doctor who can give information" (Relative 5).*

According to family members, I.O.P. could satisfy the need of psychological support (offering active listening and empathy). Furthermore, through a good information, professionalism and flexibility of the organization, it may act against the problem of complicated bureaucracy. "*A point of reference, a center where there is someone in whom, at any time of need […].I dare to call, just call, to ask also about bureaucratic practice"(Relative 1).*

Volunteers agreed that the I.O.P. can offer *"All kinds of support. The I.O.P., which is an integrated approach, could support the person and his family for needs never been talked about before [...] that's why we need more resources, because the support is heterogeneous: psychological, informational, therapeutic, in various fields" (Volunteer 1).*

General practitioner, nurses, social worker and health and social care assistants, stressed the importance of strengthening a network of heterogeneous services necessary to cancer patients' support. The opening of I.O.P. would have the advantage of concentrating the existing forces in a single meeting point, saving resources: "*It could put together all the energies, avoiding the wastes, as at present, and it would optimize many things: cost, time, stress, everything! […] in order not to leave the family alone in managing complex problems"(Health and social care assistant 6).* In particular volunteers emphasize the importance of the "*continuity of care" (Volunteer 3, Volunteer 7)*

1.2 Organization and location

For I.O.P. participants must be easy to access and visible in the territory. Nurses and oncologists, for convenience, recommended to set it in the hospital (in contiguity with the Day Hospital), while health and social care assistants, relatives and the social worker suggested that I.O.P. should have a place outside of it in the territory: *"I think it is difficult to put it by the Day Hospital, as it has happened" (Social worker).*

Some interesting hypotheses regarding the structure of the I.O.P were found. For example, among these views: "*the service could be open 24 hours a day" (Health and social care assistant 4), "through the call-center "(Oncologist 8),"with telephone availability during the night "(Relative 5).* I.O.P. is a place where *"both patients and family members can access to receive information before hospitalization" (Psychologist*), but also, in a second time, "*where you can find moments of dialogue and exchange and where you can also take part of patients' groups" (Psychologist).* An interesting perspective underline that I.O.P. has not to be *"another structure to which [the patient] goes to , but a structure that goes to the patient: this is much more difficult!"(Volunteer 4).* "It i*s I.O.P. that has to go to those in need" (Relative 3).*

Nurses, oncologists, volunteers and the social worker agreed that I.O.P. should provide a suitable space, with rooms to ensure confidential talks and not simply a one-stop front-line: *"Certainly a very private space, small, but friendly" (Social worker).*

2. Representation of patients/relatives who could benefit from I.O.P.

All participants believe that I.O.P. could be useful to all of cancer patients and their families (according to oncologists), either those from the hospital or those coming from their homes (according to nurses). Patients and family members may contact I.O.P. when patients are discharged or when they are still in hospital: *"No matter the target [...] whether call someone already discharged, or the relative of a person still hospitalized" (Nurse 6).*

In particular, I.O.P could help people to manage the disease and its consequences along with cancer pathway. People need to be reached at the time of diagnosis -*"go to people as much as possible when people find out they have cancer: a time of big bewilderment!" (Volunteer 4*)- or to be informed after their first visit with the oncologist about the opportunity of making use of I.O.P. *support -After the visit [the doctor] could say: <Look, now, if you need support, you can go to this Centre> (Patient 2).* I.O.P. activity could be extended to family members as to entire groups of patients: *"to create groups could be an interesting thing [...] giving the possibility of a space where patients and family members can meet and discuss what would be useful" (Psychologist).*

According to family members, all citizens should still be informed of the existence of I.O.P*: "A general information to the citizenry, because someone fortunately does not have that need, at this moment of life, but however they know the channels" (Relative 5).*

3. Representation of ideals operators of the I.O.P.

Identifying ideal matching figures who can work at I.O.P., participants gave particular importance either to operators' personal characteristics or professionals roles and functions.

3.1 Personal characteristics

All participants stressed that I.O.P. operator must possess certain fundamental trait of personality. He/she has to be *"helpful, balanced, tolerant, and friendly" (Volunteer 5).* The ideal figure should have good knowledge and training in medical and in social-psychological field as well, to create a trust relationship in order to meet the needs, and to direct the person *"tactfully" (Relative 1).*

Ideal professionals have to be prepared and competent and also know the person discharged from the hospital. "*They must be familiar with the physical and family situations (Patient 4).* They have to be "*people specialized in many things [...] able to be a point of reference" (Volunteer 1) "with both professional skills and human qualities [...]" (Relative 3)* fulfilling *"the [I.O.P.] needs to have a very well prepared and selected professionals" (Volunteer 4).*

3.2 Professional roles

Professional roles suggested by participants as a point of reference are various: psychologists, oncologists, nurses, social workers and volunteers, but also a plastic surgeon, beautician, physiotherapist, speech pathologist and radiation oncologist: *"Many professionals […] and not only oncologists and nurses. I think those figures are essential to understand certain emergen-*

cies and fundamental things"(Relative 5) as well as "a person who knows about work issues, laws, assistance such as volunteers" (Health and social care assistant 6). The psychologist imagines nurses as a reference figure, even for self-help groups. The general practitioner, instead, reaffirms the need to have a psycho-oncologist: *"Certainly I.O.P. requires competent people who have become a point of reference for patients and their families. It could be a psycho-oncologist, that mainly abroad is part of the team, monitoring and guiding the patient in the course of treatment "(General practitioner). "It looks good to have a nurse, a physician and a psychologist in order to answer all of the questions"(Nurse 7).*

For all of the participants however I.O.P. should be managed by a multidisciplinary team that has developed a strong capabilities to guide and support: "*I expect, especially with respect to such a program [...] that nurses should be part of the operating unit, as supporting figures [...] and psychologists as references. I wonder if, in addition to these figures institutionally part of the operating unit, should be important to consider other figures [...] such as members of associations [...] if you want to set up a supporting activity to finalize, and optimize the relationship not only by a healthcare point of view, but by a more global perspective, in a view of global care "(Oncologist 1).*

Even patients said that within I.O.P. should be *"present operators of the hospital and the territory together, to integrate the different aspects of care and strengthen the network" (Patient 4)*, with a *"psycho-social more than medical training" (Patient 3).*

4. Evaluation of I.O.P. and potential prospects

4.1 Advantages and strengths of I.O.P.

According to the almost unanimous opinion of family members, nurses, general practitioners, oncologists, health and social care assistants, patients and volunteers, the establishment of an I.O.P. is deemed very important to inform and give acceptance: *"It is important that all those involved in cancer patients be aware of the existence of I.O.P. and that they give the correct information for its use [...]. Well, maybe in the future, this could become a useful tool for other types of patients too" (General practitioner); "Definitely helpful!" (Nurse 7); "An information point "(Oncologist 8)." "It could be a point of reference!" (Health and social care assistant 4).*

In particular, nurses emphasized the center's capacity to be a point of connection that could compensate the lack of a network, promoting the continuity of care: *"When the patient goes away from [the hospital] is definitely useful!" (Nurse 1).*

Even volunteers assess the possibility that I.O.P. might serve as reference center by the ability to integrate resources: *"I see this very positive, because of the integrated resources, [...] the fact is that a lost person needs points of reference, not only as people support, but also as places where to go" (Volunteer 1).*

All patients are favorable to the establishment of I.O.P. considering it useful at the Cancer Center, because it is more convenient for patients, much visible and accessible: *"I think it's really a nice project!" (Patient 2).*

For some families, I.O.P. would be advantageous to maintain a high quality of care services dedicated to cancer patients: *"In my opinion, yes, I.O.P. is very useful, because the city has many good qualities in the medical field and this would be an additional excellence" (Relative 1).* Even for the Health and social care assistant, the opening of I.O.P. is viewed positively because it is a place where those in need can find help and a psychosocial support: *"I.O.P. is the only way to help people in need! Just that! (Health and social care assistant 4)* and it allows the person to get out of the state of loneliness caused by the disease: *"I.O.P. opens communication and allows to live less completely alone (Health and social care assistant 1).*

4.2 Obstacles to the implementation of I.O.P.

Is in the opinion of health and social care assistants that fragmentation of the various services not working on a network level and therefore not adopting a systemic point of view constitute hard obstacles to the foundation of an I.O.P. *"There is still little work of network; currently there are services, but each one takes care of their own piece and is hard to put all of the pieces together "(Health and social care assistant 6).* Furthermore quite often patients themselves are those who do not want to talk about the disease, because of *"Fear and shame"* (*Health and social care assistant* 1); "*They does not speak about cancer and then they avoid coming to ask" (Health and social care assistant 4).* It follows that people who could access I.O.P. services would not be the people who have a real need. For these people the access to the center is much more difficult: *"The only doubt I have is that I.O.P. may be accessed by people who know they have this type of disease and are therefore well aware. The problem is to facilitate access to people that don't' know or who choose not to know for several reasons" (Health and social care assistant 6).* Although volunteers do not assume that, through I.O.P., it is possible to reach those who actually need and in particular *"the cancer patient discharged and no longer hospitalized for chemotherapy or continuous therapy. It is difficult for the patient himself to take the initiative and go looking for someone who can help him/her [...] it is not enough to wait for them to come and ask, because they won't do it (Volunteer 1).*

Social worker's evaluation of I.O.P. is quite positive: *"Well, it could be very interesting" (Social worker)*, while some concerns were expressed by the psychologist on the clarity of the tasks and functions: *"The inclusion of IOP within the Oncology Day Hospital, could be perceived as intrusive; so roles and tasks must be coordinated and designed at its best "(Psychologist).* It is also important to highlight the risk of confusion between associations, Oncology Day Hospital and I.O.P.: *"The risk is that patients get confused "(Psychologist).* Finally, nurses, as well as families, glimpsed the actual implementation of I.O.P. complicated given the small financial resources: *"How much money do we have?" (Nurse 5).*

Discussion

The aim of this study was to evaluate, through an action-research study, whether an Integrated Operative Point (I.O.P.) -meant for supporting and orienting cancer patients and families- could provide answers to cancer patients' needs. Such needs often appear in this study, as well as in literature, not yet satisfied.

Interpretation of thematic contents emerged from the focus groups allows us to sketch out some key elements that I.O.P. should have in order to support people affected by cancer disease and their families. These were: *integration of services, continuity of care, and cooperation between professionals involved* (figure 1).

I.O.P. will help to develop a useful and "virtuous" integration between health and social services given the output of participants of focus groups and interviews. According to Gröne and Garcia-Barbero (28) the "[Integrated care] is a concept bringing together inputs, delivery, management and organization of services related to diagnosis, treatment, care, rehabilitation and health promotion […] to improve services in relation to access, quality, user satisfaction and efficiency".

The design of an integrated operating point (I.O.P.) offers an invaluable opportunity to rethink and re-organize the provision of complex care needs, in response to different scenarios of disease (17). The answer to health problems, through implementation of social interventions, makes use of a defined national legal reference (Legislative Decree n. 229/1999) which describes the social-health integration as a set of "activities to meet, through a complex process of care, health needs of the person, requiring unitary health care and social protection measures" (29). The integration has, however, also a professional meaning to improve health outcomes and to protect the more vulnerable social groups, improving knowledge about the utilities' location and the access to correct information. The integration of all operators is therefore essential to avoid the

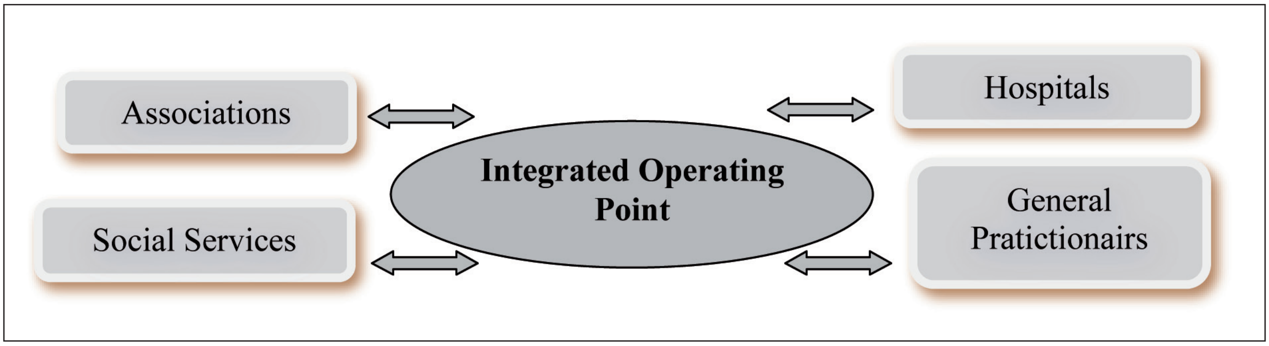

Figure 1. Integrated Operating Point

sense of abandonment and insecurity, experienced by patients and their families (30). Although the regulations and guidelines of socio-health program highlight the importance of an integrated approach to care, are well known the difficulties of integration management at the local level for what concerns: the collaboration among institutions in implementing the network of services; the definition of integrated care pathways useful to vicarious repetitions and/or overlapping of individual interventions and communication among professionals as a result of low use of specific tools integration (17). Only interdisciplinary and inter-professional integration may provide a complex care, sharing tasks and responsibilities and a rational use of resources, including the economic aspect.

In the opinion of those interviewed, especially nurses and volunteers I.O.P. could represent an important organizational way to promote the *continuity of care.* More precisely, the definition and adoption of integrated care pathways are perceived as a prerequisite for achieving the continuity of care, a goal set out forcefully to design services able to keep responses in step with the times. The continuity of care is also one of the most sensitive indicators of the functions of a health service as it adds to the traditional concept of "cure" the idea of "taking care" within different levels of care network divided between hospital and community (30).

According to the findings the location and the organization of I.O.P. would ensure the continuity of contacts with patients and family and attending the course of disease management. The Italian socio-sanitary contexts, however, highlight critical issues related to both the widespread difficulties in ensuring continuity of care at the time of hospital discharge, and to ensure the continuity of taking over at later stages. As mentioned by some participants, the activation of I.O.P. does not mean giving birth to another "health facility", but it means to fix an organizational model oriented to the individuality of contacts between health services and citizens and aimed to protect and take charge of patients care needs (17).

The continuity of care must have procedures and instruments for its ordinary realization (30). In this sense, cooperation among departments, hospital and territory associations, patients and their families is a key strategy of the operating point of an integrated structure that forms the active cooperation aimed at overcoming the present fragmentation in a synergistic way and to ensure the appropriateness of care pathways. To re-organize the provision of assistance in accordance with an I.O.P. means, in effect, to direct the person within a complex system, simplifying the information and reducing the bureaucracy (17). Specifically, it means to facilitate the comprehension, processing histories of disease, offering an experience exchange and shared resources, providing the interconnection with the network of services (31). The public health is moving from an organizational model focused on the supply, to an integral model, based on a request: citizens are headed to care pathways by specific reference structures which in turn direct those to the appropriate services (30).

According to the representations of the participants of the present study, the I.O.P. has different functions: orientation/information and facilitation of access to services. I.O.P. constitutes one of the possible integrations between social and health professions, a deputy to intercept the need to ensure continuity of care. The participants had the mandate to discuss the feasibility of opening an I.O.P. In this sense, the discussion has highlighted important issues which still remain open, such as: need to manage problems during the weekend; possible availability of telephone counselling during services' closing times to handle problems who do not require access to the hospital services; need to have spaces dedicated to listening; an easy access and traceability of I.O.P. in the territory or in a hospital placement in contiguity with the Day Hospital.

The hypothesis of a concrete opening of a I.O.P. is based on the possibility of relying on a precise set of *professional resources* that, in a interdisciplinary and synergistic way, breaks through the cultural barriers that often demarcate individual professionals (17) In particular, in several focus groups of this study there were debates about roles of institutional reference, pointing out that some barriers must be torn down as soon as the function of listening on a single point of reference was identified. The cultural reference is a current culture that sees specialists -identified as ideal figure- as the only professional problem-solver (e.g.: the psycho -oncologists). It was noted also that would be "extremely important to insist and urge the sensitivity of general practitioners in relation to knowledge of different settings [...] through tighter relationships with institutions" (30). Several participants highlighted the important role of reference for directing and coordinating actions, paths, strategies to be deployed to meet the complex needs of cancer patients. The study of Bellentani et al. (17) have led to differentiate the case manager, as responsible clinician, that coincides with the general practitioner, and the manager for the "care " that, in close relation with the responsible clinician, has the role of "director" and follows the implementation of care project, interconnecting all of the resources. The emerging continuity of care is provided by the "care-pathway manager". Often it is a nurse or a social worker, based on the prevalence of health, or family- relationship needs. This nurse, monitoring of the multiple needs of the person, is also the "plotter" that links into the network of community care through the activation of voluntary or self-help groups. However, in oncology and palliative care, the problems are so complex that the whole team has put in a position of listening and dialogue. This is why it is believed that the staff dedicated to I.O.P., as well as those working in oncology and palliative care, should be specifically trained and motivated and that the psychologist is not considered as the only figure to delegate listening and decoding of need The reference team does not imply a necessarily stable staff. The I.O.P., from time to time depending on the individual case, is able to integrate different aspects of care. The systemic perspective is designed to overcome the fragmentation of services that still shows discrepancy between social and health care, including hospitals and local associations of patients, whereas it would be important to promote really cooperative relationships, strengthening the services network (30).

In sum, the research project launched to the interlocutors of the focus groups the challenge to rethink the answer to the organizational change to meet cancer patients' needs, according to continuity and integration. Starting from the formulation of organizational models able to respond to changing needs of health care settings, social welfare and people who work there (32), the I.O.P. is positioned as a system of functional integration between services, professionals and users (17) characterized by health and social integration, by interconnections between hospital and territory, with a view to sharing of assumptions and practices (33) where the intensification of integration and professional collaboration required to start, first, the construction of relations before the organization networks (34).

Limitation

Focus groups are expected to capture experiences and opinions from many people in a short amount of time with facilitating effect because of the inclusion of patients, relatives and professionals who have similar experiences (35). Limitations of the present research are the restricted number of each focus group participants and the convenience sampling here used. Moreover the focus group are not always balanced between genders. In the coming future research it will be also interesting to testify whether different results would be gleaned from different patients and professionals and to compare results obtained by mixed method analysis.

Acknowledgment

The research is supported by the University Hospital of Parma and by Department of Psychology –University of Parma within the course "The Psychosocial Research for Health Professions".

References

1. Foà C, Copelli P, Cornelli MC, De Vincenzi F, Fanfoni R, Ghirardi L, Artioli G, Mancini T. Meeting the needs of cancer patients: identifying patients', relatives' and professionals' representations. Acta Bio Medica For Health Professions 2014; 85(3): 41-51.
2. Beesley V, Eakin E, Steginga S, Aitken J, Dunn J, Battistutta D. Unmet needs of gynecological cancer survivors: implications for developing community support services. Psycho-Oncology 2008; 17(4):392-400.
3. Copelli P, Foà C, Devincenzi F, et al. I bisogni del paziente con patologia oncologica e le risposte negli statuti di servizi sanitari dedicati e associazioni [The needs of patients with oncological disease and the responses offered by statutes of dedicated health services and associations] AIR 2011; 30(1): 24-33.
4. Iconomou G, Viha A, Koutras A, Vagenakis AG, Kalofonos HP. Information needs and awareness of diagnosis in pa-

tients with cancer receiving chemotherapy: A report from Greece. Palliative Medicine 2002; 16: 315-321.

5. Jefford M, Tattersall MHN. Informing and involving cancer patients in their own care. The Lancet Oncology 2002; 3(10): 629-637.
6. Rutten LJF, Arora NK, Bakos AD, Aziz N, Rowland J. Review: Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). Patient Education and Counseling 2005; 57(3): 250-261.
7. Arantzamendi M, Kearney N. The psychological needs of patients receiving chemotherapy: an exploration of nurse perceptions. Eur J Cancer Care 2004; 13(1): 23-31.
8. Vivar CG, Canga N, Canga AD, Arantzamendi M. The psychosocial impact of recurrence on cancer survivors and family members: a narrative review. J Adv Nurs 2009; 65 (4): 724-736.
9. Walton LM, Reeve J, Brown PM, Farquhar CM. Gynaecologic cancer patients' needs and experiences of supportive health services in New Zealand. Psycho-Oncology 2010; 19(2): 201-8.
10. Marlow B, Cartmill T, Cieplucha H, Lowrie S. An interactive process model of psychosocial support needs for women living with a diagnosis of breast cancer. Psycho-Oncology 2003; 12: 319-330.
11. Alfieri SM, Carver CS, Artoni MF, et al. An exploratory study of social support, distress, and life disruption among low-oncome Hispanic women under treatment for early stage breast cancer. Health Psychology 2001; 20(1): 41-46.
12. Helgeson VS, Cohen S. Social support and adjustment to cancer: reconciling descriptive, correlational, and intervention research. Health Psychology 1996; 15: 135-148.
13. Nelles WB, McCaffrey RJ, Blanchard CG, Ruckdeschel JC. Social support and breast cancer: a review. J Psychosoc Oncol 1991; 9: 21-34.
14. Talley A, Molix L, Schlegel RJ, Bettencourt A. The influence of breast cancer survivors' perceived partner social support and need satisfaction on depressive symptoms: a longitudinal analysis. Psychol Health 2010; 25(4): 433-49.
15. Baile WF, Aaron J. Patient-physician communication in oncology: past, present, and future. Curr Opin Oncol 2005; 17: 331-335.
16. Fallowfield L, Jenkins V. Current concepts of communication skills training in oncology. Recent Results Cancer Res 2006; 168: 105-12.
17. Bellentani MD, Inglese SA, Banchero A. Punto unico di accesso, presa in carico, continuità assistenziale. Monitor. Elementi di analisi e osservazione del sistema salute. Trimestrale dell'Agenzia nazionale per i servizi sanitari regionali 2008; Anno VII, 21(2): 7-22.
18. Passalacqua R, Caminiti C, Campione F et al. Prospective, multicentrer, randomized trial of a new organizational modality for providing information and support to cancer patients. J Clin Oncol 2009; 27(11): 1794-1799.
19. Teresi N. I dieci anni del centro di ascolto. Gigi Ghirotti Notizie/Notiziario 2009 - Retrived from: http://www.fondazioneghirotti.it/index.phppption=com_content&view=article&id=158:i-dieci-anni-del-centro-di-ascolto&catid=68:notiziario&Itemid=185.
20. World Health Organization (WHO), Cancer Prevention. http://www.who.int/cancer/prevention/en/
21. National Cancer Institute's Cancer Information Service (NCI's CIS), Retrived in from http://www.cancer.gov/aboutnci.
22. Cancer Call Centre-0861-ask-now in People Living With Cancer (PLWC), Retrived from http://plwc.org.za/blog/2009/11/25 /cancer-call-centre.
23. American Psychosocial Oncology Society (APOS), Retrived from http://www.apos-society.org/
24. American Society of Clinical Oncology (ASCO), Retrived from http://www.asco.org/ Homepage
25. Telematic Services in Cancer (Telescan), Retrived from http://telescan.nki.nl/ Homepage
26. Lewin, K. Action research and Minority problems, Journal of Social Issues 1946; (2): 34-46.
27. Meyer J. Using qualitative method in health related action research. BMJ 2000; 320: 178.1.
28. Gröne O, Garcia-Barbero M; WHO European Office for Integrated Health Care Services. Integrated care: a position paper of the WHO European Office for Integrated Health Care Services. Int J Integr Care 2001; 1: e21.
29. Decreto legislativo 229/1999. Retrived from: www.parlamento.it/parlam/leggi/deleghe/99229dl.htm.
30. ACP (Associazione Cure Palliative) – Onlus. Retrieved from: http://curepalliative.valeostudio.it.
31. Di Nicola P. (Ed,) Rete: metafora dell'appartenenza. [Network: metaphor of belonging]. Franco Angeli Editore, Milano, 1998.
32. Di Nicola P. Reti in movimento, politica della prossimità e società civile. [Moving networks; policy of proximity and civil society] Sociologia e politiche sociali 2004; 7(1): 5-175.
33. The Quality of Health Care Received by Older Adults, Santa Monica, Calif.: RAND Corporation, RB-9051, 200a. As of January 2008; Retrived from www.rand/org/pubs/research_briefs/RB9051
34. Folgheraiter F.Nel welfare delle relazioni (oltre I Piani di zona). [In welfare relationships (over the Area Plans)] Centro Studi Erikson, Trento. 2006.
35. Flynn KE, Jeffery DD, Keefe FJ, Porter LS, Shelby RA, Fawzy MR, Gosselin TK, Reeve BB, and Weinfurt KP. Sexual Functioning Along the Cancer Continuum: Focus Group Results from the Patient-Reported Outcomes Measurement Information System (PROMIS™). Psycho-Oncology 2011; 20(4): 378-386.

Accepted: 18 november 2015

Correspondence:
Chiara Foà
University Teaching Hospital, Parma, Italy
E-mail: chiara.foa@unipr.it