

## Exploring Continuity of Care: The Patient Voice

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### Abstract

**Background:** Oncology is one of the priorities of public health given its high incidence and prevalence. In 2010 there were 8 million deaths caused by cancer. In Italy neoplastic disease is the second highest cause of death. Considering these data, we need to guarantee appropriate, quality healthcare responses. In order to monitor the quality of cancer care pathways, we intend to explore continuity of care from patients' perspective, identifying the dimensions that define continuity.

**Methods:** Semi-structured interviews with 30 cancer patients (4 colorectal and 26 breast cancer) who received treatment at different service points of the Area Vasta Network (AVR), Italy. To identify the macro-categories of continuity, all interviews were transcribed and analysed using framework analysis, assisted by a computer software package for analysis of qualitative data (N-VIVO 10). Simultaneously, a literature review was carried out using the Pubmed database to examine the continuity of care measures validated.

**Results:** From the narratives of 30 patients, different continuity of care's dimensions emerged, for example the presence of a professional who knows the patient's illness history and takes him/her from initial diagnosis to follow-up care, guaranteeing him/her accurate information; a multi-professional team. The same aspects result central and transversal to 5 questionnaires identified in literature.

**Conclusions:** The analysis allows us to identify 3 central and transversal dimensions of continuity of care: informational, organizational and relational; confirming the continuity of care model produced by Haggerty et al. It follows that in order to cater to the needs of cancer patients; we need to focus simultaneously on these three dimensions along the cancer care pathway. In line with these results, we are developing the first Italian patients experience continuity of care tool.

**Keywords:** Continuity of patient care; Colorectal and breast neoplasm; Qualitative research; Literature review; Questionnaire; Patient perspective

### Introduction

In 2010 there were 8 million deaths worldwide caused by cancer, accounting for 15.1% of all deaths [1]. According to a report published by the World Health Organization (2014) [2], it has been estimated that this figure may rise to 13 million deaths by 2030. Furthermore, 20% of all deaths in Europe are caused by cancer, with more than 1.7 million deaths annually [3,4].

In Italy neoplastic disease is the second highest cause of death after cardiovascular disease and represents about one third of all deaths [5]. Specifically, a consideration of the incidence data for 2012 shows the most frequent kind of cancer to be colorectal with more than 54,000 new diagnoses in both sexes, followed by breast, prostate and lung cancers (respectively 50,394, 42,604 and 36,555 estimated incident cases) [6].

Finally, it has been estimated that the trend of some cancers will rise until 2015 [6], from 43 per 100,000 people/year in 1970 to around 120 per 100,000 people/year in 2015 for breast cancer; from 40 to 38 per 100,000 women between 2004 and 2015 and an increase up to 71 per 100,000 men/year in 2015 for colorectal cancer.

These epidemiological data support the need to pay attention to the requirements of cancer patients and to guarantee, in line with the directions in the document of the Council of the European Union of 23 June 2008, interventions characterised by "a comprehensive, interdisciplinary and psychosocial approach" [7,8]. The recommendations of the Italian Ministry of Health are also moving in the same direction, stressing the need to ensure that the patient is taken into consideration throughout the care pathway [8,9], and to consider the patient's point of view and experience in order to check that the

structured pathways are meeting their perceived needs effectively and that they are capable of guaranteeing quality care [7,10-12].

Over the course of treatment, patients with cancer commonly experience distressing and debilitating side effects, and considerable emotional strain [13-15], which may undermine their treatment compliance [16,17]. This condition requires particular sensitivity, empathy, and interpersonal skill on the part of health-care providers [16] in dealing with patients' concerns about the nature, course and prognosis of their disease [8,17]. Recent evidence indicates that satisfied patients feel that health-care professionals give them proper consideration, emotional support [17-19] and adequate information regarding their clinical condition and treatment programme [9,19-24].

One of the constructs used in literature to assess the appropriateness of the care provided is that of continuity of care [25,26], defined by Haggerty et al. [27] in the primary care setting, as the degree to which a series of discreet health-care events are experienced as coherent and consistent with the patient's medical needs and personal circumstances. More specifically, three types of continuity of care were reported by these authors to be relevant across all care settings: informational continuity, relational continuity and management continuity. Informational

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continuity links providers to one another and health care events to one another so that aspects of the person's medical condition, treatment preferences and the circumstances of their illness are taken into account [28]. Relational continuity refers to the presence of a professional team that "works with" patients rather than simply providing them with a service [29]. Management continuity is guaranteed when different healthcare services are provided in a coordinated, coherent, complementary and timely fashion [29-33]; it "can be thought of as the "seamlessness" of care and involves crossing boundaries and bridging gaps in care systems that are increasingly complex and specialised [34-36]. According to Freeman et al. [37], the experiencing of continuity is a good outcome of care coordination because it reflects the experience of a coordinated and smooth progression of care from the patient's point of view. Since patients are the parties experiencing the care from multiple providers' first-hand, they are uniquely positioned to assess the continuity of care [34].

Moreover, because cancer services represent a microcosm of broader health system performance (including health promotion, cancer prevention/screening, surgical and medical treatments, supportive and palliative care) where care is provided by a wide range of professionals (e.g., surgeons, medical oncologists, radiation oncologists, nurses, radiation therapists, social workers, community healthcare providers, etc.) in different care settings (e.g., specialised/comprehensive cancer centres, teaching and community hospitals, primary care settings, home), it provides a potentially useful context in which to investigate the concepts of integration and continuity from a patient experience perspective and to understand better what aspects of the patient experience are sensitive to their promotion [38].

In this perspective, a study of the continuity of care as perceived by patients appears to be a valuable instrument for monitoring the appropriateness and effectiveness of the health services offered.

## Materials and Methods

The survey was divided into stages.

In stage I, we conducted qualitative research to identify the key elements that make up continuity of care from the perspective of people with breast and colorectal cancer [39] who had received care from different services points of the AV Network. The AV Network is a clinical network that serves 1,128,570 residents [40] in the Ravenna, Forlì-Cesena and Rimini provinces and was established in 2007 to provide standardised, appropriate, efficient therapeutic and follow-up services, to improve the quality of care for patients with cancer, to promote research and to optimise the allocation of resources [41]. The network has a hub & spoke structure [20]; the 'hub' is located in Meldola at the I.R.S.T.- Istituto Scientifico Romagnolo per lo Studio e la Cura dei Tumori (Scientific Institute of Romagna for the Study and Treatment of Cancer) and the 'spokes' are located in the three Oncology Departments of Forlì, Cesena and Rimini and in the Department of Oncology and Haematology of Ravenna, that provide 1<sup>st</sup> and 2<sup>nd</sup> level interventions. IRST is a third-level referral institution for innovative treatments (specifically pharmacological) and for technologically intense interventions. IRST is also the hub for research and for coordination of the care at the spoke institutions. The coordination is mostly clinical, and consists of the promotion of workgroup activities centred on specific oncological pathologies (breast cancer, colorectal cancer, etc.) and in the adoption of common guidelines [42], although the process needs to be developed and assessed not only in relation to its health and economic aspects, but also with respect to cultural shifts, new roles of professionals and the organisational changes resulting from this kind of organisation [43].

Specifically, IRCSS IRST identified 30 participants, from a hospital administrative data list, adults of both sexes, with diagnoses of breast and/or colorectal cancer, resident in Ravenna and having previously undergone surgery and who, at the time of the research, were in follow-up therapy at the centres of the oncological network. Participants were excluded if they were at the terminal stage of the disease, were living in a hospice, were undergoing palliative treatment or were unaware of their clinical status.

Given the nature of the study, a stratified sampling was carried out, in which the first layer was provided by the type of pathway (classified as either "continuous" or "discontinuous" based on information provided by the hospital discharge records) and the second by the type of tumour pathology; also taken into account was the incidence of the different levels of complexity of the illness, the stage of the disease (advanced yes/no) and the treatment in progress (yes/no) present in the layers. The random selection of the subjects was made simultaneously for all types of care pathway:

- 10 residents of Ravenna who received the entire care plan at the Spoke (Local Health Authority of Ravenna)
- 10 residents of Ravenna who received part of the care plan at the Hub (IRCCS)
- 10 residents of Ravenna who received the entire care plan at the Hub (IRCCS)

These 3 groups are homogeneous in terms of pathology, age, gender, disease stage (advanced yes/no), and ongoing treatment (yes/no).

Written consent for participation was obtained when the subjects met with the study researcher. The interviews, which had a mean duration of 60 minutes, were conducted in a private room at the hospital, separately from routine care, by a trained psychologist. During the interviews, participants were invited to report their experience and to identify for each phase of the care pathway positive and negative elements that had improved or compromised their perception of the quality and continuity of care. All interviews were recorded and transcribed verbatim. Each participant was assigned an identification number that was used to code each interview.

Thematic analyses were conducted on the transcribed interviews. In particular, using the framework approach [44], sub-themes were identified for each interview and then integrated to generate a list of themes capturing shared experiences. Interviews were coded by two researchers: there was a mean rate of disagreement in codes of 8,2%, which were settled by consensus. Recurrent themes were subjected to scrutiny in subsequent interviews until the process reached saturation. In addition, other members of the research team reviewed a selection of the transcripts and hence regular discussion occurred on the emerging themes [45]. The themes codex were indexed and transferred to QSR Nvivo v. 10 for framework analysis [46].

In stage II, we conducted a literature review.

In order to provide as complete a picture as possible of the theoretical models adopted and with a view to identifying the dimensions of the continuity in the field of oncology, articles were identified in the PubMed database in English and Italian, up to 5 November 2013, using a string constructed using the PICO method (Population, Intervention, Confrontation, Outcome, although the Confrontation part was left out since it was not relevant to our goals):

- Population (neoplasm[MH] OR cancer OR cancers OR neoplasm OR neoplasms OR tumor OR tumour OR tumors OR tumours)
- Intervention (evaluat\* OR assess\* OR measure\* OR apprais\*)
- Outcome (continuity of patient care [MH] OR continuity of care OR care continuity OR care continuum).

All the extracted articles were analysed by two independent researchers in order to select only the works that measured the continuity perceived by cancer patients through questionnaires and/or structured scales. Instead, literature reviews and surveys conducted using only qualitative methods (interviews and/or focus groups) were excluded.

## Results

### Stage I: Qualitative research

The next section will present the main results obtained from the qualitative study, first of all quantifying the “continuous” and the “discontinuous” paths of patients with colorectal or breast cancer based on whether or not the individuals received diagnosis and treatment in the same facility.

Thereafter, in line with the objectives of this study the reasons for the continuity or discontinuity of the pathway will be presented, paying attention to the variables identified by all participants as being capable of influencing the care trajectory.

### Participants and continuity/discontinuity of the care pathway

Three men and twenty seven women between the ages of 40 and 70 participated in the study.

Among the participants 5 people had received a diagnosis of colorectal cancer (3M and 2F), while 25 women had been diagnosed with breast cancer.

In the case of the diagnoses of colorectal cancer, the five people surveyed said they had received a continuous care pathway: four of them were cared for in the ‘spoke’ facility of the Local Health Authority nearest to their home and one, instead, at the ‘hub’, the IRCSS, because of previous positive experiences in that facility.

In the case of the diagnosis of breast cancer, among the twenty-five women interviewed, seven (about 28% of the entire sample) believed they had experienced a continuous pathway: three of them stated that they had been cared for by the IRCCS, because of past personal/family experiences; four had been cared for in the ‘spoke’ facility closest to their home (of these, 2 people had requested a Second Opinion at the IRCCS: one was referred there by the oncologist and the other went privately to obtain feedback on the appropriateness of the treatment plan being prescribed).

Of the women interviewed who had breast cancer, 72% stated that they had experienced a discontinuous care pathway. Of these:

- 11% decided to go to another surgeon on the recommendation of the personnel who had made the diagnosis;
- 17% decided to obtain private treatment in Bologna, returning to the IRCSS for chemotherapy on the instruction of the private institution;
- 22% chose to be treated by the IRCSS based on its reputation and social standing;

- 50% of the women switched to another facility due to “loss of confidence” in the professionals who had treated them, especially during the initial investigations (of these, five women turned to other facilities at the suggestion of friends and/or family, three of them going outside the region, and then returned to the IRCCS for chemotherapy, and one chose the IRCCS after obtaining several second opinions outside the region).

We will now look at the variables that influenced the decision of people diagnosed with colorectal cancer or breast cancer to continue or change the care pathway.

### Variables that influence the continuity/discontinuity of the care pathway

From a thematic analysis of the content, 6 thematic nodes reveal a frequency greater than 20 and are found in almost two thirds of the interviews carried out. Below will be described and explored the nodes that are most frequent and that, from what the participants said, influence the describing and perceiving of a pathway as continuous.

#### Fluidity in the care centres (frequency 29)

A necessary condition to ensuring that the patient experiences continuity between the various healthcare professionals and the various treatment sessions is the fact of feeling that they are being looked after by the professionals in the network of care services, hence “... *the patient does not have to chase around, or queue* (interview 9)”; and it is the healthcare personnel who “*automatically make all the appointments*” (interview 19).

Another factor influencing this feeling is the existence of a system, in part computer based that enables the sharing of clinical data among the various facilities of the network. In this regard, various witnesses describe a lack of interaction between the ‘hub’ and the ‘spoke’ facilities: in some instances it was the patients who provided the doctor with hard copy results of tests carried out in other facilities.

#### Relational quality (frequency 27)

*The doctor was relaxed when she greeted me, indeed, she greeted me and not a number* (interview 24)

Closely connected with the decision to continue on a care pathway or to abandon it is the patient’s feeling that he/she can trust the person providing the care?

In line with a recent review of literature [47], the feeling of trust results from professionals having three essential qualities: their professional training, their humanity and empathy, and their ability to communicate.

*Doctor: “But, yes, it is a very small tumour, we’ll give you a local anaesthetic and remove the area.” I ask: “But aren’t you going to do sentinel lymph node biopsy? Tests, magnetic resonance imaging?” Doctor: “No, no, it’s very small. Why do you want me to do a sentinel lymph node biopsy?” “OK.” In the meantime I speak to my family doctor, and she too was rather puzzled ... I trust him and I have the operation. When the histological test results arrive they reveal activity on the edges. So the same doctor says, “OK, we’ll do a minor operation using local anaesthetic,” and I say, “But, aren’t we going to do more tests to see how extensive the activity is?” And he says, “There’s no need.” But I was very worried [...] I speak to my doctor ... When the surgeon’s secretary telephones me and says “Don’t make a fuss. It’s just a minor operation,” ... I say to her, “I’m sorry but your superficiality and arrogance make me want to have nothing more to do with you.” So I left ...” (Interview 7)*

Having trust in skilled professionals is of paramount importance at the different stages of the care pathway.

### Trust in “caring” professionals

*“I was welcomed like a friend, giving me a touch, and at those times a touch... at other times it doesn't mean anything, but for me a touch of my hair and a pat on the shoulder saying: ‘Your problem is serious but not as serious as you have been told.’ That meant so much to me. So I went with my instincts and decided to be treated there” (Interview 2)*

*“I remember that I said, ‘Professor, I've been kicked in the teeth for a month ...and he said, ‘Well OK, I'm the dentist’” (Interview 11)*

Respect for the person is also conveyed through kindness, a willingness to answer questions, to accommodate the concerns, requests and emotions, and to talk “person-to-person”: *“The doctor was relaxed when she greeted me, indeed, she greeted me and not a number” (interview 24).*

Many people reaffirm the importance of having key individuals constantly on hand to guide the patient through the various stages of the care.

### Trust in professionals with communications skills

Professional training can also be seen in the doctor's ability to convey clear information on what will happen next, on possible complications, and on the available services.

*“He explained it to me in detail ... everything. A calm, comprehensive explanation. With the calmness and tranquillity that is needed when before you is a person who is facing a challenging therapy” (interview 1).*

*“The doctor .. said to me, ‘Let's do the chemotherapy because we want to be sure that it doesn't come back. It's like saying that when I go biking I should attach stabilisers so I don't fall over.’ In this way ... she helped me to understand what had happened to me and what I had to do and I really felt that she was a person who wanted me to understand ..., but it is equally important that I was given this information tactfully and kindly” (interview 8).*

### The appropriateness of the information (frequency 25)

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### Reference oncologist (frequency 23)

The interviewees felt it was essential to have someone as a point of reference to talk to in the event of doubts about his/her health, the treatment plan, etc. Although in a project with the Local Health Authority of Ravenna it was established that there should be a reference oncologist for cancer treatment pathways, 3 interviewees expressed concern about this individual, who seemed to have been imposed from above, ignoring the relationships already established between the patient and other oncologists.

The following experiences are significant: *“I also have a reference doctor who I think works in alphabetical order... I only found out that he was my reference doctor by chance... because every time I stamp my ticket his name always comes out.. I'm not at all clear about this. No-one told me anything during the conversations. Perhaps this transfer should be reviewed ... when all is said and done he is my reference doctor, but he is the one with whom I have spoken least “ (Interview 4). “But just to understand why when Dr. X calls Dr. Y, in my head, because the next day I'm going for an appointment with Dr. Y when we will plan everything, it seemed logical to assume that Dr. Y should continued to look after me. .. In fact I have not seen nor heard from him nor called him again, and scanning my tax card in the reader I saw that it said “Reference Doctor Z”. It makes no difference to me, however, perhaps a phone call to say, “Look, I Dr. Y am dealing with this part and not the other ...” (Interview 1).*

In most cases, however, the possibility of having a reference doctor to contact in case of necessity, even by cellular telephone or via e-mail, *“gives a sense of protection, and a person who you can turn to in case of need provides a strong sense of security to a person when he/she knows that even from home one can get the most appropriate information should it be necessary [47-50].*

In line with the literature, when this person is missing, for example, when being transferred from one facility to another, the patient feels disoriented and interpreting any unwell feeling as an “alarming symptom” (e.g. the effects of radiation or chemotherapy) turns to the Accident & Emergency department.

### The role of the General Practitioner (GP) (frequency 20)

There are cases where it is necessary to enable and facilitate the integration of the hospital into the local community, to avoid a situation where the patient is left alone during the various stages of the care pathway: in these instances the involvement of the General Practitioner is of fundamental importance. For most of the interviewees the GP is a main point of reference, especially in the first stages of the process [51,52], when he/she should diagnose the cancer promptly by initiating the most appropriate investigations and directing the person to specialist doctors and services (the role of gatekeeper).

During surgical and chemo and/or radiotherapy treatment, the GP should still be involved with the person, intervening at certain times at the request of the patient to improve the quality of the care pathway and to facilitate certain steps, as described in the following experience: *“The oncologist [...] told me that he could put me in touch with a doctor who was right for me [...] ... but the days went by and nothing ... he told me that he had not been able to contact him, maybe has was on holiday ... so I called my doctor because I didn't know where to turn ... he told me to get the name of this doctor so that maybe he could try to find her ... he also left me his cell phone number, something he normally doesn't do ... in the evening he left me a message on the answering machine, he had found the doctor, she had not been available because she was at a conference in Ravenna, but he had managed to find her there and told me that she would be waiting for me the next day ... (inter.14) “*

After the active treatment, during the follow up, the GP reassumes the primary and central role, becoming once more the point of reference for prescribing and checking the various assessments of his patients.

### To feel that your case is being properly managed (frequency 22)

If all of the above aspects are guaranteed, the person feels that they are being *“hand-held ...” “as if everyone was on their side” (Interview 15),*

and these feelings help the person to deal with the entire pathway “if I get through it all easily it is also because I felt someone was always with me and managing my case” (interview 5).

### Additional data

The interviews also allowed us to identify some actions for improvement of the care pathway for colorectal and breast cancers in the Ravenna Local Health Authority, such as:

- facilitating and improving the structuring of information sharing systems, especially in the transfers between the various facilities of the Local Health Authority and between them and the IRCCS, in order to overcome a system in which, in some cases, the transmission of clinical information still takes place on paper through the initiative of the patient who finds him/herself acting as the glue holding the various facilities together;
- managing and ensuring continuity of exchanges and collaboration between health services and community services, primarily by promoting dialogue and the involvement of GPs in their patients' care pathway and giving greater visibility and clarity to the role of the oncologist and the nurse in charge;
- Paying attention to the doctor-patient relationship and promoting greater awareness in professionals of the importance in the care pathway, of trust and the sharing of a “therapeutic pact” between professionals and patients.

The results described so far highlight the importance of three principal aspects of a quality care pathway: the humanisation of services, linked with proper doctor-patient communication; the taking of overall responsibility, linked with the appropriateness of the care trajectory; the continuity of the pathway [48-50].

We then sought to determine whether these components are also found in the literature.

### Stage II: models and measures of continuity of care from the literature

We obtained 886 articles from 1987 to 2013, 20 of which met the criteria for inclusion. Of these, 7 measure continuity through the administration of a questionnaire prepared for the purpose [26,27, 53, 54] or obtained by adapting an existing one [36,37,55,56]; 6 attribute it to the frequency and/or dispersion with which the patient is being cared for by the same physician [57-62]. In addition, 6 studies measure continuity as a subscale of larger scales designed to measure the more general experience of the cancer patient in relation to the services [63-68]. Finally Chen et al. [69] offer four health indicators of the continuity/discontinuity of the care pathway: levels of prolonged hospitalisation; non-adherence to treatment; unplanned hospital admission and analysis of the cause; planned hospitalisation for active treatment. Given the objectives of this study, the focus will be on the questionnaires that operationalise the continuity in different dimensions. Specifically, in a recent Cochrane review on actions aimed at improving the continuity of care for cancer patients during follow-up [70]; it was noted that the only instrument that could directly measure the continuity of care of this type of patient was that of King et al. [28, 29]. We instead, were able to identify another four scales, one of which [54], in a way similar to what was done by King et al. [28, 29] was developed for the purpose from the results of qualitative studies; the other three scales [36, 37,55,56] were adaptations to the cancer field of existing instruments used to measure respectively the perception of continuity of care in patients discharged from the hospital 4 weeks earlier and in patients with chronic conditions being cared for in the primary care setting.

**Instruments adapted for the purpose:** Two teams of independent researchers have developed a scale of *continuity of care*, starting from a review of literature and the results of qualitative and focus group interviews with healthcare workers and cancer patients. The first group was from London [28, 29, 31] and validated a questionnaire containing 17 items with 5 point Likert scale responses [53]. The authors proposed to use the total score of the scale, which gives a measure of the continuity of care as perceived by patients with colorectal, breast and lung cancer, at different times during the care pathway (initial diagnosis, end of the treatment, remission, relapse, palliative care). Carrying out an analysis of the content on the scale items, three macro dimensions were identified. the perceived degree of support coming from family and friends; the perception of having fully received adequate and appropriate assistance during the development of the disease; the perception of being capable of coping with the effects of the treatment and the illness on one's own. Something that shone through was the vision of *empowering* the patient: a person with cancer can become an active participant in the management of his condition when the team delivering the treatment provides him/her with detailed information.

A second group of researchers from Australia refined the CCCQ (*Cancer Care Coordination Questionnaire*) [54]. While agreeing with the conceptualisation of King et al. [28] of the importance of communication between professionals and between workers and patients, for these researchers, the organisational aspect of the continuity was of central importance, defined by Uijen et al. [71], as *cross-boundary continuity*: in other words, the person with cancer should be guided through the care services, should receive clear information about the roles of the various professionals involved and should be put in a position to learn about their disease and to monitor their health and the effects of various treatments. Specifically, in their study of 686 patients with different types of cancer (colorectal, breast, lung, uterus, and others), coming from different areas (metropolitan, regional and rural) of New South Wales in Australia, continuity is investigated through the use of 21 items, which are divided into two macro components:

- the quality and appropriateness of the information provided to the patient and exchanged between the various providers, including between *primary* and *secondary* care (Communication)
- how infrequently the patient has to do his/her own “navigating”, i.e. moving “blindly” between the various services in order to obtain information, make appointments and identify the individuals to whom to refer in case of need (Navigation).

### Existing Continuity of Care instruments adapted to the oncology environment

#### *Patient Continuity of Care Questionnaire (PCCQ)*

The PCCQ [55, 72] comes from a reinterpretation of the *Heart Continuity of Care Questionnaire*, aimed at discharged heart disease patients [73] and was validated with patients with colorectal neoplasia discharged 4 weeks earlier. From the initial version of the instrument with 41 items with a 5-point Likert response scale, the authors produced a shortened version, with good reliability indices, using 27 items, in which continuity is reduced to 6 aspects, of which the authors proposed considering the average scores:

1. the quality of the care received in hospital and in particular of the emotional support, the information provided and the quality of both communication and the relationship established with the workers (Relations in hospital)

2. the adequacy and consistency of the information given to the patient about symptoms to watch out for and who to contact in case of need after discharge and/or between one treatment and the next (Transfer of information)
3. the adequacy and appropriateness of the information given to patients and caregivers about support services in the local community, such as home care, support groups, self-management tools and educational materials (journals, books, tapes, videos, etc.) (Support provided in the community)
4. the proper management of clinical documentation (Management of documentation)
5. the appropriate management of follow up, in terms of accurate information on the tests and assessments involved (Management of follow up)
6. the proper communication and exchange of clinical information between hospital professionals and those in the community (Management of communications).

The instrument described above was adopted by a group of Canadian researchers who used it to measure the continuity of care of 246 cancer patients during follow up [55]. This version of the PCCQ gives attention primarily to the continuity perceived by patients in the transfer (*interface*) from the specialist care services (*secondary care*) to the management of the disease at the community level (*primary care*). In view of the purposes of the study, the instrument does not include the 'Relations in hospital' element and changes the term 'hospital' to 'services'. The use of the tool made it possible to discriminate between patients with different perceptions of continuity, the cut-off between high and low continuity being given by the obtaining of average scores  $\geq 4$  in all the subscales considered.

#### Medical Care Questionnaire (MCQ) and Continuity and Coordination of Care Questionnaire (CCCQ)

MCQ and CCCQ derive from the application in oncology of the *Components of Primary Care Index* (CPCI) [74] an instrument on the continuity of care in patients with chronic conditions cared for in the primary care setting that, in the original version, consisted of 20 items related to 4 factors: interpersonal communication, the knowledge of the patients possessed by the doctors, the coordination of different forms of care and the patient's preference to see his/her own doctor regularly. These four subscales are reused in the adaptation by Husain et al. in the CCCQ (2013) [56], while the adaptation procedure of the CPCI carried out by a group of British researchers [36,37] led to a reduced version of the instrument, the MCQ, with 15 items and 3 macro-factors excluding the dimension of "knowledge of the patients possessed by the doctors". Specifically, the authors initially supported the revision of the continuity of care instruments used in literature with the results obtained from a comparison with a pool of experts, and this made it possible to adapt the CPCI tool and to administer it to 200 patients waiting for an oncology appointment, and being cared for at the local level. From the data collected and from the validation analyses this version, reduced to 15 items, was identified and administered to a further 477 patients having similar characteristics. From the exploratory factor analyses the *continuity of care* of patients was associated with:

1. the feeling that they can discuss with their doctor even matters that are not necessarily clinical, but associated with the everyday life of the person, any changes in routine or in the psychological state (Communication);

2. the patient's perception that medical information is being exchanged and shared by different professionals and the freedom of the patient to speak freely with the doctor (Coordination);

the preference to always to be treated by the same healthcare professional (Preference).

This last subscale tends to recur in many quantitative studies and implies the idea that continuity of care is ensured when the same professional regularly treats a patient and becomes their "reference doctor".

#### In summary

The various instruments described above reveal different aspects of continuity of care that, in our opinion, and in response to the objectives of this study, are attributable to the 3 macro-dimensions proposed by Haggerty et al. [27,75]. In fact transversally to the individual scales it is possible to identify informational (in King, Communication in CCCQ; Transfer of information and Transfer of information between primary and secondary care in PCCQ; Communication in MCQ and CCCQ) and organizational (Navigation in CCCQ; Management of follow-up, Management of documentation, Relations with the community in PCCQ and Coordination in MCQ and CCCQ) continuity. The third component, relational continuity, can be traced in the subscales of CCCQ "knowledge of the patients possessed by the doctors" and "the patient's preference to see his/her own doctor regularly," and in all the algorithms that investigate the continuity of the doctor-patient relationship.

In addition to these transversal issues, we can trace some details, provided by the items that investigate patient empowerment, which is the patient's ability to take charge of their condition [28,29,67], and those that explore the support and the backing given by the family environment and the community condition [28,29,55].

#### Discussion

The purpose of this paper was to analyse continuity of care through the experience of patients on completion of treatment for breast and colorectal cancer in the Area Vasta Network and through a review of literature.

Our findings on patients' experience are similar to those of other studies in cancer environments and emphasise the relevance of informational, management and relational continuity [27, 75]. First, we found that a long-term relationship with the same professional facilitated continuity of care (relational continuity): patients in fact emphasised the importance of being seen and treated by the same team, as individuals rather than numbers, in line with other findings from literature [31,76]. Moreover, patients with breast and colorectal cancer regarded their oncologists as the key professionals in ensuring unbroken care.

Our results, in line with those of Nazareth et al. [31] and Cook et al. [77], indicate that many patients experienced a feeling of abandonment when they did not have a provider in charge of their care. Poor communication also increased these feelings [78]. But, although people with cancer may say that they want as much information as possible [79, 80], sensitivity is required in monitoring receptiveness and the capacity to handle such information [81]; in some cases the information proved to be overwhelming and detrimental to decision making [82].

Moreover, many patients reported that they felt responsible for managing the information exchange across the various phases of the care pathway, because the existing administrative systems were

inadequate and did not permit effective communication between primary and secondary care, as reported by Nazareth et al. [31,83]. So it would be useful to develop structured management plans in order to improve cooperation across the interface and to define better the GPs' role and responsibilities [84-87].

Interestingly, the three dimensions described above (informational, organizational and relational) can also be identified in the individual scales that emerged from the literature review.

It follows that when we are called upon to assess how effectively a care pathway really meets the needs of people with cancer, attention must be given to these three dimensions simultaneously. To date, in the Italian context there is no instrument available that can detect these aspects of continuity, so the Romagna – Ravenna Local Health Authority, the IRCCS IRST in Meldola and AgeNas are developing a measurement tool, integrating the results obtained from the interviews with the scientific literature on the subject [88].

This research perspective is consistent with the guidance documents issued by the Ministries and is of central importance since it is capable of verifying the effectiveness and appropriateness of the various organizational models implemented in the context of oncology.

Future perspectives include designing a quantitative study, using standardised self-administered questionnaires to gather more structured, detailed information on the adequacy or inadequacy of the care pathway and the extent to which the care pathway defined by the protocols of the LHA correspond with the patients' needs. The data collected in this study are also valuable at governance level since they could inform choices in organising services to ensure continuity of care.

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#### Conflict of Interest Statement

The authors declare that they have none and confirm that patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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