Universitat Rovira i Virgili

Communication related to diagnosis and prognosis to patients with advanced cancer: ethics at stake

Paola Melis

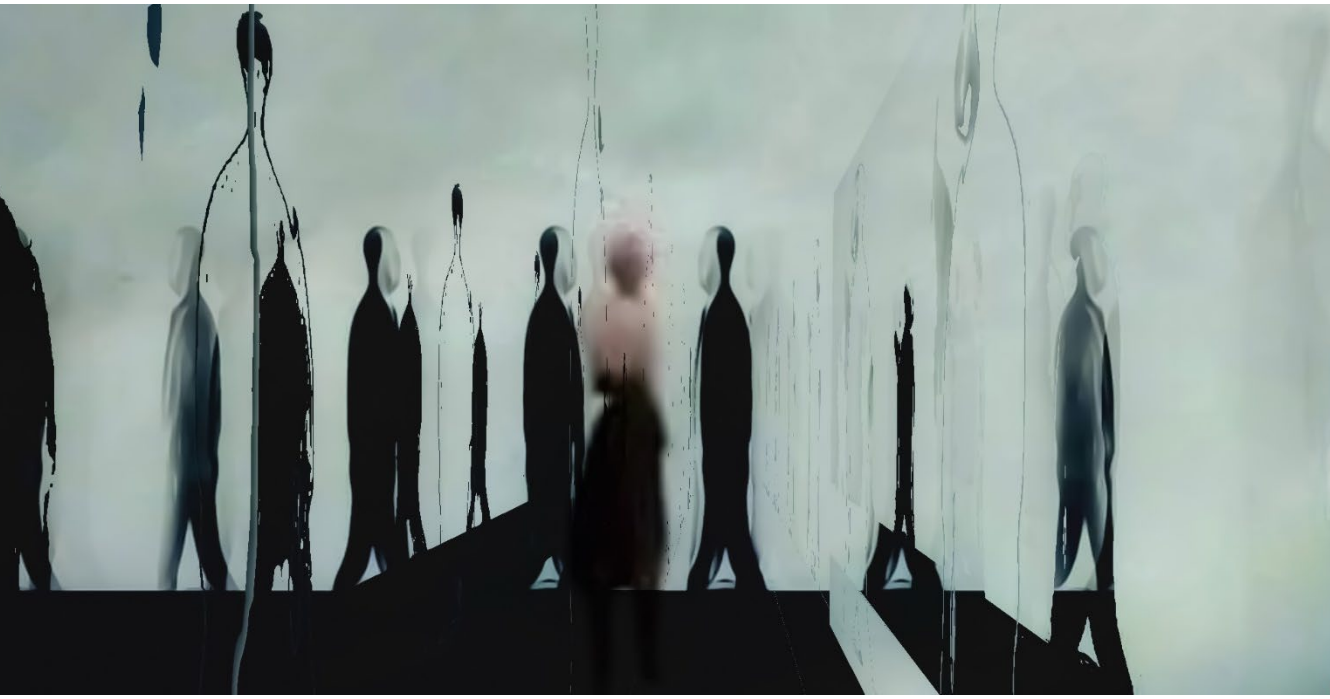
ADVERTIMENT. L'accés als continguts d'aquesta tesi doctoral i la seva utilització ha de respectar els drets de la persona autora. Pot ser utilitzada per a consulta o estudi personal, així com en activitats o materials d'investigació i docència en els termes establerts a l'art. 32 del Text Refós de la Llei de Propietat Intel·lectual (RDL 1/1996). Per altres utilitzacions es requereix l'autorització prèvia i expressa de la persona autora. En qualsevol cas, en la utilització dels seus continguts caldrà indicar de forma clara el nom i cognoms de la persona autora i el títol de la tesi doctoral. No s'autoritza la seva reproducció o altres formes d'explotació efectuades amb finalitats de lucre ni la seva comunicació pública des d'un lloc aliè al servei TDX. Tampoc s'autoritza la presentació del seu contingut en una finestra o marc aliè a TDX (framing). Aquesta reserva de drets afecta tant als continguts de la tesi com als seus resums i índexs.

ADVERTENCIA. El acceso a los contenidos de esta tesis doctoral y su utilización debe respetar los derechos de la persona autora. Puede ser utilizada para consulta o estudio personal, así como en actividades o materiales de investigación y docencia en los términos establecidos en el art. 32 del Texto Refundido de la Ley de Propiedad Intelectual (RDL 1/1996). Para otros usos se requiere la autorización previa y expresa de la persona autora. En cualquier caso, en la utilización de sus contenidos se deberá indicar de forma clara el nombre y apellidos de la persona autora y el título de la tesis doctoral. No se autoriza su reproducción u otras formas de explotación efectuadas con fines lucrativos ni su comunicación pública desde un sitio ajeno al servicio TDR. Tampoco se autoriza la presentación de su contenido en una ventana o marco ajeno a TDR (framing). Esta reserva de derechos afecta tanto al contenido de la tesis como a sus resúmenes e índices.

WARNING. Access to the contents of this doctoral thesis and its use must respect the rights of the author. It can be used for reference or private study, as well as research and learning activities or materials in the terms established by the 32nd article of the Spanish Consolidated Copyright Act (RDL 1/1996). Express and previous authorization of the author is required for any other uses. In any case, when using its content, full name of the author and title of the thesis must be clearly indicated. Reproduction or other forms of for profit use or public communication from outside TDX service is not allowed. Presentation of its content in a window or frame external to TDX (framing) is not authorized either. These rights affect both the content of the thesis and its abstracts and indexes.

UNIVERSITAT ROVIRA i VIRGILI

Communication related to diagnosis and prognosis to patients with advanced cancer: ethics at stake



Paola Melis
DOCTORAL THESIS
2021

Communication related to diagnosis and prognosis to patients with advanced cancer: ethics at stake

Paola Melis

Doctoral Thesis

Supervised by Dr. Maria Jiménez-Herrera, PhD, RN, MB

Universitat Rovira i Virgili (URV)

Department of Nursing

UNIVERSITAT ROVIRA i VIRGILI

Tarragona 2021

UNIVERSITAT
ROVIRA i VIRGILI

FAIG CONSTAR que aquest treball, titulat "Comunicació relacionada amb el diagnòstic i el pronòstic a pacients amb càncer avançat: l'ètica en joc", que presenta Paola Melis per a l'obtenció del títol de Doctor, ha estat realitzat sota la meva direcció al Departament d'Infermeria d'aquesta universitat.

HAGO CONSTAR que el presente trabajo, titulado "Comunicación relacionada con el diagnóstico y el pronóstico a pacientes con cáncer avanzado: la ética en juego", que presenta Paola Melis para la obtención del título de Doctor, ha sido realizado bajo mi dirección en el Departamento de Enfermería de esta universidad.

I STATE that the present study, entitled "Communication related to diagnosis and prognosis to patients with advanced cancer: ethics at stake", presented by Paola Melis for the award of the degree of Doctor, has been carried out under my supervision at the Department of Nursing of this university.

Tarragona, 17 de febrer de 2021

María Francisca
Jiménez Herrera -
DNI 39682575P
(AUT)

Firmado digitalmente por
María Francisca Jiménez
Herrera - DNI 39682575P (AUT)
Fecha: 2021.02.17 09:47:46
+01'00'

Maria Jiménez-Herrera

Directora de la tesi doctoral
Directora de la tesis doctoral
Doctoral Thesis Supervisor/s

Curriculum Vitae

After graduating from the Vocational Nursing School of Parma, Paola Melis began working as a staff nurse at the Hospital of Parma, where she remained until 2003. Starting in 2004 her professional career continued in Sardinia, in Cagliari, where she worked as a clinical nurse in a surgery department of the University Hospital of Cagliari until 2019. In 2019 she joined the staff of the Training Service. Paola Melis deepened her professional skills with a specialization course for nurses at the London School for tropical medicine and gained international experience doing a year (1995-1996) of volunteering as a nurse at an Outpatient Service in Ongata Rongai (Kenya). Upon returning from her experience in Africa, she enrolled at university and in 2004 obtained a master's degree in philosophy with a thesis in theoretical philosophy. In 2005 and 2006 she specialized in Bioethics and in she obtained a 2nd level master’s degree in Bioethics and Education from the Catholic University of the Sacred Heart, Rome. Since 2009 she has held seminars in Bioethics for nursing students and has been a speaker at many national and international conferences. During the academic years of

2017-18 and 2018-19 she taught Clinical Nursing at the Faculty of Medicine and Surgery of the University of Cagliari, where she currently holds the role of academic tutor. Driven by the increasingly widespread and pervasive challenges that come from the clinic and that are grafted into the nurse-patient relationship and supported by the passion for research in both the clinical and theoretical fields, she applied for a PhD position within the doctoral program of University of Rovira i Virigili (URV), in Spain. During her doctoral studies at URV she had the opportunity to meet and interact with international scholars working in the field of nursing ethics and bioethics. The PhD thesis results have been published in SCI index as first author, such as the Nursing Ethics (doi: 10.1177/0969733020916771, **2020**) and the European Journal of Oncology Nursing (doi: 10.1016/j.ejon.2021.101904, **2021**)

Acknowledgements

Ringrazio tutti coloro che, con il loro aiuto e il loro sostegno hanno fatto sì che io potessi iniziare e portare a termine questo cammino. Ringrazio Rita e Valeria, esempio e orgoglio per il loro prezioso impegno e professionalità, ringrazio Cesar per la spinta propositiva, Maura per il suo aiuto, Piera Poletti e Renzo Zanotti per I loro preziosi insegnamenti e la loro generosità, Luciano per la sua collaborazione, Barbara Cau (anche) per la foto di copertina, Rachele per il prezioso aiuto e tutti I miei amici e colleghi che mi hanno sostenuto. In questi ringraziamenti ricordo anche Salvatore e la sua generosità.

Agradezco a Maria por haberme guiado a través de este camino con tanta paciencia, sabiduría y corazón (y le agradezco haberme narrado incluso la dificultad del camino cuando los pies están doloridos); asimismo le agradezco a Rosa Idalia su caluroso abrazo.

“Tutti siamo migranti in questa terra”
“Todos somos migrante in esta tierra”
“Tots som migrants en aquesta terra”
“We are all migrants in this land”

Table of Contents

Summary 17

Resumen 25

Resum 33

1. Introduction 45

2. Background 51

  2.1 Communication 53

  2.2 Theoretical references of the concept of communication 56

  2.3 Cultural aspects in cancer communication 59

  2.4 International Codes and the Italian Laws related to Medical Communication and Information 62

  2.5 Theoretical reference in respect to the “Patient Centred Approach” 67

  2.6 The multidisciplinary dimension in communication 69

    2.6.1 The importance of an inclusive research approach 70

    2.6.2 Nurse’ role in cancer communication 71

    2.6.3 Theoretical reference in respect to Nursing 72

2.7 Caregivers role in cancer communication 77

2.8 Theoretical ethical framework 78

2.9 Literature review summary 81

3. Aims of the study 93

4. Methodology 97

4.1 Methodological references 98

4.2 Design 103

4.3 Setting 104

4.4 Rigor of the Studies 105

4.5 Ethics considerations 108

4.6 Study 1: Experiencing Communication Related to Knowing Cancer Diagnosis and Prognosis: A Multi-perspective Interpretative Phenomenological Study 110

4.6.1 Inclusion and exclusion criteria 110

4.6.2 Data collection 111

4.6.3 Participants and Recruitment 112

4.6.4 Data Analysis 113

4.7 Study 2: Ethical perspectives in communication in cancer care: an interpretative phenomenological study 116
4.7.1 Inclusion and exclusion criteria.................................... 116
4.7.2 Data collection.. 116
4.7.3 Participants and Recruitment... 119
4.7.4 Data analysis 119
5. Findings... 127
5.1 Study 1: Experiencing Communication Related to Knowing Cancer Diagnosis and Prognosis: A Multi-perspective Interpretative Phenomenological Study.................................... 127
5.1.1 Participant characteristics... 127
5.1.2 Findings: Themes 129
5.2 Study 2: Ethical perspectives in communication in cancer care: an interpretative phenomenological study 158
5.2.1 Participant characteristics... 158
5.2.2 Findings: Themes 159
6. Discussion 183
7. Limitations and future implications 215

8. Relevance and Applicability 225

9. Conclusion 235

Reference 241

List of tables 270

List of figures 271

List of abbreviations 272

List of publications 273

Addenda 277

- Addendum n.1: Coreq Checklist 279
- Addendum n. 2: Study Protocol 299
- Addendum n. 3: Ethics Committee Approval 321
- Addendum n. 4: Head of Department Approvals 329
- Addendum n. 5: Informed Consent 339
- Addendum n. 6: Original Article 345
- Addendum n.7: Original Article 367

Summary

Title: Communication related to diagnosis and prognosis to patients with advanced cancer: ethics at stake

Background: The nurse-patient relationship is the essence of nursing and an integral component of the nursing practice. The relevance of the nurse-patient relationship emerges and may develop from the communication that occurs between a nurse and a patient. In fact, communication represents the necessary and essential means through which a nurse establishes the relationship with the cared person and their family. On this basis, communication has received, as an issue, a lot of attention and, as a topic, has been largely investigated in medical and nursing literature. The Italian Code of Ethics for Nurses (2019) in the section titled *Professional relationships* dedicates several articles to information and communication. Article 15 is titled "Information about health status" and states:

The Nurse makes sure that the person, or the person indicated by him or her as a reference, receives precise, complete and timely information on his or her state of health, shared with the care team,

in accordance with his or her needs and in culturally appropriate ways. It does not replace other professional figures in providing information that is not of its own competence.

This means that the nurse is expected to have an active role in communication. In fulfilling this role, the nurse must relate the content of the information, the patient's information needs, and the meanings and implications of communication. It needs to be added that the nurse-patient communication is a phenomenon that occurs in an interactional context that encompasses the whole healthcare team, patients and the patient’s family and caregivers. In accordance with this, international recommendations and guidelines seem to agree on inviting to consider communication as a global phenomenon to be addressed with a comprehensive approach. Nevertheless, the majority of literature available on communication related to cancer diagnosis and prognosis still focuses on dyadic interactions only. It rarely highlights the communicative interactions that occur at a group level, between the patient and those who care for him or her, namely their caregivers, the attending physician, and the nurse.

This study approaches communication related to diagnosis and prognosis as a phenomenon occurring in an interactional context.

Phenomenology is a specific form of qualitative inquiry, but it encompasses different approaches, following the vast philosophical references that underlie the methodological structures. This study conforms to Martin Heidegger's famous definition of phenomenology.

My starting point is that of enabling nurses to attend to the patient's communication needs in cancer care; therefore, to fulfil the nurse's professional mandate and be respectful of all stakeholders, it is essential to approach communication, and more specifically communication related to diagnosis and prognosis, as a complex phenomenon that, having the patient at the centre of it, involves all players that interact with him or her in the caring process. The research question that guided this phenomenological study is: how do patient, their caregivers, attending nurses and physicians experience their communication interactions in relation to diagnosis and prognosis?

Aim: The main aim is to explore the phenomenon of communication related to diagnosis and prognosis, by comparing the perspectives of advanced cancer patients with those of their caregivers, physicians, and nurses. The secondary aims are: (a) To enlighten the meanings attached to communication by the four key stakeholders. (b) To understand the phenomenon of communication related to knowing diagnosis and prognosis by the four stakeholders. (c) To individuate the ethical challenges perceived by the four groups of participants in communication related to cancer diagnosis and prognosis.

Methodology: In order to achieve the objectives of this research two studies have been conducted. The first one is a qualitative study that adopted the interpretative phenomenological analysis. It was guided by the purpose of understanding the phenomenon of communication related to knowing diagnosis and prognosis by exploring the perspectives of patients with advanced cancer and those of their caregivers, physicians and nurses. Drawing upon a multi-perspective design, a total of 27 semi-structured interviews were conducted involving the four different groups of stakeholders (7 patents, 7 caregivers, 6 physicians and 7 nurses) – who were linked by a care-cared relationship- in two oncology departments of two hospitals in Sardinia. The second study is too a qualitative study that adopted the interpretative phenomenological analysis. It intended to investigate the phenomenon of communication related to diagnosis and prognosis as experienced by patients, their caregivers, and both their attending nurses and physicians in order to enlighten the meanings attached to communication by the four parties. A purposive sampling of 6 patients, 6 caregivers, 7 nurses and 5 physicians was performed in the two hospitals already mentioned. To sum up: a total of fifty-one semi-structured interviews have been conducted in two oncological departments of two big hospitals in South Sardinia, Italy. The data collection started on August 2016 and finished in February 2017. The patients were enrolled through two purposive sampling, the other participants were enrolled based on their connection to the patient and included their caregivers, attending oncologists and nurses. A rich description of the samples characteristics has been provided. Interviews were transcribed verbatim and a thematic analysis was performed following Jonathan Smith's steps of analysis. The data analysis was supported by Atlas.ti. version 7.5.7.

The two studies respect the methodological rigour of qualitative studies by taking into account the criteria indicated by Guba and Lincoln: dependability and confirmability, credibility, and transferability. In realizations with expert advice, great attention was paid to self-reflexivity.

Findings: In the first study data analysis made it possible to identify three main themes: (a) The availability of nurses and doctors as communicators conditioned by contextual factors; (b) The "what is it?" and the "what will happen to me?"; (c) Matching and mismatching in identifying the others as speakers. In the second study data analysis produced three themes as well: (d) The infinite range of possibilities in knowing and willing to know; (e) Communication with the patient as a conflicting situation; (f) The bind of implicit and explicit meaning of communication.

Findings depict a context where diagnosis and prognosis-related communication is managed by health professionals in an isolated way, though the team approach is referred by some health professionals as a desired perspective. In this context the health professionals fail to acknowledge the patient's whole communication process. This disempowers nurses as patient's advocates and debilitates their efforts to meet their patient's (and their caregivers) multiple and evolving communication needs. Besides, in a context of scarcely integrated communication interactions, the four parties fail to find each other as resources in the communication process and, when it happens, it does so on an idiosyncratic basis. From an ethical perspective, the interplay of meanings attributed by patients, their caregivers, their oncologists and attending nurses to communication related to diagnosis and prognosis has highlighted complexities and ambiguities that have not yet been resolved. Perplexities and contradictions are still discussed as a result of the contrast between the principle of autonomy and the principle of beneficence and remain unresolved.

Conclusions: The research has allowed to have a comprehensive understanding of the phenomenon of communication related to diagnosis and prognosis and has permitted to enlighten communicative interactions and the meanings attached to the phenomenon of communication by patients, nurses, caregivers, and physicians. This offers a novel insight to reflect on the ethical issues that are at stake in communication related to diagnosis and prognosis in the context of cancer care. The major issue emerging in both studies is the shared perception of extraneousness of the nurse's role in communication related to diagnosis and prognosis.

In summary, the comprehensive understanding of the phenomenon of communication related to diagnosis and prognosis allowed by the multi-perspective design and the interpretative approach enlightened how the different parties involved interact and reciprocally influence each other. Recognizing and reflecting on the complex interactions in which communication develops can help to analyze singular and shared responsibilities towards the patient, to move towards a personalized communicative approach and to achieve a more patient-centred care.

Keywords: Communication, diagnosis and prognosis, cancer, knowledge, meanings, ethics, multi-perspective, IPA.

Resumen

Título: Comunicación relacionada con el diagnóstico y el pronóstico a pacientes con cáncer avanzado: la ética en juego

Introducción: La relación enfermera(o)-paciente es la esencia de la enfermería y un componente integral de la práctica enfermera. La relevancia de la relación enfermera(o)-paciente surge y se desarrolla en la comunicación que se da entre ellos. De hecho, la comunicación representa el medio necesario e indispensable a través del cual la/el enfermera(o) establece la relación con la persona asistida y su familia. Sobre esta base, la comunicación ha recibido gran atención en la práctica clínica y se ha investigado ampliamente en la literatura médica y de enfermería. El Código de Ética de la/el Enfermera(o) Italiana(o) (2019) en la sección Relaciones Profesionales dedica varios artículos a la información y la comunicación. El artículo 15 se titula "Información sobre el estado de salud" y establece:

La /el Enfermera(o) asegura que el interesado o la persona que él indique como referencia reciba información veraz, completa y oportuna sobre su estado de salud, compartida con el equipo de

atención, de acuerdo con sus necesidades y de manera culturalmente adecuada. No reemplaza a otras figuras profesionales al brindar información que no es de su propia relevancia.

Esto significa que la/el enfermera(o) debe tener un papel activo en la comunicación. En el cumplimiento de este rol, la/el enfermera(o) debe relacionar el contenido de la información, las necesidades de información del paciente y los significados e implicaciones de la comunicación. Cabe añadir que la comunicación enfermera(o)-paciente es un fenómeno que se da en un contexto de interacción que incluye al equipo sanitario, los pacientes, la familia del paciente y los profesionales de la salud. De acuerdo con lo dicho, las recomendaciones y lineamientos internacionales coinciden en invitarnos a considerar la comunicación como un fenómeno que hay que afrontar desde un enfoque global. Sin embargo, la mayor parte de la literatura disponible sobre la comunicación relacionada con el diagnóstico y el pronóstico del cáncer todavía se centra solo en las interacciones diádicas. Rara vez arroja luz sobre las interacciones comunicativas que ocurren a nivel grupal, entre el paciente y quienes lo cuidan, es decir, sus cuidadores, el médico tratante y la/el enfermera(o).

Este estudio aborda la comunicación relacionada con el diagnóstico y el pronóstico, fenómeno que ocurre en un contexto de interacción. La fenomenología es una forma específica de investigación cualitativa, pero abarca diferentes enfoques, siguiendo las referencias filosóficas de M. Heidegger.

Mi punto de partida es que para que el/la enfermero/a pueda atender las necesidades comunicativas de las personas con cáncer, pueda cumplir con su mandato profesional como enfermera(o) y tener en cuenta a todos los interesados, es necesario estudiar la comunicación, y en particular la comunicación relativa al diagnóstico y pronóstico, como un fenómeno complejo que, posicionando al paciente en el centro de la atención involucrando a todos aquellos participantes que interactúan con él en el proceso de atención. La pregunta de investigación que impulsó este estudio fenomenológico es: ¿Cómo experimentan los pacientes, sus cuidadores, sus enfermeras(os) y médicos sus interacciones comunicativas relacionadas con el diagnóstico y el pronóstico?

Objetivos: El objetivo principal del estudio fué explorar el fenómeno de la comunicación relacionado con el diagnóstico y pronóstico, comparando las perspectivas de los pacientes con cáncer avanzado con las de sus cuidadores, médicos y enfermeras(os). Los objetivos secundarios fueron: (a) Destacar los significados asociados a la comunicación por los cuatro actores. (b) Comprender el fenómeno de la comunicación relacionado con el conocimiento del diagnóstico y pronóstico por los cuatro actores. (c) Identificar los desafíos éticos percibidos por los cuatro grupos de participantes en la comunicación relacionada con el diagnóstico y pronóstico del cáncer.

Metodología: Se realizaron dos estudios para perseguir los objetivos de esta investigación. El primer estudio es cualitativo de corte interpretativo utilizando análisis temático. Se guio por el propósito de comprender el fenómeno de la comunicación relacionada con el conocimiento del diagnóstico y el pronóstico, explorando las perspectivas de los pacientes con cáncer avanzado y las de sus cuidadores, médicos y enfermeras. Basándose en un diseño multiperspectivo, se llevaron a cabo un total de 27 entrevistas semiestructuradas en las que participaron los cuatro grupos diferentes de participantes (7 pacientes, 7 cuidadores, 6 médicos y 7 enfermeras) -vinculados por la relación de cuidados, en dos unidades de oncología de dos hospitales de Cerdeña. El segundo estudio también es un estudio cualitativo que utiliza el análisis fenomenológico interpretativo. Su objetivo es investigar el fenómeno de la comunicación relacionada con el diagnóstico y el pronóstico, tal y como lo experimentan los pacientes, sus cuidadores y las enfermeras y médicos que los atienden, con el fin de esclarecer los significados atribuidos a la comunicación por las cuatro partes. Se realizó un muestreo intencionado de 6 pacientes, 6 cuidadores, 7 enfermeras y 5 médicos en los dos hospitales ya mencionados.

Se realizaron un total de cincuenta y una entrevistas semiestructuradas en dos servicios de oncología de dos grandes hospitales del sur de Cerdeña, Italia. La recopilación de datos comenzó en agosto de 2016 y finalizó en febrero de 2017. Los participantes se reclutaron a través de dos muestreos intencionados, los otros se reclutaron en función de su conexión con el paciente e incluyeron a sus cuidadores, médicos y enfermeras(os). Se proporcionó una descripción detallada de las características de las muestras. Las entrevistas fueron transcritas textualmente y se realizó un análisis temático siguiendo los pasos de análisis descritos por Jonathan Smith. El análisis de datos fue apoyado por Atlas.ti. Versión 7.5.7.

Los dos estudios satisfacen el rigor de los estudios cualitativos siguiendo los criterios indicados por Guba y Lincoln: fiabilidad y confirmabilidad, credibilidad y transferibilidad.

Resultados: En el primer estudio, el análisis de los datos permitió identificar tres temas principales: (a) La disponibilidad de las enfermeras y los médicos como comunicadores condicionada por factores contextuales; (b) El "¿qué es?" y el "¿qué me va a pasar?"; (c) La coincidencia y la falta de coincidencia en la identificación de los otros como interlocutores. En el segundo estudio, el análisis de los datos aportó también tres temas: (d) El infinito abanico de posibilidades en el saber y el querer saber; (e) La comunicación con el paciente como situación conflictiva; (f) El vínculo del significado implícito y explícito de la comunicación.

Los hallazgos describen un contexto en el que el diagnóstico y la comunicación relacionados con el pronóstico son gestionados por los profesionales sanitarios de forma aislada, aunque algunos profesionales sanitarios se refieren al enfoque de equipo como una perspectiva deseada. En este contexto, los profesionales sanitarios no reconocen todo el proceso de comunicación del paciente. Esto toma el poder de las/los enfermeras(os) como defensores de los pacientes y socava sus esfuerzos para satisfacer las múltiples y cambiantes necesidades de comunicación de los pacientes y sus cuidadores. Además, en un contexto de interacciones comunicativas poco integradas, las cuatro partes no se reconocen a sí mismas como recursos en el proceso de comunicación y, cuando esto sucede, lo hacen de manera idiosincrásica.

Desde una perspectiva ética, la interacción de los significados atribuidos por los pacientes, sus cuidadores y sus oncólogos y enfermeras(os) involucrados en el diagnóstico y la comunicación relacionada con el pronóstico ha puesto de relieve la complejidad y ambigüedades que aún no han sido resueltas.

Las perplejidades y contradicciones siguen presentes y no resueltas y se derivan del contraste entre el principio de autonomía y el principio de beneficencia.

Conclusiones: La investigación ha permitido tener una comprensión amplia del fenómeno de la comunicación relacionada con el diagnóstico y el pronóstico y nos ha permitido iluminar las interacciones comunicativas y los significados relacionados con el fenómeno de la comunicación por parte de pacientes, enfermeras(os), cuidadores y médicos. Esto ofrece una nueva visión para reflexionar

sobre las cuestiones éticas que están en juego en la comunicación sobre el diagnóstico y el pronóstico en el contexto de la atención del cáncer. El principal problema que surge en ambos estudios es la percepción compartida de la extrañeza del papel de la enfermera(o) en la comunicación sobre el diagnóstico y el pronóstico.

En resumen, la comprensión global del fenómeno de la comunicación relacionado con el diagnóstico y el pronóstico que permite el diseño del estudio de múltiples perspectivas y el enfoque interpretativo ha puesto de relieve cómo los diferentes interlocutores interactúan e influyen entre sí. El reconocimiento y la reflexión sobre las complejas interacciones en las que se desarrolla la comunicación pueden ayudar a analizar las responsabilidades individuales y compartidas hacia el paciente, con miras a un enfoque de comunicación personalizado y una atención más centrada en el paciente.

Palabras clave: comunicación, diagnóstico y pronóstico, cáncer, conocimiento, significados, ética multiperspectivo, IPA

Resum

Títol: Comunicació relacionada amb el diagnòstic i el pronòstic a pacients amb càncer avançat: l'ètica en joc

Introducció: La relació infermera(r)-pacient és l'essència de la infermeria i un component integral de la pràctica infermera, la rellevància de la relació infermera(r)-pacient sorgeix i es desenvolupa en la comunicació que es dóna entre ells. De fet, la comunicació representa el mitjà necessari i indispensable a través del qual la infermera(r) estableix la relació amb la persona assistida i la seva família. Sobre aquesta base, la comunicació ha rebut gran atenció en la pràctica clínica i s'ha investigat àmpliament en la literatura mèdica i d'infermeria. El Codi d'Ètica de la Infermera Italiana (2019) en la secció Relacions Professionals dedica diversos articles a la informació i la comunicació. L'article 15 es titula "Informació sobre l'estat de salut" i estableix:

La Infermera assegura que l'interessat o la persona que ell indiqui com a referència rebi informació veraç, completa i oportuna sobre el seu estat de salut, compartida amb l'equip d'atenció, d'acord amb les seves necessitats i de manera culturalment adequada. No

reemplaça a altres figures professionals en brindar informació que no és de la seva pròpia rellevància.

Això significa que la infermera(r) ha de tenir un paper actiu en la comunicació. En el compliment d'aquest rol, la infermera(r) ha de relacionar el contingut de la informació, les necessitats d'informació del pacient i els significats i implicacions de la comunicació. Cal afegir que la comunicació infermera(r)-pacient és un fenomen que es dóna en un context d'interacció que inclou a l'equip sanitari, els pacients, la família del pacient i els professionals de la salut. D'acord amb el que s'ha dit, les recomanacions i lineaments internacionals coincideixen a convidar-nos a considerar la comunicació com un fenomen que cal afrontar des d'un enfocament global. No obstant això, la major part de la literatura disponible sobre la comunicació relacionada amb el diagnòstic i el pronòstic del càncer encara se centra només en les interaccions diàdiques. Rares vegades llança llum sobre les interaccions comunicatives que ocorren a nivell grupal, entre el pacient i els qui el cuiden, és a dir, els seus cuidadors, el mèdic tractant i la infermera(r).

Aquest estudi aborda la comunicació relacionada amb el diagnòstic i el pronòstic, fenomen que ocorre en un context d'interacció. La fenomenologia és una forma específica de recerca qualitativa, però abasta diferents enfocaments, seguint les referències filosòfiques de M. Heidegger.

El meu punt de partida és que perquè la infermera(r) pugui atendre les necessitats comunicatives de les persones amb càncer, pugui complir amb el seu mandat professional com a infermera(r) i tenir en compte a tots els interessats, és necessari estudiar la comunicació, i en particular la comunicació relativa al diagnòstic i pronòstic, com un fenomen complex que, posicionant al pacient en el centre de l'atenció involucrant a tots aquells participants que interactuen amb ell en el procés d'atenció. La pregunta de recerca que va impulsar aquest estudi fenomenològic és: Com experimenten els pacients, els seus cuidadors, les seves infermeres(rs) i metges les interaccions comunicatives relacionades amb el diagnòstic i el pronòstic?

Objectius: L'objectiu principal de l'estudi va ser explorar el fenomen de la comunicació relacionat amb el diagnòstic i pronòstic, comparant les perspectives dels pacients amb càncer avançat amb les dels seus cuidadors, metges i infermeres(rs). Els objectius secundaris van ser: (a) Destacar els significats associats a la comunicació pels quatre actors. (b) Comprendre el fenomen de la comunicació relacionat amb el coneixement del diagnòstic i pronòstic pels quatre actors. (c) Identificar els desafiaments ètics percebuts pels quatre grups de participants en la comunicació relacionada amb el diagnòstic i pronòstic del càncer.

Metodologia: Es van realitzar dos estudis per assolir els objectius d'aquesta recerca. El primer estudi és qualitatiu de tall interpretatiu utilitzant anàlisi temàtica. Es va guiar pel propòsit de comprendre el fenomen de la comunicació relacionada amb el coneixement del diagnòstic i el pronòstic, explorant les perspectives dels pacients amb càncer avançat i les dels seus cuidadors, metges i infermeres. Basant-se en un disseny multiperspectiu, es van dur a terme un total de 27 entrevistes semiestructurades en les quals van participar els quatre grups diferents de participants (7 pacients, 7 cuidadors, 6 metges i 7 infermeres) -vinculats per la relació de cures, en dues unitats d'oncologia de dos hospitals de Sardenya. El segon estudi també és un estudi qualitatiu que utilitza l'anàlisi fenomenològica interpretativa. El seu objectiu és investigar el fenomen de la comunicació relacionada amb el diagnòstic i el pronòstic, tal com l'experimenten els pacients, els seus cuidadors i les infermeres i metges que els atenen, amb la finalitat d'esclarir els significats atribuïts a la comunicació per les quatre parts. Es va realitzar un mostreig intencionat de 6 pacients, 6 cuidadors, 7 infermeres i 5 metges en els dos hospitals ja esmentats. Es van realitzar un total de cinquanta-una entrevistes semiestructurades en dos serveis d'oncologia de dos grans hospitals del sud de Sardenya, Itàlia. La recopilació de dades va començar a l'agost de 2016 i va finalitzar al febrer de 2017. Els participants es van reclutar a través de dos mostrejos intencionats, els altres es van reclutar en funció de la seva connexió amb el pacient i van incloure als seus cuidadors, metges i infermeres(rs). Es va proporcionar una descripció detallada de les característiques de les mostres. Les entrevistes van ser transcrites textualment i es va realitzar una anàlisi temàtica seguint els passos d'anàlisis descrites per Smith. L'anàlisi de dades es va realitzat amb suport del programari Atles.ti. Versió 7.5.7.

Els dos estudis satisfan el rigor dels estudis qualitatius seguint els criteris indicats per Guba i Lincoln: fiabilitat i confirmabilidad, credibilitat i transferibilitat.

Resultats: En el primer estudi, l'anàlisi de les dades va permetre identificar tres temes principals: (a) La disponibilitat de les infermeres i els metges com a comunicadors condicionada per factors contextuals; (b) El "què és?" i el "què em passarà?"; (c) La coincidència i la falta de coincidència en la identificació dels altres com a interlocutors. En el segon estudi, l'anàlisi de les dades va aportar també tres temes: (d) L'infinit ventall de possibilitats en el saber i el voler saber; (e) La comunicació amb el pacient com a situació conflictiva; (f) El vincle del significat implícit i explícit de la comunicació.

Les troballes descriuen un context en el qual el diagnòstic i la comunicació relacionats amb el pronòstic són gestionats pels professionals sanitaris de forma aïllada, encara que alguns professionals sanitaris es refereixen a l'enfocament d'equip com una perspectiva desitjada. En aquest context, els professionals sanitaris no reconeixen tot el procés de comunicació del pacient. Això pren el poder de les/els infermeres(us) com a defensors dels pacients i soscava els seus esforços per a satisfer les múltiples i canviants necessitats de comunicació dels pacients i els seus cuidadors. A més, en un context d'interaccions comunicatives poc integrades, les quatre parts no es reconeixen a si mateixes com a recursos en el procés de comunicació i, quan això succeeix, ho fan de manera idiosincràtica.

Des d'una perspectiva ètica, la interacció dels significats atribuïts pels pacients, els seus cuidadors i els seus oncòlegs i infermeres(us) involucrats en el diagnòstic i la comunicació relacionada amb el pronòstic ha posat en relleu la complexitat i ambigüitats que encara no han estat resoltes. Les perplexitats i contradiccions segueixen presents i no resoltes i es deriven del contrast entre el principi d'autonomia i el principi de beneficència.

Conclusions: La recerca ha permès tenir una comprensió àmplia del fenomen de la comunicació relacionada amb el diagnòstic i el pronòstic i ens ha permès il·luminar les interaccions comunicatives i els significats relacionats amb el fenomen de la comunicació per part de pacients, infermeres(rs), cuidadors i metges. Això ofereix una nova visió per a reflexionar sobre les qüestions ètiques que estan en joc en la comunicació sobre el diagnòstic i el pronòstic en el context de l'atenció del càncer. El principal problema que sorgeix en tots dos estudis és la percepció compartida de l'estranyesa del paper de la infermera(o) en la comunicació sobre el diagnòstic i el pronòstic.

En resum, la comprensió global del fenomen de la comunicació relacionat amb el diagnòstic i el pronòstic que permet el disseny de

l'estudi de múltiples perspectives i l'enfocament interpretatiu ha posat en relleu com els diferents interlocutors interactuen i influeixen entre si. El reconeixement i la reflexió sobre les complexes interaccions en les quals es desenvolupa la comunicació poden ajudar a analitzar les responsabilitats individuals i compartides cap al pacient, amb la intenció d'un enfocament de comunicació personalitzat i una atenció més centrada en el pacient.

Paraules clau: comunicació, diagnòstic i pronòstic, càncer, coneixement, significats, ètica multiperspectivo, IPA.

1. Introduction

1. Introduction

The focus of this dissertation is communication related to diagnosis and prognosis in patients with advanced cancer disease and a shortened life expectancy. Cancer is to this day one of the most widespread diseases, and it causes a lot of suffering and death. Advances in treatment have allowed many affected people to recover and survive from cancer, but cancer is still a terrible disease. It is commonly assumed that cancer is a disease characterized by several distinguishable evolving stages and generally oncologists can predict life expectancy.

Much has been written on the topic of communication in oncology and many guidelines have been published on how to approach the disclosure. However, most of the research and studies on the topic focus and limit the analysis to a portion of the context of care. Besides, several studies show evidence of the persistent difficulties that nurses encounter in understanding their role in relation to communication related to diagnosis and prognosis. There is also evidence that nurses involved in cancer care feel challenged by the ethical dilemmas connected to communicating and disclosing diagnosis and prognosis. Existing literature also reports that patients have expressed the need to interact with nurses to better manage the process of being aware and accepting their diagnosis and prognosis, and to find -and feel- support and understanding. This data supports the notion that communication related to diagnosis and prognosis is a relevant topic for nurses. It understands how nurses relate to patients that have a fatal prognosis and how patients perceive nurses as their professional caregivers. To investigate the communicative interactions of the different stakeholders means to widen the researcher's perspective so to understand how the key stakeholders influence and perceive each other. This comprehensive new perspective intends to avoid reproducing in the research focus and approach the sectionalisation present in many clinical settings, and to serve the patient centred cause.

Therefore, this dissertation approaches communication as a comprehensive phenomenon involving physicians, nurses, patients, and their caregivers. It addresses a specific gap in the literature by comparing the perspectives of advanced cancer patients with those of their caregivers, physicians, and nurses. This will allow to explore the meanings that participants assign to their communication interactions when it comes to knowing diagnosis and prognosis. The ethical issues as perceived and interpreted by the key stakeholders involved will also be addressed and discussed.

2. Background

2. Background

Cancer is the second leading cause of death worldwide (WHO, 2018). It was responsible for around 9,6 million deaths in 2018 (WHO, 2018). To put this into perspective, it means that globally about 1 in 6 deaths are due to cancer. In Italy alone there have been 415 269 new cancer cases in 2020. The five-year prevalence is 1 230 693; cancer deaths are 174 759 (Globocan 2020).

It is considered a chronic disease characterized by different distinct evolving stages. McCarthy et al. (2000) studied a large sample of cancer patients who died within 1 year of their index hospitalization and found that the last 6 months of life for patients with cancer is characterized by a functional decline and by poorly controlled severe pain and confusion. Generally, oncologists can predict life expectancy: in the study conducted by Lamont & Christakis (2001) physicians were able to formulate prognoses for over the 96% of the evaluable patients. The most predictable evolution of the disease would allow for timely personalized communication on prognosis and treatment preferences. However, revealing the prognosis or, more generally, telling the truth is still a very controversial issue in cancer care and all too often an unresolved clinical dilemma. In fact, the pre-assumption of this thesis is that predictability is a challenge to communication and that it affects all parties involved.

The emotional and psychological impact of any disease always need to be taken into account by health professionals but, in cancer care, this is even more necessary because of the persistent stigma associated to the disease, the worries and fears about its progression, and the impact of treatments. In fact, although there have been positive shifts in attitudes about cancer awareness, cancer-related stigma is still a difficult-to-erase phenomenon. Stigmas and taboos are different from one country to another and have a different pervasiveness, yet they are widespread all over the world. Daher (2012) has shown that cancer stigma still poses significant challenges to disease management. He argued that stigma could have a silencing effect, causing a detrimental decrease in cancer awareness and care delivery. Furthermore, he noted that the negative impact of stigma not only affects health, but also extends to the social, emotional, and financial spheres. The belief that cancer is a deadly disease with no chance of survival and the symptoms of cancer, or the parts of the body affected by the disease experienced as a stain of shame are just two examples of the cultural myths and taboos found in cancer. Daher (2012) suggests that communication has a critical role in decreasing cancer-related troubles. He poses that an open communication approach to cancer could raise awareness and favour the dissemination of cancer education.

2.1 Communication

Nowadays it is quite clear to everyone that communication cannot be thought of as simple information, this scheme has proved completely inadequate to explain the complexity of communication. The "Emitter-Message-Receiver" scheme is grounded in the Behavioural communication models, which were quite popular in the first half of the past century (Zani et al., 2002). According to this model, communication can be explained by the stimulus-response paradigm, the receiver of the message being the passive pole. This model has been widely criticized by many authors; Bavelas et al. (2000), for example, showed in their seminal research how the "listeners" of a story are, exactly for their listening activity, active "co-narrators" of that story. The flaws found in the Behavioural Communication Models have been overpassed by the Interactive Models, which introduced the concepts of background and feedback: communication has to do with the context in which it takes place, with the knowledge and experiences of the interlocutors and with reciprocal feedback. These models are rooted in the paradigm of socio-constructivism and, although they allow us to clarify how personal and social constructs determine the different forms of communication, they present some weaknesses such as considering communicative interactions consisting of single finite communicative interactions. The most recent theories emphasise that in the communication process the interlocutors are simultaneously, and not at different and successive moments, broadcasters, and recipients. Among the most relevant current theories there is the worldwide famous Paul Watzlawick's "Pragmatics of Human Communication". He was a theoretician in communication as well as a convinced constructivist; he sustained that communication is a process of interaction between people, and that one cannot fail to communicate. Watzlawick and his colleagues argued that each communication process between human beings has two distinct dimensions: the content, what the words are saying, and the relationship, or what the speakers mean verbally and more often non-verbally, about the quality of the relationship between them. Therefore, Watzlawick recognizes a pragmatic function of communication, which is the ability to have behavioural consequences in the contexts in which people interact. It also implies that any phenomenon remains inexplicable without the contextual framework that encompasses it. Watzlawick's axioms entail also that there is no communication without a behaviour, nor a behaviour without it conveying any meaning. A related key finding is that every communication is also a metacommunication with respect to the interrelationships between communicators.

Communicating diagnosis and prognosis in cancer is certainly a crucial step in the care process, and a special challenge is communicating the diagnosis and prognosis to patients with advanced and incurable cancer: the content of the information is a fatal sentence. In such a situation the picture is usually described as the patient confronted by the reception of bad news about a life-limiting illness, and the doctor who has been mandated to tell the truth without breaking down hope.

2.2 Theoretical references of the concept of communication

The concept of communication used here is grounded in the so-called dialogical approach to communication (Zani et al.,2002). According to this approach, communication is a process in which the subjects, interacting with each other, create the meanings of that interaction and produce the very context in which the process takes place. The co-constructed view of the communication of interaction implies that:

"every interactional moment is potentially an opportunity space for some participant to redirect the unfolding of the discourse such that individual understandings, human relationships, and the social order might be changed." (Jacoby & Ochs, 1995, p. 178)

In the dialogical model of communication intersubjectivity is a central concept. It refers to a characteristic figure of communication interactions that is achieved when communicators mutually assume the other's point of view, so to share a common reference panel. According to this model, the communication process undergoes a sort of constant monitoring of the mutual understanding of the interlocutors: the recipient of a message, decoding it, makes its meaning explicit and starts from a set of hypotheses of the speaker. That is why the meaning of the message cannot be but co-determined by the interlocutors, and the relationship that exists between them supported the communication interaction. In this sense, the content and understanding of the messages cannot be studied apart from the relationships between the interlocutors. In summary, the dialogical model shows communication as an *irreducible relational fact* in which individuals know and make themselves known by actuating intersubjectivity. This concept of communication implies that the social world of the subjects is transformed during the course of their interaction and should be considered an important dynamic factor of the communicative exchange, and not a static background element. Dialogical models of communication are connected to the theory of Socio-constructionism, that poses that the different descriptions of the world, e.g., the different theories, are formed historically, in the relationship between individuals, through their agreements, negotiations and co-constructed shared meanings (Berger & Luckmann, 1969). The fact that meanings are co-created by people has important implications for human sciences approaches meanings are never permanently fixed, neither stable, nor unchangeable; they are somehow indeterminate and always different (because they depend on the context). Besides, it follows that there is no truer meaning, but rather a contextual way of understanding it. Underpinned by this theoretical premises, my study adopts a multi-perspective design to better understand how communication related to diagnosis and prognosis is experienced by the key stakeholders when life expectancy is no more than one year, in the context of an oncological ward. The experience explored is framed by a given period of time identified along the trajectory of the disease - advanced cancer disease with a life expectancy of less than 1 year - and a defined place - hospital ward. Perception, being inherent to a subject, cannot dismiss its subjective attributes: perception is always partial and perspective and, consequently, is a function of one's spatial and relational place in the world. This concept of experience, of a person's experience, of always being "in relation to the world" recalls the work of the German philosopher Martin Heidegger. His theories of Being and his concept of the Phenomenon have been a reference to many theories of the human system which state that events and processes are best understood by exploring what happens between the individuals involved.

The choice to adopt a multi-perspective design to conduct this research is also underpinned by the theoretical position of **symbolic interactionist** (Berger & Luckmann, 1969). This positioning emphasizes professional roles and identities as entities co-constructed by the ways in which individual professionals interact with the social world in which they live. This implies that the perceived and self-perceived professional roles of nurses and doctors are inevitably influenced by their mutual interactions and the interactions and expectations of patients and caregivers, i.e., the social world in which they live.

2.3 Cultural aspects in cancer communication

In our multi-ethnic societies it happens more and more often to find ourselves in cross-cultural contexts in which patients, their families and health professionals do not share the same values and the same ways of perceiving and dealing with cancer. Concordantly, cancer disclosure communication appears strongly associated to the cultural humus, healthcare, and social system in which it is set

(Surbone, 2008; Abazari et al., 2016). Literature shows that in many cultures there is still a strong resistance against the full disclosure of the diagnosis and prognosis (Shahidi, 2010). In her review Surbone (2006) reported that in underdeveloped countries only 30% of people with cancer expect the doctor to tell them the truth, a value that rises over 90% in most industrialized societies. Conversely, Western medical practice promotes open and free communication with patients, so that they are fully aware of their disease and treatment, and patients are fully encouraged and supported to be involved in the medical decision making (Oliffe et al., 2007). Therefore, it can be said that disclosure is a "cultural sensitive" issue and that, being influenced by the socio-cultural context in which it takes place, it reflects that same socio-cultural way to deal with disease and death. The issue of cultural sensitivity in communication in life-threatening diseases has been studied and developed in both popular and scientific literature for a long time. Many scholars have shown that all the questions arising about the disclosure issue can be understood and addressed only by taking in due consideration the specific socio-cultural context in which those questions are expressed (Sarafis et al. 2014; Oikonomidou et al., 2016). In Italy there is still a rather high rate of partial disclosure or non-disclosure in cancer care: a study conducted by Milo et al. (2007) in hospices located in the north of Italy found that just 60% of the patients were informed of their diagnosis and only 3.5% of their prognosis and on the meaning of palliative care (3.5%). The level of information of caregiver was higher on both patient's diagnosis and palliative care (93.2%, 48.8%). The study highlights the flaws in accompanying patients along the process of adaptation to the disease, both with respect to the diagnosis and transmission of prognostic information, and in the adoption of personalized communication approaches. However, it can be said that there has been an evolution both in communication practices and in laws and protocols, in line with the spread of the principle of autonomy (Surbone et al., 2004). Nevertheless, this evolution seems to be incomplete amongst Italian physicians: many of them are still reluctant to fully disclose and even when they declare themselves in favour of disclosure, most of them do not act in line with their own statements (Di Giacomo et al., 2012). This is not just an Italian trend: other authors in other cultural contexts have found that even when physicians plead in favour of disclosure, most of them are not consistent with their own declarations (Dolbeault & Brédart, 2010; Abazari et al., 2016; Oikonomidou et al., 2017)

2.4 International Codes and the Italian Laws related to Medical Communication and Information

The rights of the individual in relation to any medical act and any experimental treatment are the subject of numerous codes, declarations, conventions, guidelines at national and international level. Many of these are not legally binding, but equally constitute references whose authority is unanimously recognized. These codes and declaration are therefore pertinent to the issue of diagnosis and prognosis communication. Next, I am going to present some of these documents.

The Convention on Human Rights and Biomedicine (ETS No 164) signed on the 4th of April 1997 in Oviedo (Spain) is the only international legally binding instrument on the protection of human rights in the biomedical field. It establishes fundamental principles applicable to daily medical practice and is regarded as such by the European treaty on patient's rights. Among the patient's rights, special attention is paid to information: In chapter II, entitled "Consent", the article 5 states:

"An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks. The person concerned may freely withdraw consent at any time". (art. 5, ETS No 164)

And following, on chapter III, the article 10 specifies that:

"Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed" (art. 10, ETS No 164).

In the current Italian Code of Medical Ethics, updated in 2017, information to the patient is discussed in Title III which deals with relationships with the assisted person. In this grouping of articles, Article 20, entitled "Care Report" states:

The relationship between doctor and patient is based on freedom of choice and on the identification and sharing of their respective autonomies and responsibilities.in the relationship the doctor pursues the alliance of care based on mutual trust and mutual *respect for values and rights and on comprehensible and complete information, considering the time of communication as the time of care.* (p. 17)

The article then describes the relationship with the assisted person as an alliance in which, although distinct, their respective autonomies and responsibilities are placed on the same level. At the same time, the physician's commitment to providing complete and understandable information is mentioned. The very communicative interaction must be considered as an act of care.

In Title IV Information and communication are discussed in reference to consent and dissent to treatment. Article 30 reads:

The doctor guarantees the assisted person, or his legal representative, understandable and exhaustive information on prevention, on the diagnostic path, on diagnosis, on prognosis, on therapy and on any diagnostic-therapeutic alternatives, on foreseeable risks and complications, as well as on the behaviours that the patient will have to observe in the care process. The doctor adjusts the communication to the understanding capacity of the assisted person or his legal representative, corresponding to each request for clarification, taking into account their sensitivity and *emotional reactivity, in particular in case of serious or fatal prognosis, without excluding elements of hope. The doctor respects the necessary confidentiality of the information and the will of the assisted person not to be informed or to delegate the information to another subject, reporting it in the health documentation.* (p. 24)

Article 30 meets the current Italian health legislation and provides further guidelines on the doctor's communication approach. Particular attention is paid to the emotional repercussions caused by receiving this type of information, especially in case of poor prognoses. Also, when giving bad news the doctor is invited to never leave out elements of hope. This article collects all the incentives that in the age of medical paternalism led to a concealment of diagnosis and prognosis to the patient in serious conditions and reconverts them into a more acceptable approach for current Italian social ethics.

The principle of autonomy provides the ethical reference to informed consent which is constituted as a deontological duty and legal obligation.

The 2019 Italian Code of Ethics for Nurses pays special attention to communication with the assisted person. In Chapter I, which presents the principles and values, article 4 describes the "care relationship" as this:

> *In professional action, the Nurse establishes a relationship of care, also using listening and dialogue. We guarantee that the assisted person is never left in abandonment, involving, with the consent of the person concerned, his reference figures, as well as other professional and institutional figures. Relationship time is cure time.* (p. 9)

This is the relationship that underlies every other action: listening and dialogue are means through which the relationship is built. Further on, states Article 13 entitled "Competent action, advice and information sharing" declares:

> *The nurse participates to the cure-path and works to ensure that the assisted person has the information shared with the team, necessary for his life needs and for the conscious choice of the proposed cure-paths.* (p. 13)

The article does not mention who should provide the information but focuses on patients and the information they need in order to be the protagonist of their own life, and to make informed decisions. The nurse is assigned the role and responsibility of ensuring that the patient, having been informed, has the possibility to make informed decisions about therapies.

2.5 Theoretical reference in respect to the "Patient Centred Approach"

The Patient-Centred approach will be approached not as a rigorous model of care, but as the kind of patient approach which, today, is widely accepted and assumed by healthcare professionals and commonly evoked by healthcare organizations and institutions in the Western world. The Patient-Centred approach is also cited in many documents written by the hospital where the field data has been collected. The proposal to put the patient at the centre of the healthcare system emerges, for example, in the Triennial annual programming 2020-2022 report signed by the General Manager of the Azienda Ospedaliero Universitaria of Cagliari. This official and formal document states that:

The AOU, as an integral part of the Regional Health System, pursues its institutional mission, in compliance with the following founding value: - centrality of the person. It places the citizen at the

> *centre of its activity in order to meet their needs and expectations transparently, promoting the humanization of health services.* (p. 17)

The locution “patient centred” was firstly introduced by psychoanalytic scholars in the late sixties (Balint, 1969), and has later been widely used in many fields, like health policy, bioethics and so on. It can be said that the patient centred approach represents the upside down of the former widespread medical paternalistic perspective. It demands the clinicians to focus and organise their activity having the patient and their needs as a starting point. The respect of the patient’s values and will is no longer a mere permission but a pre-requisite of every health care interaction. Bensing and colleagues (2003) add that the patient-centred approach should focus on the entire communication process rather than the mere results of the decision-making process. Therefore, patient-centred care must refer to both information content and co-constructed processes of information sharing.

2.6 The multidisciplinary dimension in communication

Nowadays recommendations for a multidisciplinary approach to cancer care are numerous from many institutions and associations. The Associazione Italiana di Oncologia Medica [AIOM] guidelines (2018) also prompt an approach to cancer care that involves all those who, for various reasons, are involved in the care process, in order to truly offer a patient-centred healthcare system that can be beneficial for the emotional state and give a better outcome. So far, it is important that care is provided according to a multidisciplinary approach and that this approach is well coordinated and integrated. In this sense, it can be said that exploring communication in cancer care also means taking into account communication within the medical team. Literature shows that the quality of the healthcare provided and the quality of communication between the doctor and the patient relays on the quality of the communication and coordination within the team (Dolbeault & Brédart, 2010; Villalobos et al., 2019). Since good communication is at the basis of good collaboration between healthcare professionals and therefore related to high quality care, it is important to understand how it works. Moreover, the quality of communication among health professionals has been related not just to the quality of care but has also been studied in relation to ethical dilemmas that arouse in clinical settings. Sundin-Huard & Fahy (1999) note the relevance of understanding the perspectives of others, particularly in situations that may be ethically problematic, or whenever the ethically desirable outcomes are divergent. Other authors approach the problem from a theoretical perspective and observe that with cure and care not yet reconciled, end-of-life family conversations are still thwarted and inter-professional relationships between health workers are hindered (Omilion-Hodges et al., 2017).

2.6.1 The importance of an inclusive research approach

Since it involves multiple interacting parties, we should be aware of the reductionist approach resulting from the splitting of communication and its study into separate professional sectors. This does not mean that there are no professional roles or skills and specific responsibilities involved in communicating diagnosis and prognosis, but that we must be aware that the phenomenon is also made up of interconnections of perspectives, and that even if we want to study it just as a phenomenon of medical information transmission, we must take into consideration all the parties involved and the interaction of their perspectives.

2.6.2 Nurse’ role in cancer communication

Nurses’ critical role in cancer communication and information transmission is starting to get more attention. A recent literature review showed that patients and relatives turn to their nurse to better understand diagnosis and prognosis-related information received from doctors (Newman, 2016). Also Koutsopoulou et al. (2010) in their review found that nurses are often referred to by patients as a preferred source of information, especially in regards to aspects relating to daily life, such as symptoms, treatment of side effects, family issues, but also in reference to diagnosis. Another systematic review of qualitative studies (King et.al., 2015), aimed at examining the experience and needs of prostate cancer patients, highlighted the role of the nurse in facilitating the discussion of the non-medical aspects of the disease as well as in developing coping skills. The AIOM Guidelines for psycho-social assistance to cancer patients

(2018) suggest that information should also be transmitted by nurses, based on the nurse’ educational role and on the existing evidence in literature. Along with evidence of growing awareness of the nurse's role in cancer care, there is much evidence of barriers and difficulties in nurse-patient communication. The inadequacy in the management of emotional aspects is among the most frequent findings (Tay et al., 2011). Many authors call for further exploration of doctors 'and patients' perceptions of the role of nurses.

2.6.3 Theoretical reference in respect to Nursing

Since Florence Nightingale gave the first definition and theoretical basis to Nursing, many scientific works, theoretic foundations, key-concepts, epistemological clarifications have contributed to the development of Nursing as a discipline. Moreover, since Florence Nightingale, the importance of the nurse-patient interpersonal relationship and communication with the patient received great attention. As reported by Kiteley and Vaitekunas (2006), Nightingale urged nurses to keep the patient informed, since apprehension, uncertainty, waiting and expectation, cause a patient more harm than any exertion.

Beyond all the different scientific contributions and positions, some claims are widely accepted and deemed as proper and distinctive for contemporary Nursing. These claims are: (a) Nursing is to take care of the person as a whole; (b) Nursing is always patient centred; (c) Nursing is about the promotion of health, the prevention of illness, the care of ill, disabled and dying people. The centrality of the nurse-patient relationship in respect to the ethical dimension is clearly posed by Fry (1989):

"the value foundations of nursing ethics are derived from the nature of the nurse-patient relationship instead of from models of patient good, rights-based notions of autonomy" (p.9).

Here the caring relationship is considered as the very essence of Nursing and appears as primitive to any type of moral discourse or, at least, as the first requisite of it. Henceforth, the only goal of Nursing cannot be the biological or medical aspects of care but, by virtue of its essence, it must always be sensitive and deal with medicine and human sciences. This implies that nurses cannot fail to have a complete understanding of the patient's needs (Skilbeck & Payne, 2003). It can be said that all the principal theorists in Nursing served these assumptions. Among them there is Francoise Colliere

(1982). She referred to communication as the means through which sharing happens. She argued that it is only through a constant and open sharing that the patient-nurse relationship can flourish. It is only in the sharing process that the nurse can determine the nature of the care to be provided and the means by which to carry it out. In fact, if the nursing caring process is based on the encounter of two persons, then each of them possesses some elements of the process itself.

The fundamental connection between the nurse-patient relationship and communication has been also explored and underlined also by Peplau's Nursing Theory (1997). She identifies a kind of nurse-patient relationship that originates from those communication interactions described as the employment by nurses of an investigative inquiry and an attentive listening to the patient narrating their personal experiences. This is supposed to allow a greater self-understanding and, therefore, promote the patient's autonomy. She also warned that the nurse-patient interaction can be productive only when the nurse uses a method of communication that allows to identify and adopt common meanings (Peplau, 1997).

For the purpose of this thesis, I am framing the issue of communication with the patient within the primitive and foundational nature of the patient-nurse relationship.

The concept of advocacy, as developed by many nurse theorists, sustains that in the context of the patient-nurse relationship, the nurse must commit to guarantee to their patients not just the information, but also the conditions and freedom to make their own decision concerning their care. The role of nurse as patient's advocate in the process of diagnosis and prognosis disclosure has been enlighten by many authors (Kendall 2006; Helft et al. 2011). McLennon et al. (2013) showed that nurses advocating for patients commit themselves in prognostic communication to ensure that patients receive care that is consistent with their preferences and goals.

In the context of cancer care, there is evidence (Koutsopoulou et al. 2010; King et.al.2015; Newman, 2016) about nurses being confronted by patients asking questions related to their diagnosis and prognosis, expressing their feelings, doubts and thoughts. This is also my personal experience as a nurse working in an oncological surgical ward for many years, and later in a palliative care centre. As health professionals, well-informed about the patient’s disease and healthcare pathways, and having access to the patient’s medical records, nurses do not ignore patients’ diagnosis and prognosis. Therefore, nurses cannot avoid confronting themselves with the question about what is at stake in communicating diagnosis and prognosis and reflecting upon what their positions in respect to disclosing this information is. The quality of communication between nurses and physicians has been proved to generate a lack of mutual trust and gave rise to misunderstandings and disappointments. In fact, doctors’, and nurses' perceptions of ethical problems in end-of-life decisions have been shown to be a source of tension for health professionals (Oberle & Hughes, 2001). Misunderstandings and conflicts may come from differing perceptions of ethical problems. Mystakidou et al. (2005) have exemplified it as a triangle consisting of the health care professionals, the patient, and the family where “*each part supports the other two and is affected by the changes that happen in the triangle*” (p.175).

2.7 Caregivers role in cancer communication

Cancer has been widely considered to be a disease that affects not only the individual but also their loved ones and particularly the caregiver. Caring for a person with advanced cancer can be both physically and psychologically challenging. As a counterpart, caregivers can play a crucial role not only in managing the practical aspects of care, but also in supporting the patient in the psychosocial challenges they encounter along the trajectories of the disease. Communication on diagnosis and prognosis can be considered one of these challenges. However, it is not long ago that the literature recognized and highlighted the important role of caregivers in cancer management and studied its influence on patient outcomes. The practical and emotional support provided by the caregiver was associated with better outcomes (Hubbard et al., 2010; Hobbs et al., 2015) and, therefore, appropriate involvement of the family and caregivers in the communication process received more attention.

2.8 Theoretical ethical framework

Today communication of the diagnosis is treated as a deontological and ethical obligation and as a legal requirement. Ethical references are complex and extremely relevant and have been extensively studied in the literature. Next, I will provide a brief presentation of the ethical issues related to communicating the diagnosis and prognosis.

A specific feature of the communication of diagnosis and prognosis is the position asymmetry between the information provider and the recipient. Many scholars describe the communicative relationship that is established between healthcare professionals and the patient as an asymmetrical relationship: the health professional is the expert with a scientific background and a specific know-how, while the patient is a person with health problems who turns to the expert to find answers. In this sense, the asymmetry arising from the epistemic background lies in the imbalance of knowledge and also of power, since having knowledge means having the possibility of controlling reality. How healthcare professionals communicate the diagnosis and prognosis, the words they choose, the words they say and the words they do not say, can interfere with the patient's ability to express themselves and their needs, may allow them to make informative choices or precluding them, can empower or deprive them of power, preserve hope or open the door to despair. In their review Germeni et al. (2014), for instance, showed that information seeking behaviour is influenced not just by patient characteristics and/or disease characteristics, but by the context of cancer care as well. It means that the context of care can facilitate or hinder the individuals' willingness and potential to assume the role of informed patient and be, in the end, an active participant in the decision-making process. And this, in turns, means that the context of care has its own specific ethical dimension.

In short, information and communication are tools to enable the patient to take control over the disease and take decisions about the treatments. But it can also interfere with health professionals' ability to determine patient preferences and goals.

The truthfulness and completeness of medical information has been a key topic of bioethics since its inception. However, even before Beauchamp and Childress developed, in 1999, their "Principles Biomedical Ethics", giving the principle of autonomy a central role, the telling of the truth was addressed in many documents and codes of ethics referring to doctors and nurses. It has become a public topic since the 1960s and 1970s, when the civil rights movement promoted greater concern for patient self-determination. During that time, telling the truth was firmly connected to the patient's need to know their diagnosis in order to make informed choices. As far as nursing is concerned, the question of telling the truth has mostly been considered in reference to the relationship of trust that is established with health professionals.

In that period, the milestones that pinned medical information on diagnosis and prognosis to the concept of autonomy were many. Among these can be cited "A Patient's Bill of Rights" (1972) by the Board of Trustees of the American Hospital Association which stated that the patient is entitled to complete and current information regarding his diagnosis, treatment, and prognosis in terms that the patient should understand. However, disclosure as a tool to increase patient autonomy (and not just as a legal fulfilment) together with the interconnections and influences between communication and the healthcare context (and therefore the healthcare context as a factor to be considered in the ethical analysis) remain open questions. in ethics. They can represent the difficulties faced by ethical principles when applied to the real clinical world.

2.9 Literature review summary

A literature search to identify the publication on communication-related diagnosis and prognosis in cancer care, conducted via Medline, Cinhal, and Ebsco hosts, resulted in 175 studies included for abstract reading. Subsequently, 89 studies were selected for full reading. The keywords related to the research question informed the research strategy: communication, cancer, diagnosis and knowledge of prognosis, multi-perspective, ethics. Like Smith et al. (2009) suggest, the literature has been used to maintain an exploratory approach to investigation. Next, I will outline some of the key findings in the literature related to my topic and the specific knowledge gap that justifies this research study. The paradigm of patient-physician information transmission and the type and quantity of information transmitted by the physician to the patient have long been among the main issues investigated in communication in cancer care treatment. Overall, these studies aimed to explore the cognitive aspects of communication. Following this topic, a recent systematic review and meta-analysis (Chen et al. 2017) found that at best only half of advanced / terminal cancer patients accurately understood their prognosis, although there was significant variation by region. and evaluation methods. The authors comment that healthcare professionals still need to make efforts to thoroughly assess the preferences of advanced / terminal cancer patients for prognostic information. A shift beyond the cognitive factors implied in diagnosis and prognosis communication has been given by the introduction of the so-called Patient-Centred-Communication approach. This approach, as previously written, focuses on the patient as a "whole person", expression of a specific social and psychological microcosm and, consequently, promotes practices such as exploring the patient's perceptions and concerns and engaging the patient in consultation and decision making and so on (Mallinger et al., 2005). Hence, literature has been increasingly approaching cancer communication as a multidimensional process that often is still described by patients and their caregivers with plenty of ambiguity and uncertainty (Hansen et al., 2012; Sajjadi et al., 2016). Another line of studies has investigated the patient - healthcare-professionals relationship as a moderating factor in communication. Considering this, a multicentre study (Fenton et al., 2017) found that prognostic discussion is not intrinsically detrimental to the patient-physician relationship and may even strengthen the therapeutic alliance between patients and oncologists.

Several benefits have been linked to good communication in the context of cancer care. Evidence is concordant in showing that diagnosis and prognosis-related communication can increase patients' awareness about their illness, the acceptance of the diagnosis and decisions related to the treatment, and the ability to cope with the illness (Innes & Payne, 2009). Information on disease and prognosis has clearly been shown to affect rational decision making about therapy and treatment planning (Hagerty et al. 2005). Good communication regarding diagnosis and prognosis is relevant not only in terms of accepting one's diagnosis (Daugherty & Hlubocky 2008) and the ability to make thoughtful treatment decisions, but also to cope with feelings of confusion, doubts, fears and to process the existential meaning of the experience of illness (Innes & Payne, 2009). Therefore, it can be argued that the importance of communication in cancer care is well established. However, a poor patient-healthcare communication quality (Back et al., 2008; Covvey et al., 2019) and a consequent failure to meet patients' preferences and information needs are still observed in the context of advanced cancer. (Pardon et al., 2011; Buiar and Goldim, 2019). The main barriers to effective communication and information sharing lie in fragmented communication, ineffective referral systems, uncertainty about patient consent, and the unacknowledged existence of overlapping care plans (Lawn et al., 2015). The persistence of difficulties and barriers is also found in reports on low rates of prognostic awareness. The authors of a systematic review (Applebaum et al., 2014) aimed at summarizing the complex literature on prognostic awareness in cancer commented on their results stating that: *"surprisingly, high percentage of patients (up to 75%) were unaware of their poor prognosis, and in several studies, even their cancer diagnosis (up to 96%)"* (p.1103).

Many communication skills training courses for healthcare professionals have been implemented and reported in the literature. A recent Cochrane review (Moore et al., 2018) that looked at randomized controlled trials and controlled before and after trials - the primary findings of which were changes in the communication skills of healthcare professionals - concluded that although some trials appeared effective in improving healthcare providers' communication skills, they were unable to determine whether the effects of educational trials were sustained over time. Another study (Wittenberg et al., 2018) on communication training needs for oncology nurses reported that although communication training programs and curricula have been more prevalent and welcomed, nonetheless changes to institutional practices are needed to achieve and deliver an effective patient-centred communication. In summary, the literature highlights the difficulties encountered both in implementing initiatives to promote good communication and in conducting research aimed at understanding which interventions are most effective. Among these, what happened in Italy a few years ago is exemplary: some hospital oncology centres have adopted an organizational model that provided for the creation of Support Information Points for patients and family members, managed by trained nurses. Its effectiveness on psychological distress was evaluated by an RCT (Passalacqua et al., 2009) conducted on all centres scattered throughout Italy but the intervention did not give the expected results. However, the problem was that in most cases the intervention was not conducted according to the protocol. When this was followed, the intervention proved to be effective, but the data is not statistically significant due to the low power of the study.

Therefore, despite the great attention brought to patient-centred communication, the evidence provided by the literature, and the dissemination of the educational training course on communication, I will agree and conclude with Epstain et al. (2017) that "*there has been little headway over the past 20 years*" (p. 97).

In the previous sections of this thesis, I have illustrated that communication about diagnosis and prognosis can be considered a multi-layered phenomenon occurring in an interactional context: patient, caregiver, physician, and nurse are all interwoven by numerous communication interactions and reciprocal influences. Yet, communication as a global enterprise and as a phenomenon involving different actors, all intertwined, has not received due attention either in the clinical context, nor in education and research. Few attempts have been made to understand the intertwined perspective of those involved in communication related to diagnosis and prognosis and to investigate how different communicative interactions and perceptions affect the communication experience. Most of the literature on cancer communication has focused on information exchanges between patient and clinician, the role of the family (Arraras et al., 2011) and the most appropriate way to deliver bad news. Girgis, back in 1999, suggested an evaluation of the appropriateness of guidelines for breaking bad news comparing the perceptions of different healthcare providers with those of patients. Yet, she received little attention since Shahidi in 2010 renewed the appeal to investigate the contributing factors coming from the relatives, doctors, and healthcare systems so to better understand attitudes and existing problems in cancer disclosure.

Orri et al. (2015) noticed that the patient, caregiver, physician, and nurse's perspectives about communication and disclosure of information are rarely considered and compared together in the context of cancer care. Dyadic interactions, e.g., patient-nurse, patient-physician, and patient-caregiver, have been commonly investigated in previous studies (Kimberlin et al., 2004; Furber et al., 2013) There have also been a few other studies adopting a triadic perspective (Laidsaar-Powell et al., 2013; Orri et al., 2017) but they limit the analysis to a portion of the context of care. All these authors agree in suggesting the need to consider the perspectives of all the actors involved in cancer care.

Studies with a multi-perspective design and adopting IPA are quite recent and still few (Dallos & Denford, 2008). I could only two qualitative studies investigating the issue of cancer disclosure from the perspective of the patient, physician, nurse, and caregiver, all together (Abazari et al., 2016; Ehsani et al., 2016). These studies revealed that obstacles to cancer disclosure are related to the healthcare system and to social, cultural, and professional reasons. Furthermore, they highlighted the important role of different members of the healthcare team in meeting the multiple needs of patients during their cancer trajectories. In summary, there is a growing evidence base for the adoption of multi-perspective approaches in cancer care issues and there is a growing awareness of the usefulness of multiple perspectives for understanding the relational context of diagnosis and communication of cancer prognosis (Orri et al. 2017). Examining the experience of diagnosis and communication of prognosis as a multi-stakeholder issue offers the opportunity to observe how communication interactions are managed at the group level and how communication related to diagnosis and prognosis flows between patient and caregivers.

This research study intends to comprehensively analyse the phenomenon of communication related to cancer diagnosis and prognosis by adopting a multi-perspective approach that includes all the parties involved in the clinical experience of diagnosis and prognosis-related communication. It concerns how the different parties experience each other in communication related to diagnosis and prognosis. I believe that this knowledge will serve to better understand how subjectivity is experienced by each stakeholder in an interactional context.

3. Aims of the study

3. Aims of the study

The aims of this research are to explore and compare the perspectives of the four stakeholders ": advanced cancer patients, their caregivers, attending physicians and nurses"; explore and understand the meaning that participants assign to their communicative interactions regarding diagnosis and prognosis and, from this new global perspective, consider the ethical implications. To achieve this purpose, I will address the following specific aims:

To explore the phenomenon of communication related to knowing diagnosis and prognosis by the four stakeholders.

To enlighten the meanings attached to communication by the four stakeholders.

To identify the ethical challenges perceived by the four stakeholders in communication related to diagnosis and prognosis.

The research question that guided this phenomenological study is: *How do patient, their caregivers, attending nurses and physicians experience their communication interactions in relation to diagnosis and prognosis?*

4. Methodology

4. Methodology

There are many different research approaches operating in nursing, among them, qualitative research methods. They offer a useful and valid approach to grasp and serve the wealth of complex and multifaceted phenomena such as communication. Adopting a qualitative approach means relying on a paradigmatic vision, capable of providing the basis for the exploration of phenomena and the generation of knowledge. Interpretative Phenomenological Analysis (IPA) has been the methodological reference for this study, aimed at exploring the complexity of experiencing communication related to cancer diagnosis and prognosis. IPA is a well-established qualitative research approach. Its methodological reference has been followed since the formulation of the research questions, then the development of the interview guide and the formulation of the probing questions used during the interviews, throughout the analysis of the process data. Therefore, IPA approach and its philosophical underpins, have been the methodological references throughout the entire analysis process.

4.1 Methodological references

IPA has a tripoidal theoretical reference. The phenomenological reference, in fact, embraces a corpus of different philosophies and methodological approaches that starts from Husserl to Gadamer and many other scholars. Edmund Husserl (1859-1938) has the merit of having opposed, in the era of Positivism, the idea that empirical science is the only basis for reaching an understanding of the world. His philosophical approach gives relevance to the “Lifeworld” or lived experience and places "Intentionality" - the conscious awareness of internal meaning - at the centre of the knowledge process. The phenomenological position is an integral part of IPA and is achieved through special attention to the lived experience of people in their lifeworld. Drawing on this position, Smith et al. (2009) could argue that IPA is particularly well suited for exploring health-related experiences in a way that allows one to go beyond the biomedical model of disease to explore the meanings individuals assign to those experiences. As they noted, IPA values *"a detailed experiential account of the person’s involvement in the context"* (Smith et al., 2009, p.196). In IPA studies it is therefore highly recommended to frame participants' experiences within their cultural, social, and personal world by providing rich descriptive notes (Smith et al., 2009; Pietkiewicz & Smith, 2012).

As an **interpretative** approach, IPA is grounded on Heidegger's philosophy as it allows to explore the meanings that people assign to their experiences. Martin Heidegger (1889-1976) acknowledges that individuals cannot be separated from the world in which they live but claimed that it is impossible to describe it without interpreting it. Heidegger's theory, therefore, led to the formulation of hermeneutic or interpretative phenomenology, which involves understanding how people make sense of a phenomenon. Rostill-Brookes et al (2011) point out that IPA researchers are committed to *"approach the phenomenon under investigation from the research participant's perspective"* (p. 330) but at the same time, in agreement with IPA interpretative stance, researchers personal background cannot be set apart. The researchers themselves are engaged in the interpretation of the experiences and perceptions of the participants (López $ Willis, 2004). Therefore, in IPA, researchers, their experience, and knowledge, represent a tool for conducting the analysis (Smith, 2009; Reiners, 2012). This feature, that scholars refer to as the double-hermeneutic circle, is so exemplified by Smith and Osborn (2008, p.53) "*the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world*". It recalls the concept of "hermeneutic circle" that has been introduced by Gadamer. The philosopher stressed the point that to really understand a phenomenon we need to acknowledge the impact that historical events have on our understanding of them. In respect to IPA, it can be said that the researchers, being a tool for interpreting participants' meaning making of their experiences, have an active role in elaborating data. IPA, as a method, does not reject its descriptive position as it undertakes to grasp the phenomenon under consideration from the participant's point of view. Indeed, a new understanding is reached along the process that starts from the voice of the participants and the narratives of the experience and goes through the interpretation of what it is.

Concordant with the reciprocal position of researcher(s) and research participant(s), IPA accounts for a broadly phrased research question so to elicit participants in expanding the phenomenon's comprehension and thus generate further questioning.

The third key stance informing IPA is **idiography** (Smith et al., 2009). This stance, usually presented as antithetical to nomothetic inquiry, describes the aim to grasp the meaning of the experience of a phenomenon that cannot be but contingent, unique, and subjective. To accomplish IPA idiographic stance this study has provided detailed examination of convergences and divergences of each singular case and given attention to each individual interaction.

The crucial role of researchers in IPA endowers an important methodological procedure, **reflexivity**: researchers are asked to reflect on how their experiences may influence the research (Smith et al., 2009). The practice of reflexivity is not intended to put in brackets or eliminate researchers' viewpoints (it is not possible to stay outside the hermeneutical circle) but helps the researchers, and the research's readers, to acknowledge researchers' interpretative role and be critically aware of their preconceptions. In fact, there is not such a thing like true or a false interpretation, but a correct or an incorrect way to enter in the hermeneutical circle. To complete the reflexivity procedure, I will introduce myself and the co-authors who collaborated with me in conducting the two research studies that preceded this PhD dissertation. The writer and author of this thesis is an experienced clinical nurse, she also holds a degree in Philosophy and has worked for many years with people with cancer. The results of the literature resonate with her experience: as a nurse she does not agree on how communication related to advanced cancer diagnosis and prognosis is handled and, on many occasions, has also experienced poor communication approaches within the healthcare team. Next, I am going to briefly introduce the collaborators who helped in the data analysis process. C.I.A.G. is an expert clinical nurse and works in ICU. M.G. is a psychologist and associate professor in Nursing. P.C. is a full-time professor, holds a PhD and is an expert of research in Promotion of Health. M.F.J.H. is an associate professor in Nursing, she holds a PhD and is an expert in bioethics. All researchers have direct or indirect experience in the treatment and cure of cancer. Operational tools used to foster self-reflexivity were (a) field notes – taken after interviews – including reflections on both feelings and emotions of the interviewer, which were commented with the other researchers during the data analysis procedure, and (b) audits conducted among the researchers during the different phases of the study. As such, it can be said that all research members have an insider perspective on the subject of cancer, both as health professionals and as individuals. The interviewer retains that her clinical experience and, at the meantime, her extraneousness, as employee, to the departments where the participants have been enrolled, afforded a sense of trust and intimacy between the interviewed and the interviewer. This self-perception was confirmed by the participants themselves after the recordings, when debriefing after the interview.

4.2 Design

This study adopts a multi-perspective design to achieve a comprehensive understanding of the phenomenon of communication as experienced in an oncological ward. The perspectives of the four parties involved in communication have been studied simultaneously and compared to each other. To prompt the narration of one's perspective means to prompt the interpretation of one's experience, this is why IPA has been adopted as a research approach. IPA is a suitable methodological approach to be used in multi-perspective studies' design as it retains, concordantly with Heidegger's note about individuals' realities as invariably influenced by the world in which they live, that meanings are always created through interactions with others (Lopez & Willis, 2004). IPA was already adopted to investigate disease and care experiences in the context of complex relationship networks in which they take place (Antoine et al. 2013; Loaring et al., 2015). This approach has permitted to investigate meanings assigned by people, individually, and in a combined form, regarding a shared experience. Nevertheless, studies with a multi-perspective design adopting IPA are still quite few and recent (Orri et al., 2015; Larkin et al., 2019).

4.3 Setting

This research was carried out in two Oncology Departments of two large hospitals in Sardinia, Italy. In these departments, the patient is usually cared for by the same physician throughout the course of the disease. Nurses care for patients based on groups of rooms to which they are assigned on each shift. All enrolled patients, with the exception of two cases, were hospitalised more than once in the wards in which they were recruited, and they were under the care of the interviewed nurse during previous hospital admissions too. There is no psychologist in the staff of the two wards, but the oncologist can ask for psychological consulting and support. No specific nursing model is adopted in the wards. The entire clinical path typical of a patient includes recurrent hospitalizations for therapy or deterioration of health and periods spent at home, alternating with medical visits and checks.

4.4 Rigor of the Studies

These studies were conducted by using the criteria indicated by Guba and Lincoln, which is to pursue rigour in qualitative studies (Lincoln & Guba, 1985). Nevertheless, some scholars (de Witt & Ploeg, 2006) suggested that not all criteria used to determine rigour in other qualitative research fit so adequately for IPA studies. In any case, this research is conducted in such a way as to satisfy all those requirements considered distinctive of IPA studies. The first four criteria are those indicated by the seminal work of Lincoln and Guba (1985). To achieve **credibility**, a constant engagement with the transcripts was maintained throughout the entire data analysis process, and a rich amount of interview quotes were provided. The constant return to the words of the participants is an integral part of the phenomenological interpretative process and is highly recommended by Smith and Osborn (2008) to ensure that the words and meanings of the participants are captured. **Reliability** was attained through retracing back all steps of data analysis by the researchers once the first blind phase was accomplished and by triangulation of the researchers' findings. **Transferability** was fostered by a sampling conducted in two different healthcare organizations and by a rich description of the samples. **Transparency** was achieved by disclosing the challenges and difficulties of the studies. **Saturation** is a requirement assigned to many qualitative approaches but, in my opinion and other scholars, it is not relevant to the interpretative phenomenological approach, not only because the goal here is the analysis of unique experiences but, above all, because, assuming that the double hermeneutic cycle is an iterative process, it is arbitrary to identify a stop in the iteration. Therefore, it is contradictory to say that this identification is permissible and feasible. Similarly, Saunders et al. (2017) pointed out that *"It is less straightforward to identify a role for saturation in qualitative approaches that are based on a biographical or narrative approach to analysis, or that, more generally, include a specific focus on accounts of individual informants (e.g., interpretative phenomenological analysis)"* (p. 1989). This can be seen either as an intrinsic limit or as a heuristic potential, but any methods have its pros and cons and what matters is to be aware of them.

As recommended by experts and by Smith et al. (2009), the researchers paid great attention to **self-reflexivity** with respect to their own values and orientation. In this way, we have fulfilled Mackey's (2005) invitation to researchers who adopt IPA to situate not only the patient's experience in his or her personal lifeworld, but also to provide researchers with the role of interpreters within the study. The multidisciplinary team favoured the comparison of their personal and professional background and the attention on how these could influence the different phases of the study. The operational tools used to foster self-reflection were: (1) field notes - taken after the interviews - including reflections on both the interviewer's feelings and emotions, which were commented on with other investigators during the procedure data analysis; (2) audits conducted among researchers during the different phases of the study.

The COREQ guidelines were used in preparation of both the research studies (See Addendum 1).

From this point onward the two studies present specific features. Next to the ethical approval and considerations section I will present the two studies separately up to the findings sections. These two sections are structured according to the indications of Smith et al. (2009): development of a narrative highlighted by detailed commentary on data extracts, theme by theme interpretation, visual guide (figure) presentation of the themes. Thereafter there will be a common discussion section, as the two studies are complementary. Each study, in fact, focuses on specific secondary objectives of this doctoral study and, in so doing, provides results to satisfy the main one: to explore the phenomenon of communication related to diagnosis and prognosis, comparing the perspectives of patients with advanced cancer with those of their caregivers, physicians and nurses.

4.5 Ethics considerations

The study complies with the principles of the Declaration of Helsinki and to the Italian privacy Law (GDPR 679/2016). The study protocol (see Addendum 2) was approved by the Independent Ethics Committee of the Azienda Ospedaliero-Universitaria di Cagliari, Italy (Act n.2.27; July 25, 2016. See Addendum 3). The study protocol was also approved by the Head of Department of the wards where the field research was carried out (see Addendum 4). The study also complies with the International Ethical Guidelines for Health-related Research Involving Humans released by the Council of International Medical Science Organizations (CIOMS) in 2016 and, in particular: protection of privacy and confidentiality of data, conditions of authentic dialogue and prevention of damage due to conflicts of interest, protection of the frail subjects participating in the study. Participants were provided with oral and written information about the purposes of the study and signed the Informed Consent (see Addendum 5). Participation was voluntary and confidentiality was guaranteed. All participants were informed that they could leave the study at any time without any consequences. To preserve confidentiality, pseudonyms were used for all patients. Furthermore, to avoid traceability of single participants I decided to carry out sampling in at least two different healthcare facilities. Specific attention was given to explain the multi-perspective design of the study to all participants.

4.6 Study 1: Experiencing Communication Related to Knowing Cancer Diagnosis and Prognosis: A Multi-perspective Interpretative Phenomenological Study

4.6.1 Inclusion and exclusion criteria

The inclusion criteria for patient recruitment were (1) being an adult (≥18 years) individual with a life expectancy of less than 1 year as estimated by the attending oncologist; (2) Availability of at least one caregiver (e.g., relatives or friends); (3) Availability of at least one nurse and one physician who cared for recruited patients. All interviewed nurses confirmed they were informed on the patient's clinical data, including their reduced life expectancy. The life expectancy criterion allowed researchers to select a homogeneous sample of patients with respect to their prognosis, but it was also meant to select homogeneous subsamples of healthcare professionals with respect to their knowledge of the patient's prognosis. An inclusion criterion for the nurses was that they had cared for the patients recruited for at least two shifts. The physicians who cared for the recruited patients were asked to participate to the study. The caregivers were selected and enrolled in the study upon indication of patients as having a significant role in their disease trajectory. A general exclusion criterion was cognitive impairment.

4.6.2 Data collection

Semi-structured interviews were conducted from October 2016 to February 2017. All interviews were conducted by the first author, in the ward where the patients were admitted. Semi-structured interviews are the most common method for data collection in IPA studies, as they elicit a rich first-person account of experiences of the phenomenon under investigation (Smith & Osborn, 2008). An interview guide (see Table 1) was used flexibly to foster a natural conversation and encourage individuals to elaborate their perceptions. The language was adapted to the participants’ linguistic competence. Field notes were taken to support the analysis of the interviews.

Table 1. Interview Questions Guide in study 1

Topic	**Questions for the Patient**	**Questions for Caregiver, Physician, and Nurse**
Diagnosis and Prognosis knowledge	Please, tell me about your disease.	Please, tell me about what the patient knows of his/her disease.
Perspectives about communication of diagnosis and prognosis	Please, tell me about your preference on knowing your diagnosis and prognosis.	Please, tell me about patient's preference about communication on his or her diagnosis and prognosis.
Interactions with health professionals	Please, tell me about your talking with your physician and attending nurses about your diagnosis and prognosis.	Please, tell me about your talking with the patient about his or her diagnosis and prognosis.

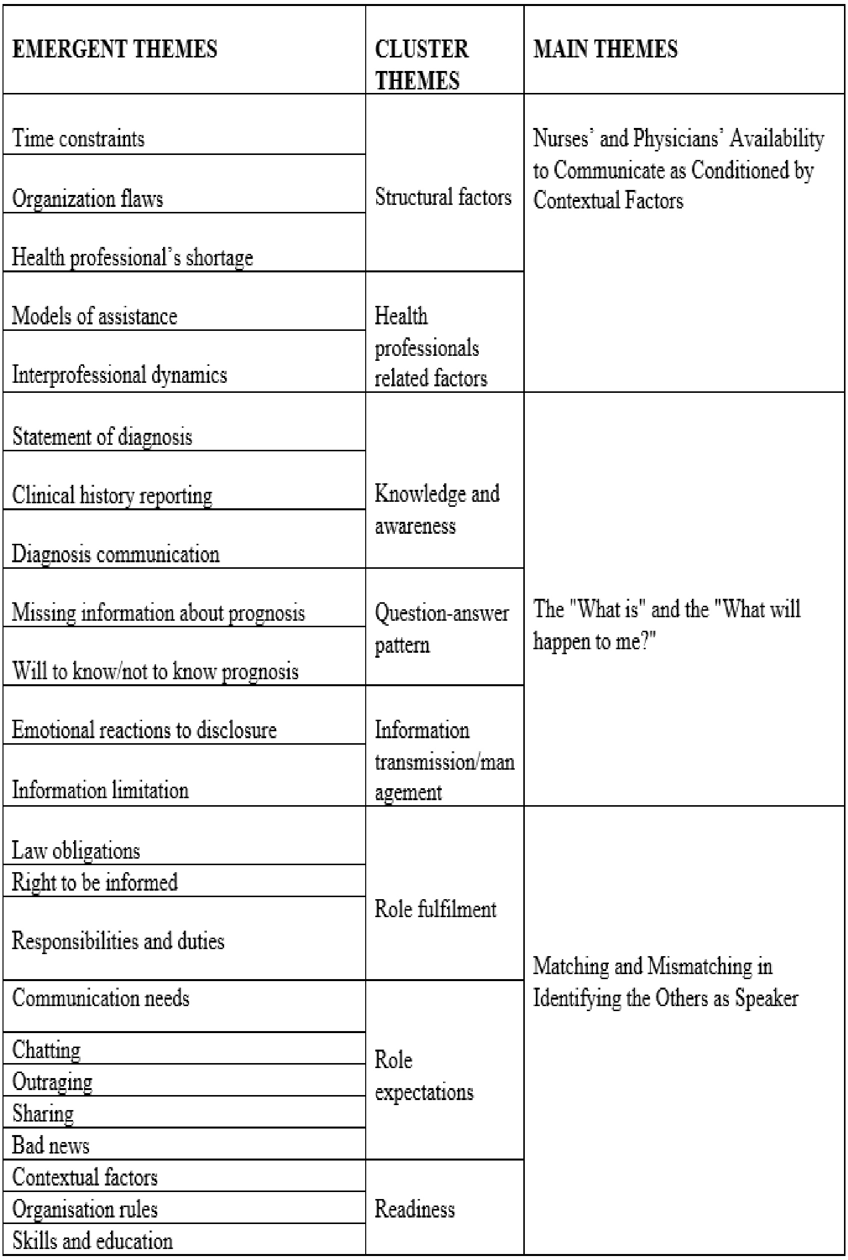
4.6.3 Participants and Recruitment

Staff nurses introduced the interviewer to the patients and explained the purpose of the research. After obtaining the patient's informed consent, the other three parties were contacted to verify the eligibility criteria. If all inclusion criteria were met, the patient entered the study. The eligible nurses were enrolled purposefully once the patient was enrolled. The patient was interviewed first, and then the caregiver. The recruited nurses and physicians were interviewed later during working hours. All but two of the patients enrolled were hospitalised more than once during the wards in which they were recruited, and in some cases, they had already been assisted by the interviewed nurse during previous hospital admissions. One of the physicians was interviewed twice because she was in charge of two patients.

4.6.4 Data Analysis

The interviews were audio recorded and verbatim transcribed, including a short description of the non-verbal aspects of the interviewees. According to IPA standards, a thematic analysis was conducted following Smith and Osborn's guidelines (2008). In an initial phase, the researchers proceeded separately: a first step was to read each interview and take initial notes (e.g., descriptive notations, use of language, conceptual notations). The next step was to identify emergent themes, focusing on discrete pieces of the transcript and, in the meantime, taking into account the notations of the previous phase. This process allowed each researcher to develop a list of initial themes, and was repeated for all interview transcripts, proceeding from individual interviews (idiographic level) to a group-unit (patient, caregiver, nurse, and physician) to another, and analysing the transcripts according to the chronological order of the interviews. Then, the interpretative possibilities were developed by weighing and comparing themes across cases, ending up with a list of cluster themes by each researcher. In the following phase, the researchers met to triangulate their findings and discuss on themes and cluster themes identified in the previous phase. To facilitate the reconciliation of the identified themes and cluster them, two strategies were adopted: (1) both the interview transcriptions and field notes were used as a constant reference guide, and (2) queries about the meaning of what was said by the participants were formulated as an interpretative passage. A consensus based on coherence and distinctiveness of the clusters was finally reached, and the researchers converged on three overarching themes. The applied interactive analytical process allowed the researchers to bring out the interactions between the participants at a group level and offered a comprehensive point of view that represents a new understanding of the phenomenon. Each of the three themes was exemplified with excerpts from the four parties. The process through which themes were labelled, organized, and clustered is exemplified in the Coding Tree reported in Table 2. Data analysis was supported by Atlas.ti. 7.5.7 version.

Table 2. Coding Tree of study 1



EMERGENT THEMES	CLUSTER THEMES	MAIN THEMES
Time constraints	Structural factors	Nurses' and Physicians' Availability to Communicate as Conditioned by Contextual Factors
Organization flaws		
Health professional's shortage		
Models of assistance	Health professionals related factors	
Interprofessional dynamics		
Statement of diagnosis	Knowledge and awareness	The "What is" and the "What will happen to me?"
Clinical history reporting		
Diagnosis communication		
Missing information about prognosis	Question-answer pattern	
Will to know/not to know prognosis		
Emotional reactions to disclosure	Information transmission/management	
Information limitation		
Law obligations	Role fulfilment	Matching and Mismatching in Identifying the Others as Speaker
Right to be informed		
Responsibilities and duties		
Communication needs	Role expectations	
Chatting		
Outraging		
Sharing		
Bad news		
Contextual factors	Readiness	
Organisation rules		
Skills and education		

4.7 Study 2: Ethical perspectives in communication in cancer care: an interpretative phenomenological study

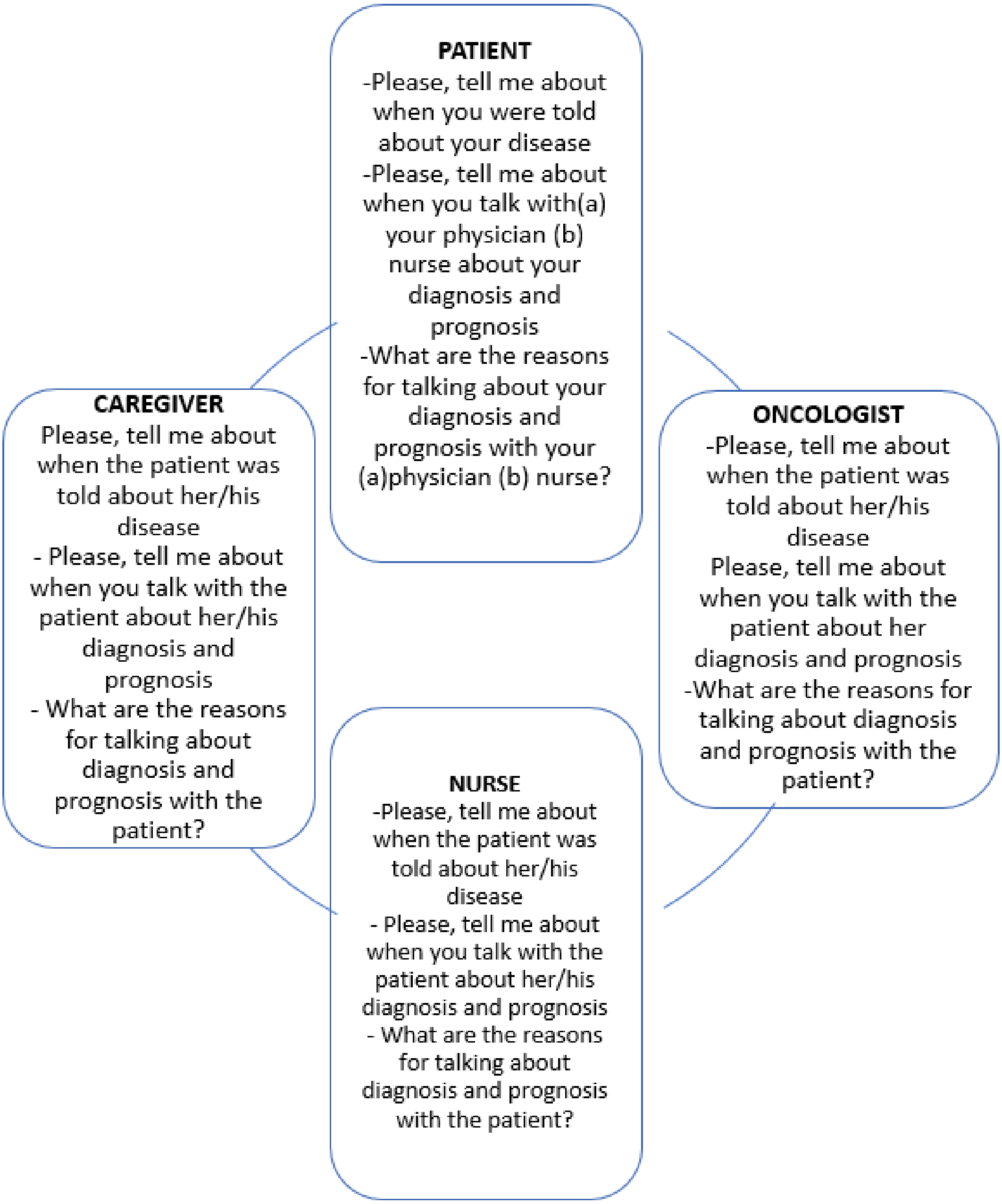
4.7.1 Inclusion and exclusion criteria

The main inclusion criteria for patients were: to be at least 18 years old and having been diagnosed with cancer. An inclusion criterion for nurses was having attended on the interviewed patient for at least two shifts. An inclusion criterion for physicians was to be the one attending on the interviewed patient. Caregivers were selected upon indication of the interviewed patients. General exclusion criteria were being younger than 18 years old and have cognitive impairment.

4.7.2 Data collection

The study was conducted in two oncology departments of two big hospitals in Sardinia, Italy. Narrative interviews were carried out in the departments in which the patients were treated. A researcher, expert on the topic, conducted the interviews from August 2016 to February 2017. A set of interview-guiding questions was developed (see Figure 1), based on previous pilot interviews; questions were used very flexibly in order to elicit the participant's experience. Prompt questions were used to encourage the interviewees to elaborate their thoughts based on their experience. All conducted interviews were audio recorded and verbatim transcribed, including a brief description of non-verbal aspects of the interviewees. The patient was always the first one to be interviewed, but it was not always possible to follow a scheduled sequence for the other participants of the subgroup, because of their unpredictable temporary unavailability. In any case, all four parties of each subgroup were interviewed within 2 or 3 days from each other, except for one group in which the interview time span was 3 weeks, due to organizational problems. There was a case where two nurses who attended on the same patient desired to be interviewed at the same time; all other interviews were conducted separately. During the recruitment process, one physician refused to be part of the study.

Figure 1: Interview guide questions for the different participants.



PATIENT
-Please, tell me about when you were told about your disease
-Please, tell me about when you talk with(a) your physician (b) nurse about your diagnosis and prognosis
-What are the reasons for talking about your diagnosis and prognosis with your (a)physician (b) nurse?

CAREGIVER
Please, tell me about when the patient was told about her/his disease
- Please, tell me about when you talk with the patient about her/his diagnosis and prognosis
- What are the reasons for talking about diagnosis and prognosis with the patient?

ONCOLOGIST
-Please, tell me about when the patient was told about her/his disease
Please, tell me about when you talk with the patient about her diagnosis and prognosis
-What are the reasons for talking about diagnosis and prognosis with the patient?

NURSE
-Please, tell me about when the patient was told about her/his disease
- Please, tell me about when you talk with the patient about her/his diagnosis and prognosis
- What are the reasons for talking about diagnosis and prognosis with the patient?

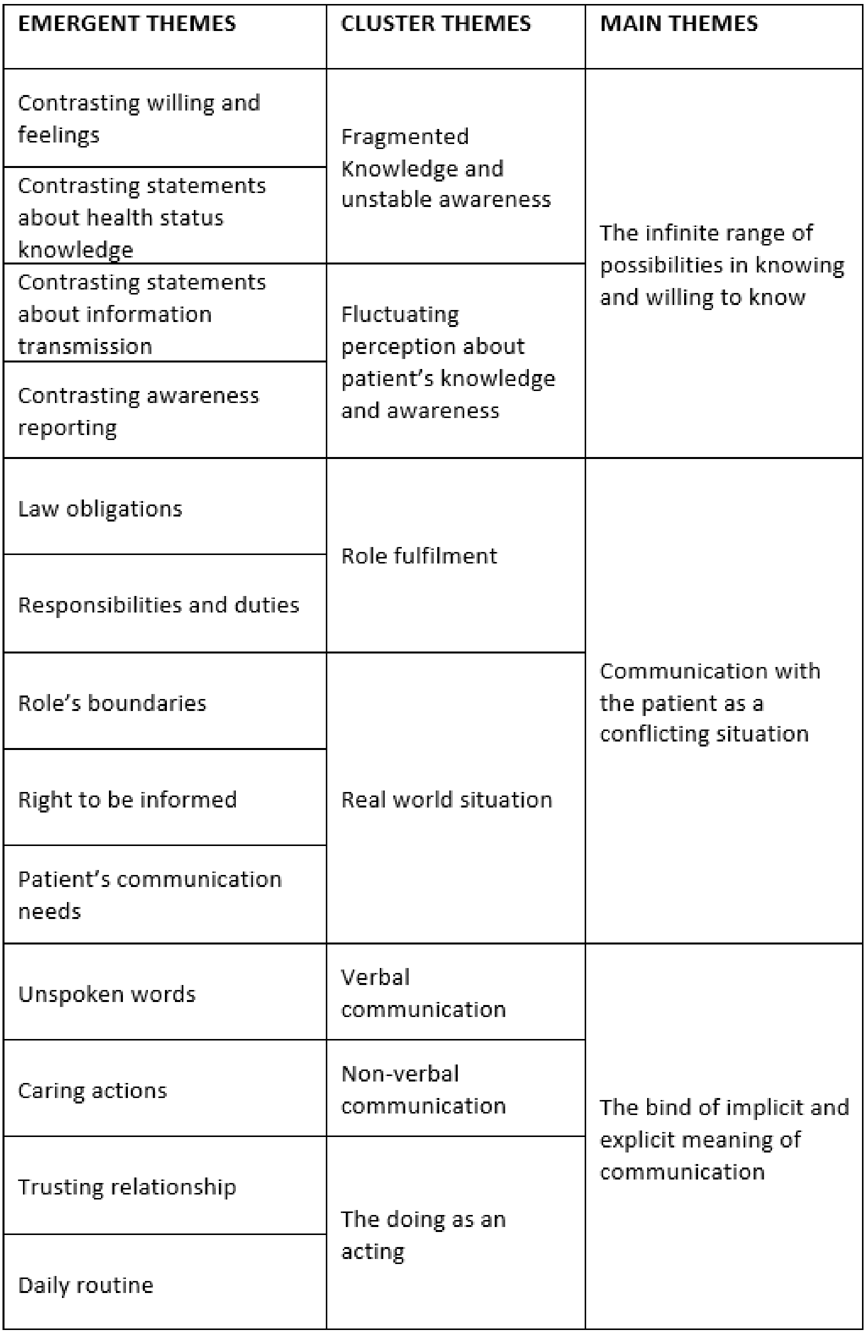
4.7.3 Participants and Recruitment

Patients were recruited upon presentation by the interviewer of the purpose of the research. Eligible nurses and oncologists were purposively enrolled after the patient. Patients were enrolled based on the homogeneity of patient life expectancy of less than 1 year, according to the attending oncologist. This selection criterion for patients was used to search for a fairly homogeneous sample, as suggested by Smith for interpretative phenomenological analysis studies (Smith et al. 2009). Successively, an available caregiver was selected, followed by the selection of the physician and nurse who attended on the patient during his or her disease trajectory.

4.7.4 Data analysis

In IPA studies, understanding the meaning of an experience is the central goal rather than recording experiences by their frequency (Smith & Osborn, 2008). In this study, a thematic analysis was performed according to the procedure indicated by Smith et al. (2009) for IPA studies. Braun and Clarke (2006) too, sustain that thematic analysis methods can be applied across a wide range of theoretical and epistemological approaches. According to this procedure, an inductive approach has been used to process data. In a first step, each researcher did an attentive reading of each transcript following the interviews' chronological order for each group unit (patient, caregiver, nurse, and physician). Secondly, once an overall sense of the data was gained, each researcher wrote initial textual notes describing any relevant issue. This was developed as a sort of line-by-line reading coding, which Smith et al (2008) call 'annotating'. They keep this step free from any strict indications but suggest writing down every connection or association that comes to mind. In the following step, emergent themes were developed by each researcher, via abductive reasoning. Therefore, in this step each researcher identified a number of themes and went on to define them. This implies reaching a higher level of abstraction and to extrapolate any emergent themes from each participant and each group report. Smith et al. (2008) recommend to only include themes that capture something about the specificity of the participant's experience of the phenomenon under investigation. This passage is unavoidably influenced by the researchers' interests and background and is foreseen by the hermeneutic standpoint of the bind between the phenomenon and its perception. In a fourth step, the researchers looked for connections across emergent themes; this process included a first analysis in which the data from each participant was analysed separately, and then analysed for each group unit and across the group units. This process intended to privilege the comparison of the four parties across the six groups and, at the same time, safeguard the connection of the four participants at the group level. Moreover, it allowed the researchers to better interpret each single part in relation to the whole and vice versa. The applied interactive analytical process allowed the team researchers to bring out interactions between the participants' reports with a wholistic point of view that represents a new understanding of the phenomenon. Until this point, the researchers proceeded separately: each researcher produced a list of few main themes. Then, the researchers met and triangulated their findings conciliating them by retracing back all previous steps. This final discussion allowed the researchers to identify the final main themes, by following a subsumption process. In fact, according to Brocki and Wearden (2006) in contrast with content analysis that produces *"a quantitative analysis of discrete categories from qualitative data"*, in interpretative phenomenological analysis the importance of the narrative portrayal is dominant, and its aim is to provide *"a detailed interpretative analysis of themes"* (p. 99). Each of the main themes was exemplified with excerpts from the four parties. The process through which themes were labelled, organized, and clustered is exemplified in the Coding Tree reported in Table 3. The software program Atlas.ti version 7.5.7. was used to structure the transcribed interviews and assist in the initial data analysis. The Atlas-ti program is a software for qualitative analysis that allows to analyse a large amount of textual data and, for this reason, suitable for exploring the richness of the data obtained through the interviews.

Table 3. Coding Tree of study 2



EMERGENT THEMES	**CLUSTER THEMES**	**MAIN THEMES**
Contrasting willing and feelings	Fragmented Knowledge and unstable awareness	The infinite range of possibilities in knowing and willing to know
Contrasting statements about health status knowledge		
Contrasting statements about information transmission	Fluctuating perception about patient's knowledge and awareness	
Contrasting awareness reporting		
Law obligations	Role fulfilment	Communication with the patient as a conflicting situation
Responsibilities and duties		
Role's boundaries	Real world situation	
Right to be informed		
Patient's communication needs		
Unspoken words	Verbal communication	The bind of implicit and explicit meaning of communication
Caring actions	Non-verbal communication	
Trusting relationship	The doing as an acting	
Daily routine		

5.Findings

5. Findings

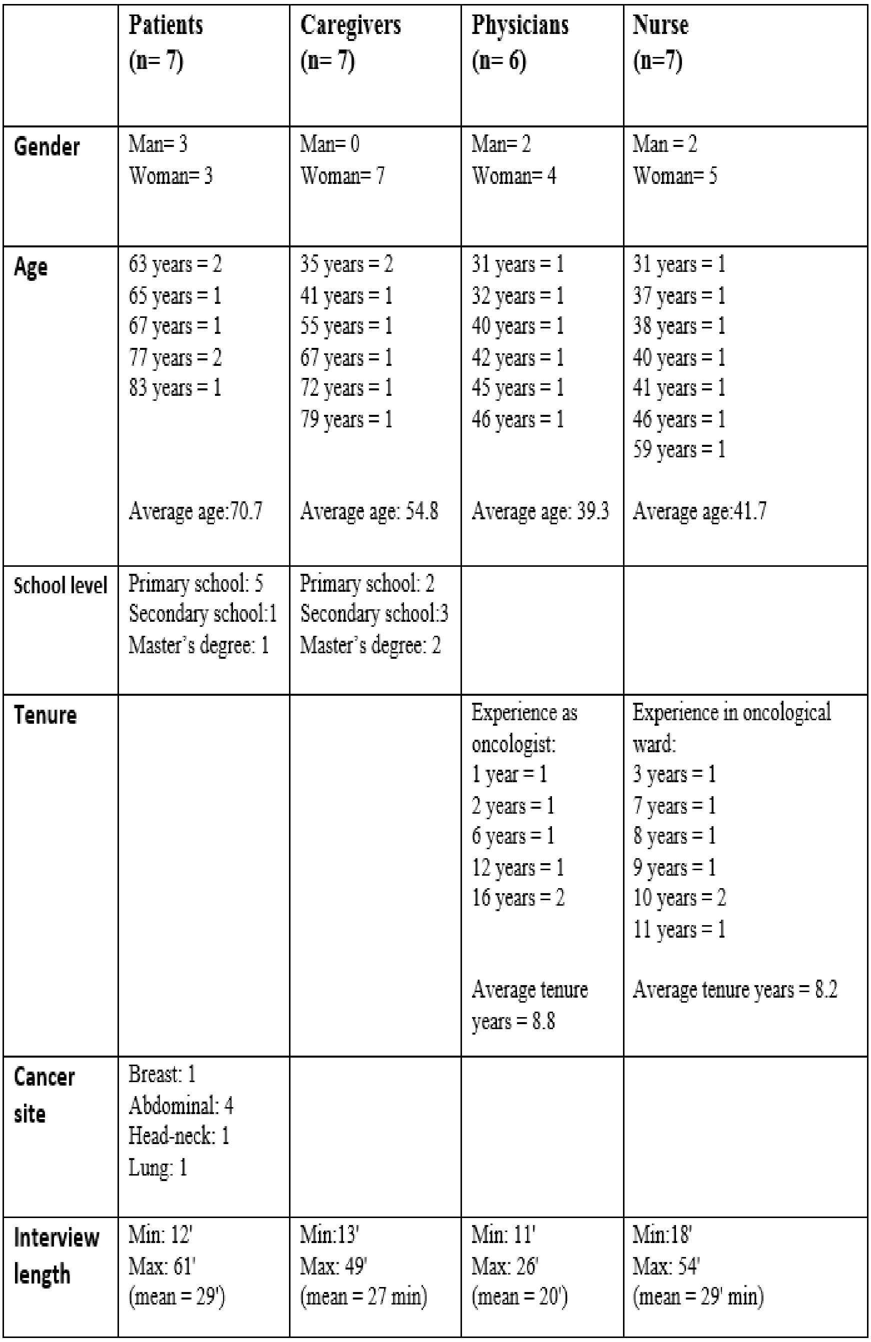
Based on the described methods, we sorted and analysed the data of the two studies and obtained the findings of the two studies as follows

5.1 Study 1: Experiencing Communication Related to Knowing Cancer Diagnosis and Prognosis: A Multi-perspective Interpretative Phenomenological Study

5.1.1 Participant characteristics

A total of 27 participants were interviewed. IPA studies usually focus on the detailed analysis of a few cases. However, in this study, the whole sample included four different categories of participants (7 patients, 7 caregivers, 7 nurses, and 6 physicians) whose perspectives were compared. Thus, this sample size is in line with other IPA dyadic and triadic studies. None of the participants was receiving palliative care. A description of the participants' characteristics is presented in Table 4.

Table 4. Participant Characteristics in study 1



	Patients (n= 7)	**Caregivers (n= 7)**	**Physicians (n= 6)**	**Nurse (n=7)**
Gender	Man= 3 Woman= 3	Man= 0 Woman= 7	Man= 2 Woman= 4	Man = 2 Woman= 5
Age	63 years = 2 65 years = 1 67 years = 1 77 years = 2 83 years = 1 Average age:70.7	35 years = 2 41 years = 1 55 years = 1 67 years = 1 72 years = 1 79 years = 1 Average age: 54.8	31 years = 1 32 years = 1 40 years = 1 42 years = 1 45 years = 1 46 years = 1 Average age: 39.3	31 years = 1 37 years = 1 38 years = 1 40 years = 1 41 years = 1 46 years = 1 59 years = 1 Average age:41.7
School level	Primary school: 5 Secondary school:1 Master's degree: 1	Primary school: 2 Secondary school:3 Master's degree: 2		
Tenure			Experience as oncologist: 1 year = 1 2 years = 1 6 years = 1 12 years = 1 16 years = 2 Average tenure years = 8.8	Experience in oncological ward: 3 years = 1 7 years = 1 8 years = 1 9 years = 1 10 years = 2 11 years = 1 Average tenure years = 8.2
Cancer site	Breast: 1 Abdominal: 4 Head-neck: 1 Lung: 1			
Interview length	Min: 12' Max: 61' (mean = 29')	Min:13' Max: 49' (mean = 27 min)	Min: 11' Max: 26' (mean = 20')	Min:18' Max: 54' (mean = 29' min)

5.1.2 Findings: Themes

Three overarching themes have been identified; they are transversal to all four parties and will be presented below.

- **Nurses' and Physicians' Availability to Communicate as Conditioned by Contextual Factors**

The interviewees claimed to perceive communication as something that occurs when people can dedicate time and pay attention to the other one. Both health professionals and patients with their caregivers, indeed, view communication as an activity that occurs only if all parties are prepared for conducting that activity. Participants experience the presence of obstacles in developing communication, which are perceived as independent from their will and related to contextual factors, such as work overload and healthcare workers shortage. For physicians and nurses, these hindrances reflect on their difficulty to be, in spite of themselves, speakers for patients and caregivers. For patients and their caregivers, these barriers translate into a difficulty in finding physicians available to receive information or to have time to converse with nurses.

Usually, both patients and caregivers express their appreciation for the work and kindness of healthcare professionals. However, some patients and caregivers complain of not being able to receive timely information from doctors, especially outside of scheduled visits, during periods of home stay, whenever they need to contact the attending physician and receive answers to problems perceived as important and urgent. Milena's caregiver, who has taken her relative for medical examinations for many years, says:

"I experienced that to speak with some doctors who gave me their cell phone and office phone number, their email—even with the email! — it took so many days to receive an answer! Maybe (...), they asked us some data and we provided them, we answered them but to have a feedback about it, to understand whether or not they had received our message it took so many days!".

The narratives of many patients report difficulties as well in keeping a communication channel open with doctors. Difficulties are generally attributed to the hospital organization that overlooks personal requests and preferences. These considerations, however, are not necessarily associated with overall negative judgments on the hospital staff and organization. Federica's story reports a similar experience. For about a couple of years, she has been treated at the same cancer department and claims to have a good relationship of trust with her doctor. However, speaking of recent events, she says:

> *"the doctor gave me her personal e-mail, to which she replies immediately, not as the institutional e-mail, where she receives twenty thousand e-mails that she probably doesn't even see, and therefore when this summer I felt very sick, therefore not (...) in short, she had given me her personal email and I wanted to ask her for explanations of why I hadn't seen her anymore .... and my son said «no, wait, maybe she isn't there on Wednesdays» because they also changed my chemo day: I used to come in on Mondays, now they told me to come in on Wednesdays. I preferred Mondays. They didn't ask me for my opinion, this bothered me, but clearly, I'm not the one to decide, it' hospital policy".*

As for nurses, both patients and caregivers describe them as very polite but constantly absorbed in their work duties. They tend to describe their expectations of communicating with nurses as a kind of free time from work duties to devote to conversation. However, several patients seem not to expect to establish any communication relationships with nurses or to seek communicative interactions with them, even if there would be time to do so, as Federica says, who reproaches herself for not being so willing to talk:

“there are many of us, then when one rings, the other one rings too, they don't even have the time, not even them, to stop and have a chat! Maybe there is some person who is more outgoing than me (....) and more talkative than me and maybe a person like that asks them something (...) but I don't feel up to it ... honestly ..., but I'm very sure that if I needed anything, they would be extremely available".

The observations and descriptions of the hospital routine reported by the caregivers are similar to those of the patients. They too report a high commitment to work by nurses and do not expect nurses to spend a lot of time on communication, which however is never presented as having a specific purpose or information content related to diagnosis and of prognosis. Milena's caregiver narrative well exemplifies both the primitive attitudes of caregivers towards communicating with nurses and the kind of activity they are used to and expect from nurses.

No, they [the nurses] don't know us .... it's not that you start telling the story of your illness so easily like that (...) the nurses seem quite .... kind, helpful, I mean, it’s ok (....) it's a rather special ward, *we all want the miracle, (...) many times maybe we want them to come immediately to your relative (...) but we must also understand that if they are three nurses and there are twenty persons who are sick at the same time, they cannot come to all those twenty, do you understand? (...) but for now I have nothing to complain about, or to say against anyone".*

Some nurses and doctors of both health organizations affirm that the organizational / care model adopted in their departments represents a dysfunctional factor for sharing information between different professionals and promoting communication with patients. Among these is Federica's doctor who - expressing her opinion as if speaking on behalf of her colleagues, believes that workload, lack of time and inadequate departmental organization models are the main factors that seriously affect interprofessional and intra-professional communication. Her personal willingness to change this state is demonstrated by the hypothesis of an organizational solution:

"In effect, a standard protocol for sharing and/or communicating information about patient's prognosis or pathology with nurses, does not exist in our unit; a (...) how to say (...) an

established protocol through which nurses and physicians communicate these things".

Nurses, more than doctors, complain about the lack of teamwork as a crucial aspect of sharing vital information about the patient care process. Sebastiano's nurse is still very young and since the beginning of her professional career she has worked in the same ward. She refers to the discrepancy in her ward versus what she is knows is a good healthcare model for an oncology ward. She says:

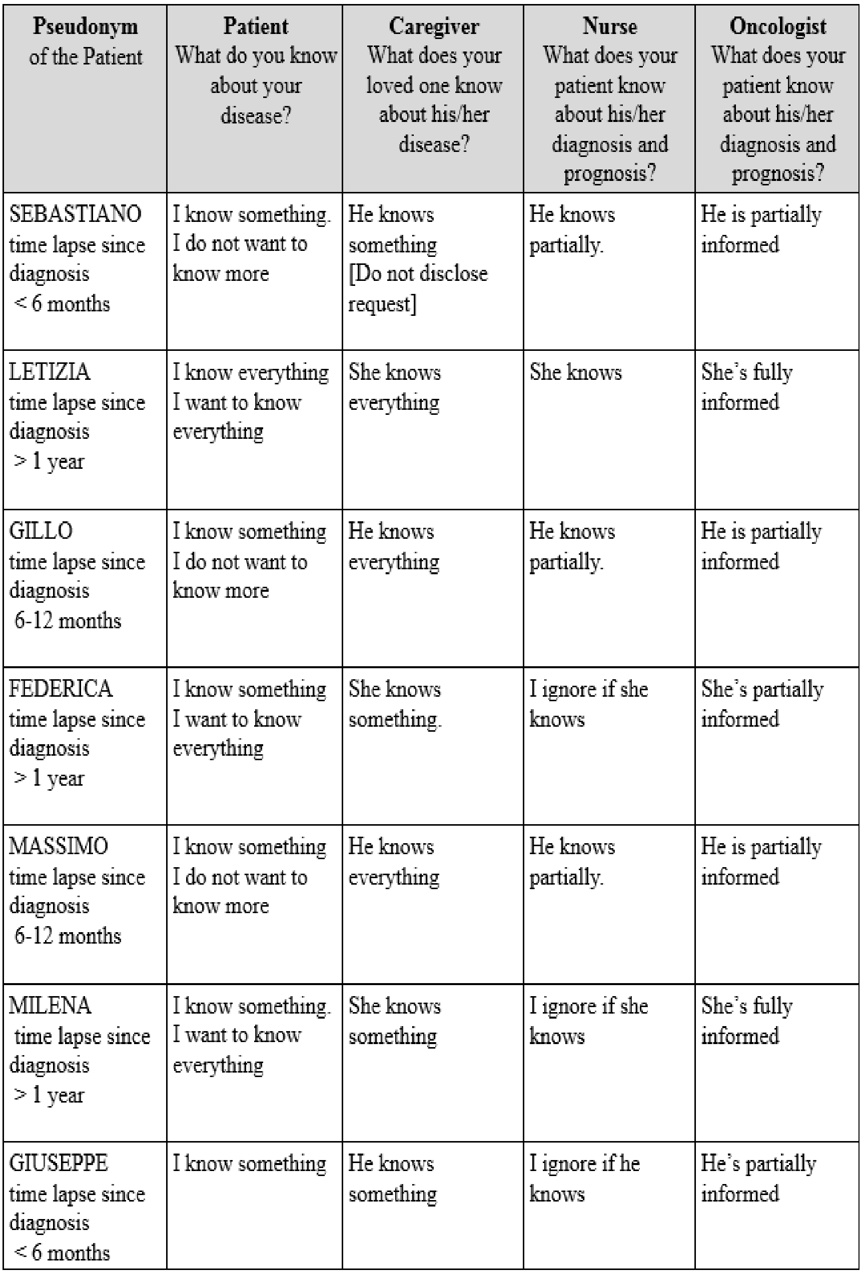
"Usually, meetings are between patient and physician, right? There is no meeting with physician, patient and nurse all together, hence (...) when diagnosis and therapy choice are communicated you don't have the opportunity to intervene and discuss with patient about them".

Thus, based on patients and caregivers' words, communication appears to be an unmet need by physicians, as informants, and by nurses, as talkers. In physicians and nurses' words communication appear to be an unaccomplished care and an unperformed interaction process. All four parties experience these difficulties and flaws as time constraints due to health professionals 'excessive workloads. Nurses and physicians underline also the limits posed by the organizational constraints, mostly in respect to interprofessional communicative interactions.

- **The "what is it?" and the "what will happen to me?"**

In the participants' stories, communication of diagnosis and prognosis seems to have two different paths. Prognosis appears to be quite problematic information to give out, sort of further information regarding the question "what-will-happen-to me?" that only a few patients require, want, and receive. This difference is traceable in all four parts and is marked by the statement that diagnosis information has been provided / received, but prognosis information is usually missing. Table 5 reports patients' statements about their current knowledge and willingness to fully understand diagnosis and prognosis, as well as caregivers, nurses, and physicians 'assessment of patients' knowledge of diagnosis and prognosis.

Table 5. Comparison of Participants' Assessment of Patient's Knowledge of Diagnosis and Prognosis in study 1



Pseudonym of the Patient	**Patient** What do you know about your disease?	**Caregiver** What does your loved one know about his/her disease?	**Nurse** What does your patient know about his/her diagnosis and prognosis?	**Oncologist** What does your patient know about his/her diagnosis and prognosis?
SEBASTIANO time lapse since diagnosis < 6 months	I know something. I do not want to know more	He knows something [Do not disclose request]	He knows partially.	He is partially informed
LETIZIA time lapse since diagnosis > 1 year	I know everything I want to know everything	She knows everything	She knows	She's fully informed
GILLO time lapse since diagnosis 6-12 months	I know something I do not want to know more	He knows everything	He knows partially.	He is partially informed
FEDERICA time lapse since diagnosis > 1 year	I know something I want to know everything	She knows something.	I ignore if she knows	She's partially informed
MASSIMO time lapse since diagnosis 6-12 months	I know something I do not want to know more	He knows everything	He knows partially.	He is partially informed
MILENA time lapse since diagnosis > 1 year	I know something. I want to know everything	She knows something	I ignore if she knows	She's fully informed
GIUSEPPE time lapse since diagnosis < 6 months	I know something	He knows something	I ignore if he knows	He's partially informed

All patients declare to know "what" they have in terms of disease condition, they use the word tumour to name it, and some of them describe in detail the disease site and diffusion. Nevertheless, all of them talk about some missing information. This information is mostly related to prognostic issues. The will to know or to want to know more comes as an explicit question addressed to the physician. This is, for example, apparent in Federica's narration:

"what she [the oncologist] has to tell me, she does tell me, but always without being (...) as if it were a matter of fact, in a very familiar way, like if to assume that «I'm telling you this but everything will be all right, everything (...) » then, when I ask «Will I survive? » then, it's clear: what could she answer me? How could she know this? Obviously, I believe".

Other patients, on the other hand, such as Gillo and Sebastiano, deliberately refrain from asking questions about the prognosis to avoid information they do not wish to have. Milena, who was diagnosed several years ago, expresses all her disappointment at not having received answers to her explicit questions about her prognosis. Giuseppe, who as a teacher talked to people, expresses his need to talk and get information, even if he does not want to ask questions. He says:

"I would like to have that power that some people have (...) to be naturally inspiring, so that it wouldn't be necessary to ask them [the physicians] (...) to do like you do, as in this interview".

There is only one patient who claims to know everything, this is Letizia. She has a long disease history, thoroughly describes her illness trajectory, talks about her feelings and presents herself as a courageous person, strong enough to accept and face her destiny. She confirms that she is perfectly aware of her health-status because she has never refrained from asking questions to physicians. Her words echo those of her caregiver, her attending nurse and her oncologist. All of them describe her as a well-informed person who always asks a lot of questions.

All caregivers claim to know their loved one's knowledge of their diagnosis. They support their claim either by saying that they were present at the time they were told of the diagnosis, or by telling what they share with the patient. Although they feel it is right and proper for their loved one to be informed of their diagnosis, they show an ambivalent attitude towards prognosis disclosure, as they give a preeminent importance to preservation of hope and sense of reassurance for their loved one. Federica's caregiver, who claims that every patient has the right to be informed and decide for themselves, recalls of when her loved one, who she thinks of as an independent personality, asked her oncologist how much time she had left, but received a vague response:

"She [the oncologist] probably told her what she [the patient] wanted to hear. Sometimes it's important to say what the other one wants to hear, isn't it? And not «Look, there is a chance that you are going to die before Christmas» what does it help? I think it is important not just to cure but to care for the patient, especially in such situations".

It is precisely in the comparison of the narratives of Gino and Massimo that there is a discrepancy between the evaluation of the caregivers and the affirmation of the patient. Said discrepancy is caused in fact by the excessive emphasis on the promises of the effectiveness of therapies given by caregivers and the patient's acknowledgement of the lack of prognostic information. The adoption of the question-answer model to obtain information on prognosis is reported in the narratives of nurses as a communication approach applied by both doctors and patients. Generally, they experience it as peripheral actors in the scene. This aspect, for instance, emerges from the story told by Letizia's young nurse. He is telling of when a patient he was attending asked to be informed of his prognosis:

"It happened I was there [in the patient's room] I had to remove a drip, when the physicians entered the room for the usual medical round, so I was just there by chance, I had nothing to do with it, to say it in brackets".

Apart from this acknowledged communication pattern, the recurring data is that many nurses admit to not knowing what the patient knows about their diagnosis and prognosis. No nurse claimed to directly investigate on what the patient knows about their diagnosis and prognosis. Letizia's and Massimo' nurses are the only ones to declare some personal interest in knowing what the patient knows about his/her health condition. All nurses feel that they cannot interfere or somehow modify the patient's knowledge status because it is not required by the role. For many of them, to be a nurse justifies their ignorance about what the patient knows about his/her health condition. Giuseppe's nurse, for example, says:

"We do not usually investigate (...), what we are doing here is taking care of the patients from a nursing point of view (...), so we are not interested in (...) finding out what patients know, instead we pay attention to (...) avoid using words that (...) might inform them".

Federica's nurse adds that patients do not perceive it as a nursing flaw because they show satisfaction with nursing care. She is the only nurse who reflects on the nurses' educational limits and their unreadiness to get involved in this kind of issues.

In some nurses' narrative the information about diagnosis and prognosis is presented in sort of a reverse direction: it is the patient who gives the news to the nurse. Federica's nurse says:

"It happens quite often that the patients give you (...) the news, for instance, about a CT scan, I mean, bad news, I mean, they tell us that the disease is worsening, and…".

All physicians claim to have always informed the patient about their diagnosis by talking directly to them. Physicians refer to have followed this protocol even when relatives had asked them to limit the quantity of information to give to the patient (as in Sebastiano's case). Information about diagnosis is presented by the oncologists as the fulfilment of a professional duty that is adjusted to each personal case by anticipating the patient's emotional reactions. Therefore, they claim to adapt the amount of information they give according to the patient's attitude. Physicians also show to be aware of the different extent to which each patient receives and understands information. Nevertheless, no effort is reported in trying to change it, rather the question-answer pattern is referred to as a sort of silent compromise between the physician and the patient. Giuseppe's physician words recite:

"Surely, in the case of a neoplastic patient with a stage four tumour, I can't tell them that they will definitely survive, because it would be a huge lie. That's why I usually leave it out if they don't ask me".

In short, the communication related to knowing diagnosis and prognosis is characterised by two different pathways. The common attitude of physicians is to give their patients step-by step information, updating them on the progress of the disease. Prognosis information is presented as information available only upon specific request of the patient. Patients often make explicit their willingness to know more and to know their prognosis by asking specific questions. Nurses report no direct interest in the patient's knowledge of their diagnosis and prognosis, despite demonstrating knowledge of related attitudes and practices implanted in their ward.

- **Matching and Mismatching in Identifying the Others as Speakers**

None of the four parties recognizes the others as reciprocal speakers on topics related to diagnosis and prognosis, although all of them display reciprocal communication interactions. Patients tend to identify physicians and caregivers as interlocutors in topics related to diagnosis and prognosis. Caregivers also display triadic communicative interactions, as they indicate patients and physicians as their speakers. Physicians present the patient as their main interlocutor, although they report to have been contacted and have interacted with caregivers as well, especially in the terminal phase of the disease. Nurses are not recognized by the other three parties as speakers in the communication related to diagnosis and prognosis. Nurses themselves show an ambivalent attitude: they tend not to recognize their role, or to limit it to generic support for patients and caregivers, but at the same time report many communicative interactions on problems related to diagnosis and prognosis with both patients and caregivers, but not with physicians. Next, I will introduce each of this position with a figure.

Figure 2. Patient’s perspective in identifying the others as Speakers.

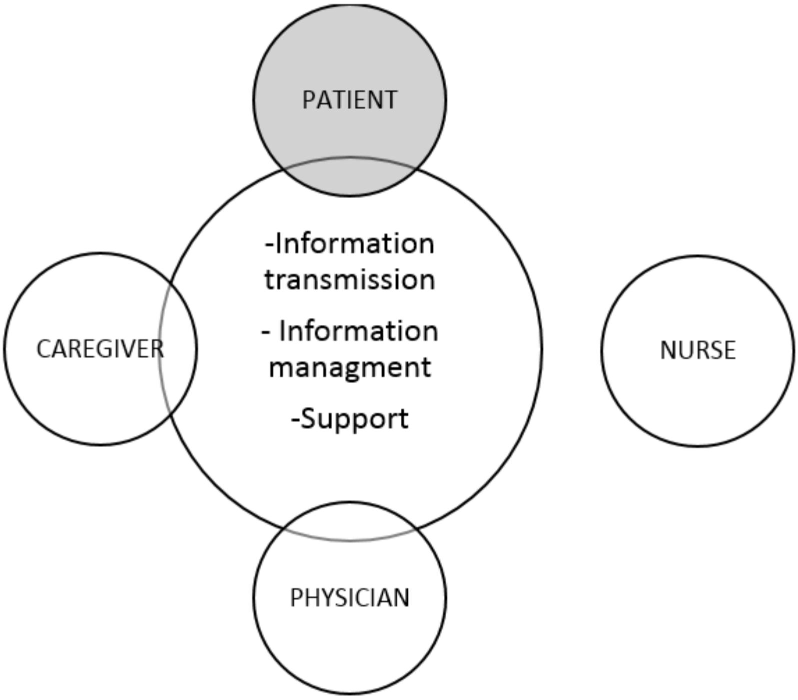


Figure 2 shows communication interactions with the other parties as perceived by the patient. The interactions with the physician are referred to as mostly related to the information transmission. No patient reports any doubts about the truthfulness of the information they received from their doctor, nor do they report having received conflicting information regarding their state of illness. Many of them attach great importance to having an attending oncologist who knows their entire disease history. Often, in fact, the request for information is made explicit only to their own attending oncologist. This is clear, for example, in Milena's story. She says:

"More than anything else, I would like to speak with my oncologist doctor -in these two days he is not around - because it is with him that I have a closer relationship: he knows my whole story so he would be the most suitable person to express all staff".

Federica and Sebastiano also insist on the encouragements received by their oncologist, and they put these encouragements at the basis of their relationship with them. Sebastiano explains this relationship like this:

"I got hope from the physicians. I trust a physician if he trusts me, this gives me strength (...) but if a physician says some other sort of things (...) then he lets me down".

In general, all patients talk about the presence of their relatives as an important support in communication, not just for practical help (e.g., memorizing information, familiarity with medical arguments, etc.) but also for the emotional support. Only Letizia says she prefers to limit information about her health status to her relatives to avoid increasing their anxiety and worries. Sebastiano clearly admits that he has accorded to his close relatives the management of information with the physicians. In short, the information sharing with one's close relatives is presented as a natural and helpful feature by patients. This is, for example, Massimo's answer to the question on whether his relatives are present when he goes for medical visits:

"For sure! They always come with me: my daughter, well, one of my daughters, and my son in law (...), to be able to better understand everything, to be informed about it all".

Patients assert they have not discussed diagnosis and prognosis-related issues with nurses. They report just occasional chats with nurses concerning practical assistance issues or generic words of encouragement. This way of interacting with nurses is presented by patients as normal and ordinary. They describe nurses as therapy providers, operators heavily conditioned by time constraints, task oriented and directed by physician's instructions. This is how Milena perceived the communication interactions with nurses regarding her health status:

"I can't tell anything about it. I don't know if they know my health status. They have my medical records, obviously, they borrow

information from doctors and administer the therapies they have been told to (...) but I can't tell you anything else".

And later on, assuring that she appreciates nurses' attitude.

"They [the nurses] are all very kind with me and very helpful, but, for the rest, they just follow physicians' orders and do whatever has to be done and that's it!

Figure 3. Caregivers' perspective in identifying the others as Speakers.

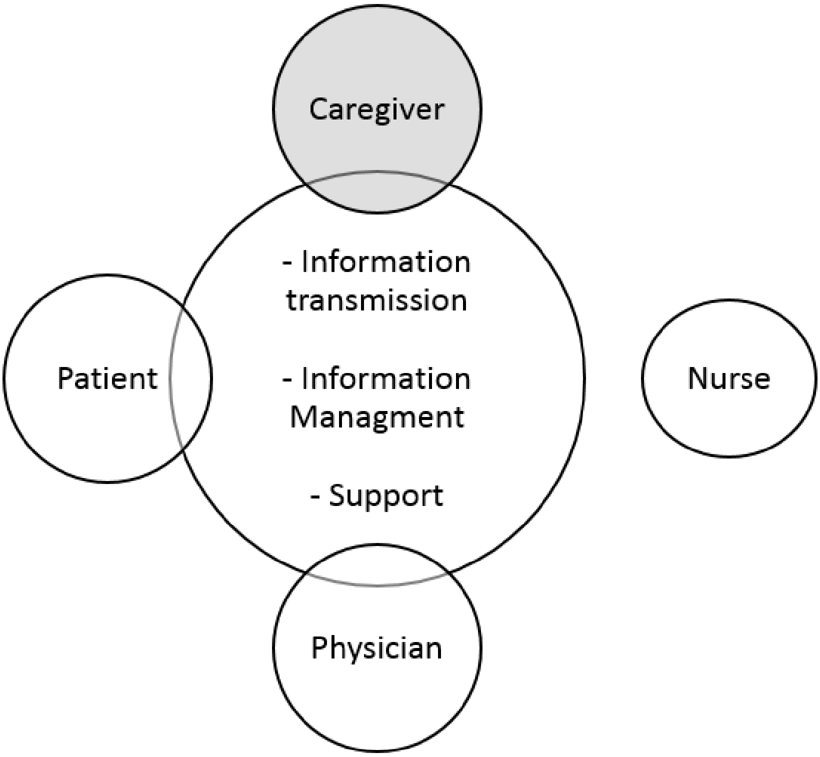


Figure 3 shows communication interactions with the other parties as perceived by caregivers. They present themselves as the patient’s support in the process of transmitting information and managing the emotional needs. This is mostly apparent when they talk about patient-physician communicative interactions: they are the ones on the patient’s side when they undergo medical visits (almost all of them said they were present when diagnosis was communicated for the very first time). Furthermore, they show that they know what the oncologist told the patient and report the patient's reaction to it. Federica's caregiver, for example, talks about a moment she had with her loved one after a conversation with the oncologist:

“I asked her it, but not soon after (...) I left her quiet, I didn’t want to rush (...) but later I told her «Do you see? Have you listened? The doctor was confident, was reassuring» and she replied «Yesss», she was in a ‘Yes’ phase, but (...) «yes, she certainly reassured me about it» In this case one should do the same thing and reinforce it”.

Caregivers also perceive themselves as the receivers of medical information, and sometimes admit receiving some more information compared to what the patient knows, particularly regarding the prognosis. They consider this additional information as an emotional overload of sorrow that they shall not pass on to their loved one. Many of them feel the weight, together with the physicians, of the moral responsibility to fully disclose what they know to their loved one. This is, for example, the narration of Milena's caregiver, who is loved one has just been dismissed from therapies because, as she says

"She has not been told that she will no longer be able to undergo chemotherapy again, do you understand? Because there is nothing left to do. They are still all half words (...) I don't know (...) if it is good, if it is bad, so that when she will understand it, maybe she will be angry also with us ... I don't know, I don't know (...). These are very upsetting situations":

All caregivers claim the absence of communication interactions related to diagnosis and prognosis with nurses. They generally describe nurses as polite and full of patience, but report communication interactions merely related to the administration of therapies and to the practical aspects of care (how to move the patient, for instance). Many caregivers justify this absence of communication interactions with nurses by referring it to their view of the professional role of nurses, as Massimo's young caregiver does:

"There has never been a dialogue about the situation with nurses (...) anyway: physician's word has always a different value, not to discriminate anyone, but the nurses act according to what they are told by physicians, so maybe they couldn't answer the questions we might ask them but didn't actually ask.".

Figure 4. Physician's perspective in identifying the others as Speakers.

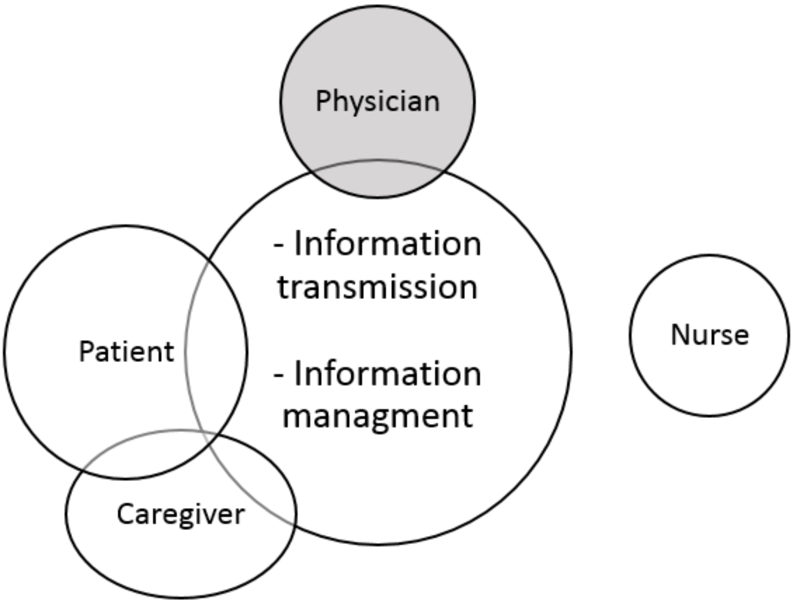


Figure 4 shows communication interactions with the other parties as perceived by physicians. Physicians describe their communication interactions mostly as giving information to the patient. The issue of discussions on terminal care is reported as a constant update on clinical status and proposed therapies. There are just two oncologists, Federica and Massimo's, who openly talk about their difficulties in dealing with the subject. Here is Massimo's young physician's narrative:

"We often arrive to the terminal stage of the disease without knowing what the patient wants. The relatives press and ask for aggressive therapies that we know to be useless and that, instead, must be considered as therapeutic obstinacy (...) sometimes patients, since they are diagnosed, tell us «Be aware, when my time comes, I don't want to be resuscitated, I don't want to be tortured! Give me some sedation and let me go in peace» But for many others we don't know, so we get to the terminal stage and (...) what happens is we ask the relatives if they want their loved one to be transferred to the hospice".

Physicians report that they interact and communicate with patients' caregivers when introduced by the patient. Otherwise, they describe their communicative interactions with caregivers as casual. The frequency of these occasions seems to be organized more on the initiative of caregivers than doctors. All doctors claim to pass information on to relatives to the extent that they are authorized to do so by patients. Often, they also manifest their concern to preserve a confidential communication channel with the patient, avoiding that their voice be overwhelmed by that of their relatives. At the meantime, physicians admitted to transmitting and acquiring information by relatives. However, from the narratives of Massimo and Sebastiano's oncologists emerge that, on the one hand, they feel pressed by family members to comply with their therapeutic requests and, on the other hand, that the physicians themselves turn to the family members to take end of life decisions. So, speaks, for example, Massimo's doctor:

"Many times, you don't know what the patient wants for him or herself when the end is close. Whenever it happens 't you have to ask relatives if they want to carry him to a hospice (...) and they don't even know what hospice is"

Apart from the Sebastiano's case in which physicians received the request to omit prognostic information to the patient by relatives, physicians report no conversation with nurses about diagnosis and prognosis related issues. This feature is referred to by physicians as standard and normal. At the question *«have you discussed any issues* *related to communication of diagnosis and/or prognosis to the patient with the nurses? »* a physician responded with a deafening laugh and a determined denial. Nevertheless, physicians generally assure that they have a good relationship with the nurse staff and that they share all relevant information about patient care. To prove this, they mention the management of surgical drainage, the adoption of medical auxilia, and so on. This appears quite plain in Giuseppe's physician narrative. She was asked if she had some talk with nurses related to Giuseppe's diagnosis and prognosis communication approach or, more broadly, to any of Giuseppe's diagnosis and prognosis related issue. She answered:

"Well, the exchange of information, I would say is absolutely basic, that is, the nurses know what Mr. Giuseppe has, what he has to do, what he must not do and therefore it is clear that on these occasions information is exchanged about the patient. (...) I give you a very practical example, okay? Mr. Giuseppe did a physiatric evaluation, the physiatrist prescribed him a bust and wrote that, wearing this bust, he can sit up, right? so, having seen this, I communicate to the nurses that the patient can also change position, right? And I tell the nurses that the patient can even sit up because

the physiatrist assessed him and so he said, okay? Here, therefore, I provide the nurses not just with technical aspect, like make him wear the bust and let him sit, but I also offer them an explanation of because he can sit up, that is because the physiatrist prescribed that type of bust, do you understand? So, let's say that nurses are informed, that is to say that usually there is an exchange of information between us".

Figure 5A: Nurse's perspective in identifying the others as Speakers.

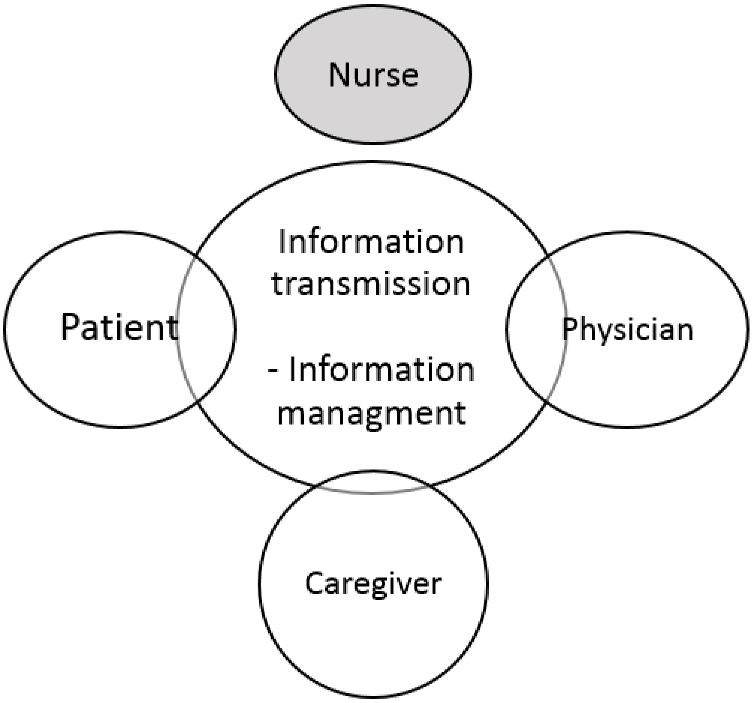


Figure 5A shows communication interactions with the other parties as perceived by nurses. The figure has two versions, the first one pertains to nurses' selves-perceived role in respect to information transmission and management. Similarly, to what the doctors say, nurses only report sporadic cases of conversations with physicians on issues related to diagnosis and prognosis. Here is Federica's nurse report of it:

"Ms. Federica has (...) I don't know what she knows, because our way of working is quite as in watertight compartments: doctors say one thing, nurses do therapy, dilute therapy, preparations, biological drugs .... but we don't have big contacts. Ours is a pretty hectic job, like an assembly line, quite unsatisfactory, very unsatisfactory for me (...) but this is how things are".

Only Sebastiano's nurse is able to report what the patient (and his caregivers) has been told by the physicians about diagnosis and prognosis, because, as she states, nurses and physicians were requested by the patient's close relatives not to talk to him about the fatal prognosis. Gillo's nurse is the only one who claims to have asked the physician what the patient had been told, yet he admits of having done it out of curiosity.

Nurses report only occasional interactions with caregivers, generally related to practical care aspects. Only in Sebastiano's case his nurse remembers the conversations with the caregivers on issues related to diagnosis and prognosis, but just as a listener and intermediary between relatives and physicians. Nevertheless, many nurses observe that, when a patient's death approaches, caregivers ask them for their opinions and advice on how to manage care in the final stages of life. Milena's nurse describes her experience with caregivers in this way:

"They usually ask us how it will be (the dying), how long will it take, how long will be left (...) they ask very direct questions, such as «do you think he'll make it through the night? Do I have to stay here tonight? »".

In situations like this, most nurses say they put the caregiver back to the physician to get more detailed information from them. Some nurses also say that it happens that relatives of patients approach them to vent about their anger and despair. Disappointment and despair, nurses say, that people do not dare to express with physicians because they perceive them as an authority.

Figure 5B**:** Nurse's perspective in identifying the others as Speakers.

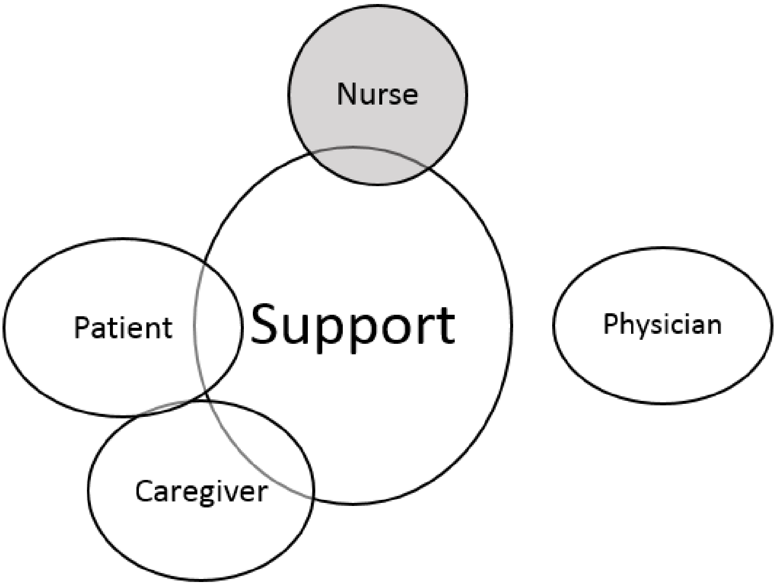


Figure 5B shows communication interactions with the other parties as perceived by nurses. This second version pertains to nurses' selves-perceived role in respect to giving support. All nurses present giving support to the patient as a specific role and commitment of the nurse, although most of the time they talk about it as *"the only thing we can do"*. Gillo, Milena, Federica and Massimo's nurses also admit feelings of discomfort and uneasiness when they are addressed by patients inquiring about their health status. Questions and comments from patients do not come as an unexpected occurrence to nurses. In fact, there are plenty of anecdotes about patients asking questions on prognosis, recovery expectancy or uttering awareness of the prognosis. Giuseppe's nurse describes it like this:

"It is very easy for them (the patients) to talk about these things whit us (...) after all, we are strangers with whom they share intimacy (...) and after all, we have the expertise".

5.2 Study 2: Ethical perspectives in communication in cancer care: an interpretative phenomenological study

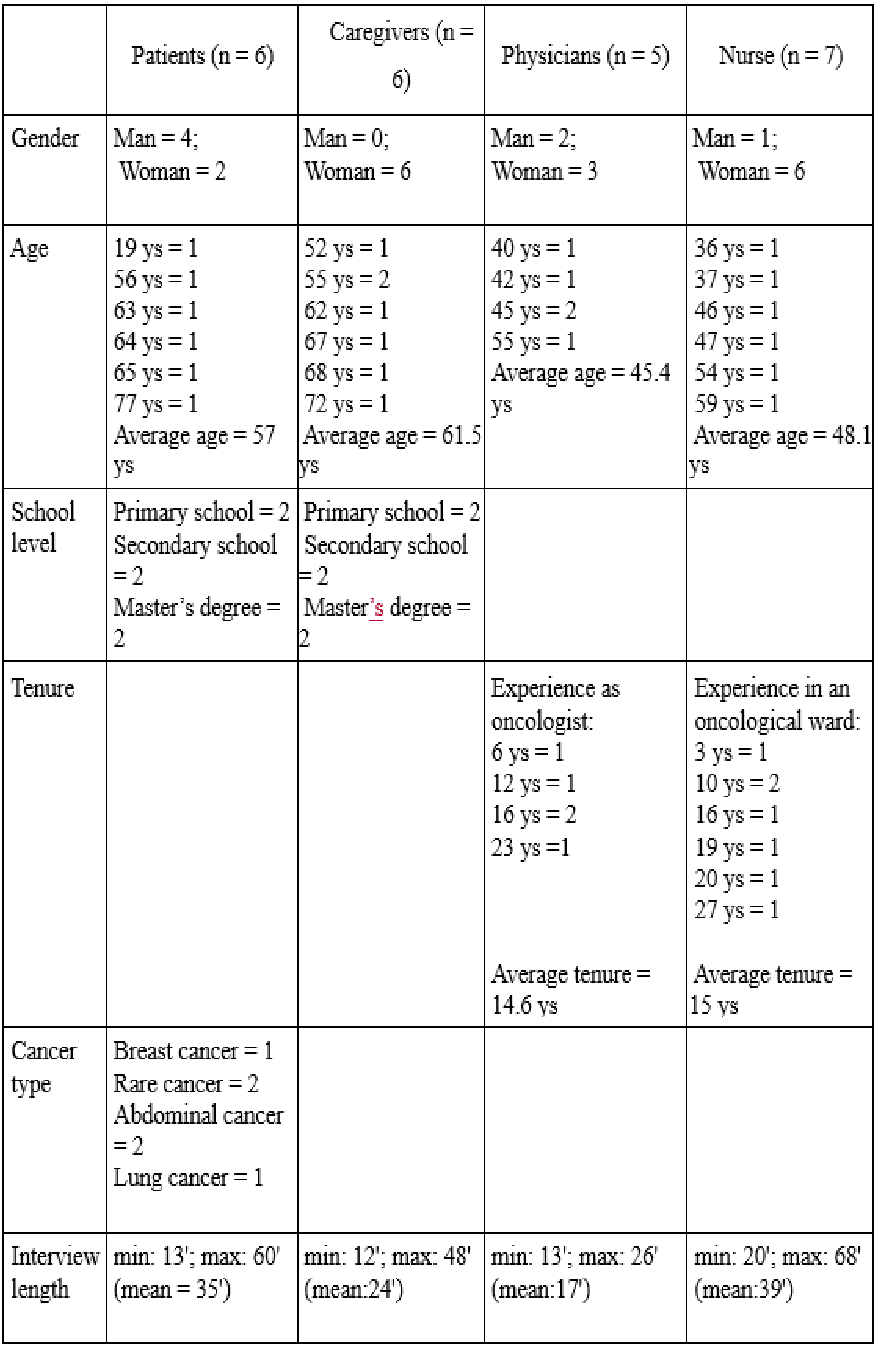
5.2.1 Participant characteristics

A total of 24 participants were recruited, six groups of four members each (patient, his or her caregiver, and his or her attending physician and nurse). According to Reid and colleagues (2005) exploring a phenomenon from multiple perspectives is a kind of triangulation that can help researchers to develop a more detailed and variegated description of that phenomenon. However, it is important to note that this is only possible with a small sample, 5–10 participants (Smith et al., 2009). Therefore, based on this suggestion, six participants for each role (patients, caregivers, physicians, and nurses) are considered as a very good sample. Table 6 shows the characteristics of study participants.

5.2.2 Findings: Themes

The findings have identified three main themes: (a) the infinite range of possibilities in knowing and willing to know, (b) communication with the patient as a conflicting situation and (c) the bind of implicit and explicit meaning of communication. The first theme is represented in all four parties and describes the mixture of cognitive and emotional reactions arousing communication related to diagnosis and prognosis. The second theme is related to the role of health professionals: how nurses and physicians interpret their role and how the patient and his or her caregiver perceive it. The third theme concerns an experience of communication as expression of a personal and intimate world. This theme takes shape in patients and caregivers as a silent but expected request of recognizance of the existential dimension, and it emerges in nurses and physicians as a fundamental part of care and cure relationship. Figure 6 summarizes main perspectives of the four participants for each theme.

Table 6. Participant characteristics in study 2



	Patients (n = 6)	Caregivers (n = 6)	Physicians (n = 5)	Nurse (n = 7)
Gender	Man = 4; Woman = 2	Man = 0; Woman = 6	Man = 2; Woman = 3	Man = 1; Woman = 6
Age	19 ys = 1 56 ys = 1 63 ys = 1 64 ys = 1 65 ys = 1 77 ys = 1 Average age = 57 ys	52 ys = 1 55 ys = 2 62 ys = 1 67 ys = 1 68 ys = 1 72 ys = 1 Average age = 61.5 ys	40 ys = 1 42 ys = 1 45 ys = 2 55 ys = 1 Average age = 45.4 ys	36 ys = 1 37 ys = 1 46 ys = 1 47 ys = 1 54 ys = 1 59 ys = 1 Average age = 48.1 ys
School level	Primary school = 2 Secondary school = 2 Master's degree = 2	Primary school = 2 Secondary school = 2 Master's degree = 2		
Tenure			Experience as oncologist: 6 ys = 1 12 ys = 1 16 ys = 2 23 ys =1 Average tenure = 14.6 ys	Experience in an oncological ward: 3 ys = 1 10 ys = 2 16 ys = 1 19 ys = 1 20 ys = 1 27 ys = 1 Average tenure = 15 ys
Cancer type	Breast cancer = 1 Rare cancer = 2 Abdominal cancer = 2 Lung cancer = 1			
Interview length	min: 13'; max: 60' (mean = 35')	min: 12'; max: 48' (mean:24')	min: 13'; max: 26' (mean:17')	min: 20'; max: 68' (mean:39')

- **The infinite range of possibilities in knowing and willing to know**

Patients and caregivers describe their experience about diagnosis and prognosis-related communication as an experience that admits an infinite range of possibilities in knowing and in the will to know. Angelo, Daniela, and Nella, in fact, describe themselves both as informed and uninformed, willing to be informed and wanting to know no more. Nella, unlike the other two patients who were diagnosed a few months ago, has been under treatment for almost 2 years, she values her autonomy a lot and admits that what costs her the most is to ask for help; she also recognizes to have contrasting feelings and attitude towards communication and information transmission and says:

"The results (for my examinations) were always picked up by me, I read them, but I don't understand them, and I ask the doctor (...) I mean (...) I don't want to understand them; it's not that I don't understand them, that's different."

Daniela, who – according to her caregiver – should well understand her health status because she has a high school–level education, declares herself willing to know and remembers all questions she already asked the doctors; she reports to having always received a proper answer, but she recognizes that all those questions are not so significant and concludes:

Even now (...) I don't find the courage to ask it (...) maybe one day I will try to ask it to my oncologist.

Some other patients, like Sergio, Piero, and Mario, talk about their decision to receive limited medical information as a shared decision with their oncologists and relatives. Mario, who is very young, is aware that he does not exactly know what is happening to his body, but he sees this ignorance as the price to pay to 'stay calm'. He knows that his disease is a very serious one: he says that he has been diagnosed more than 2 years ago and has undergone several chemo treatments. He explains his choice like this:

"I prefer to be like this (...) because if I would know more, I would have more worries...and maybe this could worsen my condition (...) maybe (...) better not to know anything and have minimal details that only can reassure".

Other patients, like Sergio, who is already retired, show difficulty to conciliate what they have been told to what they know.

He has been attending the oncological ward for few months and concludes his interview by saying,

"Sooner or later, I should know the truth, only that (...) I'm afraid of the truth (...) do you understand?"

But previously he had already admitted that.

"They (the doctors) told me that (...) they told me clearly (...) do you understand? He called me in his office – there was my wife too – and when he said it (...) the world came crushing down! Do you understand?"

Many caregivers also describe communication related to diagnosis and prognosis as an experience of conflicting wills and feelings and as a knowledge that cannot be confined to the opposite poles of knowing or not knowing. Nella's caregiver describes her loved one's attitude towards communication as the display of contrasting behaviours, but she does not interpret it as an inconsistency:

"Of course, there is an inconsistency (...) but I'm not sure whether it is an inconsistency; you would like to know more and more because you would like to discover that (...) your worries are excessive (...) that after all (...) the situation can be seen in a (...)

way..., but if you are searching more, you're afraid to discover the contrary. So, you prefer to stay in a limbo in which you would like to know, but you can't."

Caregivers recognize that the patient needs to know what is happening, but at the same time, they underlie that patient also seeks and needs continuous reassurance. In caregiver stories, the patient's character, and the emotional costs of knowing seem to be important factors in understanding the patient's attitudes and in deciding which communication approach is best suited for him or her. Angelo's caregiver declares that her loved one and she are perfectly aware of the seriousness of his health conditions because they were informed of the advanced stage of his disease by the oncologist. Nevertheless, to the question on whether she considers it is better to know or not to know, she answers:

"I don't know, I don't know: knowing too much is upsetting, but maybe knowing too little is also upsetting. Who can say which the right measure is? In between knowing and not knowing there are an infinite range of possibilities."

The theme of the various degree of knowledge emerges in physicians' narratives (and in some of the interviewed nurses) either as the patient's ability to understand the real meaning of the information received by physicians, or as partial information received by them. Physicians refer to this ability as the patient's will to confront himself or herself with bad news. Concerning that point, Sergio's physician says:

"It has been the head physician to tell him that the surgery he underwent couldn't eradicate the tumour. Therefore, he knows the diagnosis, namely a disease that is not cured by the surgery but that is still there and that is a quite severe disease, because his liver has been affected. I told him that he had to be treated just by chemo and by oral therapy. So, it has not been told anything unreal (...) if one should tell all and everything (...) I don't believe that this would be the rightest thing to do (...) I don't know (...) anyway, the patient understands what he wants to understand! Anyway, the patient was thoroughly informed of the disease."

Furthermore, Piero and Sergio's nurses consider awareness disconnected from any kind of intellectual capacity. Piero's nurse has been working in an oncological ward for many years; she loves to talk with patients and thinks that almost all of her patients know their diagnosis but, at the same time, notices:

“In our ward there were physicians that didn’t understand any (!)(...) I mean, once they have become patient, they, that were physicians and nurses (...) well, once they were admitted in our ward, they forgot to be physicians, they forgot all staff they studied (...) as if they knew nothing.”

- **Communication with the patient as a conflicting situation**

The interviewed physicians talk about their communication approach as information-giving, to let the patients know what is going on: the diagnosis and the therapeutic course they should undergo. This information transmission is perceived as something that they need to modulate because it can also cause potential harm to patients’ psychological well-being. This position is well presented by Mario’s physicians, an experienced oncologist, who explains his communication approach with his young patient:

“I believe that we have been quite detailed (...) in one case and in the other, that is both towards the patient and towards his relatives. It is a situation in which the psychological implications are very heavy (...) and (...) the (...) let’s say that the fuzziness that we have maintained in providing information to the patient is motivated

by the need not to create an excessive psychological distress that could lead him to dismiss therapy."

On this basis, physicians consider it a duty to inform the patient about his or her diagnosis, but they also believe that it is upon them to decide, case by case, the extension and the timing of disclosure. They declare to generally conform to the norm to inform the patients in order to obtain their informed consent to therapies, but they also take into account that knowledge has the power to cause huge emotional reactions such as hope or despair. These reactions are deemed a big resource or, vice versa, an insurmountable obstacle to treat and cure the patient. A practice solution adopted by most physicians to both preserve hope in patients and fulfil their duty to inform the patients, is to avoid talking about prognosis if not requested. The conflictual situation is so approached by Daniela's physicians:

"I think it's essential to know (...) but it's evident that not anybody can bear the information so I think information should be, how to say it, adjusted upon emotional sensitivity, upon the patient's capacity to manage this kind of information but, anyway information should be given to patients in a complete way, absolutely! but one

can be less explicit about prognosis, especially with regard to the advanced stages of the illness."

Only Nella's physician, highlighting a correspondence between the patient's lack of knowledge of the prognosis and the physician's lack of knowledge of the patient's desire for end-of-life care, speaks of the doctor's ethical responsibility in reconciling conflicting urgencies and implied needs in communication relating to diagnosis and prognosis. She explains:

"what is still problematic, to make the patient understand it, (...) is the choice (...) between not to do anything, because actually there is no chance to get anything better and therefore (...) just to undergo palliative care or undergo therapies until the last days. This issue, perhaps, was not faced with my patient. In some patients, this may be due to a communication problem, I mean, the difficulty to make the patient understand it and help him/her to make an aware choice, while preserving his/her dignity."

All nurses state that they usually do not investigate whether the patient knows or does not know his or her diagnosis and prognosis. Nurses even declare that they do not start conversations in any way related to diagnosis and prognosis because this issue is not their business but physicians'. They also recognize that patients and relatives do not always receive appropriate information about both prognosis and life expectancy and observe that this hampers patients' faculty to decide about end-of-life treatments. Nurses believe that their role is limited to supporting the patients' positive state of mind and not to investigate or modify the patients' knowledge or awareness about their diagnosis and prognosis. Mario's young nurse, even though she would prefer to know what the patient knows about own diagnosis and prognosis, shares this opinion as well. She explains:

"What do you want me to do more than encourage him somehow(?), that is, I would never feel like actually saying how things are or how...because in any case it's not my job and therefore not..."

Yet, all nurses report to have been asked questions about life expectancy, treatment efficacy, terminal care and so on by patients and caregivers. The nurses' narratives contain plenty of anecdotes about patients' awareness and considerations about communication related to diagnosis and prognosis. Piero's nurse affirms to conform to the norm that she was taught when she was a young nurse: never talk to the patient about his or her disease, but then goes on saying:

"...someone tells you 'I'm undergoing treatments, but I know that they don't work' Yes! It happens! There are patients that do like that. It happened to me that a patient told like that and I replayed 'Why do you follow treatment, then?'(...) 'Who knows??!! Just to try it, but anyway I know that they don't (...) that this time, this time it's not going to be fine for me'."

Nurses generally perceive the disclosure of a fatal prognosis as having a double effect: on one hand it allows patients to decide about their own life, but on the other hand, it is incompatible with maintaining hope. The perceived double effect of knowledge supports a disclosure-related communication experience as a conflict between being honest or dishonest, an unsolvable alternative between being virtuous or supporting patients' hope. Angelo's nurse, in commenting her own answer to a patient who asked her if she was going to die, explains:

"If I had said the truth, what would be changed? I would have increased her distress and she would have lived her last days more

distressed. I felt guilty because I lied. (...) I said to myself: 'liar!' But, in that moment, it was for me the only way to calm her."

Patients experience communication with their physicians as mere information about diagnostic exams: an update about the disease evolution and an explanation of the suggested therapies. However, all patients refer to have received some form of reassurance, together with information by their oncologist. Moreover, most of them retain that amount of talking they would like to have and the actual talking with the attending physician is barely coextensive. Patients with the highest school degrees as well as those with low education note that physicians use an adapted language to inform them about diagnosis and seriousness of the disease. Piero says:

"They are very delicate; they don't tell 'you have cancer' they can never tell it to you! They use terms that we, common people(...)they use terms that I don't know."

Although patients seem to expect the physician not to spontaneously tell the patient everything, they feel to determine the amount of information they would like to receive by asking or refraining from asking specific questions and feel confident to receive trustworthy information from their physicians. This is evident, for example, in Daniela's case who tells the story of when she asked a physician whether she would be able to walk again:

"She [the physician] told me it! (...) maybe because they [physicians] too want to tell the truth! Times have changed and they don't hide it to the patient anymore. I do agree with it, maybe if I were them, I'll do the same thing."

Overall, patients experience communication with their nurses as something that appears to be held back by the patients themselves. They do not identify an obstacle in nurses' attitude – who are usually described as polite and kind – but they justify this missed communication by blaming themselves for not wanting to talk about it or by telling that nurses are too busy to do it. Nella reports to never having had a real conversation with nurses and thinks that most of them are not interested in listening patients' stories. She says:

"because if they had also to bear a patient's problems (...)because here patients are patients who you meet today and in a few days you could meet them no more...and if they should put themselves in each patient else's shoes, I think it would be too hard to do as a job."

According to what patients report, most of their communication interactions with nurses concerns explanations about the therapies. No patient reports a conversation started by a nurse. Piero is very explicit about it:

"no, not with nurses. First of all, they don't talk. They put on drips, they do things, up and down, they don't know these things [disease, diagnosis and prognosis]: they have documents, they have to administer, timetable [therapies] (...) but I'm not one who bothers nurses."

All caregivers think of themselves as information receivers. They report staying close to their loved ones when information is given and to act on their behalf. They appear to be aware of the physicians' attitude to refrain from giving explicit and detailed information to the patient. Caregivers tend to support this stance because it can protect the patient from despair. However, they feel allowed to advice physicians about the communication approach they consider most suitable for their loved one. Piero's caregiver says:

"They [the physicians] have been very delicate, also because we've told them (...) because he's a very emotional person, so we

advised the physicians (...) to be very delicate in informing him [the patient] about the severity of the disease."

- **The bind of implicit and explicit meaning of communication**

In the narratives of Angelo and Nella, the communication of diagnosis and prognosis emerges as a dense bond of implicit and explicit meanings to which the participants are sensitive and, at the same time, constantly exposed. Angelo's narrative is the most explicit one: he says that since he has known his diagnosis, his main question has been 'what is happening to me?' He knows he has 'cancer', his oncologist told him so, but that is not enough to him. He thinks that none of the medical terms used by physicians can answer his question and that the usual medical way to talk about the disease is just a veil that hides the real issues at stake. He says:

"We all keep these things at a distance because we can't live always asking those questions. This is just a way to solve the problem, to also give an answer for who we are, where we come from, where we are going. But these are questions that are never asked or are asked in a banal form."

The unspoken existential meaning of ‘those questions’ can be found, according to Angelo, in those caring actions – such as changing the diaper to an adult man – that he names ‘spontaneous communication forms’, and that he considers as:

“Not much different from an intimate contact, namely, a spiritual contact with (...), with our biggest worries.”

Piero, Mario, and Angelo’s nurses point out that their communication with patients is something that often encompasses topics related to personal values and existential meanings and that could be achieved through attentive listening, gazes and touching. According to these nurses, it is by providing direct care that they have opportunity to know patients and their attitude towards the disease and, sometimes, to understand their awareness of diagnosis and prognosis. The other nurses too, describe their conversation with the patient as something that goes on while performing nursing procedures. Nevertheless, nurses also admit that nowadays they are more than ever neglecting to provide direct care because of both bureaucracy burden and time constraints, and also due to the fragmentation of care between different health workers. A tendency that nurses dislike and that older nurses compare to the past is when, as Piero's nurse says:

"The bed rounds somehow forced you to talk, not just talk of the disease, if they knew their health condition, but (...) sometimes they were saying (...) talking about themselves, of their home business, of their children, do you see? We used to spend time with them, and they were pleased to talk with us."

The perceived bond between not-explicit request of information and implicit will to not knowing one's own prognosis is the result of a reasoning that physicians adopt to justify their refraining from disclosing the prognosis. Based on this reasoning, Angelo, Sergio, and Daniela's physicians believe to respect the patients' autonomy and, at the same time, to preserve them from an avoidable psychological suffering. Daniela's oncologist declares:

"The principle that guides information transmission is that (...), every person who undergoes therapy, every kind of therapy, has to be the one to decide if he/she wants to undergo it or not. He/she has to be informed to be able to decide [what to do]."

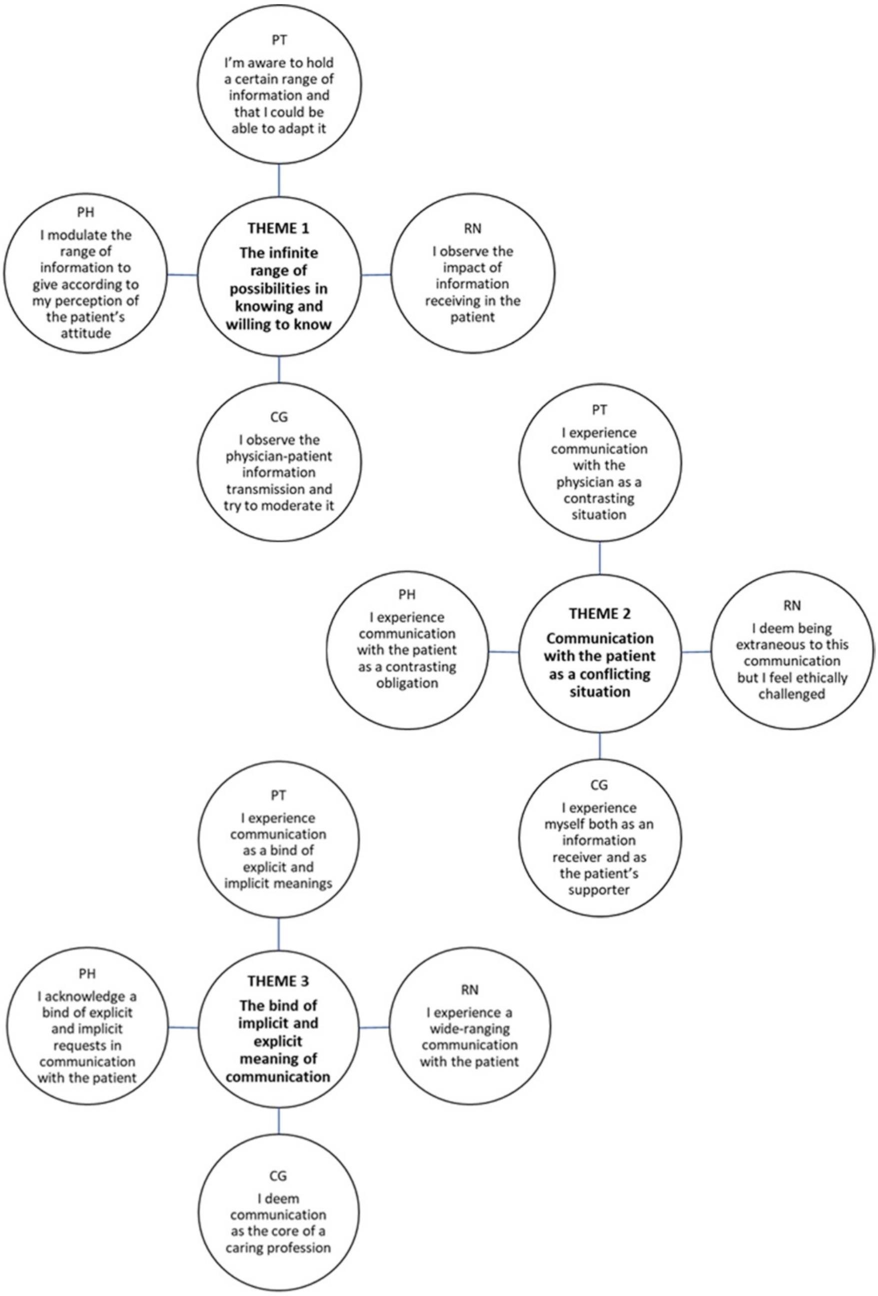
However, when it comes to asking what he thinks regarding his patients' awareness about prognosis, he says:

"I don't think she is [aware], she has asked nothing, so nothing was said about prognosis (...), but it has been emphasised that her disease was in an advanced stage and that our aim was to slow the disease down."

Nella's caregiver notes that the capacity to enter into an authentic relationship with the patient, understanding his or her feelings and how the disease is affecting his or her life, is meaningful not only to the patient but also to the attending healthcare professional, as it permits to go beyond the mere technical function. This capacity, according to Nella's caregiver, is the core of a health carer's role and, when this is not there:

"The importance of that figure [the healthcare professional] during a patient's disease trajectory could have no weight and the ill person could consider him/her simply as an instrument."

Figure 6: Perspectives of themes



6. Discussion

6. Discussion

This study aimed to understand diagnosis and prognosis-related communication by simultaneously exploring patients', nurses', doctors', and caregivers' reciprocal perspective of their communication interactions, through a phenomenological interpretative approach. By doing this, this study wants to understand how the communicative approach is experienced by the four parties, and how their reciprocal interactions are affected by it. According to the interpretative stance of the adopted phenomenological approach, the understanding has to be referred not so much to the intention of the informants but has to do with the meaning of the narratives (the text) themselves. In order to pursue these aims two studies have been conducted. The first research investigated communication related to the knowledge of the diagnosis and prognosis of cancer. The second research aimed to explore the experience of patients, caregivers, nurses and physicians on diagnosis and prognosis-related communication with respect to the connected meanings and ethical aspects.

The theme, "**Nurses' and Physicians' availability to communicate as conditioned by contextual factors**", is characterised by a strong transversal concordance between the four parties. In the narrative of all four parts, in fact, there is a sort of great premise that concerns the contextual constraints that overwhelm the individual will and ability to devote time to communication. While patients and caregivers emphasize the importance of having time for communicating and receiving psychosocial support from nurses and physicians, they talk about it as extra care, too pretentious in actual hospital wards. On the other hand, nurses and physicians, while not ignoring communication to meet the psychosocial needs of the patient (and caregivers), treat it as a secondary concern due to the limitations imposed by excessive workloads. Time constraints are not an unusual data in literature (Tay et al. 2011; Russel 2015) and generally they are acquired either by the health professionals or by the patients. This is a recent trend in literature, since in 2011 Smith and al. still complained about the almost exclusive emphasis put on the perspective of the healthcare provider, an approach also reflected in the interventions designed to improve the provider-patient communication that used to leave aside patients' point of view.

Overall, the difficulty met by patients to interact with busy health professionals and their acknowledgment of time pressures as limiting factors in communication, as emerged in the present research, are in line with previous findings in different healthcare contexts (Thorne et al.2009; Chan et al., 2013; Finset et al. 2013). The novelty in the present study is that here the feeling of being overwhelmed by these contextual factors appears and can been identified as a common experience and perception in all four key stakeholders. They all acknowledge a sort of super-structured power that limits their possibilities to have satisfactory communicative interactions. This seems to prevent conflicts among the parties, nevertheless feelings of frustration and disappointment can be detected in all stakeholders' narratives. I deem important to remark that health professionals' perception of an unchangeable and constraining context of care cannot be disregarded when planning educational programs. In fact, in order to positively influence health professionals' performance and patients' outcomes, training interventions should be grounded not just on evidence about the ideal practice, but should also be specific, contextualised, and delivered using practical modalities, a position also sustained by Parry (2008). Considering that communication skills are enhanced by making available the opportunities to communicate on an ordinary basis, it would be valuable to make any effort to build these possibilities and opportunities to realize and develop communication between healthcare professionals and patients. Another consideration can be drawn by taking into account the nurses and patients' full narratives and comparing them. In fact, time constraints often seem to be used as a prima facie justification of the scant reciprocal communication interactions. The nurses do complain about a work routine that is too frenetic, but they also describe it as mostly task-oriented, limited by strict role's boundaries and, because of it, admit to deliberately avoid taking any initiative in the communication approach somehow related to disease's awareness. On the patients and caregivers' side, although nurses are perceived as always in a hurry because of great workload, this is thought to affect the communicative interactions expected from the nurse staff just quantitatively. In fact, no patient and no caregiver talk about having, or expecting to have a conversation with nurses somehow related to diagnosis and prognosis. They just assume it would be nice to have a friendly chat with nurses, were they more available. Physicians as well tend to refer to time constraints as affecting their communication with the patient only quantitatively speaking. There are only a few nurses and even less physicians that see the contextual constraints, and in particular the work organisation, as qualitatively impacting their interprofessional communication and their approach to communicating with the patient. These attitudes should be further investigated as they might interfere with promoting changes and innovation. In conclusion, a multi-level support is needed to help nurses and physicians to make the statement that time dedicated to communication with the patient is "time of cure" come true (Italian Law 219/17 art.1). Communication skills may be honed by making opportunities to communicate continuously available.

The theme titled «**The "what is it?" and the "what will happen to me?"** » illustrates how communication about diagnosis is approached differently compared to communication about prognosis. Diagnosis is presented by physicians as giving an information, by patients as receiving an information, and by caregivers as information received together with the patient. There was no patient unable to give a name to his or her illness. This name was sometimes the medical term of their disease, other times it was the popular name tumour, or even cancer. Patient-physician communication is established on this shared information. In contrast, prognosis is a piece of information to be requested by the patient to the physician: the question-answer pattern is adopted by physicians and reported by all other participants. This pattern looks sort of like a replica of the so-called “collusion between doctors and patients” already described in literature (The et al., 2000): doctors do not want to give out a "death sentence" and patients do not want to hear it. The physician’s attitude to not directly investigate on patients’ communication needs and preferences but base their communication approach with the patient just on their own deductions has already been observed in previous research (Hack et al, 2005). The patient’s preference to have honest information but not more details than they are ready to hear, is too, already present in literature (Clayton et al.; 2005). This research offers instead, a novel overview on the caregiver, nurse, and physician’s knowledge of the knowledge that patients have of their diagnosis and prognosis. Cross checking the interviews at a group level, it can be said that the collusion appears to be a consolidated and recognised strategy, that allows physicians to intercept the will and preference in terms of communication approach in most patients.

Nevertheless, the equation "does not ask = does not want to know" appears as a culturally based assumption that cannot fit all patients (as in Giuseppe's case), and health professionals should take this into account, considering that they are invited to "*ask patients and patients' families what informational requirements are preferred*" (Tuckett, 2004, p.508), and that not all patients feel self-assured enough to freely ask anything they would like to know to their oncologist. Comparing the participants 'assessment of the patient's knowledge of the diagnosis and prognosis allows us to see that only in two cases the participants' assessments on it are all in agreement. This agreement does not seem to be an achievement of health professionals: in one case it is prompted by the patient's open attitude and direct request of complete disclosure, in another case, it is driven by relatives' direct request not to disclose prognosis. Unless the patient or his/her caregivers, make a clear statement about the information and amount of information they would like to receive, or take an initiative about the communication approach, the health professionals do not investigate on the patient's preference about information transmission and just assume what the patient wants to know by relaying on their own deductions. Besides, nurses and oncologists are not used to sharing information among themselves about the communication approach toward the patients and their family. In these cases, the patient’s awareness and willingness to know remains implicit and health professionals seem to be less aware of the patient’s knowledge or what they are willing to know. There are two discrepancies between the caregiver's assessment and the affirmation of a loved one. These can be explained by the fact that it is the caregiver who colludes with the physician, while patients recognize that they have not asked for - and therefore not received - comprehensive information on the prognosis. Ultimately, the incorrect assessment of the patient's knowledge by the caregiver seems more influenced by personal assumptions than by an open exchange of information between the patient and his caregiver. The inaccuracy of the caregiver’s perception of the extent of the knowledge and the need to receive more prognosis-related information has also emerged in Bar-Tal’s et al. study (2004). These findings show that even close caregivers are not always able to assess the actual knowledge and consider the informational needs of their loved ones. This finding suggests that health professionals should attentively ponder about how much the patient’s knowledge of their disease and prognosis is represented by their caregivers' assessment on it. This is important because the exchange of information between the patient and his or her significative caregivers can be a relevant resource to all stakeholders. The comparison of the narratives, allowed by this study design, shows that the patient, caregiver and physician have at the basis of their communication interactions the common recognition that information on the diagnosis of cancer has been provided to the patient. On the other hand, nurse–patient communication is not grounded on this shared acknowledgment, and many nurses ignore both what the patient has been told about his/her diagnosis and prognosis and what he/she knows about them. Therefore, on many occasions, nurses remain outside the narrative of the patient's diagnosis communication experience, both in the sense that they were not present at the time of diagnosis, and in the sense that no patient and no nurse report sharing the story of when the diagnosis was given, nor do they report further speeches in any way related to communicating the diagnosis. The nurses justify their ignorance and disinterest by saying that communicating diagnosis and prognosis is physicians' business. This finding is not unusual: the literature shows both the involvement of nurses by patients in discussions regarding diagnosis and prognosis, and their maintenance of this communication outside their scope of practice, nor their role (Helft et al., 2011). It has to be noted that most of the time these studies refer to the initial discussion that occurs when the oncologist tells the patient the diagnosis and related prognosis. Nevertheless, our study shows that the issue is that nurses, by keeping away from communication of diagnosis and prognosis, are also keeping away from the patient’s knowledge and awareness of their disease and health status. This is a problem because the development of a caring relationship involves coming to know the patient as a person. To be informed of the patient’s knowledge about their disease and health status, and to be aware of their will to know means to know (more) about the patient as a person. Nursing care sensitive to the ethical implications of the individual clinical case cannot ignore the knowledge and awareness of the patient's disease. Nurses cannot call themselves out of the way the patient experiences their disease and cure. Otherwise, the alternative (or the) risk is to provide a “standardised care”, based on the deontological formal norms and irrespective of the singular patient’s story and attitude towards the disease. This is an ethical challenge upon which nurses should reflect and take a position. Indeed, it can be said that they perceive it as an ethical point as they feel the owe honesty to the patient who is intitled to take informed personal decisions about treatments.

In their study Oberle and Hughes (2001) investigated doctors' and nurses' perceptions of ethical problems in end-of-life situations. They argued that both physicians and nurses were extremely concerned with the decision-making process, although nurses focused on how and why doctors came to the decision, whilst doctors bore the burden of having to make the decision. In our findings some physicians show a similar concern, but they mostly refer it to the acquisition of the informant consent than to a process of shared decision-making. In fact, most of the time, communication about diagnosis and prognosis is treated by physicians just as an information transmission that has to be accomplished in order to obtain the informant consent.

This point introduces the next theme that, though more massively present in the first study, is trackable in both studies: the **«Matching and Mismatching in Identifying the Others as Speakers»,** emerged in the data analysis of both. It illustrates how patients, caregivers, physicians, and nurses describe and give meaning to their reciprocal communication interactions. Indeed, the multi-prospective design enlightens a correspondence between the nurses' perception of their extraneousness to diagnosis and prognosis-related communication, and the descriptions and perceptions of the nurse's role reported by the other participants. However, nurses also report many conversations with patients (and caregivers) about issues such as life expectancy, effectiveness of therapies, awareness of the disease, perspective of death, and so on, and define themselves as the patient's (and caregiver's) supporters. This supporting role is described as being present for the patient and encouraging them while, unlike in other studies (McLennon et al., 2013), staying away from corroborating or clarifying information about diagnosis and prognosis. In some nurses' narratives the supporter role is even described as an ancillary role in respect to the significative role assigned to the physician who has the power to make decisions. Also, in Georgaki et al. (2002) nurses tend to consider their role in communicating with patients as subordinated to the physician's role. The mismatching in identifying themselves as a speaker in the communication related to diagnosis and prognosis, and at the same time the matching in interpreting the role of the nurse as an outsider in the communication related to diagnosis and prognosis should be carefully considered, as they represent the framework within which actions are performed, observed, and acknowledged. In fact, anything that remains outside of the frame is likely to remain unnoticed and unvalued. In fact, neither patients nor nurses acknowledge any nurses' role concerning communication of diagnosis and prognosis. I believe that the perception of nurses' extraneousness to diagnosis and prognosis-related communication has to be addressed, in consideration of the fact that they are, willingly or unwillingly, involved in the issue of disclosure (Huang et al., 2014). Newman (2016), in her integrative review, concludes that nurses play an integral role in the process of diagnostic and prognostic disclosure, although the author suggested the need for further exploration of both the physician and the patient perceptions of the nurse's role. In my study, the narrative interviews collected by the nurses are full of anecdotal stories about patients talking to them about problems related to diagnosis and prognosis, although the interviewees present it as a personal experience and not as a role experience. Nurses appear to present themselves based on what they think they should do about communicating diagnosis and prognosis but, although not explicitly, they tell more than that. Something more is told, many times in the form of anecdotes, but is not framed into the issue of communication related to diagnosis and prognosis. It seems that nurses still find it difficult to see and value their action beyond the tasks they are used to accomplish and expected to do in the ward routine. Nurses need to better identify their proper and active role in patient's care, so to avoid losing themselves in the standardised tasks (almost related to therapies) they are used to perform. The phenomenon of "bad news-reverse-direction" reported by nurses (e.g., patients who spontaneously update nurses upon their clinical situation, state their dismission from therapies, admit their terminal status) but not mentioned by any patient, can be a sign of an unrecognised communication interaction that still has to be explored and valued. The nurses' sense of extraneousness—perceived by all four parties—to diagnosis and prognosis-related communication, can be due to the fact that the nurse's role is still seen through a traditional biomedical-centric vision in which diagnosis and prognosis issues are delimitated just by information transmission and, consequently, are referred to as an exclusively medical competence. The biomedical paradigm can increase the difficulty—observed also in patient', caregiver', and physician's narratives—in considering nurses as professionals with whom patients and caregivers can discuss issues on diagnosis and prognosis. In fact, it seems that many of the communicative problems experienced by nurses are reflected in the narratives of patients and caregivers and prevent them from sharing their concerns with nurses. Considering this from a socio-cultural point of view it can be said that patients', caregivers' and physicians' description about their communication interactions with nurses reflects the Italian nurse's social image, for which nurses are mere executors of medical prescriptions (Capone et al., 2017). My considerations align with Kleinman's (1978) presentation of the biomedical model as a cultural system. He warned that medical systems are always both social and cultural systems: as cultural systems they are systems of meaning and behavioural norms, as social systems those meanings and norms are always attached to particular social relationships and institutional settings. According to Kleinman, healthcare relationships (e.g., patient-family or patient-practitioner relationships) can be studied as transactions between different "Explanatory Models" and the cognitive systems and social positions to which they are connected. As a result, the denial by patients and caregivers of communicative interactions related to diagnosis and prognosis with nurses seems to indicate that patients and healthcare professionals have difficulty perceiving and understanding the role of the nurse with respect to a specific knowledge system (nor the biomedical/professional, neither the familiar).

An unexpected finding should be further investigated and checked for connection with role's perception: almost every participant patient and every caregiver have been unable to name a nurse with whom he or she was more acquainted: just two patients were able to recollect and say the name of one or more nurses. No caregiver was able to say the name of any nurse. Vice versa, both patients and caregivers were able to indicate and name the attending physician. This unexpected finding has to be taken into due account, as existing evidence shows that patients are more likely to raise questions or concerns if they are familiar with their healthcare providers (Fisher et al. 2014). Besides, an inconsistent nurse-patient relationship could affect patients' readiness to express their feelings and needs (Sheldon et al. 2009). The nurses' sense of extraneousness to communication related to diagnosis and prognosis comes together with their feelings of uneasiness and unpreparedness to deal with this kind of communication. Also, Wittenberg et al. (2019) noticed that nurses had trouble in taking the initiative and address diagnosis and prognosis related issues with patients. Helft et al. (2011) and McLennon et al. (2013) found that nurses experience uncertainty about their own role in prognosis discussions, because they did not know whether physician disclosed prognosis to patients or their families.

With regard to the caregivers' role in communication process, this study shows that caregivers are still barely involved by health professionals. Although physicians theoretically recognise the importance to involve caregivers in cancer care, they find it difficult to implement any structured interaction or shared communicative approach with caregivers. All four parties have faced diagnosis and prognosis-related communication in a shared way only when relatives explicitly asked to limit the quantity of information for the patient (see Sebastiano's case). The relatives' request to limit the transmission of information appears to be the trigger of the communication flow that allows healthcare professionals to approach communication in an integrated manner. Only in this case the healthcare professionals approached the communication in an integrated way. The role assumed by family members to act as filters of medical information is not an unusual finding in cancer literature (Hudson et al., 2004) and in the Italian scenario (Surbone et al., 2004). Beyond the role of filter which assumed by the family caregivers, the role of patient's supporter is in line with the findings of other studies (Abazari et al., 2016). What needs to be noted is that in our study it appears to be clear that the caregiver's filter role is performed, as the patient is aware of this role. However, as in Orri et al. (2015) nurses and physicians do not seem able to integrate family members into the care process, even though they are considered an important resource for patients' quality of life.

In the second research three themes have emerged. The theme titled **"The infinite range of possibilities in knowing and willing to know"** has enlighten a context of diagnosis and prognosis related communication characterised by contradictory perceptions and fragmented experiences in which individuals struggle to rearrange their ideas and their values. The multi-perspective design has not just enabled to expand the attention to the context of communicative interactions in which disease and care are experienced, but has also allowed to better understand how meanings are attributed and interwoven and, therefore, the different moral perspectives on diagnosis and prognosis-related communication embraced by the four stakeholders participating in the study. The findings show that all participants are involved in and feel affected by diagnosis and prognosis-related communication. All participants show contradictions and ambiguities in their narratives. Patients' contradictory statements emerged also in Ohnsorge et al.'s study (2012) that investigated the wish to die in hospice cancer patients. The authors suggested that conflicting values and aims could be considered as belonging to the process of meaning-making and negotiation about normative claims, namely, those statements that *"directly or indirectly include moral claims regarding oneself or others*" (p. 630). In our research, the contradictory and fragmented process of meaning-making seems to involve all four parties interviewed and to go beyond the normative claims. Contradictions and fragmented processes emerge from the patients' narratives with respect to knowledge, feelings, expectations and will to know. Physicians use contrasting adjectives to describe their giving-information to patients: an effort to be clear enough while, at the same time, a bit fuzzy so to always leave room for hope. Nurses acknowledge a great relevance to patient's communication needs, report many informal conversations with patients about life expectancy, disease awareness and so on but still, they believe that communication related to diagnosis and prognosis is not their business. This retaining is coherent with patients' and caregivers' opinions: they report no communication interactions with nurses about diagnosis and prognosis-related issues. This finding confirms what previous research had already found, echoed in the narratives of all participants, that this could be considered a culturally based phenomenon, linked to the Italian stereotype of the role of the nurse. This stereotype fits into a framework in which the nurse remains the executor of medical orders. For all those aspects that concern the psycho-emotional component or, more broadly - the needs related to the subjective and human sphere, it does not seem that patients individuate a specific interlocutor among healthcare professionals. Even when some patients and caregivers manifest the relevance of this sphere and the needs related to it, they do not expect a professional answer to that needs from nurses. Our findings are extremely concordant with those of Chan et al.'s (2018) who found that many cancer patients were not aware of the role played by nurses in providing psychosocial care and that the few that seemed to recognize that nurses could play this role, perceived that nurses' time constraints could not allow it. The attitude displayed by some patients, to refrain to talk about their feelings and worries to not load their troubles and fears on nurses so to avoid being emotional burden to them, is another limiting factor in the nurse-patient interactions that has to be attentively addressed by nurses because it represents an ethical defiance for a caring profession. Primarily, the lack of appropriate communication between patient and nurses can lead to unrecognized and unmet patient needs and an increased risk of litigation based on what is called ethical malpractice (Fallowfield & Jenkins 2004).

Another distinct finding of this research is that all parties emphasize more the concept of ambivalence as an ethical trait of knowledge than as a product of patients' unstable desires and expectations. In fact, the vision of what will happen – caused by knowing – is considered by participants as both empowering and disempowering for the patient. Health professionals, in fact, recognise that not disclosing to patients prevent them from making proper therapeutic decisions based on their vision of life and personal goals. On the other side they fear that to burden the patient with plenty of information might overload their resilience capacity and ultimately disturb their process of decision making. Nurses tend to find confirmation of this ambivalent power of knowledge in anecdotes that they use as examples of such ambivalence. On the patients' side, some of them were quite firm in declaring their will to receive or not to receive prognostic information, others did not clearly express their will and some of them expressed an ambivalent will. In those patients who expressed the preference to not to investigate further on their own prognosis, knowledge appears to be a competing value for self-control over their own emotions. These data expand what was found by Innes & Payne (2009) in their review according to which most of the patients seem to want some broad indication of their prognosis, but that preference for wanting more detailed information were more varied. Our findings are in line with those of Kirk et al.'s (2004) that enlighten patients' ambiguous attitude towards information: they wanted to be told but, at the same time, they did not want to know. Furthermore, this finding poses another delicate and significant interrogative about the ethical consistence of the question –answer pattern adopted by physicians and emerged also in the data of the previous study I believe that it must be taken into account that this scheme, although it apparently leaves the decision to acquire or not to acquire information on their state of health, presupposes an abstract individual will and abstract expressive power. Patients' ambivalent will or unexpressed will support my point. There is evidence (Kulberg et al. 2015) that hospitalized patients who are more actively involved in their own care are the ones who initiate conversations and approach health professionals for information pertaining to their illness and self-care. Health professionals should take into account this ambivalent or unexpressed patient’s will and try to distinguish the different meanings of patient’s silence. That is to say that communication about diagnosis and prognosis should never be standardised, even on culturally accepted patterns, but personalized to each single person needs. Information’s rights are always universal, but communication approaches should be modelled on each one’s needs and will. Besides, the findings confirm the already known physician’s tendency to not going into details about some prognosis aspects, in order to save the patient’s hope (Tuckett 2004; Hancock et al., 2007).

Our data is also concordant with those of Arora, (2003) and Hack et al (2005) who found that doctors and nurses tend to rely on their own judgment, or even pre-assumption, to assess patients' needs, more than patient's direct claims. The observed tendency appears to be a controversial situation in which physicians theoretically declare to be favourable to the opportunity to communicate the truth to patients, but at the same time, they conform to the ethical norm in a flexible way and based on the context and situation. Overall, physicians tend to draw upon principles of biomedical ethics to construct arguments for their communication approach on diagnosis and prognosis. Yet, the traditional bioethical principles of beneficence and non-maleficence were named just once in an explicit form. Physicians' readiness to make exceptions to the proclaimed norm – depending on patient's characteristics as perceived by them – seems to be a not unusual finding in so-called high-context cultures, such as those of the Mediterranean basin (Rodriguez Del Pozo et al. 2012). My findings are also in line with those of another Italian study that enlightened a discordance between ethical principles declared by health professionals and communication approaches with patients (Di Giacomo et al., 2012). While physicians seem to refer to the two ethical principles ‘do good’ and ‘do not harm’ in their communicative approach, without perceiving their behaviour as conflictual, nurses seem to refer to the virtue ethics, perceiving their involvement in communication related to diagnosis and prognosis as an unsolvable dilemma between being truthful and being supportive and reassuring for patients. This reveals, on one hand, the nurses’ strong sense of ethical commitment towards the patients in staying close to them. On the other hand, it emphasizes the difficulty to accompany the patients along their path of awareness of the prognosis and prepare them for the end of life. Nurses also reported moral distress when they retained that the wrong course of action was followed and they could do nothing but continue to administer the prescribed therapies (most of the time, in fact, nurses were referring to medical obstinacy in therapies). This conflicting attitude and unconciliated ethical calls can obstruct care relationship between nurse and patient. Health professionals stuck in the conflict between contrasting ethical norms were also observed in previous studies (Buiting et al., 2011; Wagner et al., 2014). Oberle & Hughes (2001) already found that the key difference between doctors’ and nurses’ perceptions about ethical problems in end-of-life decisions was that doctors felt responsible for making decisions and nurses perceived themselves forced to live with these decisions. In my study, this condition is also manifested in nurses' worries and precautions to not trespass perceived professionals' boundaries or to give information and, at the same time, in their attention to patients' communication needs. In our research the "boundaries-concern" appears to be such an obstacle for nurses that the vast majority of them reported to having invited patients (and caregivers) to ask doctors for any information about the patient's health status. This leads to nurses dismissing any responsibility related to communication related to diagnosis and prognosis. Nevertheless, this finding has to be confronted with the next one. In fact, although in participants' narratives, communication related to diagnosis and prognosis is often framed by the medical information pattern, some participants refer to their communication experience as going beyond the usual scheme of information transmission. Professionals and informal caregivers emphasize the importance of paying attention to what is beyond the first explicit meaning in the patient's words and grasping its true inner meaning, which becomes understandable through the sensitivity and relationship established with the patient. The older nurses are the ones who refer to that kind of relationship as something that used to occur naturally and spontaneously when they used to be the main providers of direct assistance and body care to the patient. Procedures that nowadays are less frequently performed by nurses, being delegated to nurse-assistants. Actually, most of the anecdotes about conversations with the patients narrated by nurses are somehow contextualised by body care procedures. Nursing procedures, more than any conceptual model or holistic theory, are the references furnished by nurses to sustain their used easiness to enter in contact with the patient and establish a relationship with them. This finding raised a lot of questions on the self-perceived identity of the nurses: how much it has changed and what it is like now. Even though the connection between physical and psychological needs is not an issue so adequately investigated by a nursing specific point of view, this is not an isolated finding. Chan et al. (2018) also found that nurses showed a clear awareness of the interactions between patient's physical and psychological needs and the related aspects of care. Nevertheless, in Chan et al.'s study, when nurses refer to physical needs they mean medical needs (e.g., relieve from physical symptoms, such as pain or constipation). From my study emerges that, according to patients and caregivers, it is in paying attention to the whole person and not just to his or her health problems that the authentic nature of the nurse and physician professions is accomplished. The existential dimension therefore appears as the ethical background in which the phenomenon of communication resides and can be recognized by all four stakeholders. At the same time, the ability to perceive and satisfy the needs related to the existential dimension are perceived and represented as personal attitudes, supplementary to the professional role. In medical communication, it is not only aspects related to information that are considered relevant, but also the caring attitude of physicians (Back et al., 2008; Mallinger et al., 2005). Patients and family members expect health professionals to be able to deal with issues that are not strictly medical, as concluded also by Michie et al. (2003): they also expect the health professionals to show their human caring as the inner and truer essence of their profession. Nevertheless, in the narratives of patients and caregivers, these expectations are presented as theoretically driven expectations, and when it comes to contextualise them in their story and experiences, no patient and no caregiver reported having received psychosocial care in the form of emotional talks from nurses or physicians, though none of them complained about the assistance received from health professionals.

In conclusion, this study offers insights into the experience of communication related to diagnosis and prognosis in the context of advanced cancer. These insights allow us to interpret the communicative interactions between the four stakeholders as an epiphenomenon of the modern struggle between the so-called biomedical approach and the humanistic vision of care.

7. Limitation and future implications

7. Limitations and future implications

The overall study presents a number of limitations related to contextual difficulties such as scarcity of comfortable and privacy safeguarding places where to conduct interviews. Moreover, nurses and physicians' time constraint led to many unattended interview appointments, thus prolonging the phase of data collection.

The selected samples of patients are homogeneous in terms of life expectancy, but their experiences with the disease could be quite heterogeneous, even in the last year of life. Furthermore, the overall samples are quite heterogeneous with respect to participants' demographic data. This is an uncommon feature in IPA studies, although Smith and Osborn (2008) affirm that the way in which the specificity of a sample is defined can depend on the study needs. Also Loaring et al. (2015), justifying the variability present in the demographic characteristics of their sample and connected to their sampling strategies (dyadic sampling), pointed out that homogeneity can be grounded in certain sample characteristics that are deemed central to the phenomenon under investigation and in the shared experience of the phenomenon itself (communication regarding diagnosis and prognosis when cancer is advanced and patients are expected to have no more than 1 year of life expectancy from their doctor). The broad inclusion criteria for the two studies are justified by the aim to shed light on the communication interactions between the four categories of participants. Moreover, the two sub-samples of nurses and oncologists may be considered homogeneous with respect to their knowledge about diagnosis and prognosis of their patients. In conducting the interviews, it has been a constant and primary priority to preserve participants from any incidental unwanted discomfort. This meant postponing many interview appointments and to adapt their length to the participant’s comfort. It has caused a broad variability in the interviews’ length, mainly due to the patients’ tiredness and to some interruptions during the interview (all interviewed health professionals, except one, preferred to be interviewed during their working hours). Moreover, the interviewer paid significant attention to the participants’ emotional status and interrupted the interview whenever it was necessary. It has to be noted that it happened that, after having already recorded the interview, the interviewer herself was invited, in the next few days, for a talk by some of the interviewed patients and caregivers. These additional talks were used to get a better insight of the participant and to better clarify some issues emerged during the interview.

Another limitation of the two studies is that the male gender is not represented in the caregiver sub-sample. This is because the sampling procedure required the patient to indicate a caregiver significant to him/her and this has resulted in a prevalence of the female gender among caregivers. The prevalence of the female gender among caregivers is in line with the tradition that sees women as the carer of whoever is in need in the family. Furthermore, it has to be admitted that to recruit and obtain the availability of four interrelated participants (patient, his or her caregiver, and attending nurse and physician) was not an easy task and prevented the participations of several people who were willing to participate. Among the recruited participants, physicians and nurses were more reluctant than patients and caregivers to participate in the study; physicians claimed they have a limited amount of time or no interest in taking part in the research. Many nurses, on the other hand, stated that they did not treat the patient interviewed with sufficient continuity to be part in the study. There is also another study limitation: doctors' point of view was less represented if compared to that of nurses. This is because the available medical staff in the departments was not particularly numerous and not all oncologists showed interest in participating in the research (moreover in study 2 one of the attending physicians changed his mind and refused to be interviewed). The doctors' under-represented point of view implies that there may be missed relevant themes within this group of participants.

In line with all studies with an ideographic reference, transferability of the findings has to be regarded with great caution and, in any case, it is not the main aim of the two studies. Nevertheless, the comparison of the perspectives of the four participants provides additional value to the existing research and important insights that can have wider implications**.** Indeed, this study adds important experiential considerations to existing research that usually only considers the bidirectional aspects of clinical communication.

Multi-perspective design was not primarily intended to look at the correspondence of the communication contents between the different speakers. In fact, IPA approach entrusted to multi-perspective design has allowed us to look at the mutual meaning of the participants in communication and communicative interactions related to diagnosis and prognosis and, in doing so, to grasp further meanings arousing from global understanding. The adopted approach assumes the four stakeholders, the patient, their caregiver and their attending nurse and oncologist, as a whole, contrasted by the issue of communication of diagnosis and prognosis to patients with cancer in advanced stage. As already seen in the introduction chapter, although it is widely recognised that communication is a circular, global, and comprehensive phenomenon, there is little research that simultaneously study all main actors in the scene and confront their reciprocal interactions. The adopted approach allows a novel exploration of the phenomenon of communication, going beyond the usual focus on the content of communication or the intentionality of the subject (e.g., to disclose or to not disclose). In particular this approach cast a light in those human context factors that Ray (1998) considered extremely relevant to reflect on the ethical issues.

I was quite surprised with the number of patients and caregivers who could not recollect the personal name of any attending nurse but were able to recall the name of attending physicians. This unexpected occurrence should be further investigated and considered.

This study does not want and cannot be conclusive: its methodological premises and the exploratory intention and structure cannot afford much more than openness to further investigation and reflections. Nevertheless, its hermeneutic stance and the multi-perspective design have proven helpful in enlightening the meanings attributed by the various stakeholders to the reciprocal communication interactions and, in doing it, have unveiled the participants' mutual expectations in respect to communication related to diagnosis and prognosis in the context of cancer care.

8. Relevance and Applicability

8. Relevance and Applicability

In oncological literature, there are not many studies adopting a multi-perspective design (Hubbard et al., 2010; Orri et al., 2015) though this kind of design allows space for considering the context of relationships in which the disease and care are experienced (Spira & Kenemore; 2002). This thesis has investigated an already well-known issue but has done so by adopting a novel perspective and, therefore, could describe some aspects hitherto scarcely focused on cancer literature. Looking at the participants' experiences of communication related to diagnosis and prognosis as a dimension of encounters and interactions among multiple stakeholders, it has been possible to understand the participants' reciprocal level of acknowledgment of the other as speaker. This new insight allows to identify unattended ethical challenges that health professionals need to address and respond to. The findings show a fragmented communication approach by nurses and oncologists and a low level of integration between themselves and between health professionals and caregivers. Besides, the research allows to note that the difficulty experienced by the nurses in recognising their own role in communication related to diagnosis and prognosis is matched by the difficulty shown by the other participants in acknowledging the nurse's role in this scope. This gap seems to be grounded in the contemplation of diagnosis and prognosis exclusively through the medical paradigm, leaving all other dimension outside of the health-care domain and, therefore, not directly assumed by the health professionals. The difficulty of nurses to recognize themselves as speakers in communication relating to diagnosis and prognosis, and in not being recognized by others as such, hardly means identifying and assuming their own impact and professional responsibility in this type of communication interactions. If we say that to confront oneself with a responsibility means to play as a moral agent, this leads to the point that communication related to diagnosis and prognosis can be perceived as an ethical enterprise involving the nurse, only if the nurse is not a passive listener but a real interlocutor of the patients, their relatives, and caregivers. Just from this self-acknowledged - and acknowledged-by-others – position, nurses could make a real difference for the cared ones and enhance significant aspects of their practice. Recognizing themselves as speakers allows nurses to take responsibility for helping patients express their concerns, desires and will. Recognising nurses as speakers will empower the other stakeholders to look at these health-professionals as an effective and peculiar resource. Furthermore, the renewed self-recognition could help to better integrate and collaborate with the other health professionals in respect to the communication approach to the patient. The study emphasizes the importance to address communication related to diagnosis and prognosis as a phenomenon in which each party carries its own perspective and plays a role in it.

Both nurses and oncologists show that they consider the value and the burden of knowledge related to cancer diagnosis and prognosis particularly important and they also demonstrate that they strive to inform their communication approach, so as to meet the patients' information and emotional needs. Nevertheless, they rarely look at each other's profession as partners and assets in the communication approach to the patient. This aspect needs to be considered and integrated in the educational courses for health professionals. The health professionals' fragmented communication approach should be addressed and challenged by joint communication training, in which all actors' perspectives are explored, considered, and integrated. The integration of operators can represent not only a mean for a better healthcare but also an opportunity for professional growth of the different health professionals involved in it for the entire care team.

I believe that findings of this study could help nurses to reflect upon their role in communication related to diagnosis and prognosis in cancer and, ultimately, upon their identity. Contradictions and ambiguities should not be ignored but questioned; they represent a call to reflect upon how we interpret our identities and how we are perceived by others. Being aware and reflecting about everyone's role and influence in the communication process, is essential not just to ensure a consistency of communication within the multi-disciplinary team, but mostly because it allows and enables the moral agent to take its own responsibilities and be accountable for them. Moreover, understanding how the different speakers reciprocally interact and influence each other, can help to identify potential resources and hindrances in implementing effective patient-centred approaches, while avoiding silo cultures.

Some communication models need to be revised. The information-transmission based on health professionals' assumptions of what patients want or need to know has shown to not be perfectly accurate and correct. This kind of information-transmission model can be considered as physician-centred: it reproduces the old paternalistic scheme between doctors and patients, along with the hierarchical duties' organisations between doctors and nurses. Within this paternalistic scheme of interactions, though formally respectful of the patient's right to know, the concrete demand for the patient's active and effective involvement in communication and in healthcare decision cannot truly be achieved.

There is the need for nurses and physicians to reflect on their own communication interactions by specifically addressing those factors that make communication in the context of advanced cancer care so fragmented. The research findings confirm that communication between patient, caregivers and health professionals cannot be reduced to a simple information transmission about the disease and its treatment. In order to truly communicate with the patient, it is necessary to try to understand them beyond their words, without forgetting their biographical and social context. The ultimate goal of an integrated communication process is a better and more complete understanding of the person's communicational needs so as to better respond to them. Only in a mutual respect and appreciation of the different operating modes and specific skills, the health professionals enable themselves to develop a common and shared communication approach to the cancer patient. Indeed, a throughout understanding of communication exchanges among all main stakeholders is a prerequisite for the development and implementation of a patient-centred approach. Nurses, as patients' advocates, should make any effort to move away from this "silo culture" and give their contribution to the construction and implementation of the, as we shall call it, "orchestra culture".

In order to achieve the "orchestra culture" some attitudes have to be reinforced and some actions have to be taken. It is necessary that nurses identify, in their real clinical contexts, those situations and opportunities that allow them to be seen as resources by the patient and the other stakeholders. Being aware of the patient's knowledge and concern about their will are important to acknowledge the co-constructed meaning making of the communication interactions and have an active role on it. In doing so, the nurses will have new opportunities to develop the resources entrusted in nursing as humanistic culture. This is a kind of actualisation of the etymological meaning of the verb to communicate, which is to put something in common. To communicate as a health professional, as a nurse, has to do with knowing one's own impact towards the other stakeholders in communication, and with bearing specific and shared responsibilities related to communication, included the responsibility to be moral agents.

9. Conclusion

9. Conclusion

The issue of diagnosis and prognosis have surely a medical reference that can be and should be handled only by those who have this kind of competence, e.g., the physician, the oncologist. But diagnosis and prognosis cannot but be translated also into biographic, personal, and ultimately human questions that nurses should be able to intercept and to help to answer, honouring their holistic claims. The humanistic dimension of medical issues, as it is for communication related to diagnosis and prognosis, needs to be acknowledged and to receive the due attention by all health professionals. Nurses even more than other health professionals should be able to do this, as their essence is to take care of the patient as a person. The nurses should always make any effort not to dismiss the complexity and the existential dimension of any experience of disease and health related condition. The nurse who is at the service of his professional identity preserves and also provides meaning to his interaction with the patient. Communication related to diagnosis and prognosis is not strictly a medical reference and dimension, but it is part of the cared-carer relationship experienced by multiple stakeholders.

The provisional conclusion of this study is not that there is the need to provide answers to different categories of communication needs. This does not help to overcome the dichotomy in the vision and treatment of psyche and soma. Rather, the conclusion is that it is time to look at the interconnected dimension in communication and commit ourselves to approach them in a more holistic and harmonic way, so that we can be a *communicative* resource.

Reference

Reference

Abazari, P., Taleghani, F., Hematti, S., & Ehsani, M. (2016). Exploring perceptions and preferences of patients, families, physicians, and nurses regarding cancer disclosure: a descriptive qualitative study. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer*, *24*(11), 4651–4659. doi.org/10.1007/s00520-016-3308-x

Associazione Italiana di Oncologia Medica (2018) Linee guida Assistenza psico-sociale dei malati oncologici (in collaborazione con SIPO). [Guidelines for Psycho-social assistance to cancer patients (in collaboration with SIPO)]. (in Italian). Retrieved 2021 Jan 20, from: https://www.aiom.it/wp-content/uploads/2018/11/2018_LG_AIOM_Psicosociale.pdf

American Hospital Association (1972). Statement on Patient ‘s Bill of Rights. Retrieved 2021 Jan 20, from http://ethics.iit.edu/codes/AHA%201972.pdf

Antoine, P., Vanlemmens, L., Fournier, E., Trocmé, M., & Christophe, V. (2013). Young couples' experiences of breast cancer during hormone therapy: an interpretative phenomenological dyadic analysis. *Cancer nursing*, *36*(3), 213–220. doi.org/10.1097/NCC.0b013e31826429a5

Applebaum, A. J., Kolva, E. A., Kulikowski, J. R., Jacobs, J. D., DeRosa, A., Lichtenthal, W. G., Olden, M. E., Rosenfeld, B., & Breitbart, W. (2014). Conceptualizing prognostic awareness in advanced cancer: a systematic review. *Journal of health psychology*, *19*(9), 1103–1119. doi.org/10.1177/1359105313484782

Arora N. K. (2003). Interacting with cancer patients: the significance of physicians' communication behavior. *Social science & medicine (1982)*, *57*(5), 791–806. doi.org/10.1016/s0277-9536(02)00449-5

Arraras, J. I., Greimel, E., Chie, W. C., Sezer, O., Bergenmar, M., Costantini, A., Young, T., Kuljanic, K., Velikova, G., & European Organisation for Research and Treatment of Cancer Quality of Life Group (2011). Information disclosure to cancer patients: EORTC QLQ-INFO25 questionnaire. *Expert review of pharmacoeconomics & outcomes research*, *11*(3), 281–286. doi.org/10.1586/erp.11.29

Back, A. L., Anderson, W. G., Bunch, L., Marr, L. A., Wallace, J. A., Yang, H. B., & Arnold, R. M. (2008). Communication about cancer near the end of life. *Cancer*, *113*(7 Suppl), 1897–1910. doi.org/10.1002/cncr.23653

Balint E. (1969). The possibilities of patient-centered medicine. *The Journal of the Royal College of General Practitioners*, *17*(82), 269–276.

Bar-Tal, Y., Barnoy, S., & Zisser, B. (2005). Whose informational needs are considered? A comparison between cancer patients and their spouses' perceptions of their own and their partners' knowledge and informational needs. *Social science & medicine (1982)*, *60*(7), 1459–1465. doi.org/10.1016/j.socscimed.2004.08.003

Bavelas, J. B., Coates, L., & Johnson, T. (2000). Listeners as co-narrators. *Journal of personality and social psychology*, *79*(6), 941–952. doi.org/10.1037//0022-3514.79.6.941

Bensing, J., van Dulmen, S., & Tates, K. (2003). Communication in context: new directions in communication research. *Patient education and counseling*, *50*(1), 27–32. doi.org/10.1016/s0738-3991(03)00076-4

Berger, P.L., & Luckmann, T. (1969) La realtà come costruzione sociale. [Reality as social construction] (In Italian). Il Mulino, Bologna.

Braun, V., & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi.org/10.1191/1478088706qp063oa

Brocki, J., & Wearden, A. (2006) A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health*, 21 (1), 87-108. doi.org/10.1080/14768320500230185

Buiar, P. G., & Goldim, J. R. (2019). Barriers to the composition and implementation of advance directives in oncology: a literature review. *Ecancermedicalscience*, *13*, 974. doi.org/10.3332/ecancer.2019.974

Buiting, H. M., Rurup, M. L., Wijsbek, H., van Zuylen, L., & den Hartogh, G. (2011). Understanding provision of chemotherapy to patients with end stage cancer: qualitative interview study. *BMJ (Clinical research ed.)*, *342*, d1933. doi.org/10.1136/bmj.d1933

Capone, S., Sambati, V., Montanari, E., & Antonazzo, M. (2017) L'infermiere tra immagine sociale e professionale: esperienze dirette, stereotipi e ruolo dei media. [Nurse: between social and professional picture: real experience, stereotypes and media’s role.] (In Italian). *L’infermiere*, 54:4:e62-e67 Retrivied 2021 Jan 20, from https://www.infermiereonline.org/wp-content/uploads/2019/12/L-Infermiere-2017-n4.pdf

Chan, E. A., Jones, A., & Wong, K. (2013). The relationships between communication, care and time are intertwined: a narrative inquiry exploring the impact of time on registered nurses' work. *Journal of advanced nursing*, *69*(9), 2020–2029. https://doi.org/10.1111/jan.12064

Chan, E. A., Wong, F., Cheung, M. Y., & Lam, W. (2018). Patients' perceptions of their experiences with nurse-patient communication in oncology settings: A focused ethnographic study. *PloS one*, *13*(6), e0199183. doi.org/10.1371/journal.pone.0199183

Chen, C. H., Kuo, S. C., & Tang, S. T. (2017). Current status of accurate prognostic awareness in advanced/terminally ill cancer patients: Systematic review and meta-regression analysis. *Palliative medicine*, *31*(5), 406–418. doi.org/10.1177/0269216316663976

Clayton, J. M., Butow, P. N., Arnold, R. M., & Tattersall, M. H. (2005). Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers. *Cancer*, *103*(9), 1965–1975. doi.org/10.1002/cncr.21011

Collière M. F. (1998). Using anthropology to analyse healthcare situations. *Nursing inquiry*, *5*(3), 126–139. doi.org/10.1046/j.1440-1800.1998.530126.x

Council of Europe. European Treaty Series - No. 164 (1997) Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine. Oviedo. Retrived 2021 Jan 20, from https://www.coe.int/en/web/conventions/full-list/-/conventions/rms/090000168007cf98

Covvey, J. R., Kamal, K. M., Gorse, E. E., Mehta, Z., Dhumal, T., Heidari, E., Rao, D., & Zacker, C. (2019). Barriers and facilitators to shared decision-making in oncology: a systematic review of the literature. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer*, *27*(5), 1613–1637. doi.org/10.1007/s00520-019-04675-7

Daher M. (2012). Cultural beliefs and values in cancer patients. *Annals of oncology: official journal of the European Society for Medical Oncology*, *23 Suppl 3*, 66–69. doi.org/10.1093/annonc/mds091

Dallos, R., & Denford, S. (2008). A qualitative exploration of relationship and attachment themes in families with an eating disorder. *Clinical child psychology and psychiatry*, *13*(2), 305–322. doi.org/10.1177/1359104507088349

Daugherty, C. K., & Hlubocky, F. J. (2008). What are terminally ill cancer patients told about their expected deaths? A study of cancer physicians' self-reports of prognosis disclosure. *Journal of clinical oncology: official journal of the American Society of Clinical Oncology*, *26*(36), 5988–5993. doi.org/10.1200/JCO.2008.17.2221

de Witt, L., & Ploeg, J. (2006). Critical appraisal of rigour in interpretive phenomenological nursing research. *Journal of advanced nursing*, *55*(2), 215–229. doi.org/10.1111/j.1365-2648.2006.03898.x

Di Giacomo, P., Mariotti, A., Vignali, A., & Andruccioli, J. (2012). La consapevolezza della diagnosi e della prognosi nella persona con malattia a prognosi infausta: la percezione negli atteggiamenti di un gruppo di medici e infermieri [Awareness of diagnosis and prognosis in patients with unfavorable prognosis: perception of the attitudes of a group of doctors and nurses].(in

Italian). *Professioni infermieristiche*, *65*(3), 143–153.Retrivied 2021 Jan 20, from https://core.ac.uk/download/pdf/230561848.pdf (In Italian)

Dolbeault, S., & Brédart, A. (2010). Difficultés de l'annonce du côté des professionnels et de leurs patients: quels obstacles à la communication et quels recours possibles? [Announcing cancer diagnosis: which communication difficulties from professional and from patient's side? Which possible improvements?]. *Bulletin du cancer*, *97*(10), 1183–1194. doi.org/10.1684/bdc.2010.1197. (In French)

Ehsani, M., Taleghani, F., Hematti, S., & Abazari, P. (2016). Perceptions of patients, families, physicians and nurses regarding challenges in cancer disclosure: A descriptive qualitative study. *European journal of oncology nursing: the official journal of European Oncology Nursing Society*, *25*, 55–61. doi.org/10.1016/j.ejon.2016.09.003

Epstein, R. M., Duberstein, P. R., Fenton, J. J., Fiscella, K., Hoerger, M., Tancredi, D. J., Xing, G., Gramling, R., Mohile, S., Franks, P., Kaesberg, P., Plumb, S., Cipri, C. S., Street, R. L., Jr, Shields, C. G., Back, A. L., Butow, P., Walczak, A., Tattersall, M., Venuti, A., Kravitz, R. L. (2017). Effect of a Patient-Centered Communication Intervention on Oncologist-Patient Communication, Quality of Life, and Health Care Utilization in Advanced Cancer: The VOICE Randomized Clinical Trial. *JAMA oncology*, *3*(1), 92–100. doi.org/10.1001/jamaoncol.2016.4373

Fallowfield, L., & Jenkins, V. (2004). Communicating sad, bad, and difficult news in medicine. *Lancet (London, England)*, *363*(9405), 312–319. doi.org/10.1016/S0140-6736(03)15392-5

Fenton, J. J., Duberstein, P. R., Kravitz, R. L., Xing, G., Tancredi, D. J., Fiscella, K., Mohile, S., & Epstein, R. M. (2018). Impact of Prognostic Discussions on the Patient-Physician Relationship: Prospective Cohort Study. *Journal of clinical oncology: official journal of the American Society of Clinical Oncology*, *36*(3), 225–230. doi.org/10.1200/JCO.2017.75.6288

Finset, A., Heyn, L., & Ruland, C. (2013). Patterns in clinicians' responses to patient emotion in cancer care. *Patient education and counseling*, *93*(1), 80–85. doi.org/10.1016/j.pec.2013.04.023

Fisher, M. J., Broome, M. E., Friesth, B. M., Magee, T., & Frankel, R. M. (2014). The effectiveness of a brief intervention for emotion-focused nurse-parent communication. *Patient education and counseling*, *96*(1), 72–78. doi.org/10.1016/j.pec.2014.04.004

Federazione Nazionale degli ordini dei medici e chirurgici e degli Odontoiatri (FNOMeO). (2017) Codice di deontologia medica [Code of Medical Ethics] (in Italian). Retrieved 2021 Jan 20, from https://www.omceo.me.it/ordine/cod_deo/commentario.pdf

Federazione Nazionale degli Ordini delle Professioni Infermieristiche (FNOPI). (2017) Codice deontologico delle professioni infermieristiche. [Code of Ethics for Nurses] (In Italian). Retrieved 2021 Jan 20, from https://www.fnopi.it/archivio_news/attualita/2688/codice%20deontologico_2019.pdf

Fry, S. T. (1989) The role of caring in a Theory of Nursing Ethics. *Hypatia*, 4(2), 87-103 doi.org/10.1111/j.1527-2001.1989.tb00575.x

Furber, L., Cox, K., Murphy, R., & Steward, W. (2013). Investigating communication in cancer consultations: what can be learned from doctor and patient accounts of their experience?. *European journal of cancer care*, *22*(5), 653–662. doi.org/10.1111/ecc.12074

Georgaki, S., Kalaidopoulou, O., Liarmakopoulos, I., & Mystakidou, K. (2002). Nurses' attitudes toward truthful communication with patients with cancer. A Greek study. *Cancer nursing*, *25*(6), 436–441. doi.org/10.1097/00002820-200212000-00006

Germeni, E., & Schulz, P. J. (2014). Information seeking and avoidance throughout the cancer patient journey: two sides of the same coin? A synthesis of qualitative studies. *Psycho-oncology*, *23*(12), 1373–1381. doi.org/10.1002/pon.3575

Girgis, A., Sanson-Fisher, R. W., & Schofield, M. J. (1999). Is there consensus between breast cancer patients and providers on guidelines for breaking bad news?. *Behavioral medicine (Washington, D.C.)*, *25*(2), 69–77. doi.org/10.1080/08964289909595739

Global Cancer Observatory-GLOBOCAN- (2020) 380-italy-fact-sheets. Retrieved 2021 Jan 20, from https://gco.iarc.fr/today/data/factsheets/populations/380-italy-fact-sheets.pdf

Hack, T. F., Degner, L. F., Parker, P. A., & SCRN Communication Team (2005). The communication goals and needs of cancer patients: a review. *Psycho-oncology*, *14*(10), 831–847. doi.org/10.1002/pon.949

Hagerty, R. G., Butow, P. N., Ellis, P. M., Dimitry, S., & Tattersall, M. H. (2005). Communicating prognosis in cancer care: a systematic review of the literature. *Annals of oncology: official journal of the European Society for Medical Oncology*, *16*(7), 1005–1053. doi.org/10.1093/annonc/mdi211

Hancock, K., Clayton, J. M., Parker, S. M., Wal der, S., Butow, P. N., Carrick, S., Currow, D., Ghersi, D., Glare, P., Hagerty, R., & Tattersall, M. H. (2007). Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliative medicine*, *21*(6), 507–517. doi.org/10.1177/0269216307080823

Hansen, B. S., Rørtveit, K., Leiknes, I., Morken, I., Testad, I., Joa, I., & Severinsson, E. (2012). Patient experiences of uncertainty - a synthesis to guide nursing practice and research. *Journal of nursing management*, *20*(2), 266–277. doi.org/10.1111/j.1365-2834.2011.01369.x

Heidegger, M. (2005) Essere e tempo [Sein und Zeit] (In Italian). I grandi libri., Longanesi.

Helft, P. R., Chamness, A., Terry, C., & Uhrich, M. (2011). Oncology nurses' attitudes toward prognosis-related communication: a pilot mailed survey of oncology nursing society members. *Oncology nursing forum*, *38*(4), 468–474. doi.org/10.1188/11.ONF.468-474

Hobbs, G. S., Landrum, M. B., Arora, N. K., Ganz, P. A., van Ryn, M., Weeks, J. C., Mack, J. W., & Keating, N. L. (2015). The role of families in decisions regarding cancer treatments. *Cancer*, *121*(7), 1079–1087. doi.org/10.1002/cncr.29064

Huang, S. H., Tang, F. I., Liu, C. Y., Chen, M. B., Liang, T. H., & Sheu, S. J. (2014). Truth-telling to patients' terminal illness: what makes oncology nurses act individually?. *European journal of oncology nursing: the official journal of European Oncology Nursing Society*, *18*(5), 492–498. doi.org/10.1016/j.ejon.2014.04.010

Hubbard, G., Illingworth, N., Rowa-Dewar, N., Forbat, L., & Kearney, N. (2010). Treatment decision-making in cancer care: the role of the carer. *Journal of clinical nursing*, *19*(13-14), 2023–2031. doi.org/10.1111/j.1365-2702.2009.03062.x

Hudson, P. L., Aranda, S., & Kristjanson, L. J. (2004). Meeting the supportive needs of family caregivers in palliative care:

challenges for health professionals. *Journal of palliative medicine*, *7*(1), 19–25. doi.org/10.1089/109662104322737214

Innes, S., & Payne, S. (2009). Advanced cancer patients' prognostic information preferences: a review. *Palliative medicine*, *23*(1), 29–39. doi.org/10.1177/0269216308098799

Jacoby, S., & Ochs, E. (1995) Co-construction: An introduction. *Research on Language and Social Interaction*, 28(3), 171-183. doi.org/10.1207/s15327973rlsi2803_1

Kendall S. (2006). Being asked not to tell: nurses' experiences of caring for cancer patients not told their diagnosis. *Journal of clinical nursing*, *15*(9), 1149–1157. doi.org/10.1111/j.1365-2702.2006.01460.x

Kimberlin, C., Brushwood, D., Allen, W., Radson, E., & Wilson, D. (2004). Cancer patient and caregiver experiences: communication and pain management issues. *Journal of pain and symptom management*, *28*(6), 566–578. doi.org/10.1016/j.jpainsymman.2004.03.005

King, A. J., Evans, M., Moore, T. H., Paterson, C., Sharp, D., Persad, R., & Huntley, A. L. (2015). Prostate cancer and supportive care: a systematic review and qualitative synthesis of men's experiences and unmet needs. *European journal of cancer care*, *24*(5), 618–634. doi.org/10.1111/ecc.12286

Kirk, P., Kirk, I., & Kristjanson, L. J. (2004). What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *BMJ (Clinical research ed.)*, *328*(7452), 1343. doi.org/10.1136/bmj.38103.423576.55

Kiteley, C., & Vaitekunas, D. (2006). Leaving our imprints: an exploration into the nurse-patient relationship. *Canadian oncology nursing journal = Revue canadienne de nursing oncologique*, *16*(3), 180–190. doi.org/10.5737/1181912x163180184

Kleinman A. (1978). Concepts and a model for the comparison of medical systems as cultural systems. *Social science & medicine*,*12*(2B), 85–95. doi.org/10.1016/0160-7987(78)90014-5

Koutsopoulou, S., Papathanassoglou, E. D., Katapodi, M. C., & Patiraki, E. I. (2010). A critical review of the evidence for nurses as information providers to cancer patients. *Journal of clinical nursing*, *19*(5-6), 749–765. doi.org/10.1111/j.1365-2702.2009.02954.x

Kullberg, A., Sharp, L., Johansson, H., & Bergenmar, M. (2015). Information exchange in oncological inpatient care--patient satisfaction, participation, and safety. *European journal of oncology nursing: the official journal of European Oncology Nursing Society*, *19*(2), 142–147. doi.org/10.1016/j.ejon.2014.10.005

Laidsaar-Powell, R. C., Butow, P. N., Bu, S., Charles, C., Gafni, A., Lam, W. W., Jansen, J., McCaffery, K. J., Shepherd, H. L., Tattersall, M. H., & Juraskova, I. (2013). Physician-patient-companion communication and decision-making: a systematic review of triadic medical consultations. *Patient education and counseling*, *91*(1), 3–13. doi.org/10.1016/j.pec.2012.11.007

Lamont, E. B., & Christakis, N. A. (2001). Prognostic disclosure to patients with cancer near the end of life. *Annals of internal medicine*, *134*(12), 1096–1105. doi.org/10.7326/0003-4819-134-12-200106190-00009

Larkin, M., Shaw, R., & Flowers, P. (2019). Multiperspectival designs and processes in interpretative phenomenological analysis research. *Qualitative Research in Psychology, 16*(2), 182–198. doi.org/10.1080/14780887.2018.1540655

Lawn, S., Delany, T., Sweet, L., Battersby, M., & Skinner, T. (2015). Barriers and enablers to good communication and information-sharing practices in care planning for chronic condition management. *Australian journal of primary health*, *21*(1), 84–89. doi.org/10.1071/PY13087

LEGGE 22 dicembre 2017, n. 219. Norme in materia di consenso informato e di disposizioni anticipate di trattamento. (2017) [Informed Consent Law and Treatment Directives] (in Italian) GU Serie Generale n.12 del 16-01-2018. Retrieved 2021 Jan 20 from https://www.gazzettaufficiale.it/eli/id/2018/1/16/18G00006/sg

Lincoln, Y. S., & Guba, E, G. (1985) Naturalistic inquiry. Newbury Park, CA: SAGE.

Loaring, J. M., Larkin, M., Shaw, R., & Flowers, P. (2015). Renegotiating sexual intimacy in the context of altered embodiment: the experiences of women with breast cancer and their male partners following mastectomy and reconstruction. *Health psychology: official journal of the Division of Health Psychology, American Psychological Association*, *34*(4), 426–436. doi.org/10.1037/hea0000195

Lopez, K. A., & Willis, D. G. (2004). Descriptive versus interpretive phenomenology: their contributions to nursing knowledge. *Qualitative health research*, *14*(5), 726–735. doi.org/10.1177/1049732304263638

Mackey S. (2005). Phenomenological nursing research: methodological insights derived from Heidegger's interpretive phenomenology. *International journal of nursing studies*, *42*(2), 179–186. doi.org/10.1016/j.ijnurstu.2004.06.011

Mallinger, J. B., Griggs, J. J., & Shields, C. G. (2005). Patient-centered care and breast cancer survivors' satisfaction with information. *Patient education and counseling*, *57*(3), 342–349. doi.org/10.1016/j.pec.2004.09.009

McCarthy, E. P., Phillips, R. S., Zhong, Z., Drews, R. E., & Lynn, J. (2000). Dying with cancer: patients' function, symptoms, and care preferences as death approaches. *Journal of the American Geriatrics Society*, *48*(S1), S110–S121. doi.org/10.1111/j.1532-5415.2000.tb03120.x

McLennon, S. M., Lasiter, S., Miller, W. R., Amlin, K., Chamness, A. R., & Helft, P. R. (2013). Oncology nurses' experiences with prognosis-related communication with patients who have advanced cancer. *Nursing outlook*, *61*(6), 427–436. doi.org/10.1016/j.outlook.2012.12.001

Michie, S., van Stralen, M. M., & West, R. (2011). The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implementation science: IS*, *6*, 42. doi.org/10.1186/1748-5908-6-42

Milo, A., Di Giulio, P, Renga, G., & Valle, A. (2007) Consapevolezza ed aspettative dei pazienti e dei caregiver al momento del ricovero in hospice. Studio multicentrico in Piemonte. [Awareness and expectations of patients and caregivers altime of admission to hospice. Multicenter study in Piemonte] (in Italian) *La Rivista Italiana di Cure Palliative*, 2, 21-29

Moore, P. M., Rivera, S., Bravo-Soto, G. A., Olivares, C., & Lawrie, T. A. (2018). Communication skills training for healthcare professionals working with people who have cancer. *The Cochrane database of systematic reviews*, *7*(7), CD003751. doi.org/10.1002/14651858.CD003751.pub4

Mystakidou, K., Tsilika, E., Parpa, E., Katsouda, E., & Vlahos, L. (2005). Patterns and barriers in information disclosure between health care professionals and relatives with cancer patients in Greek society. *European journal of cancer care*, *14*(2), 175–181. doi.org/10.1111/j.1365-2354.2005.00554.x

Newman A. R. (2016). Nurses' Perceptions of Diagnosis and Prognosis-Related Communication: An Integrative Review. *Cancer nursing*, *39*(5), E48–E60. doi.org/10.1097/NCC.0000000000000365

Oberle, K., & Hughes, D. (2001). Doctors' and nurses' perceptions of ethical problems in end-of-life decisions. *Journal of advanced nursing*, *33*(6), 707–715. doi.org/10.1046/j.1365-2648.2001.01710.x

Ohnsorge, K., Keller, H. R., Widdershoven, G. A., & Rehmann-Sutter, C. (2012). 'Ambivalence' at the end of life: how to understand patients' wishes ethically. *Nursing ethics*, *19*(5), 629–641. doi.org/10.1177/0969733011436206

Oikonomidou, D., Anagnostopoulos, F., Dimitrakaki, C., Ploumpidis, D., Stylianidis, S., & Tountas, Y. (2017). Doctors' Perceptions and Practices of Breaking Bad News: A Qualitative Study From Greece. *Health communication*, *32*(6), 657–666. doi.org/10.1080/10410236.2016.1167991

Oliffe, J., Thorne, S., Hislop, T. G., & Armstrong, E. A. (2007). "Truth telling" and cultural assumptions in an era of informed consent. *Family & community health*, *30*(1), 5–15. doi.org/10.1097/00003727-200701000-00003

Omilion-Hodges, L. M., & Swords, N. M. (2017). Communication Matters: Exploring the Intersection of Family and Practitioner End of Life Communication. *Behavioral sciences (Basel, Switzerland)*, *7*(1), 15. doi.org/10.3390/bs7010015

Orri, M., Sibeoni, J., Labey, M., Bousquet, G., Verneuil, L., Revah-Levy, A., & QualiPRO study group (2015). Qualitative approach to patient-reported outcomes in oncology: protocol of a French study. *BMJ open*, *5*(7), e008042. doi.org/10.1136/bmjopen-2015-008042

Orri, M., Sibeoni, J., Bousquet, G., Labey, M., Gueguen, J., Laporte, C., Winterman, S., Picard, C., Nascimbeni, C., Verneuil, L., & Revah-Levy, A. (2017). Crossing the perspectives of patients, families, and physicians on cancer treatment: A qualitative study. *Oncotarget*, *8*(13), 22113–22122. doi.org/10.18632/oncotarget.12770

Pardon, K., Deschepper, R., Vander Stichele, R., Bernheim, J., Mortier, F., Schallier, D., Germonpré, P., Galdermans, D., Van Kerckhoven, W., & Deliens, L. (2011). Are patients' preferences for information and participation in medical decision-making being met?

Interview study with lung cancer patients. *Palliative medicine*, *25*(1), 62–70. doi.org/10.1177/0269216310373169

Parry R. (2008). Are interventions to enhance communication performance in allied health professionals effective, and how should they be delivered? Direct and indirect evidence. *Patient education and counseling*, *73*(2), 186–195. doi.org/10.1016/j.pec.2008.05.029

Passalacqua, R., Caminiti, C., Campione, F., Diodati, F., Todeschini, R., Bisagni, G., Labianca, R., Dalla Chiesa, M., Bracci, R., Aragona, M., Artioli, F., Cavanna, L., Masina, A., De Falco, F., Marzocchini, B., Iacono, C., Contu, A., Di Costanzo, F., Bertetto, O., & Annunziata, M. A. (2009). Prospective, multicenter, randomized trial of a new organizational modality for providing information and support to cancer patients. *Journal of clinical oncology: official journal of the American Society of Clinical Oncology*, *27*(11), 1794–1799. doi.org/10.1200/JCO.2007.15.0615

Peplau H. E. (1997). Peplau's theory of interpersonal relations. *Nursing science quarterly*, *10*(4), 162–167. doi.org/10.1177/089431849701000407

Pietkiewicz, I., & Smith, J. A. (2012) A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. Czasopismo Psychologiczne- Psychological Journal, 20(1), 7-14. doi:10.14691/CPPJ.20.1.7 [English version retrieved 21 August, 2016 from: https://www.researchgate.net/publication/263767248].

Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist, 18*(1), 20–23.

Reiners, G. M. (2012) Understanding the Differences between Husserl's (Descriptive) and Heidegger's (Interpretive) Phenomenological Research. *Journal of Nursing & Care*, 1(5). doi.org/10.4172/2167-1168.1000119

Relazione Direttore Generale Programmazione Annuale e triennale 2020-2022. AOU Cagliari. (2020) [Report of the General Manager Annual and triennal Planning 2020-2022] (in Italian) Retrieved 2021 Jan 20, from https://www.aoucagliari.it/home/resources/cms/documents/3b2dfd6e656251955746057ac086457c.pdf (In Italian)

Rodriguez Del Pozo, P., Fins, J. J., Helmy, I., El Chaki, R., El Shazly, T., Wafaradi, D., & Mahfoud, Z. (2012). Truth-telling and cancer diagnoses: physician attitudes and practices in Qatar. *The* *oncologist*, *17*(11), 1469–1474. doi.org/10.1634/theoncologist.2012-0128

Rostill-Brookes, H., Larkin, M., Toms, A., & Churchman, C. (2011). A shared experience of fragmentation: making sense of foster placement breakdown. *Clinical child psychology and psychiatry*, *16*(1), 103–127. doi.org/10.1177/1359104509352894

Russell J. (2015). Effects of Constraints and Consequences on Plan Complexity in Conversations About End-of-Life Care. *Journal of social work in end-of-life & palliative care*, *11*(3-4), 323–345. doi.org/10.1080/15524256.2015.1111286

Sajjadi, M., Rassouli, M., Abbaszadeh, A., Brant, J., & Majd, H. A. (2016). Lived Experiences of "Illness Uncertainty" of Iranian Cancer Patients: A Phenomenological Hermeneutic Study. *Cancer nursing*, *39*(4), E1–E9. doi.org/10.1097/NCC.0000000000000282

Sarafis, P., Tsounis, A., Malliarou, M., & Lahana, E. (2013). Disclosing the truth: a dilemma between instilling hope and respecting patient autonomy in everyday clinical practice. *Global journal of health science*, *6*(2), 128–137. doi.org/10.5539/gjhs.v6n2p128

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & quantity*, *52*(4), 1893–1907. doi.org/10.1007/s11135-017-0574-8

Shahidi J. (2010). Not telling the truth: circumstances leading to concealment of diagnosis and prognosis from cancer patients. *European journal of cancer care*, *19*(5), 589–593. doi.org/10.1111/j.1365-2354.2009.01100.x.

Sheldon, L. K., Ellington, L., Barrett, R., Dudley, W. N., Clayton, M. F., & Rinaldi, K. (2009). Nurse responsiveness to cancer patient expressions of emotion. *Patient education and counseling*, *76*(1), 63–70. doi.org/10.1016/j.pec.2008.11.010

Skilbeck, J., & Payne, S. (2003). Emotional support and the role of Clinical Nurse Specialists in palliative care. *Journal of advanced nursing*, *43*(5), 521–530. doi.org/10.1046/j.1365-2648.2003.02749.x.

Smith, J. A, & Osborn,M. (2008). Interpretative phenomenological analysis. In Smith, J. A, (Ed.), Qualitative psychology: a practical guide to methods (53-80). Second edn. London: Sage.

Smith, J. A., Flowers, P., &Larkin, M. (2009) Interpretative Phenomenological Analysis: Theory, Method and Research. Thousand Oaks, CA, Sage Publications.

Smith, R. C., Dwamena, F. C., Grover, M., Coffey, J., & Frankel, R. M. (2011). Behaviorally defined patient-centered communication--a narrative review of the literature. *Journal of general internal medicine*, *26*(2), 185–191. doi.org/10.1007/s11606-010-1496-5

Spira, M., & Kenemore, E. (2002) Cancer as a Life Transition: A Relational Approach to Cancer Wellness in Women. *Clinical Social Work Journal,* 30, 173–186. doi.org/10.1023/A:1015245512377

Sundin-Huard, D., & Fahy, K. (1999). Moral distress, advocacy and burnout: theorizing the relationships. *International journal of nursing practice*, *5*(1), 8–13. doi.org/10.1046/j.1440-172x.1999.00143.x

Surbone, A., Ritossa, C., & Spagnolo, A. G. (2004). Evolution of truth-telling attitudes and practices in Italy. *Critical reviews in* *oncology/hematology*, *52*(3), 165–172. doi.org/10.1016/j.critrevonc.2004.09.002

Surbone A. (2006). Telling the truth to patients with cancer: what is the truth?. *The Lancet. Oncology*, *7*(11), 944–950. doi.org/10.1016/S1470-2045(06)70941-X

Surbone A. (2008). Cultural aspects of communication in cancer care. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer*, *16*(3), 235–240. doi.org/10.1007/s00520-007-0366-0

Tay, L. H., Hegney, D., & Ang, E. (2011). Factors affecting effective communication between registered nurses and adult cancer patients in an inpatient setting: a systematic review. *International journal of evidence-based healthcare*, *9*(2), 151–164. doi.org/10.1111/j.1744-1609.2011.00212.x

The, A. M., Hak, T., Koëter, G., & van Der Wal, G. (2000). Collusion in doctor-patient communication about imminent death: an ethnographic study. *BMJ (Clinical research ed.)*, *321*(7273), 1376–1381. doi.org/10.1136/bmj.321.7273.1376

Thorne, S. E., Hislop, T. G., Stajduhar, K., & Oglov, V. (2009). Time-related communication skills from the cancer patient perspective. *Psycho-oncology*, *18*(5), 500–507. doi.org/10.1002/pon.1418

Tuckett A. G. (2004). Truth-telling in clinical practice and the arguments for and against: a review of the literature. *Nursing ethics*, *11*(5), 500–513. doi.org/10.1191/0969733004ne728oa

Villalobos, M., Siegle, A., Hagelskamp, L., Jung, C., & Thomas, M. (2019). Communication along Milestones in Lung Cancer Patients with Advanced Disease. *Oncology research and treatment*, *42*(1-2), 41–46. doi.org/10.1159/000496407

Wagner, J. Y., Wuensch, A., Friess, H., & Berberat, P. O. (2014). Surgeon-patient communication in oncology. *European journal of cancer care*, *23*(5), 585–593. doi.org/10.1111/ecc.12177

WHO. (2018) Fact sheets/Detail/Cancer. Retrieved 2021 Jan 20, from https://www.who.int/news-room/fact-sheets/detail/cancer

Wittenberg, E., Reb, A., & Kanter, E. (2018). Communicating with Patients and Families Around Difficult Topics in Cancer Care Using the COMFORT Communication Curriculum. *Seminars in oncology nursing*, *34*(3), 264–273. doi.org/10.1016/j.soncn.2018.06.007

Zani, B., Selleri, P., & David, D. (2002). La comunicazione. Modelli teorici e contesti sociali. [Comunication. Theoretical models and social contexts] (in Italian) Roma, Carocci Editore.

List of tables

Table 1 Interview Questions Guide in study 1

Table 2 Coding Tree of study 1

Table 3 Coding Tree of study 2

Table 4 Participant characteristics in study 1

Table 5 Comparison of Participants’ Assessment of Patient’s Knowledge of Diagnosis and Prognosis in study 1

Table 6 Participant characteristics in study 2

List of figures

Figure 1 Interview guide questions for the different participants.
Figure 2 Patient’s perspective in identifying the others as Speakers.
Figure 3 Caregivers’ perspective in identifying the others as Speakers.
Figure 4 Physician’s perspective in identifying the others as Speakers.
Figure 5A Nurse’s perspective in identifying the others as Speakers.
Figure 5B Nurse’s perspective in identifying the others as Speakers.
Figure 6 Perspective of themes

List of abbreviations

AIOM	Associazione italiana di Oncologia medica
AOU	Azienda Ospedaliero Universitaria
ASCO	American society of Clinical Oncology
CIOMS	Council of International Medical Science Organizations
COREQ	COnsolidated criteria for REporting Qualitative Research
ICU	Intensive Care Unit
IPA	Interpretive Phenomenological Analysis
WHO	World Health Organization

List of publications

At the time of printing, the results reported herein have been published in the following journals:

1. **Paola Melis**, Maura Galletta, Cesar Ivan Aviles Gonzalez,Paolo Contu, Maria Francisca Jimenez Herrera.

   "Ethical perspectives in communication in cancer care: An interpretative phenomenological study". Nursing Ethics.

   doi: 10.1177/0969733020916771
2. **Paola Melis**, Maura Galletta, Cesar Ivan Aviles Gonzalez, Paolo Contu, Maria Francisca Jimenez Herrera.

   "Experiencing communication related to knowing cancer diagnosis an prognosis: A multi-perspective interpretative phenomenological study". European Journal of Oncology nursing.

   doi: 10.1016/j.ejon.2021.101904.

The following publications are based on work carried out during the doctoral studies:

3. Letizia Dal Santo, Olivia Marognoli, Vanessa Previati, Cesar Ivan Aviles Gonzalez, **Paola Melis**, Maura Galletta.

   "Providing Personal Care to Patients: The Role of Nursing Students' Emotional Labor" International Journal of Nursing Education Scholarship, **2019**, 16(1) doi: 10.1515/ijnes-2018-0046.

4. Cesar Ivan Aviles Gonzalez, Maura Galletta, Elsa Chessa, **Paola Melis**, Paolo Contu, Maria Francisca Jimenez Herrera

   "Caring efficacy: nurses' perceptions and relationships with work-related factors" Acta biomedica Atenei Parmensis, **2019**, 90(11-S). 74-82 doi: 10.23750/abm.v90i11-S.8684

5. Cesar Ivan Aviles Gonzalez, Maura Galletta, **Paola Melis**, Paolo Contu, Jean Watson, Gabriele Finco, Maria Francisca Jimenez Herrera

   "Cultural adaptation and psychometric validation of the Caring Efficacy scale in a sample of Italian nurses" PLoS One, **2019**, 14(5):e0217106. doi:10.1371/journal.pone.0217106

6. Maura Galletta, Igor Portoghese, **Paola Melis**, Cesar Ivan Aviles Gonzalez, Gabriele Finco, Ernesto D'Aloja, Paolo Contu, Marcello Campagna

“The role of collective affective commitment in the relationship between work-family conflict and emotional exhaustion among nurses: a multilevel modeling approach”. BMC Nursing, **2019,** 18;5. doi: 10.1186/s12912-019-0329-z

7. Maura Galletta, Igor Portoghese, Cesar Ivan Aviles Gonzales, **Paola Melis**, Gabriele Marcias, Marcello Campagna, Luigi Minerba, Claudia Sardu.

“Lack of respect, role uncertainty and satisfaction with clinical practice among nursing students: the moderating role of supportive staff”.

Acta Bio-medica Atenei Parmensis, **2017**, Jul 18;88(3S):43-50. doi: 10.23750/abm.v88i3-S.6613.

Addenda

Addendum n.1:

Coreq Checklist

Study 1. COREQ Checklist

Domain 1: Research team and reflexivity

Personal Characteristics

1. Interviewer/facilitator: Which author/s conducted the interview or focus group?

   First author conducted the interview.

2. Credentials: What were the researcher's credentials?:

   P.M.: RN, MPhil, MS.c, PhD(c)

   M.G.: PhD

   C.I.A.G.: RN, MSN, MS.c, Ph.D(c)

   P.C.: MD, PhD.

3. Occupation: What was their occupation at the time of the study?

   P.M.: Clinical nurse, Palliative Care Service. Lecturer in Nursing.

   M.G.: Associate professor in Nursing

   C.I.A.G.: Clinical nurse in ICU. Lecturer in Nursing

   P.C. Full professor

   M.F.J.H: Associate professor in Nursing.

4. Gender: Was the researcher male or female?

The research team comprehend 3 females and 2 males. The interviewer is female.

5. Experience and training: What experience or training did the researcher have?

   All authors are experts in medical subjects and clinical research, they are all involved in academic research programs and authors of other published clinical research.

Relationship with participants

6. Relationship established: Was a relationship established prior to study commencement?

   No research member has/had a working/professional relationship/affiliation with the Departments where the research field has been conducted. The interviewer introduced herself to the Head Staff and to the Department Director and to anyone requested information about her presence in the ward.

7. Participant knowledge of the interviewer: What did the participants know about the researcher?

   They have been informed about her professional titles, working affiliation and reason for doing the research.

8. Interviewer characteristics: What characteristics were reported about the interviewer/facilitator?

   The interviewer is a clinical nurse, this was clearly stated and written in the Consent Form. Research team's pre-assumptions align with IPA theoretical references, (presented in the Design section) namely: individuals' realities are invariably influenced by the world in which they live and therefore, meanings are always created through interactions with others.

Domain 2: study design

Theoretical framework

9. Methodological orientation and Theory: What methodological orientation was stated to underpin the study?

   Phenomenology, according to Heideggerian philosophical perspective and following the Interpretative Phenomenological Analysis suggested by Smith JA.

Participant selection

10. Sampling: How were participants selected?

Purposive sampling for patients and connection with the patient for the other participants, as explained in the Participants and recruitment Section.

11. Method of approach: How were participants approached?

    All participants were approached face to face by the interviewer, except for some caregivers who were contacted by the patient and then put in contact with the interviewer who then met them face-to-face.

12. Sample size: How many participants were in the study?

    A total of 27 participants (coherent with IPA guidelines and other IPA multi-perspectives studies).

13. Non-participation: How many people refused to participate or dropped out? Reasons?

    Two patients who met the inclusion criteria couldn't be interviewed because it was not possible to have a comfortable room and guarantee privacy.

Setting

14. Setting of data collection: Where was the data collected?

    All the participants were interviewed in the Oncological ward where they were admitted or working.

15. Presence of non-participants: Was anyone else present besides the participants and researchers?

    Nobody was present except the interviewer and the interviewed. Nevertheless, many times the interview had to be stopped because of people entering in the room (for examples: to check therapies, to call out the interviewed health professional).

16. Description of sample: What are the important characteristics of the sample?

    Demographic data (age, gender), School level, Tenure, Cancer type.

    Data collection

17. Interview guide: Were questions, prompts, guides provided by the authors? Was it pilot tested?

    We provided an Interview Questions Guide. An interview pilot test was carried out but not recorded.

18. Repeat interviews: Were repeat interviews carried out? If yes, how many?

    No, we didn’t.

19. Audio/visual recording: Did the research use audio or visual recording to collect the data?

The interviews were all audio-recorded.

20. Field notes: Were field notes made during and/or after the interview or focus group?

    Fields notes were taken by the interviewer immediately after the interview. They were used during the analysis phase.

21. Duration: What was the duration of the interviews or focus group?

    The minimum and maximum interview length and its mean for each subsample has been indicated in Table 1.

22. Data saturation: Was data saturation discussed?

    It was not retained appropriate in an IPA study, as explained in the Design section.

23. Transcripts returned: Were transcripts returned to participants for comment and/or correction?

    No formal transcript return has been carried out. Nevertheless, the interviewer had the chance to meet and meet again many of the participants and discuss with them (as the interview scheduled time many times couldn’t be respected and she used to wait for it standing in the ward corridors).

Domain 3: analysis and findings

Data analysis

24. Number of data coders: How many data coders coded the data?

    As many as the research team members (5).

25. Description of the coding tree: Did authors provide a description of the coding tree?

    A Figure of the coding tree has been produced.

26. Derivation of themes: Were themes identified in advance or derived from the data?

    Derived from data.

27. Software: What software, if applicable, was used to manage the data

    Atlas.ti. 7.5.7 version.

28. Participant checking: Did participants provide feedback on the findings?

    No participants feedback is recommended in IPA studies. Nevertheless, the authors have committed themselves to provide a feedback to the health professionals participating in the research.

Reporting

29. Quotations presented: Were participant quotations presented to illustrate the themes / findings? Was each quotation identified?

    We have provided a large amount of quotations and identified the speaker by pseudonymous and relationship with the patient.

30. Data and findings consistency: Was there consistency between the data presented and the findings?

    We believe there is.

31. Clarity of major themes: Were major themes clearly presented in the findings?

    We retain to have clearly presented the overarching themes.

32. Clarity of minor themes: Is there a description of diverse cases or discussion of minor themes? Divergences and diverse. cases have been presented and discussed (see Results and Discussion sections).

Study 2. COREQ checklist

Domain 1: Research team and reflexivity

Personal Characteristics

1. Interviewer/facilitator: Which author/s conducted the interview or focus group?

   First author conducted the interview.

2. Credentials: What were the researcher's credentials?

   P.M.: RN, MPhil, MS.c, PhD(c)

   M.G.: PhD

   C.I.A.G.: RN, MSN, MS.c, Ph.D(c)

   P.C.: MD, PhD.

3. Occupation: What was their occupation at the time of the study?

   P.M.: Clinical nurse, Palliative Care Service. Lecturer in Nursing.

   M.G.: Associate professor in Nursing

   C.I.A.G.: Clinical nurse in ICU. Lecturer in Nursing

   P.C. Full professor

   M.F.J.H: Associate professor in Nursing.

4. Gender: Was the researcher male or female?

The research team comprehend 3 females and 2 males. The interviewer is female.

5. <u>Experience and training:</u> What experience or training did the researcher have?

   All authors are experts in medical subjects and clinical research, they are all involved in academic research programs and authors of other published clinical research.

   Relationship with participants

6. <u>Relationship established:</u> Was a relationship established prior to study commencement?

   No research member has/had a working/professional relationship/affiliation with the Departments where the research field has been conducted. The interviewer introduced herself to the Head Staff and to the Department Director and to anyone requested information about her presence in the ward.

7. <u>Participant knowledge of the interviewer:</u> What did the participants know about the researcher?

   They have been informed about her professional titles, working affiliation and reason for doing the research.

8. Interviewer characteristics: What characteristics were reported about the interviewer/facilitator?

   The interviewer is a clinical nurse, this was clearly stated and written in the Consent Form. Research team's pre-assumptions align with IPA theoretical references, (presented in the Design section) namely: individuals' realities are invariably influenced by the world in which they live and therefore, meanings are always created through interactions with others.

Domain 2: study design

Theoretical framework

9. Methodological orientation and Theory: What methodological orientation was stated to underpin the study?

   Phenomenology, according to Heideggerian philosophical perspective and following the Interpretative Phenomenological Analysis suggested by Smith JA.

Participant selection

10. Sampling: How were participants selected?

Purposive sampling for patients and connection with the patient for the other participants, as explained in the Participants and recruitment Section.

11. Method of approach: How were participants approached?

    All participants were approached face to face by the interviewer, except for some caregivers who were contacted by the patient and then put in contact with the interviewer who then met them face-to-face.

12. Sample size: How many participants were in the study?

    A total of 24 participants corresponding to six groups of four members each.

13. Non-participation: How many people refused to participate or dropped out? Reasons?

    During the recruitment process, one physician refused to be part of the study. She said to have no time and no interest in it.

Setting

14. Setting of data collection: Where was the data collected?

    All the participants were interviewed in the Oncological ward where they were admitted or working.

15. <u>Presence of non-participants</u>: Was anyone else present besides the participants and researchers?

    Nobody was present except the interviewer and the interviewed. Nevertheless, many times the interview had to be stopped because of people entering in the room (for examples: to check therapies, to call out the interviewed health professional).

16. <u>Description of sample</u>: What are the important characteristics of the sample?

    Demographic data (age, gender), School level, Tenure, Cancer type.

Data collection

17. <u>Interview guide:</u> Were questions, prompts, guides provided by the authors? Was it pilot tested?

    We provided an Interview Questions Guide. An interview pilot test was carried out but not recorded.

18. <u>Repeat interviews:</u> Were repeat interviews carried out? If yes, how many?

    No, we didn’t.

19. <u>Audio/visual recording:</u> Did the research use audio or visual recording to collect the data?

The interviews were all audio-recorded.

20. <u>Field notes</u>: Were field notes made during and/or after the interview or focus group?

    Fields notes were taken by the interviewer immediately after the interview. They were used during the analysis phase.

21. <u>Duration</u>: What was the duration of the interviews or focus group?

    The minimum and maximum interview length and its mean for each subsample has been indicated in Table 1.

22. <u>Data saturation:</u> Was data saturation discussed?

    I didn't pursue data saturation for all the perspectives because, in the hermeneutics circle, there is always new information to be add.

23. <u>Transcripts returned</u>: Were transcripts returned to participants for comment and/or correction?

    No formal transcript return has been carried out. Nevertheless, the interviewer had the chance to meet and meet again many of the participants and discuss with them (as the interview scheduled time many times couldn't be respected and she used to wait for it standing in the ward corridors).

Domain 3: analysis and findings

Data analysis

24. <u>Number of data coders:</u> How many data coders coded the data?

    As many as the research team members (5).

25. <u>Description of the coding tree</u>: Did authors provide a description of the coding tree?

    A Figure of the coding tree has been produced

26. <u>Derivation of themes:</u> Were themes identified in advance or derived from the data?

    Derived from data.

27. <u>Software:</u> What software, if applicable, was used to manage the data

    Atlas.ti. 7.5.7 version.

28. <u>Participant checking:</u> Did participants provide feedback on the findings?

    No participants feedback is recommended in IPA studies. Nevertheless, the authors have committed themselves to provide a feedback to the health professionals participating in the research.

Reporting

29. Quotations presented: Were participant quotations presented to illustrate the themes / findings? Was each quotation identified?

    We have provided a large amount of quotations and identified the speaker by pseudonymous and relationship with the patient.

30. Data and findings consistency: Was there consistency between the data presented and the findings?

    We believe there is.

31. Clarity of major themes: Were major themes clearly presented in the findings?

    We retain to have clearly presented the overarching themes.

32. Clarity of minor themes: Is there a description of diverse cases or discussion of minor themes? Divergences and diverse cases have been presented and discussed (see Results and Discussion sections).

Addendum n. 2:

Study Protocol

STUDIO SULLA QUALITÀ DELLA COMUNICAZIONE DI CARATTERE MEDICO E -ASSISTENZIALE IN RELAZIONE AI PERCORSI DIAGNOSTICI-TERAPEUTICI NELLE PERSONE AFFETTE DA MALATTIA NEOPLASTICA IN FASE AVANZATA

Responsabile del progetto
PAOLA MELIS

Studentessa di Dottorato di Ricerca in Scienze Infermieristiche e Salute
Infermiera Aou Cagliari

Tutor di Dottorato
PROFESSORESSA MARIA FRANCISCA JIMENEZ HERRERA
Professore Ordinario Della Facoltà D’Infermieristica
UNIVERSITÀ ROVIRA I VIRGILI
TARRAGONA SPAGNA
2016

Obiettivo: indagare gli aspetti qualitativi e informativi della comunicazione di carattere medico e assistenziale in relazione ai percorsi diagnostici- terapeutici nelle persone affette da neoplasia in stadio avanzato.

Utilizzare i dati ottenuti per costruire un progetto ad hoc per migliorare la risposta ai bisogni comunicativi della persona affetta da neoplasia in stadio avanzato

Introduzione

Assicurare ai pazienti informazioni appropriate sulla diagnosi, la prognosi e le terapie oltre che essere il presupposto dell'esistenza e validità del consenso informato che si richiede al paziente, è un requisito fondamentale dal punto di vista etico e deontologico.[1] Un'informazione appropriata costituisce, in effetti, una dimensione fondamentale del processo di comunicazione. In ambito di cure oncologiche, è avviata già da tempo una discussione sulla comunicazione della diagnosi e della prognosi alla persona affetta da neoplasia. In particolare, in Italia, si è osservato il passaggio da un comportamento di nascondimento e dissimulazione da parte del medico, in nome

[1] Manuale per la comunicazione in oncologia.,a cura di Stefano Vella, Francesco De Lorenzo, Istituto Superiore di Sanità, IRCCS e AIMaC per il Servizio Nazionale di Accoglienza e Informazione in Oncologia, Progetto di Alleanza Contro il Cancro 2011.

del principio del *noli nocere,* ad un'adozione di prassi e protocolli volti a rispondere al diritto d'informazione del paziente [2] [3]. L'evoluzione normativa e i recenti codici deontologici rispecchiano e confermano questa tendenza.

Tuttavia la comunicazione non si basa solo sulla conoscenza (aspetto di informazione), ma anche sulle emozioni e su fattori culturali e contestuali[4]. La letteratura scientifica, inoltre, ha costantemente confermato come una buona comunicazione abbia ripercussioni positive anche su una serie di alcuni indicatori di salute quali il controllo del dolore e il miglioramento del benessere fisico e psicologico del paziente[5]. Questo comporta un ampliamento del concetto di responsabilità terapeutica e l'utilizzo della relazione, costruita attraverso una comunicazione efficace, come luogo di cura.

Il ruolo di medici e infermieri, ossia degli "health care professional", quali figure titolate a fornire informazioni al

[2] Andruccioli J, Raffaeli W, La consapevolezza di malattia nel paziente oncologico La Rivista Italiana di Cure Palliative, N. 3, 2005: 41 – 50.

[3] Aldo Lamberto A, Levaggi R, La comunicazione fra medico e paziente: aspetti di costo efficacia, Politiche sanitarie, Vol. 5, N. 1, Gennaio-Marzo 2004: 52 – 59.

[4] Josephine M. Clayton, Sustaining hope when communicating with terminally ill patients and their families: a systematic review, Psycho-Oncology, July 2008, Volume 17, Issue 7: 641–659.

[5] Vedi nota 1.

paziente e alla sua famiglia è ormai consolidato[6]. La letteratura rileva tuttavia una diffusa discordanza tra l'informazione clinica fornita dai medici e quella recepita e ricordata dai pazienti[7]. Alcune evidenze indicano la scarsa capacità dei medici di individuare quali informazioni vogliano i pazienti e la loro tendenza a sottostimare la relativa richiesta di informazioni[8] [9] [10]. Molti operatori sanitari, inoltre, riferiscono disagio

---

[6] Vedi nota 1, p. 15.

[7] Pisu et al.: Reassessing the approach to informed consent: the case of unrelated hematopoietic stem cell transplantation in adult thalassemia patients. Philosophy, Ethics, and Humanities in Medicine 2014, 9:13.

[8] Degner LF, Kristjanson LJ, Bowman D, et al. Information needs and decisional preferences in women with breast cancer. *JAMA* 1997; 277:1485-1492.

[9] Haidet P, Hamel MB, Davis RB, et al. Outcomes, preferences for resuscitation, and physician-patient communication among patients with metastatic colorectal cancer. SUPPORT InvestigatorsStudy to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Am J Med* 1998; 105: 222-229.

[10] Teno J, Lynn J, Wenger N, et al. Advance directives for seriously ill hospitalized patients: effectiveness with the patient self determination act and the SUPPORT intervention. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *J Am Geriatr Soc* 1997; 45: 500-507.

nell'affrontare questi argomenti[11] [12]. Non sorprende quindi che esistano ancora riscontri sulla mancata consapevolezza di malattia e sulle distorsioni della comunicazione con le persone affette da neoplasia[13] [14] [15] [16] [17] [18] e che gli studi condotti in ambito oncologico abbiano individuato carenze nella comunicazione tra il personale sanitario e i pazienti

---

[11] VandeKieft GK. Breaking bad news. *Am Fam Physician* 2001; 64: 1975-1978.

[12] Mueller PS. Breaking bad news to patients: the SPIKES approach can make this difficult talk easier. *Postgrad Med* 2002; 112: 15-16.

[13] Grassi L, Giraldi T, Messina EG, Magnani K, Valle E, Cartei G (2000) Physicians' attitudes to and problems with truth-telling to cancer patients. Support Care Cancer 8:40–45.

[14] Qasem AA, Ashour TH, Al-Abdulrazzaq HK, Ismail ZA (2002) Disclosure of cancer diagnosis and prognosis by physicians in Kuwait. Int J Clin Pract 56 (3):215–218.

[15] Mystakidou K, Parpa E, Tsilila E, Katsouda E, Vlahos L (2004) Cancer information disclosure in different cultural contexts. Support Care Cancer 12:147–154.

[16] Ferraz Goncalves J, Castro S (2001) Diagnosis disclosure in a Portuguese oncological centre. Palliat Med 15:35–41.

[17] Seo M, Tamura K, Shijo H, Morioka E, Ikegame C, Hirasako K (2000) Telling the diagnosis to cancer patients in Japan: attitude and perception of patients, physicians and nurses. Palliat Med 14:105–110.

[18] Chochinov HM, Tataryn DJ, Wilson KG, et al. Prognostic awareness and the terminally ill. *Psychosomatics* 2000; 41: 500-504.

relativamente alle questioni della prognosi e del fine vita[19] [20] [21] . Alcuni dati sembrano indicare la tendenza ad un'informazione più aperta quando si è in presenza di una diagnosi di neoplasia ai primi stadi, mentre l'atteggiamento dei medici verso una comunicazione completa sembra ridursi quando si affrontano le fasi avanzate e terminali della patologia neoplastica[22] [23].

---

[19] Gysels M, Richardson A, Higginson I. Communication training for health professionals who care for patients with cancer: a systematic review of effectiveness. *Support Care Cancer* 2004; 12: 692-700.

[20] Costantini M, et al. Diagnosis and prognosis disclosure among cancer patients. Results from an Italian mortality follow-back survey. Ann Oncol 2006;17:853-9.

[21] Vedi nota 1.

[22] Yu Jiang Different attitudes of oncology clinicians toward truth telling of different stages of cancer Support Care Cancer (2006) 14: 1119–1125.

[23] Carlos Centeno Cortés, Juan Manuel Núñez Olarte Estudios sobre la comunicación del diagnóstico del cáncer en España, Medicina Clínica, Vol 110 Num 19, Mayo 1998.

Al contempo, la letteratura ha messo in evidenza numerose conferme sul desiderio dei pazienti oncologici di essere informati sulla diagnosi e la loro malattia[24] [25] [26] [27] [28].

---

[24] Rubio Arribas V, Sampedro Martinez E, Zapirain Sarasola M, Gil Benito I, Ayechu Redin S, Tapiz Ibanez V (2004) Cancer diagnosis: do we want to know the truth? Aten Primaria 33:368–373

[25] Noone I, Crowe M, Pillay I, O'Keeffe ST (2000) Telling the truth about cancer: views of elderly patients and their relatives. Ir Med J 93:104–105

[26] Fallowfield LJ, Jenkins VA, Beveridge HA. Truth may hurt but deceit hurts more: communication in palliative care. *Palliat Med* 2002; 16: 297-303.

[27] Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; 284: 2476-2482.

[28] Wenrich MD, Curtis JR, Shannon SE, et al. Communicating with dying patients within the spectrum of medical care from terminal diagnosis to death. *Arch Intern Med* 2001; 161: 868-874.

Ulteriori studi riportano che la conoscenza della propria prognosi contribuisce a una maggiore soddisfazione per le cure prestate e a minori livelli di depressione nei pazienti[29] [30].

Indagare sul "vissuto della comunicazione", e non solo sulla quantità e tipo d'informazione fornita, è utile e importante anche in considerazione del fatto che le decisioni che il paziente è chiamato a condividere, rispetto al proprio percorso terapeutico, sono influenzate anche da fattori emotivi e contestuali.

I dati ottenuti e le conoscenze acquisite da questo studio consentirebbero una maggiore consapevolezza da parte dei sanitari sulle modalità comunicative personali e interprofessionali e sulle loro ricadute sul vissuto dei pazienti. La maggiore consapevolezza e la riflessione critica conseguente possono costituirsi come risorsa per favorire la costruzione di percorsi formativi e modelli comunicativi realmente soddisfacenti per tutte le persone coinvolte nel rapporto di cura.

---

[29] Chochinov HM, Tataryn DJ, Wilson KG, et al. Prognostic awareness and the terminally ill. *Psychosomatics* 2000; 41: 500-504.

[30] Schofield PE, Butow PN, Thompson JF, et al. Psychological responses of patients receiving a diagnosis of cancer. *Ann Oncol* 2003; 14: 48-56.

In particolare, questo studio intende cogliere l'aspetto corale della comunicazione attraverso la voce delle principali figure coinvolte nel processo di cura e intende far emergere le peculiarità del processo comunicativo rispetto ad uno stadio avanzato di malattia neoplastica.

Gli aspetti qualitativi e informativi della comunicazione saranno indagati in un campione di pazienti affetti da neoplasia in stadio avanzato, esplorando:

- le conoscenze del paziente rispetto al proprio piano diagnostico-terapeutico
- le eventuali discrepanze tra l'informazione fornita dai sanitari e quella recepita dal paziente
- il desiderio d'informazione del paziente
- le attitudini di medici e infermieri rispetto alla comunicazione del piano diagnostico terapeutico e assistenziale dei pazienti affetti da neoplasia in stadio avanzato

La traccia per le interviste semi-strutturate tiene conto di quanto riportato nelle Linee guida per la comunicazione della prognosi e di argomenti connessi alla fine della vita con adulti affetti da patologie in fase avanzata e a limitata aspettativa di vita e con i loro familiari[31].

Keyword : comunicazione, piano diagnostico-terapeutico, neoplasia in stadio avanzato

---

[31] Josephine M. Clayton, Sustaining hope when communicating with terminally ill patients and their families: a systematic review, Psycho-Oncology Volume 17, Issue 7, pages 641–659, July 2008

METODOLOGIA DELLA RICERCA

Studio Qualitativo

Setting dell'indagine: Servizio e reparto oncologico dell'AOU di Cagliari Servizio e reparto oncologico del Businco di Cagliari

Campione: pazienti adulti affetti da neoplasia in stadio avanzato (con aspettativa di vita inferiore ai due anni), medici ospedalieri curanti, personale infermieristico responsabile dell'assistenza, parenti dei pazienti affetti da malattia neoplastica avanzata intervistati
(almeno una trentina di interviste per "nucleo di cura")

Materiale e Metodo

Conduzione di interviste semi-strutturate ad un campione non probabilistico di pazienti affetti da neoplasia in stadio avanzato.
Conduzione di interviste semi-strutturate ai medici ospedalieri che hanno in cura i pazienti già intervistati.
Conduzione di interviste semi-strutturate agli infermieri che hanno seguito il paziente (almeno per tre diversi turni).
Conduzione di interviste semi-strutturate ai parenti dei pazienti intervistati.

Le interviste saranno anonime e si accompagneranno ad una breve raccolta di dati demografici. L'analisi e la validazione dei dati avverranno tramite trascrizione e lettura dettagliata delle interviste, codificazione e catalogazione tematica dei dati, analisi e interpretazione dei dati secondo la metodologia fenomenologica, comparazione per unità comunicative.

L'indagine richiederà inoltre la consultazione della cartella clinica al fine di reperire i seguenti dati:
-diagnosi (diagnosi di ricovero, diagnosi istologica)
- terapie intraprese e terapie proposte
- consenso informato agli atti medici
- consenso alla trasmissione di informazioni sanitarie a terzi

Aspetti Etici

La partecipazione dei pazienti, dei medici e degli infermieri a questo progetto di ricerca sarà di carattere volontario, medici e infermieri saranno coinvolti in ragione del loro legame di cura con il paziente arruolato. Ogni persona arruolata potrà abbandonare in qualunque momento lo studio, verrà assicurata e garantita la confidenzialità dei dati e l'anonimato nella gestione dei dati e delle informazioni raccolte nel corso della ricerca.

Il ricercatore avrà la responsabilità di conservare i dati ottenuti e informare le persone che partecipano allo studio sulla pubblicazione di quanto emerso dallo studio, consentendo così la loro approvazione.

Si chiederà l'autorizzazione per la conduzione delle interviste ai Direttori di struttura e ai Coordinatori delle Unità Operative, nonché ai singoli arruolati allo studio.

DICHIARAZIONE DI CONSENSO INFORMATO

STUDIO SULLA COMUNICAZIONE E INFORMAZIONE DI DIAGNOSI E PROGNOSI IN ONCOLOGIA

Obiettivi della ricerca: lo studio si propone di indagare la qualità della comunicazione di carattere medico e assistenziale in relazione ai percorsi diagnostici- terapeutici nelle persone in cura presso i reparti e/o i servizi di oncologia.

Lo studio è un progetto di ricerca spontaneo, senza sponsor né fondi istituzionali, ma rientra nelle attività di ricerca di dottorato in Nursing and Health (Infermieristica e Salute) con indirizzo Bioetica della dott.ssa Paola Melis, pertanto non è previsto alcun beneficio economico per i singoli partecipanti, né per gli sperimentatori né per la struttura.
Il/la sottoscritto/a:

____

dichiara di essere a conoscenza che:

- La ricerca include la raccolta di risposte su conoscenze, stati d'animo, opinioni e valutazioni);
- Ogni partecipante è libero/a di chiedere chiarimenti sulla procedura di raccolta dati e su qualsiasi aspetto dello studio.
- Ogni partecipante è libero/a di rifiutare l'intervista in qualsiasi momento; l'eventuale rifiuto non comporta alcuna conseguenza negativa per il partecipante.
- I dati personali raccolti verranno elaborati in forma anonima e non verranno in alcun modo t[Rev. 01]rasmessi a persone non direttamente coinvolte nella ricerca.

Quanto emerso dalla ricerca sarà presentato in forma anonima e con ogni cautela necessaria a evitare l'identificabilità dei partecipanti.
La ricerca è condotta nel rispetto del Codice Etico relativo alla ricerca con partecipanti umani, in ambito nazionale o internazionale.

Rev. 01

La ricerca ha ottenuto il parere favorevole del Comitato Etico Indipendente dell'A.O.U. e dell'Ospedale Businco di Cagliari.
Il/la sottoscritto/a dichiara inoltre
- di essere maggiorenne.
- di aver letto con attenzione tutti i punti della dichiarazione;
- di dare il proprio consenso a partecipare alla ricerca.

Tutte le informazioni ottenute saranno mantenute riservate in conformità del decreto legislativo 196/2003

Data____________________FIRMA____________________________________

CONSENSO AL TRATTAMENTO DEI DATI SENSIBILI
Il/la sottoscritto/a
____

☐ Acconsente
☐ Non acconsente

Al trattamento dei propri dati personali e sensibili raccolti nell'ambito della presente ricerca nei termini e modi indicati nei precedenti punti.
L'elaborazione dei dati raccolti nell'ambito della ricerca, la loro comunicazione a soggetti terzi e/o pubblicazione per scopi scientifici sono consentite, ma potranno avvenire soltanto dopo che i dati medesimi saranno stati resi anonimi, a cura e sotto la responsabilità diretta del responsabile della ricerca.
Tutti i ricercatori coinvolti nella raccolta dati sono vincolati alla segretezza sull'identità
dei partecipanti.

Data____________________
FIRMA____

Paola Melis
Dottoranda in Scienze Infermieristiche e Salute
Responsabile della ricerca e incaricata della raccolta dati
tel. 3283221949

CANOVACCIO PER RACCOLTA DATI PAZIENTE

Dati socio-demografici e clinici del paziente

Genere:

Età:

Scolarità:

Stato civile:

Lavoro

DATI RILEVATI DALLA CARTELLA CLINICA:

Sede tumore:

Stadiazione neoplastica:

Trattamento:

Traccia per l'intervista semi-strutturata al paziente:

- Mi parli della sua malattia

- Quali sono le sue preferenze rispetto al conoscere o meno la sua diagnosi?

- Quali sono le sue preferenze rispetto al conoscere o meno la sua prognosi?

-Che senso ha per lei conoscere/non conoscere la sua diagnosi/prognosi?

- Mi racconti di quando parla con il suo medico della sua diagnosi/prognosi

- Mi racconti di quando parla con il suo caregiver della sua malattia

- Mi racconti di quando parla con gli infermieri della sua diagnosi/prognosi

CANOVACCIO PER RACCOLTA DATI PER IL CAREGIVER

Dati socio-demografici raccolti dal caregiver

Genere:

Età (anni)

Scolarità (anni)

Stato civile:

Relazione con il paziente/caregiver:

Lavoro:

Traccia per l'intervista semi-strutturata al caregiver:

- Mi parli di quello che il suo caro sa della sua malattia

- Mi parli di quando è stata comunicata la diagnosi/prognosi al suo caro

- Mi racconti di quando parla con il suo caro della sua diagnosi/prognosi

- Mi parli di quelle che sono le preferenze del suo caro rispetto al conoscere o meno la sua diagnosi

- Mi parli di quelle che sono le preferenze del suo caro rispetto al conoscere o meno la sua prognosi

- Qual è lo scopo di parlare con medico/infermiere della diagnosi/prognosi del suo caro?

CANOVACCIO PER RACCOLTA DATI PER L'INFERMIERE

Dati socio-demografici raccolti dal medico

Genere:

Età (anni)

Stato civile

Anni di lavoro come infermiere:

Corsi di aggiornamento sulla comunicazione

Traccia per l'intervista semi-strutturata all'infermiere

- *Mi racconti di quello che il paziente conosce della sua diagnosi/prognosi*
- *Mi parli di quelle che sono le preferenze del paziente rispetto al conoscere o meno la sua diagnosi*
- *Mi racconti di quando parla con il paziente della sua diagnosi/prognosi*
- *Mi racconti di quando parla con il caregiver della diagnosi/prognosi del suo caro*
- *Mi racconti di quando parla con il medico della comunicazione di diagnosi/prognosi del paziente*
- *Qual è lo scopo di parlare con il paziente/caregiver/medico della diagnosi/prognosi del paziente?*

CANOVACCIO PER RACCOLTA DATI PER IL MEDICO

Dati socio-demografici raccolti dal medico

Genere:

Età (anni):

Anni di lavoro come medico:

Anni di lavoro come oncologo:

Corsi di aggiornamento sugli aspetti comunicativi

Traccia per l'intervista semi-strutturata al caregiver

- Mi racconti di quello che il paziente conosce della sua diagnosi/prognosi

- Mi parli di quelle che sono le preferenze del paziente rispetto al conoscere o meno la sua diagnosi

- Mi racconti di quando parla con il paziente della sua diagnosi/prognosi

- Mi racconti di quando parla con il caregiver della diagnosi/prognosi del suo caro

- Mi racconti di quando parla con l'infermiere della comunicazione di diagnosi/prognosi del paziente

- Qual è lo scopo di parlare con il paziente/caregiver/infermiere della diagnosi/prognosi del paziente?

Addendum n. 3:

Ethics Committee Approval

Communication related to diagnosis and prognosis to patients with advanced cancer:
ethics at stake
Paola Melis

Firmato digitalmente da
ERNESTO D'ALOJA
CN = D'ALOJA ERNESTO
O = non presente
C = IT

AZIENDA OSPEDALIERO – UNIVERSITARIA DI CAGLIARI
Comitato Etico
Via Ospedale 54 - 09124 Cagliari
Telefono 070.6092262 – Fax 070.609.2262

2.27
Riunione del 20/07/2016

Prot. NP/2016/4525 **Cagliari, 25/07/2016**

Oggetto: presa d'atto.

Studio sulla qualità della comunicazione di carattere medico e assistenziale in relazione ai percorsi diagnostici-terapeutici nelle persone affette da malattia neoplastica in fase avanzata
Responsabile della Sperimentazione: **Dott.ssa Paola Melis (dottorato di Ricerca in Scienze Infermieristiche e Salute)**
Centro di Sperimentazione: **Oncologia AOU - Oncologia Businco**
Presidio Ospedaliero: **Duilio Casula Monserrato AOU – Businco AOB**
Promotore/Sponsor: **Dott.ssa Paola Melis (dottorato di Ricerca in Scienze Infermieristiche e Salute)**
Struttura di appartenenza: **AOU Cagliari – AOB Cagliari**
Già discusso e approvato con prescrizioni al punto 2.21 dell'o.d.g. della riunione del 23/06/2016.

Le richieste formulate dal Comitato Etico nella riunione del 23/06/2016 sono state adempiute tramite l'invio della seguente documentazione integrativa:

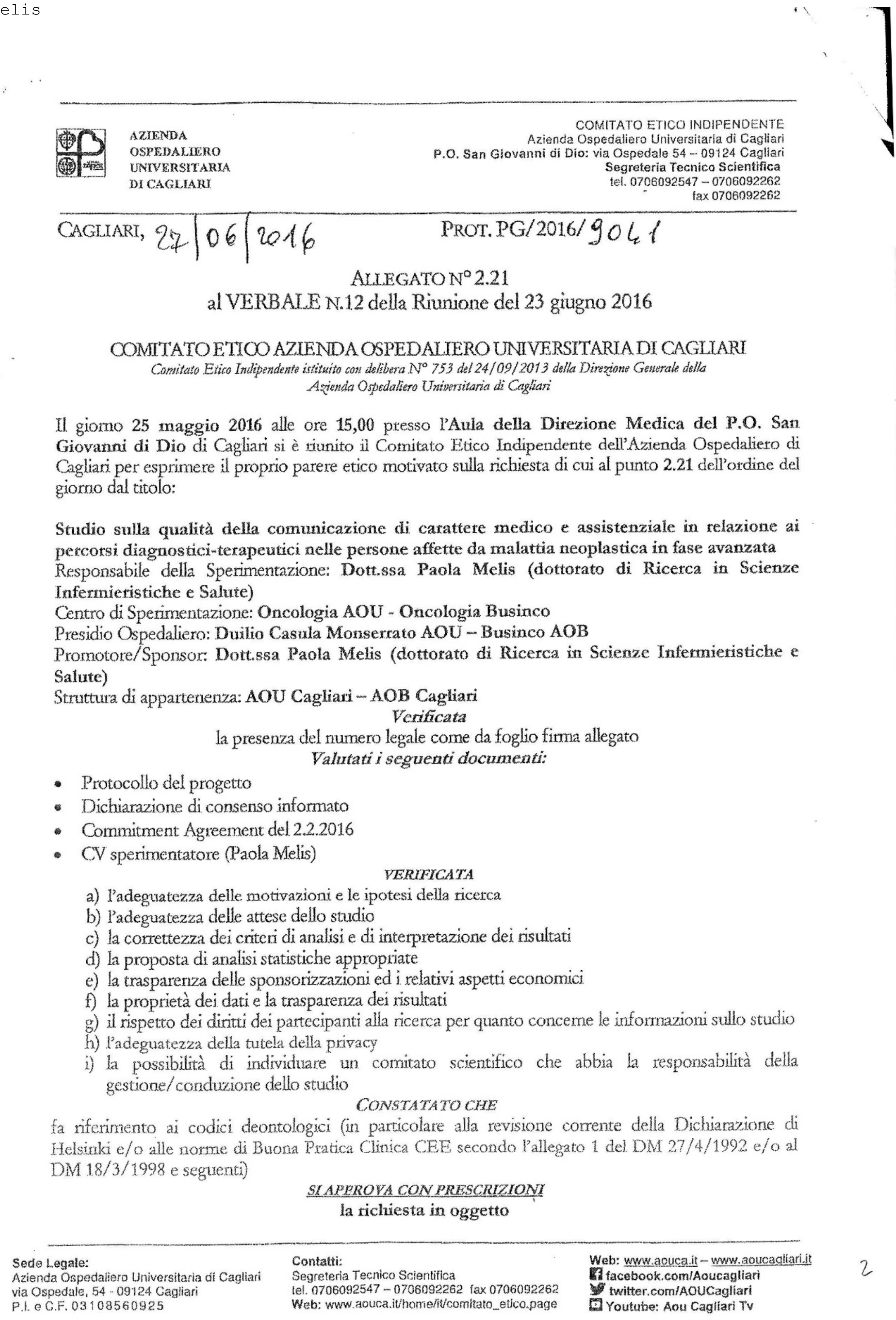
- Allegato A1 firmato 8.7.2016
- Allegato M1 firmato 8.7.2016
- Autorizzazione Direzione Sanitaria AOU Cagliari 24.6.2016
- Autorizzazione Direzione Sanitaria AOB Cagliari e accettazione collaborazione Dott. Defraia Responsabile Oncologia Medica AOB
- Accettazione collaborazione Prof. Scartozzi Responsabile Oncologia Medica PO Duilio Casula – Monserrato AOU Cagliari
- Progetto con inclusa dichiarazione di consenso corretta secondo prescrizioni

SI PRENDE ATTO
dell'adempimento alle richieste formulate e si dichiara lo Studio definitivamente
APPROVATO

Si ricorda che lo Sperimentatore è obbligato ad informare il CE sull'andamento della sperimentazione ogni sei mesi, con relazione scritta riportante il numero dei casi arruolati tramite compilazione dell'Allegato L della modulistica di questo CE (rapporto sullo stato di avanzamento D.M. 15 Luglio 1997). Lo Sperimentatore è inoltre tenuto ad informare lo scrivente CE dell'inizio e della conclusione della sperimentazione. Il parere sopra espresso s'intende limitato esclusivamente alle versioni ed alla documentazione presentata ed espressamente citata in oggetto. Ogni variazione allo stesso deve obbligatoriamente essere sottoposta al parere di questo CE, così come previsto dalle vigenti norme nazionali ed europee. Tutte le segnalazioni relative ad eventi avversi seri e inattesi, la conclusione dello studio ed ogni eventuale sua integrazione dovranno essere comunicati allo scrivente CE. **Lo studio potrà essere intrapreso solo a seguito della autorizzazione del Direttore Generale formalizzato da apposito atto deliberativo.** I farmaci per la sperimentazione dovranno essere consegnati esclusivamente per il tramite del Servizio di Farmacia dell'Azienda ospedaliera. Lo sperimentatore è tenuto ad interpellare in qualsiasi momento il CE ogni qual volta si renda necessaria una nuova valutazione etica.

***"Si attesta che questo Comitato Etico è organizzato ed opera in conformità alla normativa vigente in Italia in materia di GCP-ICH, in osservanza a quanto previsto dall'allegato del D.M. 15/07/1997, dal D.M. 18/03/1998 e dal D.L. n. 211/2003" (Recepimento delle linee guida dell'Unione Europea di buona pratica clinica per l'esecuzione delle sperimentazioni cliniche dei medicinali), nonché della Legge n. 189 del 08/11/2012 e del D.M. della Salute 08/02/2013.**
Si allega lista dei presenti e assenti e delle relative funzioni.

Il Presidente
Prof. Ernesto d'Aloja



AZIENDA
OSPEDALIERO
UNIVERSITARIA
DI CAGLIARI

COMITATO ETICO INDIPENDENTE
Azienda Ospedaliero Universitaria di Cagliari
P.O. San Giovanni di Dio: via Ospedale 54 – 09124 Cagliari
Segreteria Tecnico Scientifica
tel. 0706092547 – 0706092262
fax 0706092262

CAGLIARI, 27|06|2016 PROT. PG/2016/9061

ALLEGATO N° 2.21
al VERBALE N.12 della Riunione del 23 giugno 2016

COMITATO ETICO AZIENDA OSPEDALIERO UNIVERSITARIA DI CAGLIARI

Comitato Etico Indipendente istituito con delibera N° 753 del 24/09/2013 della Direzione Generale della Azienda Ospedaliero Universitaria di Cagliari

Il giorno **25 maggio 2016** alle ore **15,00** presso l'**Aula della Direzione Medica del P.O. San Giovanni di Dio** di Cagliari si è riunito il Comitato Etico Indipendente dell'Azienda Ospedaliero di Cagliari per esprimere il proprio parere etico motivato sulla richiesta di cui al punto **2.21** dell'ordine del giorno dal titolo:

Studio sulla qualità della comunicazione di carattere medico e assistenziale in relazione ai percorsi diagnostici-terapeutici nelle persone affette da malattia neoplastica in fase avanzata
Responsabile della Sperimentazione: **Dott.ssa Paola Melis (dottorato di Ricerca in Scienze Infermieristiche e Salute)**
Centro di Sperimentazione: **Oncologia AOU - Oncologia Businco**
Presidio Ospedaliero: **Duilio Casula Monserrato AOU – Businco AOB**
Promotore/Sponsor: **Dott.ssa Paola Melis (dottorato di Ricerca in Scienze Infermieristiche e Salute)**
Struttura di appartenenza: **AOU Cagliari – AOB Cagliari**

Verificata
la presenza del numero legale come da foglio firma allegato
Valutati i seguenti documenti:

- Protocollo del progetto
- Dichiarazione di consenso informato
- Commitment Agreement del 2.2.2016
- CV sperimentatore (Paola Melis)

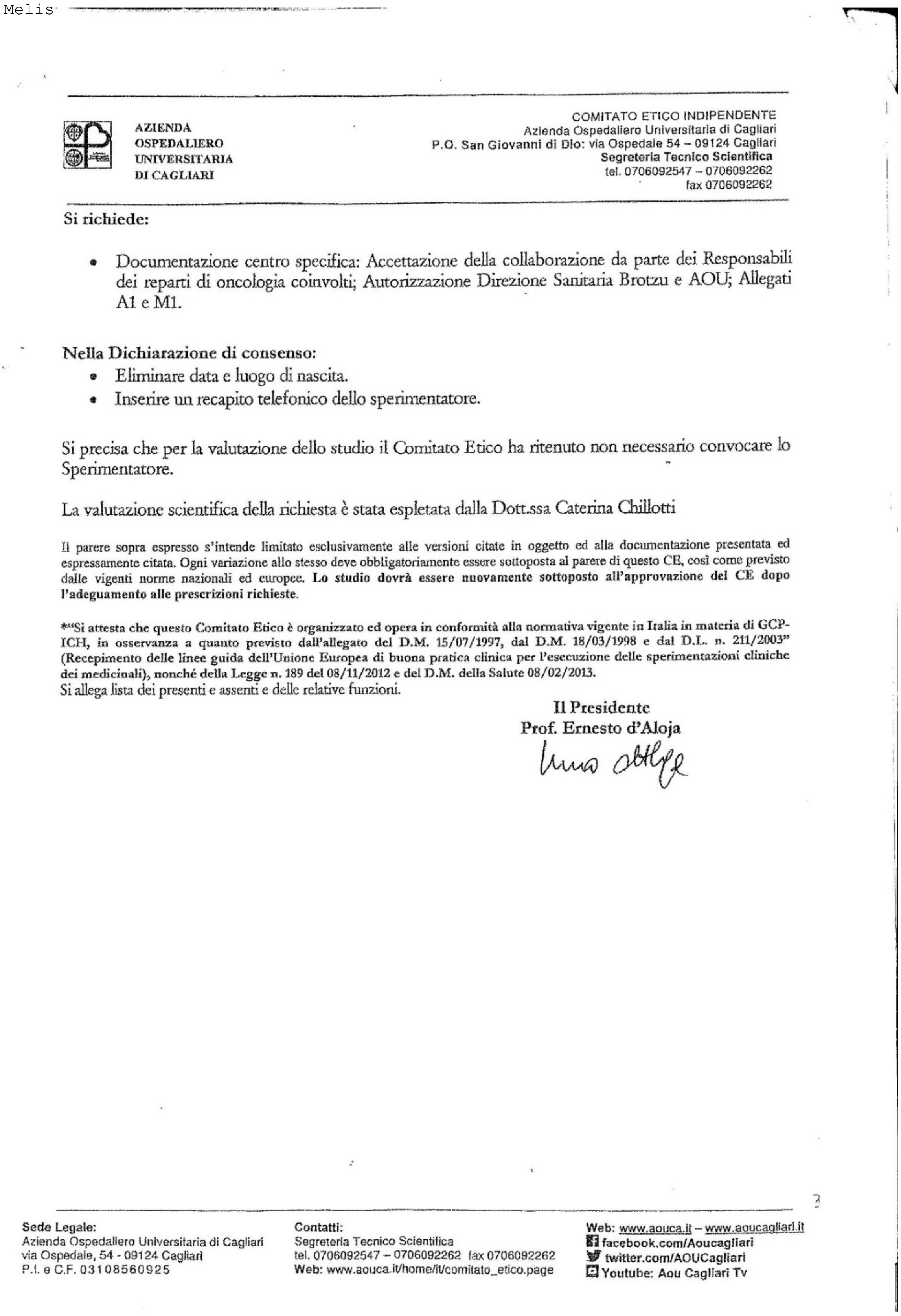
VERIFICATA

a) l'adeguatezza delle motivazioni e le ipotesi della ricerca
b) l'adeguatezza delle attese dello studio
c) la correttezza dei criteri di analisi e di interpretazione dei risultati
d) la proposta di analisi statistiche appropriate
e) la trasparenza delle sponsorizzazioni ed i relativi aspetti economici
f) la proprietà dei dati e la trasparenza dei risultati
g) il rispetto dei diritti dei partecipanti alla ricerca per quanto concerne le informazioni sullo studio
h) l'adeguatezza della tutela della privacy
i) la possibilità di individuare un comitato scientifico che abbia la responsabilità della gestione/conduzione dello studio

CONSTATATO CHE

fa riferimento ai codici deontologici (in particolare alla revisione corrente della Dichiarazione di Helsinki e/o alle norme di Buona Pratica Clinica CEE secondo l'allegato 1 del DM 27/4/1992 e/o al DM 18/3/1998 e seguenti)

SI APPROVA CON PRESCRIZIONI
la richiesta in oggetto



AZIENDA
OSPEDALIERO
UNIVERSITARIA
DI CAGLIARI

COMITATO ETICO INDIPENDENTE
Azienda Ospedaliero Universitaria di Cagliari
P.O. San Giovanni di Dio: via Ospedale 54 – 09124 Cagliari
Segreteria Tecnico Scientifica
tel. 0706092547 – 0706092262
fax 0706092262

Si richiede:

- Documentazione centro specifica: Accettazione della collaborazione da parte dei Responsabili dei reparti di oncologia coinvolti; Autorizzazione Direzione Sanitaria Brotzu e AOU; Allegati A1 e M1.

Nella Dichiarazione di consenso:

- Eliminare data e luogo di nascita.
- Inserire un recapito telefonico dello sperimentatore.

Si precisa che per la valutazione dello studio il Comitato Etico ha ritenuto non necessario convocare lo Sperimentatore.

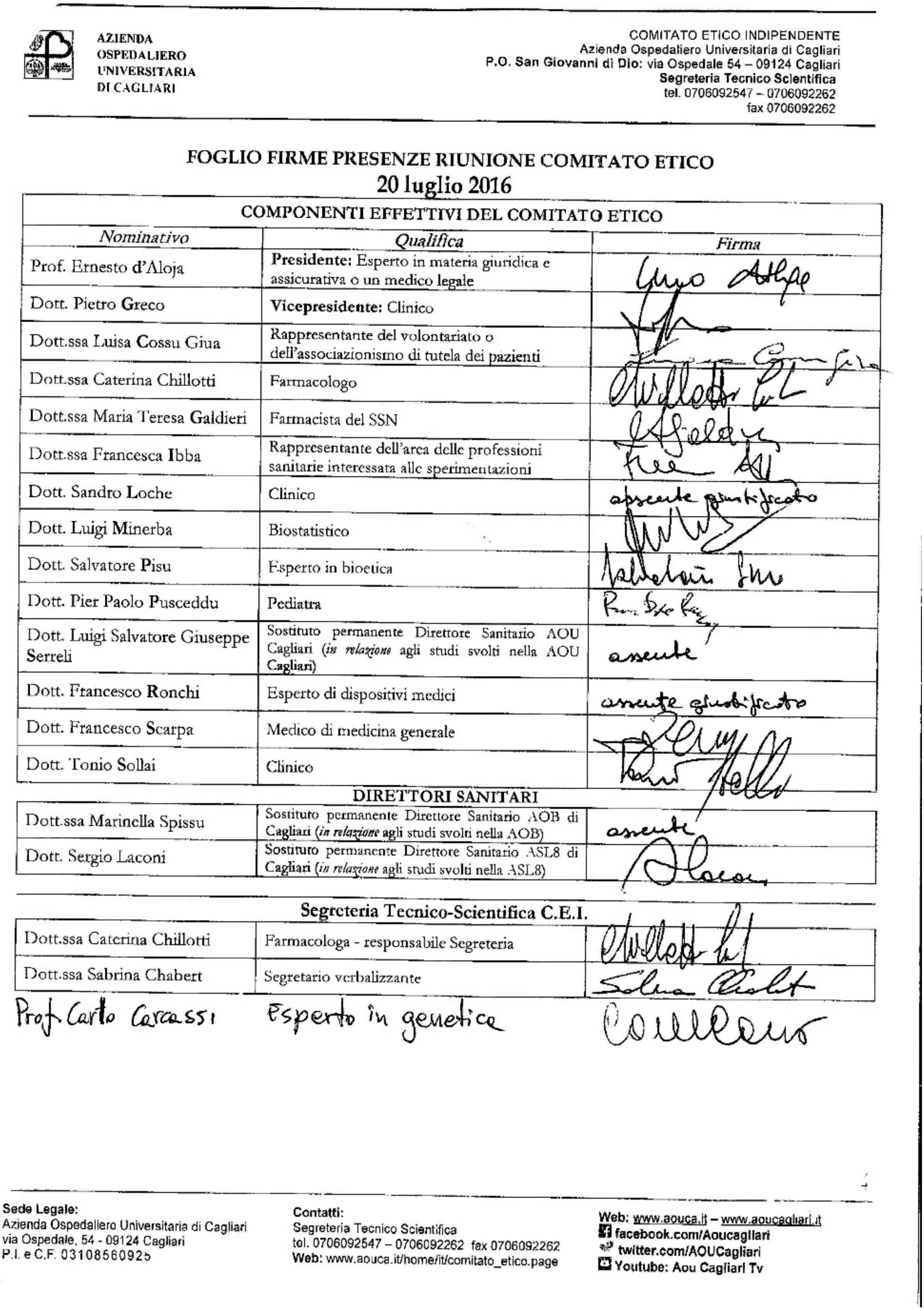
La valutazione scientifica della richiesta è stata espletata dalla Dott.ssa Caterina Chillotti

Il parere sopra espresso s'intende limitato esclusivamente alle versioni citate in oggetto ed alla documentazione presentata ed espressamente citata. Ogni variazione allo stesso deve obbligatoriamente essere sottoposta al parere di questo CE, così come previsto dalle vigenti norme nazionali ed europee. **Lo studio dovrà essere nuovamente sottoposto all'approvazione del CE dopo l'adeguamento alle prescrizioni richieste.**

***"Si attesta che questo Comitato Etico è organizzato ed opera in conformità alla normativa vigente in Italia in materia di GCP-ICH, in osservanza a quanto previsto dall'allegato del D.M. 15/07/1997, dal D.M. 18/03/1998 e dal D.L. n. 211/2003" (Recepimento delle linee guida dell'Unione Europea di buona pratica clinica per l'esecuzione delle sperimentazioni cliniche dei medicinali), nonché della Legge n. 189 del 08/11/2012 e del D.M. della Salute 08/02/2013.**
Si allega lista dei presenti e assenti e delle relative funzioni.

Il Presidente
Prof. Ernesto d'Aloja

3



**AZIENDA
OSPEDALIERO
UNIVERSITARIA
DI CAGLIARI**

COMITATO ETICO INDIPENDENTE
Azienda Ospedaliero Universitaria di Cagliari
P.O. San Giovanni di Dio: via Ospedale 54 – 09124 Cagliari
Segreteria Tecnico Scientifica
tel. 0706092547 – 0706092262
fax 0706092262

FOGLIO FIRME PRESENZE RIUNIONE COMITATO ETICO
20 luglio 2016

COMPONENTI EFFETTIVI DEL COMITATO ETICO

Nominativo	*Qualifica*	*Firma*
Prof. Ernesto d'Aloja	**Presidente:** Esperto in materia giuridica e assicurativa o un medico legale	
Dott. Pietro Greco	**Vicepresidente:** Clinico	
Dott.ssa Luisa Cossu Giua	Rappresentante del volontariato o dell'associazionismo di tutela dei pazienti	
Dott.ssa Caterina Chillotti	Farmacologo	
Dott.ssa Maria Teresa Galdieri	Farmacista del SSN	
Dott.ssa Francesca Ibba	Rappresentante dell'area delle professioni sanitarie interessata alle sperimentazioni	
Dott. Sandro Loche	Clinico	assente giustificato
Dott. Luigi Minerba	Biostatistico	
Dott. Salvatore Pisu	Esperto in bioetica	
Dott. Pier Paolo Pusceddu	Pediatra	
Dott. Luigi Salvatore Giuseppe Serreli	Sostituto permanente Direttore Sanitario AOU Cagliari (*in relazione* agli studi svolti nella AOU Cagliari)	assente
Dott. Francesco Ronchi	Esperto di dispositivi medici	assente giustificato
Dott. Francesco Scarpa	Medico di medicina generale	
Dott. Tonio Sollai	Clinico	

DIRETTORI SANITARI

Dott.ssa Marinella Spissu	Sostituto permanente Direttore Sanitario AOB di Cagliari (*in relazione* agli studi svolti nella AOB)	assente
Dott. Sergio Laconi	Sostituto permanente Direttore Sanitario ASL8 di Cagliari (*in relazione* agli studi svolti nella ASL8)	

Segreteria Tecnico-Scientifica C.E.I.

Dott.ssa Caterina Chillotti	Farmacologa - responsabile Segreteria	
Dott.ssa Sabrina Chabert	Segretario verbalizzante	
Prof. Carlo Carcassi	Esperto in genetica	

Addendum n. 4:

Head of Department Approvals

Al Direttore dell'Oncologia Medica dell'AOU Cagliari Prof. Mario Scartozzi

Oggetto: Richiesta di autorizzazione alla conduzione dello studio clinico osservazionale dal titolo: "Studio sulla qualità della comunicazione di carattere medico e assistenziale in relazione ai percorsi diagnostici-terapeutici nelle persone affette da malattia neoplastica in fase avanzata"

La sottoscritta, Paola Melis, nata a Fidenza (Pr) il 02-04-1971, in qualità di Dottoranda in Nursing and Health, indirizzo Bioetica, presso l'Università Rovira e Virgili di Tarragona (Spagna), al fine di poter condurre uno studio di ricerca valido per la propria Tesi di Dottorato

CHIEDE

Di poter condurre lo studio su citato presso l'Oncologia dell'AOU Cagliari, Presidio Ospedaliero Duilio Casula di Monserrato

A tal fine dichiara:

- che lo studio ha carattere osservazionale
- che lo studio prevede la conduzione di trenta interviste semistrutturate rivolte a medici, infermieri, pazienti, care-giver
- di aver già ricevuto **l'approvazione con prescrizione** del Comitato Etico Azienda Ospedaliero Universitaria di Cagliari in data 27/06/2016 PRT.. PG/2016/9041
- che la prescrizione richiede la Documentazione centro specifica:
  -accettazione della collaborazione da parte dei Responsabili dei Reparti di oncologia coinvolti
  - Autorizzazione della Direzione Sanitaria Brotzu e AOU
  - Allegati A1 e M1 (allegati alla presente e da consegnare al CE)
  Oltre a:
  eliminare data e luogo di nascita (come eliminato nella nuova dichiarazione di Consenso allegata)
  inserire un recapito telefonico dello sperimentatore (come inserito nella nuova dichiarazione di Consenso allegata).

Dichiara inoltre

- di avere inoltrato richiesta di autorizzazione alla conduzione dello studio presso la Direzione generale di codesta Azienda
- di essere l'unica Responsabile e Promotrice della Sperimentazione
- che non è prevista l'esecuzione di esami strumentali e di laboratorio e che nessuna spesa graverà sull'AOU

Allega alla propria richiesta
- Protocollo di Ricerca presentato al CE dell'AOU di Cagliari (con le modifiche richieste dal CE)
- Copia del Verbale n.12 della Riunione del CE del 23 giugno 2016 recante l'approvazione con prescrizione dello studio di ricerca già citato
- Allegati A1 e M1 datati e firmati

In fede Paola Melis

Approvato e pronti
a partecipare una
volta ricevuto il parere
definitivo da parte del
Comitato Etico.

Azienda Ospedaliero-Universitaria di Cagliari
P.O. *Duilio Casula* - MONSERRATO
S.C. ONCOLOGIA MEDICA
Il Direttore *Prof. Mario Scartozzi*

T

Al Commissario Straordinario AOB Cagliari Dr.ssa Graziella Pintus
Al Direttore Sanitario AOB Cagliari Dr.ssa Maria Gabriella Nardi
Al Direttore Sanitario del P.O. A. Businco Dr.ssa M. Teresa Addis

Oggetto: Richiesta di autorizzazione alla conduzione dello studio clinico osservazionale dal titolo: "Studio sulla qualità della comunicazione di carattere medico e assistenziale in relazione ai percorsi diagnostici-terapeutici nelle persone affette da malattia neoplastica in fase avanzata"

La sottoscritta, Paola Melis, nata a Fidenza (Pr) il 02-04-1971, in qualità di Dottoranda in Nursing and Health, indirizzo Bioetica, presso l'Università Rovira e Virgili di Tarragona (Spagna), al fine di poter condurre uno studio di ricerca valido per la propria Tesi di Dottorato

CHIEDE

Le venga concessa l'autorizzazione a condurre lo studio su citato presso l'Oncologia dell'AOB Cagliari, Ospedale Businco

A tal fine dichiara:

- che lo studio ha carattere osservazionale
- che lo studio prevede la conduzione di trenta interviste semistrutturate rivolte a medici, infermieri, pazienti, care-giver
- di aver già ricevuto **l'approvazione con prescrizione** del Comitato Etico Azienda Ospedaliero Universitaria di Cagliari in data 27/06/2016 PRT.. PG/2016/9041
- che la prescrizione richiede la Documentazione centro specifica:

  -accettazione della collaborazione da parte dei Responsabili dei Reparti di oncologia coinvolti

  - Autorizzazione della Direzione Sanitaria Brotzu e AOU
  - Allegati A1 e M1 (allegati alla presente e da consegnare al CE)

  Oltre a:

  eliminare data e luogo di nascita (come eliminato nella nuova dichiarazione di Consenso allegata)

  inserire un recapito telefonico dello sperimentatore (come inserito nella nuova dichiarazione di Consenso allegata).

Dichiara inoltre

- di essere l'unica Responsabile e Promotrice della Sperimentazione
- che non è prevista l'esecuzione di esami strumentali e di laboratorio e che nessuna spesa graverà sull'AOB

Allega alla propria richiesta

- Protocollo di Ricerca presentato al CE dell'AOU di Cagliari (con le modifiche richieste dal CE)
- Copia del Verbale n.12 della Riunione del CE del 23 giugno 2016 recante l'approvazione con prescrizione dello studio di ricerca già citato
    - Allegati A1 e M1 datati e firmati

In fede Paola Melis

si prega di inviare le comunicazioni all'indirizzo mail:
pmelis@aoucagliari.it

Parere favorevole

AO Brotzu - Caglia
P.O. BUSINCO
S.C. ONCOLOGIA MEDICA
DEGENZE
DIRETTORE: DOTT. EFISIO DEFRA

Parere favorevole

AO Brotzu - Cag
DIREZIONE SANITARIA P.O. BUSI
Dirigente Medico - matr. 7499
Dott. Paolo Mundul

AO Brotzu

Sistema Sanitario
Regione Sardegna

Deliberazione 1988

adottata dal DIRETTORE GENERALE in data - 3 NOV. 2016

Oggetto: Autorizzazione studio dal titolo: "studio sulla qualità della comunicazione di carattere medico e assistenziale in relazione ai percorsi diagnostici-terapeutici nelle persone affette da malattia neoplastica in fase avanzata" Responsabile: Dr.ssa Paola Melis (dottoranda di ricerca in Scienze Infermieristiche e Salute) – U.O.C. Oncologia P.O. Businco

---

Pubblicata all'Albo Pretorio dell'Azienda a partire dal - 3 NOV. 2016 per 15 giorni consecutivi e posta a disposizione per la consultazione.

Il Direttore Amministrativo

Il Direttore Generale Dott.ssa Graziella Pintus
coadiuvato da
Direttore Amministrativo Dott.ssa Laura Balata
Direttore Sanitario Dott. Vinicio Atzeni

Su proposta della Direzione Sanitaria Aziendale

PREMESSO che con Deliberazione n. 753 del 24/09/2013 della Direzione Generale dell'Azienda Ospedaliero Universitaria di Cagliari è stato istituito il Comitato Etico Indipendente;

VISTA la documentazione tecnica inviata dal Promotore ai sensi della normativa vigente per la richiesta di sottomissione al Comitato Etico al fine di espressione di parere e per la successiva autorizzazione da parte dell'A.O. Brotzu;

VISTO l'allegato 2.21 al verbale della Riunione del 26 giugno 2016 approvato con prescrizione e poi l'allegato 2.27 al verbale della Riunione del 20 Luglio 2016 con il quale il Comitato Etico Azienda Ospedaliero Universitaria di Cagliari ha approvato definitivamente lo studio indicato in oggetto che si allega al presente atto per farne parte integrante e sostanziale (Allegato A);

CONSIDERATO che lo studio in oggetto potrà essere intrapreso solo a seguito di autorizzazione mediante atto deliberativo dell'A.O. Brotzu di Cagliari;

RITENUTO di dover autorizzare lo Studio indicato in oggetto;

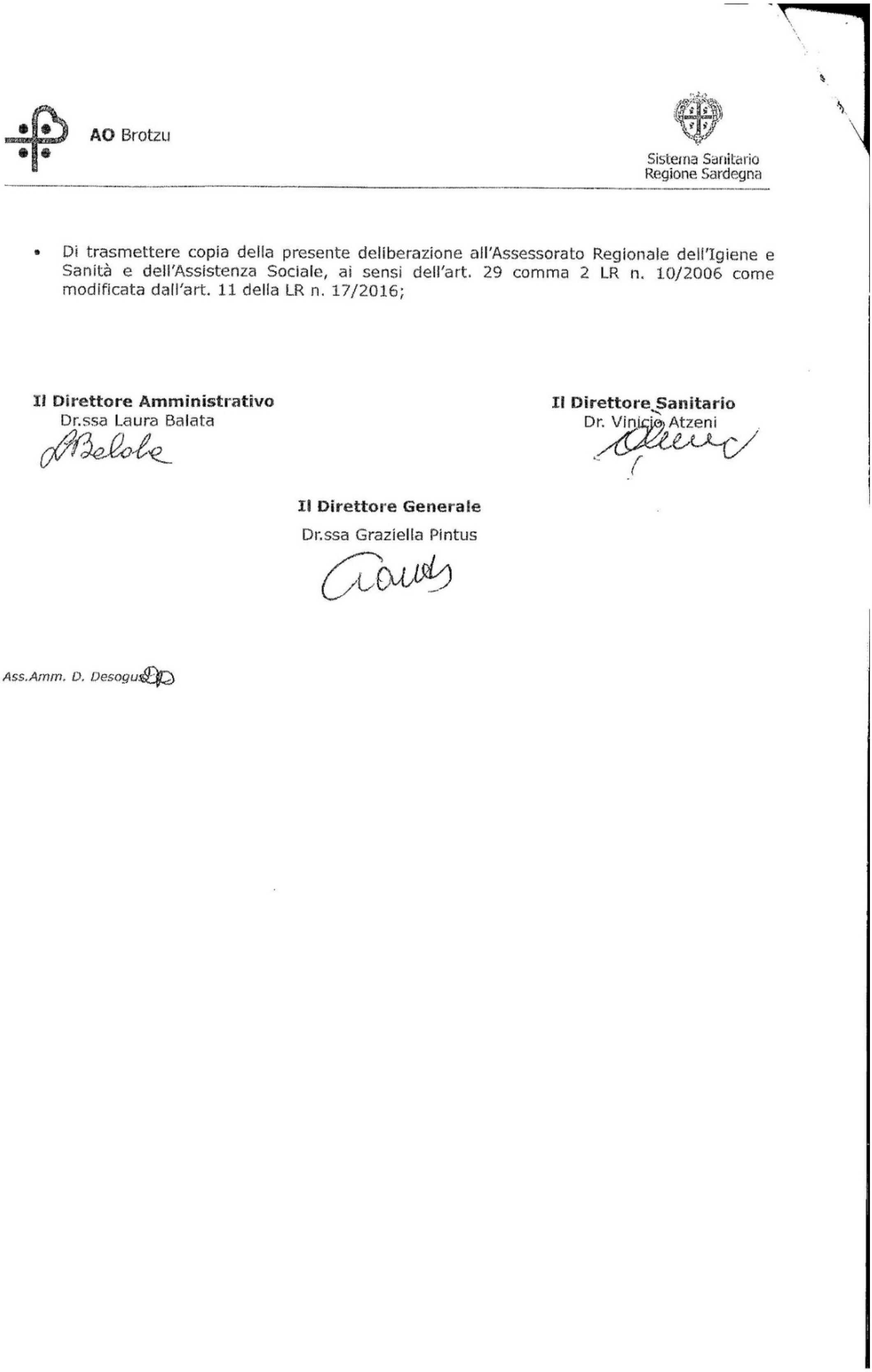
ACQUISITO il parere favorevole del Direttore Amministrativo e del Direttore Sanitario;

DELIBERA

Per i motivi indicati in premessa:

- Di provvedere all'autorizzazione dello studio Clinico: "Studio sulla qualità della comunicazione di carattere medico e assistenziale in relazione ai percorsi diagnostici-terapeutici nelle persone affette da malattia neoplastica in fase avanzata" Responsabile: Dr.ssa Paola Melis (dottoranda di ricerca in Scienze Infermieristiche e Salute) – U.O.C. Oncologia P.O. Businco

- Di dare atto che la presente Deliberazione non comporta ulteriori costi a valere sul bilancio aziendale;



- Di trasmettere copia della presente deliberazione all'Assessorato Regionale dell'Igiene e Sanità e dell'Assistenza Sociale, ai sensi dell'art. 29 comma 2 LR n. 10/2006 come modificata dall'art. 11 della LR n. 17/2016;

Il Direttore Amministrativo
Dr.ssa Laura Balata

Il Direttore Sanitario
Dr. Vinicio Atzeni

Il Direttore Generale
Dr.ssa Graziella Pintus

Ass.Amm. D. Desogus

Addendum n. 5:

Informed Consent

DICHIARAZIONE DI CONSENSO INFORMATO

STUDIO SULLA COMUNICAZIONE E INFORMAZIONE DI DIAGNOSI E PROGNOSI IN ONCOLOGIA

Obiettivi della ricerca : lo studio si propone di indagare la qualità della comunicazione di carattere medico e assistenziale in relazione ai percorsi diagnostici- terapeutici nelle persone in cura presso i reparti e/o i servizi di oncologia.

Lo studio è un progetto di ricerca spontaneo, senza sponsor né fondi istituzionali, ma rientra nelle attività di ricerca di dottorato in Nursing and Health (Infermieristica e Salute) con indirizzo Bioetica della dott.ssa Paola Melis, pertanto non è previsto alcun beneficio economico per i singoli partecipanti, né per gli sperimentatori né per la struttura.

Il/la sottoscritto/a: [redacted]

dichiara di essere a conoscenza che:

- La ricerca include la raccolta di risposte su conoscenze, stati d'animo, opinioni e valutazioni);
- Ogni partecipante è libero/a di chiedere chiarimenti sulla procedura di raccolta dati e su qualsiasi aspetto dello studio.
- Ogni partecipante è libero/a di rifiutare l'intervista in qualsiasi momento;

l'eventuale rifiuto non comporta alcuna conseguenza negativa per il partecipante.

- I dati personali raccolti verranno elaborati in forma anonima e non verranno in alcun modo t[Rev. 01]rasmessi a persone non direttamente coinvolte nella ricerca.

Quanto emerso dalla ricerca sarà presentato in forma anonima e con ogni cautela necessaria a evitare l'identificabilità dei partecipanti.

La ricerca è condotta nel rispetto del Codice Etico relativo alla ricerca con partecipanti umani, in ambito nazionale o internazionale.

La ricerca ha ottenuto il parere favorevole del Comitato Etico Indipendente dell'A.O.U. e dell'Ospedale Businco di Cagliari.

Rev. 01

Il/la sottoscritto/a dichiara inoltre

- di essere maggiorenne.
- di aver letto con attenzione tutti i punti della dichiarazione;
- di dare il proprio consenso a partecipare alla ricerca.

Tutte le informazioni ottenute saranno mantenute riservate in conformità del decreto legislativo 196/2003

Data 24.08.16 FIRMA [redacted]

CONSENSO AL TRATTAMENTO DEI DATI SENSIBILI

Il/la sottoscritto/a

____

☒ Acconsente

☐ Non acconsente

Al trattamento dei propri dati personali e sensibili raccolti nell'ambito della presente ricerca nei termini e modi indicati nei precedenti punti.

L'elaborazione dei dati raccolti nell'ambito della ricerca, la loro comunicazione a soggetti terzi e/o pubblicazione per scopi scientifici sono consentite, ma potranno avvenire soltanto dopo che i dati medesimi saranno stati resi anonimi, a cura e sotto la responsabilità diretta del responsabile della ricerca.

Tutti i ricercatori coinvolti nella raccolta dati sono vincolati alla segretezza sull'identità dei partecipanti.

Data 24.08.16

FIRMA [redacted]

Paola Melis
Dottoranda in Scienze Infermieristiche e Salute
Responsabile della ricerca e incaricata della raccolta dati
tel. 3283221949

Addendum n. 6:

Original Article

Original Manuscript

Nursing Ethics
2020, Vol. 27(6) 1418–1435

10.1177/0969733020916771
journals.sagepub.com/home/nej
SAGE

Ethical perspectives in communication in cancer care: An interpretative phenomenological study

Paola Melis
University of Cagliari, Italy; Universitat Rovira i Virgili, Spain

Maura Galletta
University of Cagliari, Italy

Cesar Ivan Aviles Gonzalez
University of Cagliari, Italy; Universitat Rovira i Virgili, Spain

Paolo Contu
University of Cagliari, Italy

Maria Francisca Jimenez Herrera
Universitat Rovira i Virgili, Spain

Abstract

Background: In cancer care, many clinical contexts still lack a good-quality patient–health professional communication about diagnosis and prognosis. Information transmission enables patients to make informed choices about their own healthcare. Nevertheless, disclosure is still an ethically challenging clinical problem in cancer care. High-quality care can be achieved by understanding the perspectives of others. The perspective of patients, their caregivers, physicians and nurses have seldom been simultaneously studied.
Objective: To investigate the phenomenon of diagnosis and prognosis-related communication as experienced by patients, their caregivers, and both their attending nurses and physicians, to enlighten meanings attached to communication by the four parties.
Methods: A qualitative study using interpretative phenomenological analysis was performed.
Participants and research context: Purposive sampling of six patients, six caregivers, seven nurses and five physicians was performed in two oncological hospitals in Italy.
Ethical considerations: Local Ethics Committee approved the study. It was guided by the ethical principles of voluntary enrolment, anonymity, privacy and confidentiality.
Results: Three main themes were identified: (a) the infinite range of possibilities in knowing and willing to know, (b) communication with the patient as a conflicting situation and (c) the bind of implicit and explicit meaning of communication.
Conclusion: The interplay of meanings attached by patients, their caregivers, and their attending oncologist and nurse to communication about diagnosis and prognosis revealed complexities and

---

Corresponding author: Maura Galletta, Department of Medical Sciences and Public Health, University of Cagliari, SS 554 Bivio per Sestu, Monserrato, Cagliari 09042, Italy.
Email: maura.galletta@gmail.com

ambiguities not yet settled. Physicians still need to solve the ethical tensions in their caring relationship with patients to really allow them 'to choose with dignity and being aware of it'. Nurses need to develop awareness about their role in diagnosis and prognosis-related communication. This cognizance is essential not just to assure consistency of communication within the multi-disciplinary team but mostly because it allows and enables the moral agent to take its own responsibilities and be accountable for them.

Keywords
Cancer, communication, diagnosis and prognosis, ethics, interpretative phenomenological analysis, meanings, multi-perspective

Introduction

In Western countries, the process of diagnosis and prognosis-related communication in cancer care is approached as a phenomenon related to information exchanges between patient and clinician and within healthcare professionals, as well as to the relationships occurring among all the speakers, including caregivers.[1] This suggests that quality of health professional–patient communication is linked to the quality of communication and coordination within the team,[2] and that informal caregivers also play a crucial role in managing patients' cancer disease.[3,4] Nevertheless, literature highlights that many clinical contexts are still lacking a good-quality patient–health professional communication regarding end-of-life preferences and prognosis disclosure,[5,6] and information preferences for patients with advanced cancer are still unmet.[7] As information transmission enables patients to make informed choices about their own healthcare, it can be said that, in cancer care, disclosure issue is still an ethically challenging clinical problem. Moreover, although there has been advancement in cancer treatments, cancer is still associated with suffering and death. Perceptions and beliefs surrounding cancer disease still hamper regular interactions and communication.[8,9] There is evidence that the main barriers to effective communication and information sharing are fragmented communication, uncertainty around patient consent and the unacknowledged existence of overlapping care plans.[10] On the contrary, prognostic disclosure has been associated with more realistic patients' expectations of life expectancy,[11] and discussions on prognosis seem to strengthen the relationship between patient and oncologist.[12] Literature has also shown that good collaboration among health professionals is essential for high-quality care[4] and that patient-centred care is enhanced by both good inter-professional communication and acknowledgement of the interdependence of each one's role.[13] However, the perspectives of patients, caregivers, physicians and nurses have been seldom studied all together.[14] Dyadic[15] and triadic[16] communicative interactions have been investigated in some previous qualitative studies, but they limit the analysis to a portion of the context of care. Interpretative phenomenological analysis is a qualitative method used in health-related research to understand human experiences that are essential to the participants. Interpretative phenomenological analysis contributes to move beyond a biomedical model of the disease to get insights about self-reported experiences and the meanings that individuals assign to those experiences.[17] Studies with a multi-perspective design and adopting interpretative phenomenological analysis are quite recent and still few.[14,18] In our research, we focused on the communication experience by investigating simultaneously the perspectives of patients, their caregiver, their attending oncologist and their attending nurse. This study is part of a larger research aimed to explore communication issues related to diagnosis and prognosis in oncological wards.

Aim

This study intended to investigate the phenomenon of diagnosis and prognosis-related communication as experienced by patients, their caregivers, and both their attending nurses and physicians, in order to enlighten the meanings attached to communication by the four groups of participants.

Methods

This study was conducted using an interpretative phenomenological analysis, which is a qualitative research approach that values 'a detailed experiential account of the person's involvement in the context' (p. 196).[19] Interpretative phenomenological analysis allows for catching communication meanings through narration of participants' experiences within a cultural, social and personal world,[19] so, it can be said that the method implies an interpretative approach enriched by descriptive notes.[20] Following interpretative phenomenological analysis philosophical roots – that come from Heidegger's philosophy – meanings are always created through interactions, including those with researchers.[21] According to it, the researchers' preconceived concepts and personal world cannot be kept apart from the investigation, but they can represent a tool to conduct the analysis.[22] On this basis, interpretative phenomenological analysis develops a double-hermeneutic circle where 'the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world' (p. 53).[23] According to the idiographic focus of interpretative phenomenological analysis, this study explores the perspectives of individuals in their unique context of life. Besides, this study adheres to interpretative phenomenological analysis' request to illustrate and describe themes by a rich reporting of excerpts from participants' accounts.[19]

Study inclusion and exclusion criteria

The main inclusion criteria for patients were to be at least 18 years old and being diagnosed with cancer. An inclusion criterion for nurses was attending on the interviewed patient for at least two shifts. An inclusion criterion for physicians was attending on the interviewed patient. Caregivers were selected upon indication of the interviewed patients. General exclusion criteria were to be less than 18 years old and have cognitive impairment.

Study participants

Patients were recruited upon introduction by the interviewer of the research purpose. Eligible nurses and oncologists were purposively enrolled after the patient. Patients were enrolled based on homogeneity of patients' life expectancy of less than 1 year, according to the attending oncologist. This selection criterion for patients was used to pursue a fairly homogeneous sample, as suggested by Smith for interpretative phenomenological analysis studies.[19] Successively, available caregiver was selected and the physician and nurse who attended on the patient during his or her disease trajectory were selected. A total of 24 participants corresponding to six groups of four members each (patient, his or her caregiver, and his or her attending physician and nurse) were recruited. According to Reid and colleagues,[24] exploring a phenomenon from multiple perspectives is a kind of triangulation that can help researchers to develop a more detailed and variegated description of that phenomenon. Nevertheless, this is possible only with a small sample (5–10 participants).[25] Therefore, based on this suggestion, six participants for each role (patients, caregivers, physicians and nurses) are considered as a very good sample.

Table 1 shows the characteristics of the study participants.

Table 1. Summary of participants' characteristics.

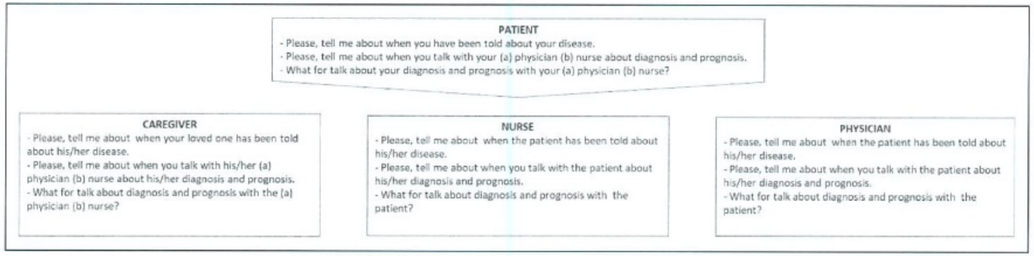
	Patients (n = 6)	Caregivers (n = 6)	Physicians (n = 5)	Nurse (n = 7)
Gender	Man = 4; woman = 2	Man = 0; woman = 6	Man = 2; woman = 3	Man = 1; woman = 6
Age	19 years = 1 56 years = 1 63 years = 1 64 years = 1 65 years = 1 77 years = 1 Average age = 57 years	52 years = 1 55 years = 1 62 years = 1 67 years = 1 68 years = 1 72 years = 1 Average age = 62.7 years	40 years = 1 42 years = 1 45 years = 2 55 years = 1 Average age = 45.4 years	36 years = 1 37 years = 1 46 years = 1 47 years = 1 54 years = 1 58 years = 1 59 years = 1 Average age = 48.1 years
School level	Primary school = 2 Secondary school = 2 Master degree = 2	Primary school = 2 Secondary school = 2 Master degree = 2		
Tenure			Experience as oncologist: 6 years = 1 12 years = 1 16 years = 2 23 years = 1 Average tenure = 14.6 years	Experience in an oncological ward: 3 years = 1 10 years = 2 16 years = 1 19 years = 1 20 years = 1 27 years = 1 Average tenure = 15 years
Cancer type	Breast cancer = 1 Rare cancer = 2 Abdominal cancer = 2 Lung cancer = 1			
Interview length	Minimum: 13 min; maximum: 60 min (mean = 35 min)	Minimum: 12 min; maximum: 48 min (mean = 24 min)	Minimum: 13 min; maximum: 26 min (mean = 17 min)	Minimum: 20 min; maximum: 68 min (mean = 39 min)

Ethical considerations

The study complies with the principles of the Declaration of Helsinki and the Italian Privacy Law (GDPR 679/2016). The study was approved by the Independent Ethics Committee of the Azienda Ospedaliero-Universitaria di Cagliari, Italy (Act n.2.27; 25 July 2016). At the enrolment stage, researchers provided written and oral information about the purpose of the study. Participation was voluntary and anonymous; confidentiality was assured and guaranteed to all participants. All the interviewees gave their written informed consent and were informed that they could leave the study at any time without penalty. Pseudonyms were used for all patients in order to preserve anonymity. Moreover, the researchers paid attention to the participant's emotional status and respected it by shortening and finishing the interviews when needed.

Data collection procedure

The study was conducted in two oncology departments of two big hospitals from southern Italy. Narrative interviews were carried out in the departments in which the patients were treated. A researcher expert on the topic performed interviews from August 2016 to February 2017. A set of interview guiding questions was developed (see Figure 1), based on previous pilot interviews; questions were used very flexibly in order to



PATIENT

- Please, tell me about when you have been told about your disease.
- Please, tell me about when you talk with your (a) physician (b) nurse about diagnosis and prognosis.
- What for talk about your diagnosis and prognosis with your (a) physician (b) nurse?

CAREGIVER

- Please, tell me about when your loved one has been told about his/her disease.
- Please, tell me about when you talk with his/her (a) physician (b) nurse about his/her diagnosis and prognosis.
- What for talk about diagnosis and prognosis with the (a) physician (b) nurse?

NURSE

- Please, tell me about when the patient has been told about his/her disease.
- Please, tell me about when you talk with the patient about his/her diagnosis and prognosis.
- What for talk about diagnosis and prognosis with the patient?

PHYSICIAN

- Please, tell me about when the patient has been told about his/her disease.
- Please, tell me about when you talk with the patient about his/her diagnosis and prognosis.
- What for talk about diagnosis and prognosis with the patient?

Figure 1. Interview guide questions for the different participants.

elicit the participant's experience. Prompt questions were used to encourage the interviewees to elaborate their thought based on their experience. All the performed interviews were audio recorded and verbatim transcribed, including a brief description of non-verbal aspects of the interviewees.

The patient was always the first one to be interviewed, but it was not always possible to follow a scheduled sequence for the other participants of the subgroup, because of their unpredictable temporary unavailability. In any case, all the four parties of each subgroup were interviewed within 2 or 3 days from each other, except for one group in which the interview time span was of 3 weeks, due to organizational problems. In a case, two nurses who attended on the same patient desired to be interviewed at the same time; all the other interviews were conducted separately. During the recruitment process, one physician refused to be part of the study. Thus, our final sample of 24 participants included six patients, six caregivers, seven nurses and five physicians.

Data analysis and rigour

Data analysis was conducted according to the procedure indicated by Smith et al.[19] for interpretative phenomenological analysis studies. According to this procedure, an inductive approach has been used to process data. In a first step, each researcher did an attentive reading of each transcript following the interviews' chronological order for each group unit (patient, caregiver, nurse and physician). Second, once an overall sense of the data was gained, each researcher wrote initial textual notes describing any relevant issue; in the following step, emergent themes were developed by each researcher, via abductive reasoning. In a fourth step, the researchers looked for connections across emergent themes; this process included a first analysis in which data from each participant were analysed separately, and then they were analysed for each group unit and across the group units. This process intended to privilege the comparison of the four parties across the six groups and, at the same time, safeguard the connection of the four participants at the group level. Moreover, it allowed the researchers to better interpret each single part in relation to the whole and vice versa. Until this point, the researchers proceeded separately: each researcher produced a list of few main themes. Then, the researchers met and triangulated their findings conciliating them by retracing back all the previous steps. This final discussion allowed the researchers to identify the final main themes, by following a subsumption process. In fact, according to Brocki and Wearden,[17] in contrast with content analysis that produces 'a quantitative analysis of discrete categories from qualitative data', in interpretative phenomenological analysis 'the importance of the narrative portrayal is dominant', and its aim is to provide 'a detailed interpretative analysis of themes' (p. 99).

Data analysis was supported by using Atlas.ti version 7.5.7. To achieve credibility, a constant engagement with the data was maintained throughout the entire data analysis process and a rich amount of interview quotes has been provided. Confirmability was attained through triangulation of all the steps of data analysis by the researchers. Transparency was achieved by highlighting the study's challenges and difficulties.

Researchers also paid attention to self-reflexivity with respect to their own values and orientation, as it is required by interpretative phenomenological analysis method. The multi-disciplinary team fostered comparison of their personal and professional background and the attention on how those could influence on different phases of the study. Moreover, the researchers have background and expertise adequate to conduct this kind of study and to manage potential method bias. Specifically, P.M. is an expert clinical nurse, she also earnt her master degree in Philosophy and worked for many years with people with cancer. C.I.A.G. is an expert clinical nurse and worked in mental health contexts. M.G. is psychologist and associate professor in Nursing. She is PhD and expert of quantitative e qualitative research. M.F.J.H. is associate professor in Nursing. She is PhD and expert in bioethics. P.C. is full professor, PhD and expert of research in Health Promotion. Almost all the researchers have been also caregivers of a close relative affected by cancer.

Operational tools used to foster self-reflexivity were (a) field note – taken after interviews – including reflections on both feelings and emotions of the interviewer, which were commented with the other researchers during the data analysis procedure, and (b) audits conducted among the researchers during the different phases of the study.

Results

The results have identified three main themes: (a) the infinite range of possibilities in knowing and willing to know, (b) communication with the patient as a conflicting situation and (c) the bind of implicit and explicit meaning of communication. The first theme is represented in all the four parties and describes the mix up of cognitive and emotional reactions arousing communication related to diagnosis and prognosis. The second theme is related to the role of health professionals: how nurses and physicians interpret their role and how the patient and his or her caregiver perceive it. The third theme concerns an experience of communication as expression of a personal and intimate world. This theme takes shape in patients and caregivers as a silent but expected request of recognizance of the existential dimension, and it emerges in nurses and physicians as a fundamental part of care and cure relationship. Figure 2 summarizes main perspectives of the four participants for each theme.

The infinite range of possibilities in knowing and willing to know

Patients and caregivers describe their experience about diagnosis and prognosis-related communication as an experience that admits an infinite range of possibilities in knowing and in the will to know. Angelo, Daniela and Nella, in fact, describe themselves both as informed and uninformed, willing to be informed and wanting to know no more. Nella, different from the other two patients who were diagnosed few months ago, is under treatment since almost 2 years, she values a lot her autonomy and admits that what cost her the most is to ask for help, she also recognizes to have contrasting feelings and attitude towards communication and information transmission and says,

> The results (for my examinations) were always picked up by me, I read them, but I don't understand them and I ask the doctor [. . .] I mean [. . .] I don't want to understand them; it's not that I don't understand them, that's different.

Daniela, who – according to her caregiver – should well understand her health status because she has a high school–level education, declares a willing to know and recalls all the questions she already asked the doctors; she refers to have always received a proper answer, but she recognizes that all those questions are not so significant and concludes,

> Even now [. . .] I don't find the courage to ask it [. . .] maybe one day I will try to ask it to my oncologist.

Some other patients, like Sergio, Piero and Mario, present their decision to receive limited medical information as a shared decision with their oncologists and relatives. Mario, who is very young, is aware that he does not exactly know what is happening to his body, but he values this ignorance as the price to 'stay calm'. He knows that his disease is a very serious one: he tells that he has been diagnosed more than 2 years ago and has undergone several chemo treatments. He explains his choice like this:

> I prefer to be like this [. . .] because if I would know more I would have more worries . . . and maybe this could worsen my condition [. . .] maybe [. . .] better not to know anything and have minimal details that only can reassure.

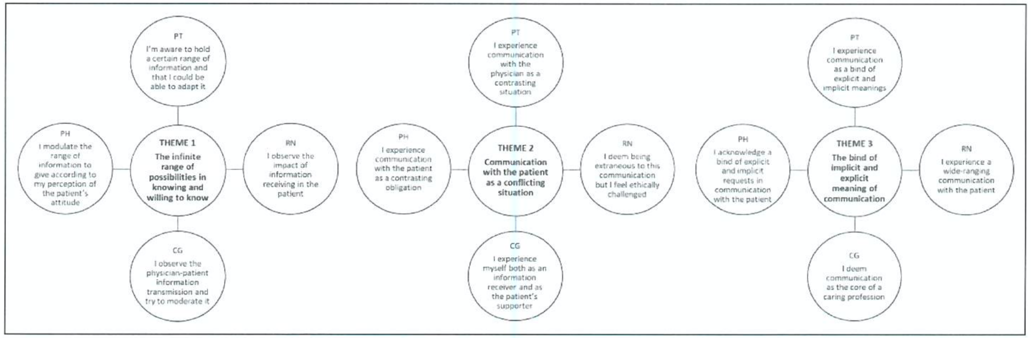


Figure 2. Summary of the perspectives emerged from the four parties for each theme.
PT: patient; RN: registered nurse; CG: caregiver; PH: physician.

Other patients, like Sergio, who is already retired, show difficulty to conciliate what they have been told and what they know. He is attending the oncological ward since few months and concludes his interview by saying,

> Sooner or later, I should know the truth, only that [. . .] I'm afraid of truth [. . .] do you understand?

But previously he had already admitted that

> They [the doctors] said me that [. . .] they told me clearly [. . .] do you understand? He called me in his office – there was my wife too – and when he said it [. . .] the world fell on me! Do you understand?

Many caregivers also describe communication related to diagnosis and prognosis as an experience of contrasting willing and feelings and as a knowledge not possible to confine into the opposite poles of knowing or not knowing. Nella's caregiver describes her loved one's attitude towards communication as the display of contrasting behaviours, but she does not interpret it as an inconsistency:

> Of course there is an inconsistency [. . .] but I'm not sure whether it is an inconsistency; you would like to know more and more because you would like to discover that [. . .] your worries are excessive [. . .] that after all [. . .] the situation can be seen in a [. . .] way . . . , but if you are searching more, you're afraid to discover the contrary. So, you prefer to stay in a limbo in which you would like to know, but you can't.

Caregivers recognize that patient needs to know what is happening, but at the same time, they underlie that patient also seeks and needs continuous reassurance. In the caregivers' stories, the patient's character and the emotional costs of knowledge appear to be important factors to understand the patient's attitudes and to decide which communication approach is more suited for him or her. Angelo's caregiver declares that her loved one and she are perfectly aware of the seriousness of his health conditions because they were informed of the advanced stage of his disease by the oncologist. Nevertheless, to the question if she considers it is better to know or not to know, she answers,

> I don't know, I don't know: knowing too much is upsetting, but maybe knowing too little is also upsetting. Who can say which the right measure is? In between knowing and not knowing there are an infinite range of possibilities.

The theme of the various degree of knowledge emerges in physicians' narratives (and in some of the interviewed nurses) either as the patient's capacity to understand the real meaning of the information received by physicians or a partial information received by them. Physicians refer this capacity as the patient's will to confront himself or herself with bad news. Concerning that point, Sergio's physician says,

> It has been the head physician to tell him that the surgery he underwent couldn't eradicate the tumour. Therefore, he knows the diagnosis, namely a disease that is not cured by the surgery but that is still there and that is a quite severe disease, because his liver has been affected. I told him that he had to be treated just by chemo and by oral therapy. So, it has not been told anything unreal [. . .] if one should tell all and everything [. . .] I don't believe that this would be the rightest thing to do [. . .] I don't know [. . .] anyway, the patient understands what he wants to understand! Anyway, the patient was thoroughly informed of the disease.

In addition, Piero's and Sergio's nurses consider awareness disconnected by any kind of intellectual capacity. Piero's nurse is working in an oncological ward since many years; she loves to talk with patients and thinks that almost all her patients know their diagnosis but, at the meantime, notices,

> In our ward there were physicians that didn't understand any (!) [. . .] I mean, once they have become patient, they, that were physicians and nurses [. . .] well, once they were admitted in our ward, they forgot to be physicians, they forgot all the staff they studied [. . .] like if they knew nothing.

Communication with the patient as a conflicting situation

The interviewed physicians talk about their communication approach as an information-giving to let the patients know what is going on: the diagnosis and the therapeutic course they should undergo. This information transmission is perceived as something that they need to modulate because it is also a potential harm to patients' psychological well-being. This position is well presented by Mario's physicians, an expert oncologist, who explains his communication approach with his young patient:

> I believe that we have been quite detailed [. . .] in one case and in the other, that is both towards the patient and towards his relatives. It is a situation in which the psychological implications are very heavy [. . .] and [. . .] the [. . .] let's say that the fuzziness that we have maintained in providing information to the patient is motivated by the need not to create an excessive psychological distress that could lead him to dismiss therapy.

On this basis, physicians consider as a duty to inform the patient about his or her diagnosis, but they also maintain that it is upon them to decide, case by case, the extension and the timing of information. They declare to generally conform to the norm to inform the patients in order to obtain their informed consent to therapies, but they also take into account that knowledge has the power to provoke huge emotional reactions such as hope or despair. These reactions are deemed a big resource or, vice versa, an insurmountable obstacle to treat and cure the patient. A practice solution adopted by most physicians to both preserve hope in patients and fulfil their duty to inform the patients is to avoid talking about prognosis if not requested. The conflictual situation is so approached by Daniela's physicians:

> I think it's essential to know [. . .] but it's evident that not anybody can bear the information so I think information should be, how to say it, adjusted upon emotional sensitivity, upon the patient's capacity to manage this kind of information but, anyway information should be given to patients in a complete way, absolutely! but one can be less explicit about prognosis, especially with regard to the advanced stages of the illness.

Only Nella's physician, by highlighting a correspondence between the missed knowledge of prognosis by the patient and the missed knowledge of the patient's will about end-of-life care by the physician, speaks of physicians' ethical responsibility in conciliating contrasting urgencies and needs implicated in diagnosis and prognosis-related communication. She explains,

> [. . .] what is still problematic [to make the patient understand] [. . .] is the choice [. . .] between not to do anything, because actually there is no chance to get anything better and therefore [. . .] just to undergo palliative care, or undergo therapies until the last days. This issue, perhaps, was not faced with my patient. In some patients, this may be due to a communication problem, I mean, the difficulty to make the patient understand it and help him/her to make an aware choice, while preserving his/her dignity.

All the nurses state that they usually do not investigate if the patient knows or does not know his or her diagnosis and prognosis. Nurses even declare that they do not start conversations somehow related to diagnosis and prognosis because this issue is not their business but physicians'. They also recognize that patients and relatives not always receive appropriate information about both prognosis and life expectancy and observe that this hampers patients' faculty to decide about end-of-life treatments. Nurses believe that their role is limited to support patients' positive state of mind and not to investigate or modify patients' knowledge or awareness about their diagnosis and prognosis. Mario's young nurse, although she would prefer to know what the patient knows about own diagnosis and prognosis, shares that opinion as well. She explains,

> What do you want me to do more than encourage him somehow(?), that is, I would never feel like actually saying how things are or how . . . because in any case it's not my job and therefore not . . .

Yet, all the nurses report to have been addressed by patients and caregivers' questions about life expectancy, treatment efficacy, terminal care and so on. Nurses' narratives are also plenty of anecdotes about patients' awareness and considerations about communication related to diagnosis and prognosis. Piero's nurse affirms to conform to the norm that she was taught when she was a young nurse: never to talk to the patient about his or her disease but, then goes along telling,

> . . . someone tells you 'I'm undergoing treatments, but I know that they don't work' Yes! It happens! There are patients that do like that. It happened to me that a patient told like that and I replayed 'Why do you follow treatment, then?' . . . 'Who knows??!! Just to try it, but anyway I know that they don't [. . .] that this time, this time it's not going to be fine for me'.

Nurses generally perceive disclosure, when prognosis is fatal, as an ambivalent value: a positive value because it allows patients to decide about their own life and a negative one because it is incompatible with maintaining hope. The perceived ambivalent value of knowledge sustains an experience of communication related to disclosure as a conflict between being truthful or dishonest, an unsolvable alternative between being virtuous or supporting patients' hope. Angelo's nurse, in commenting her own answer to a patient who asked her if she was going to die, explains,

> If I had said the truth, what would be changed? I would have increased her distress and she would have lived her last days more distressed. I felt guilty because I lied. [. . .] I said to myself: 'liar!' But, in that moment, it was for me the only way to calm her.

Patients experience communication to their physicians as mere information about diagnostic exams: an update about disease evolution and an explanation of the proposed therapies. However, all the patients refer to have received some form of reassurance, together with information by their oncologist. Moreover, most of them retain that the wishful amount of talking and the actual talking with the attending physician is barely coextensive.

Patients with the highest school degrees as well as those with low education note that physicians use an adapted language to inform them about diagnosis and seriousness of the disease. Piero says,

> They are very delicate; they don't tell 'you have cancer' they can never tell it to you! They use terms that we, common people . . . they use terms that I don't know.

Although patients seem to expect that the physician do not spontaneously tell the patient everything, they feel to determine the amount of information they desire to receive by asking or refraining from asking specific questions, and feel confident to receive trustworthy information from their physicians. This is evident, for example, in Daniela who tells of when she asked to a physician if she would have been able to walk again:

> She [the physician] told me it! [. . .] maybe because they [physicians] too want to tell the truth! Times have changed and they don't hide it to the patient anymore. I do agree with it, maybe if I were them, I'll do the same thing.

Overall, patients experience communication to their nurses as something that appears to be withheld by the patients themselves. They do not identify an obstacle in nurses' attitude – who usually are described as polite and kind – but they justify this missed communication by blaming themselves to not want to talk about or by telling that nurses are too busy to do it. Nella refers to have never had a real conversation with nurses and thinks that most of them are not interested in listening patients' story. She says,

> [. . .] because if they had also to bear a patient's problems . . . because here patients are patients who you meet today and in a few days you could meet them no more . . . and if they should put themselves in each patient else's shoes, I think it would be too hard to do as a job.

According to the patients' report, most of their communication interactions with nurses regard explanations about the therapies. No patient tells about conversations started by a nurse. Piero is very explicit about it:

> [. . .] no, not with nurses. First of all, they don't talk. They put on drips, they do things, up and down, they don't know these things [disease, diagnosis and prognosis]: they have documents, they have to administer, timetable [therapies] [. . .] but I'm not one who bothers nurses.

All the caregivers refer themselves as information receivers. They refer to stay close to their loved one when information is given and to act on their behalf. They appear to be aware with regard to the physicians' attitude to refrain from giving explicit and detailed information to the patient. Caregivers tend to support this stance because it can protect the patient from despair. However, they feel allowed to advice physicians about the communication approach they consider most suitable for their loved one. Piero's caregiver says,

> They [the physicians] have been very delicate, also because we've told them [. . .] because he's a very emotional person, so we advised the physicians [. . .] to be very delicate in informing him [the patient] about the severity of the disease.

The bind of implicit and explicit meaning of communication

In Angelo's and Nella's narratives, diagnosis and prognosis communication emerge as a dense bind of implicit and explicit meanings to which participants are sensible and, in the meantime, constantly exposed. Angelo's narrative is the most explicit: he says that since he has known his diagnosis, his main question is 'what is happening to me?' He knows he has 'cancer', his oncologist told him, but that is not enough to him. He thinks that no medical terms used by physicians can answer to his question and that the medical usual way to talk about the disease is just a veil that hides the real issues at stake. He says,

> We all keep these things at a distance because we can't live asking always those questions. This is just a way to solve the problem, to give an answer also for who we are, where we come from, where we are going. But these are questions that are never asked or are asked in a banal form.

The unspoken existential meaning of 'those questions' can be found, according to Angelo, in those caring actions – such as changing the diaper to an adult man – that he names 'spontaneous communication forms', and that he considers as

> Not much different from an intimate contact, namely, a spiritual contact with [. . .], with our biggest worries.

Piero's, Mario's and Angelo's nurses point out that their communication with patients is something that often encompasses topics related to personal values and existential meanings and that can be realized through attentive listening, gazes and touching.

According to these nurses, it is by providing direct care that they have opportunity to know the patients and their attitude towards the disease and, sometimes, to understand their awareness of diagnosis and prognosis. The other nurses too, describe their conversation with the patient as something that goes on while performing nursing procedures. Nevertheless, nurses also admit that nowadays they are evermore neglecting to provide direct care because of both bureaucracy burden and time constraints and because of fragmentation of the care among different health workers as well. A tendency that nurses dislike and that the older nurses compare to the past when, as Piero's nurse says:

> The bed rounds somehow forced you to talk, talk not just of the disease, if they knew their health condition, but [. . .] sometimes they were saying [. . .] talking about themselves, of their home business, of their children, do you see? We used to spend time with them, and they were pleased to talk with us.

The perceived bond between not-explicit request of information and implicit will to not knowing one's own prognosis is the result of a reasoning that physicians adopt to justify their refraining from prognosis disclosure. Based on this reasoning, Angelo's, Sergio's and Daniela's physicians believe to respect the patients' autonomy and, at the meantime, to preserve them from an avoidable psychological suffering. Daniela's oncologist declares,

> The principle that guides information transmission is that [. . .], every person who undergoes therapy, every kind of therapy, has to be the one to decide if he/she wants to undergo to it or don't. He/she has to be informed to be able to decide [what to do].

However, when it comes to ask what he thinks regarding his patients' awareness about prognosis, he says,

> I don't think she is [aware], she has asked nothing, so it was said nothing about prognosis [. . .], but it has been emphasised that her disease was in an advanced stage and that our aim was to slow down the disease.

Nella's caregiver notes that the capacity to enter into an authentic relationship with the patient, understanding his or her feelings and how the disease is affecting his or her life, is meaningful not only for the patient but also for the attending healthcare professional, as it permits to go beyond the mere technical function. This capacity, according to Nella's caregiver, is the core of a healthcarer's role and, when this is not there

> The importance of that figure [the healthcare professional] during a patient's disease trajectory could have no weight and the ill person could consider him/her simply as an instrument.

Discussion

This study aimed to explore the experience of patients, caregivers, nurses and physicians on diagnosis and prognosis-related communication with respect to the connected meanings. In the oncological literature, there are not many studies adopting a multi-perspective design,[14] but this kind of design allows for considering the context of relationships in which disease and care are experienced.[26] Moreover, looking at how meanings are attributed and interwoven allows for seeing and comparing the different moral perspectives on diagnosis and prognosis-related communication embraced by the four figures participating in the study. Our findings show that all the participants are involved in and feel affected by diagnosis and prognosis-related communication. The context of diagnosis and prognosis-related communication appear to be characterized by contradictory perceptions and fragmented experiences in which individuals struggle to rearrange their ideas and their values. Patients' contradictory statements emerged also in Ohnsorge et al.'s[27] study that investigated the wish to die in hospice cancer patients. The authors suggested that conflicting values and aims could be considered as belonging to the process of meaning-making and negotiation about normative claims, namely, those statements that 'directly or indirectly include moral claims regarding oneself or others' (p. 630).[27] In our study, the contradictory and fragmented process of meaning-making seems to involve all the four parties interviewed and to go beyond the normative claims. Contradictions and fragmented processes emerge from the patients' narratives with respect to knowledge, feelings, expectations and will to know. Nurses too refer contradictions with respect to the perception of patients' information needs. Physicians use contrasting adjectives to describe their giving-information to patients and point out that they usually face conversations about diagnosis and prognosis just according to a therapeutic perspective. In addition, nurses are aware of being addressed by patients and caregivers in conversations related to diagnosis and prognosis. However, in the meantime, they retain that this is not their issue. This is coherent with patients' and caregivers' opinions as well: they refer no communication interactions with nurses about diagnosis and prognosis-related issues. This missed communication seem to be linked to both the stereotype of the common Italian nurse[28] – who does not speak about diagnosis and prognosis with patients, because they are only medical competencies – and the patients' perception of being an emotional burden for nurses. We think that these aspects can limit the interactions between nurse and patient and nurse and physician, and deserve to be attentively addressed by nurses because they represent a main ethical challenge for a caring profession. Chiefly, the lack of appropriate communication between patient and nurses may lead to unrecognized and unsatisfied patients' needs and to increased risk of litigation based on what is called ethical malpractice.[29] Ambivalence is perceived by the participants as knowledge's ethical trait and not just as a feature of patients' unstable wishes and expectations. In fact, the vision of what will happen – induced by the knowledge – appears to participants as both empowering and disempowering for the patient. In our study, not all patients declared willing to have prognostic information, some did not express his or her will and some expressed an ambivalent will. These data expand what was found by Innes and Payne[30] in their review according to which most of the patients wanted some broad indication of their prognosis, but that preferences for detailed information were more varied. Our data are also concordant with Kirk et al.'s[31] findings that enlighten patients' ambiguous attitude towards information: they wanted to be told but they did not want to know at the meantime. In those patients who expressed the preference to not to investigate further on their own prognosis, knowledge appears to be a competing value for self-control over their own emotions. The patients' different attitudes and priorities regarding disclosure highlight the ethical importance to provide a personalized diagnosis and prognosis communication in accordance with each single person needs. On health professional side, we observed a physician's tendency to not deepening prognosis aspects in order to save the patient's hope; this is a phenomenon well known in literature.[32,33] The observed tendency appears to be a controversial situation in which physicians theoretically declare to be favourable to the opportunity to communicate the truth to patients, but at the same time, they conform to the ethical norm in a flexible way and based on the context and situation. Overall, physicians tend to draw upon principles of biomedical ethics to construct arguments for their communication approach on diagnosis and prognosis. Physicians' readiness to make exceptions to the proclaimed norm – depending on patient characteristics – seems to be a not unusual finding in so-called high-context cultures, such as those of the Mediterranean basin.[34] Our findings are also in line with those of another Italian study that enlightened a discordance between ethical principles declared by health professionals and communication approaches with patients.[35] While physicians in their communicative approach seem to refer to the two ethical principles 'do good' and 'do not harm', without perceiving their behaviour as conflictual, nurses seem to refer to the virtue ethics, perceiving their involvement in communication related to diagnosis and prognosis as an unsolvable dilemma between being truthful and being supportive and reassuring for patients. This reveals, on one hand, the nurses' strong sense of ethical commitment towards the patients in staying close to them. On the other hand, it emphasizes the difficulty to accompany the patients along their path of awareness of the prognosis and prepare them for the end of life. This conflicting attitude and unconciliated ethical calls can obstruct care relationship between nurse and patient. Health professionals stuck in the conflict between contrasting ethical norms were also observed in previous studies.[36,37] Oberle and Hughes[38] already found that the key difference between doctors' and nurses' perceptions about ethical problems in end-of-life decisions was that doctors felt responsible for making decisions and nurses perceived themselves forced to live with these decisions. In our study, this condition is manifest also in nurses' worries and precautions not to trespass professionals' boundaries or to give information and, at the meantime, in their attention to patients' communication needs. Besides, the assumption of responsibilities on diagnosis and prognosis-related communication appears quite different between physicians and nurses. Nurses, in fact, tend to dismiss any responsibility, considering communication related to diagnosis and prognosis as a physician's duty. Although in participants' narratives, communication related to diagnosis and prognosis is often framed by the medical information pattern, participants refer their communication experience as going beyond the simple information receiving/transmitting scheme. Professionals and informal caregivers, in fact, underlie the importance to pay attention on what is beyond the first explicit meaning in the patient's words and catch the real inner meaning that become comprehensible through sensitivity and the relationship established with the patient. Nurses experience this kind of communication not only as a form of holistic attention to the person, but also as personal attitude, at the boundary of their own professional role. Vice versa, for patients and caregivers, it is paying attention to the person and not just to his or her health problems that is accomplished by the authentic nature of nurse and physician profession. The existential dimension referred by all the participants describes the ethical background in which communication is perceived: the respect of the individual dimension is at the core of any caring relationship. This finding expands what is already emerged in literature: in medical communication, not only information aspects are considered relevant but also physicians' caring attitudes.[39,40] Patients and family members expect health professionals to be able to deal also with not strictly medical issues.[41]

Strengths and limitations

The present research has encountered several difficulties. First, the patients' clinical conditions and the timing of ordinary care impacted the average length of the interviews. Second, nurses and physician constraint of time caused many unattended appointments for interviews, thus prolonging the phase of data collection. There are also some study limitations: doctors' point of view was less represented if compared with that of nurses. This is because one of the attending physicians changed idea and refused to be interviewed. Another limitation is that caregivers were represented only by the female gender. This is because, during the recruitment process, we asked patients to freely select a significant caregiver for them, thus resulting in a prevalence of women among caregivers. Furthermore, the difficulty of recruiting groups of four interrelated participants (patient, his or her caregiver, and attending nurse and physician) implicated that the selected sample of patients was homogeneous regarding life expectancy, but their disease-related experiences could be quite heterogeneous, also in the last year of life. Moreover, available staff in the departments was not so numerous and not all the oncologists and nurses showed interest in participating in the research. For these reasons, we were not able to reach data saturation for all the perspectives because, in line with Dickie,[42] 'there was always new information to be had' (p. 52). This limitation, together with contextual problems, reduces generalizability of our results. Nevertheless, this study adds important experiential considerations to the existing research that usually considers only bi-directional aspects of clinical communication. In fact, in our study, we investigated both shared and distinct perspectives of the four participant parties, which is an additional value for qualitative research.

Conclusion

Our study shows that diagnosis and prognosis-related communication, when prognosis is fatal, is experienced by patients and caregivers as a puzzle of contrasting perceptions and feelings by physicians and nurses as a scenario of concurrent and conflictual values. Moreover, the perceived bind of explicit and implicit meaning in communication underlies the importance of the existential level and the significance of the relationship among carers and cared. The interplay of meanings attached by patients, their caregivers, and their attending oncologists and nurses to diagnosis and prognosis-related communication has revealed complexities and ambiguities not yet settled. Physicians still need to resolve the ethical tensions present in diagnosis and prognosis-related communication. Oncologists find themselves at an impasse when they have to 'make the patient understand' that 'there is no chance to get anything better' and when they should 'help him or her to make an aware choice, while preserving his or her dignity'. We suggest that physicians, in their effort to provide realistic and patient-tailored information, can be more able to prefigure hope through different means than just the cure; collaboration may be sought from caregivers and from nursing staff. Nurses should address and reflect upon the fact that they perceive their role extraneous to diagnosis and prognosis-related communication but, at the same time, they prefer to be involved by patients and caregivers in similar conversations, thus owing them support and truthfulness. This implies that nurses need to develop awareness and reflect upon their role in communication related to diagnosis and prognosis. Awareness and reflection about everyone's role and influence in the communication interplay is essential not just to assure consistency of communication within the multi-disciplinary team but mostly because it allows and enables the moral agent to take its own responsibilities and be accountable for them. Reflection upon the meaning that patients and caregivers attach to communication related to diagnosis and prognosis could be helpful for assisting nurses and physicians to provide sensitive care and to prompt a personalized communication approach.

Acknowledgements

The research team would like to thank Tanya Castagna for her invaluable contribution in reviewing the manuscript for English language considerations.

Conflict of interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

ORCID iD

Maura Galletta https://orcid.org/0000-0002-0124-4248

References

1. Arraras JI, Greimel E, Chie WC, et al. Information disclosure to cancer patients: EORTC QLQ-INFO25 questionnaire. *Expert Rev Pharmacoecon Outcomes Res* 2011; 11(3): 281–286.

2. Dobrozsi S, Trowbridge A, Mack JW, et al. Effective communication for newly diagnosed pediatric patients with cancer: considerations for the patients, family members, providers, and multidisciplinary team. *Am Soc Clin Oncol Educ Book* 2019; 39: 573–581.
3. Abazari P, Taleghani F, Hematti S, et al. Exploring perceptions and preferences of patients, families, physicians, and nurses regarding cancer disclosure: a descriptive qualitative study. *Support Care Cancer* 2016; 24(11): 4651–4659.
4. Villalobos M, Coulibaly K, Krug K, et al. A longitudinal communication approach in advanced lung cancer: a qualitative study of patients', relatives' and staff's perspectives. *Eur J Cancer Care (Engl)* 2018; 27(2): e12794.
5. Covvey JR, Kamal KM, Gorse EE, et al. Barriers and facilitators to shared decision-making in oncology: a systematic review of the literature. *Support Care Cancer* 2019; 27(5): 1613–1637.
6. Robinson JD and Jagsi R. Physician-patient communication – an actionable target for reducing overly aggressive care near the end of life. *JAMA Oncol* 2016; 2(11): 1407–1408.
7. Shin DW, Cho J, Kim SY, et al. Patients' and family caregivers' understanding of the cancer stage, treatment goal, and chance of cure: a study with patient-caregiver-physician triad. *Psychooncology* 2018; 27(1): 106–113.
8. Campagne DM. Cancer: communicating the diagnosis and prognosis. *Semergen* 2019; 45(4): 273–283.
9. Vehling S, Malfitano C, Shnall J, et al. A concept map of death related anxieties in patients with advanced cancer. *BMJ Support Palliat Care* 2017; 7(4): 427–434.
10. Lawn S, Delany T, Sweet L, et al. Barriers and enablers to good communication and information-sharing practices in care planning for chronic condition management. *Aust J Prim Health* 2015; 21(1): 84–89.
11. Enzinger AC, Zhang B, Schrag D, et al. Outcomes of prognostic disclosure: associations with prognostic understanding, distress, and relationship with physician among patients with advanced cancer. *J Clin Oncol* 2015; 33(32): 3809–3816.
12. Fenton JJ, Duberstein PR, Kravitz RL, et al. Impact of prognostic discussions on the patient-physician relationship: prospective cohort study. *J Clinical Oncol* 2018(36): 225–231.
13. Bennett AH, Hassinger JA, Martin LA, et al. Developing patient-centered teams: the role of sharing stories about patients and patient care. *Fam Syst Health* 2015; 33(3): 203–212.
14. Orri M, Sibeoni J, Bousquet G, et al. Crossing the perspectives of patients, families, and physicians on cancer treatment: a qualitative study. *Oncotarget* 2017; 8(13): 22113–22122.
15. Opsomer S, Joossens S, De Wit C, et al. Losing health symbols because of nutrition-related problems in advanced cancer: an interpretative phenomenological analysis. *J Hosp Palliat Nurs* 2018; 20(5): 492–499.
16. Towsley GL, Hirschman KB and Madden C. Conversations about end of life: perspectives of nursing home residents, family, and staff. *J Palliat Med* 2015; 18(5): 421–428.
17. Brocki J and Wearden A. A critical evaluation of the use of interpretative phenomenological analysis (IPA). *Health Psychol* 2006; 21(1): 87–108.
18. Orri M, Sibeoni J, Labey M, et al. Qualitative approach to patient-reported outcomes in oncology: protocol of a French study. *BMJ Open* 2015; 5(7): e008042.
19. Smith JA, Flowers P and Larkin M. *Interpretative phenomenological analysis: theory, method and research*. London: SAGE, 2009.
20. Pietkiewicz I and Smith JA. A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. *Czasopismo Psychologiczne* 2012; 18: 361–369, https://www.researchgate.net/publication/263767248 (accessed 21 August 2016).
21. Lopez KA and Willis DG. Descriptive versus interpretive phenomenology: their contributions to nursing knowledge. *Qual Health Res* 2004; 14(5): 726–735.
22. Reiners GM. Understanding the differences between Husserl's (descriptive) and Heidegger's (interpretive) phenomenological research. *J Nurs Care* 2012; 1: 5.
23. Smith J and Osborn M. Interpretative phenomenological analysis. In: Smith JA (ed) *Qualitative psychology: a practical guide to research methods*. 2nd ed. London: SAGE, 2008, p. 53.

24. Reid K, Paul F and Larkin M. Exploring lived experience. *Psychologist* 2005; 18(1): 20–23.
25. Smith JA. Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qual Res Psychol* 2004; 1: 39–54.
26. Spira M and Kenemore E. Cancer as a life transition: a relational approach to cancer wellness in women. *Clin Soc Work J* 2002; 30: 173–186.
27. Ohnsorge K, Keller HR, Widdershoven GA, et al. 'Ambivalence' at the end of life: how to understand patients' wishes ethically. *Nurs Ethics* 2012; 19(5): 629–641.
28. Gradellini C, Idamou S and Lusetti S. Nursing between ethic and aesthetic. *Prof Inferm* 2013; 66(1): 32–38.
29. Fallowfield L and Jenkins V. Communicating sad, bad, and difficult news in medicine. *Lancet* 2004; 363(9405): 312–319.
30. Innes S and Payne S. Advanced cancer patients' prognostic information preferences: a review. *Palliat Med* 2009; 23(1): 29–39.
31. Kirk P, Kirk I and Kristjanson LJ. What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *BMJ* 2004; 328: 7452.
32. Hancock K, Clayton JM, Parker SM, et al. Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliat Med* 2007; 21(6): 507–517.
33. Tuckett AG. Truth-telling in clinical practice and the arguments for and against: a review of the literature. *Nurs Ethics* 2004; 11(5): 500–513.
34. Rodriguez Del Pozo P, Fins JJ, Helmy I, et al. Truth-telling and cancer diagnoses: physician attitudes and practices in Qatar. *Oncologist* 2012; 17(11): 1469–1474.
35. Di Giacomo P, Mariotti A, Vignali , et al. Awareness of diagnosis and prognosis in patients with unfavourable prognosis perception of the attitudes of a group of doctors and nurses. *Prof Inferm* 2012; 65(3): 143–153.
36. Buiting HM, Rurup ML, Wijsbek H, et al. Understanding provision of chemotherapy to patients with end stage cancer: qualitative interview study. *BMJ Support Palliat Care* 2011; 1: 33–41.
37. Wagner JY, Wuensch A, Friess H, et al. Surgeon-patient communication in oncology. *Eur J Cancer Care (Engl)* 2014; 23(5): 585–593.
38. Oberle K and Hughes D. Doctors' and nurses' perceptions of ethical problems in end-of-life decisions. *J Adv Nurs* 2001; 33(6): 707–715.
39. De Valck C, Bensing J, Bruynooghe R, et al. Cure-oriented versus care-oriented attitudes in medicine. *Patient Educ Couns* 2001; 45(2): 119–126.
40. Mallinger JB, Griggs JJ and Shields CG. Patient-centered care and breast cancer survivors' satisfaction with information. *Patient Educ Couns* 2005; 57(3): 342–349.
41. Michie S, Miles J and Weinman J. Patient-centredness in chronic illness: what is it and does it matter. *Patient Educ Couns* 2003; 51(3): 197–206.
42. Dickie VA. Data analysis in qualitative research: a plea for sharing the magic and the effort. *Am J Occup Ther* 2003; 57(1): 49–56.

Addendum n.7:

Original Article

European Journal of Oncology Nursing xxx (xxxx) xxx-xxx

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: http://ees.elsevier.com

Experiencing communication related to knowing cancer diagnosis and prognosis: A multi-perspective interpretative phenomenological study

Paola Melis[a], Maura Galletta[b,*], Cesar Ivan Aviles Gonzalez[c], Paolo Contu[b], Maria Francisca Jimenez Herrera[a]

[a] *Departament d'Infermeria, Universitat Rovira i Virgili, Tarragona, Spain*
[b] *Department of Medical Sciences and Public Health, University of Cagliari, Italy*
[c] *Anesthesia and Intensive Care Department, University of Cagliari, Italy*

ARTICLE INFO

Keywords
Communication
Cancer diagnosis and prognosis knowledge
Interpretative phenomenological analysis
Multi-perspective study

ABSTRACT

Purpose: To understand the phenomenon of communication related to knowing diagnosis and prognosis, by exploring the perspectives of patients with advanced cancer and those of their caregivers, physicians and nurses.
Methods: Drawing upon a multi-perspective design, a total of 27 semi-structured interviews involving four different groups of stakeholders (7 patients, 7 caregivers, 6 physicians, and 7 nurses) ——who were linked by a carer-cared relationship——were conducted in two Oncology Departments of two Italian hospitals. Interpretative Phenomenological Analysis was used to interpret the participants' narratives.
Results: Two overarching themes were identified: The first theme "the «what is it?» and the «what will happen to me?»" illustrates the two different paths of communication of diagnosis and prognosis. The second theme "Matching and mismatching in identifying the others as speakers" shows that not each of the four parties recognizes the others as reciprocal speakers on topics related to diagnosis and prognosis, although all of them display reciprocal communication interactions.
Conclusions: Communication related to diagnosis and prognosis is often handled by health professionals without a comprehensive and integrated understanding of the communication approach. There is a correspondence between the nurses' perception of their extraneousness to the diagnosis and the prognosis related communication, and the descriptions and perceptions of the nurse's role reported by the other participants.Relevance to clinical practice. Understanding how the different groups of stakeholders reciprocally interact and influence each other, can help to identify potential positive resources and detect hindrance in the implementation of an effective patient-centered approach, while avoiding silo cultures.

1. Introduction

Cancer is a disease characterized by different distinct evolving stages, and oncologists can generally predict life expectancy (Lamont and Christakis, 2001). This would allow for a timely personalised communication about prognosis and care preferences. This is important because diagnosis and prognosis-related communication can increase patients' awareness about their illness, the acceptance of the diagnosis and decisions related to the treatment, and the ability to cope with the illness (Innes and Payne, 2009). Nevertheless, there is evidence that cancer patients still lack of knowledge about their diagnosis (Hinchey et al., 2016) as the information usually is provided using other words or euphemisms (Font-Ritort et al., 2016). Along with it, many cancer patients are not knowledgeable of their prognosis, although they would desire more information (Kim et al., 2018). Literature shows that discordance about survival prognosis is still quite common, so that patients rarely know that their opinions differ from those of both their oncologists (Gramling et al., 2016) and their caregivers (Ghoshal et al., 2019). In many cultures, a strong resistance against full disclosure of diagnosis and prognosis is still found (Shahidi, 2010; Sarafis et al., 2013). In Italy, quite a high rate of partial or non-disclosure is still reported in cancer care (Repetto et al., 2009), along with a still persistent opinion——among healthcare professionals too——that a fatal prognosis should be not disclosed (Di Giacomo et al., 2012). As remarked by Surbone et al. (2004), this attitude is not yet overcome by the evolution in both communication practices and laws and protocols, in accordance with the diffusion of the self-determination principle (Surbone et al., 2004). There is evidence that even when physicians plead in favour of disclosure, most of them are not consistent with their own declarations (Abazari et al., 2016; Oikonomidou et al., 2017). Other actors are also taking to the stage: nurses' critical role in the process of diagnostic and prognostic disclosure is getting new attention

---

* Corresponding author. Department of Medical Sciences and Public Health, University of Cagliari, SS 554 Bivio per Sestu, 09042, Monserrato, Cagliari, Italy.
E-mail address: maura.galletta@unica.it (M. Galletta)

https://doi.org/10.1016/j.ejon.2021.101904
Received 3 May 2020; Received in revised form 12 December 2020; Accepted 26 January 2021
Available online xxx

(Warnock, 2014). A recent literature review shows that patients and relatives ask the nurse to better understand diagnosis and prognosis-related information received from the doctor (Newman, 2016). The author calls for further exploration of both physicians' and patients' perception of the role of nurses. There is also evidence of the role of good interprofessional collaboration and communication to help the patient in processing the information related to diagnosis and prognosis (Villalobos et al., 2019). Besides, the relevant role of cancer patient carers in directing information flow and in deciding the amount and type of information about diagnosis and prognosis has been acknowledged and associated with improved outcomes (Hubbard et al., 2010; Hobbs et al., 2015). Thus, communication about diagnosis and prognosis can be considered a phenomenon occurring in an interactional context: patient, caregiver, physician and nurse are all interwoven by numerous communication interactions and reciprocal influences. In accordance with this, the need to explore patients, health providers and caregivers' shared understandings and different perspectives is getting more attention (Fagerlind et al., 2012). Shahidi (2010) already argued that to better understand attitudes and problems in disclosure, the contributing factors related to the relatives, doctors and healthcare systems need to be explored and better understood. In fact, each group offers important and unique perspectives on what constitutes good quality care. Nevertheless, to the best of our knowledge, patient, caregiver, physician, and nurse's perspectives about communication related to knowing cancer diagnosis and prognosis have never been simultaneously compared all together. There are many studies adopting a dyadic perspective (Furber et al., 2013), less studies adopting a triadic perspective (Orri et al., 2017), all these authors are concordant in suggesting the need to consider the perspectives of all the actors involved in cancer care. Furthermore, it is pertinent to remark that communication related to cancer disclosure is strongly associated to the cultural humus, healthcare and social system (Surbone, 2008; Abazari et al., 2016), so the need to extend investigation to different cultural contexts is valuable. This study is part of a larger research exploring cancer diagnosis and prognosis-related communication from the point of view of the patients, their caregivers and the involved nurses and physicians.

2. Aim of the study

This study aims to understand the phenomenon of communication related to knowing diagnosis and prognosis, by simultaneously exploring the perspectives of patients with advanced cancer with those of their caregivers, physicians, and nurses.

3. Methods

3.1. Design

This study has a phenomenological qualitative approach and adopts Interpretative Phenomenological Analysis (IPA) and a multi-perspective design aimed to explore the sense that patients, physicians, nurses and caregivers give to their experience of communication related to diagnosis and prognosis. IPA, as a phenomenological approach, allows for exploring the lived experience of people and, as an interpretative approach, allows for exploring the meanings that people attach to their experiences (Smith et al., 2009). In this process, the researchers are engaged in interpretation of the participants' experiences and perceptions according to the so-called double-hermeneutic circle (López and Willis 2004). Rooted in Heidegger's philosophy showing how individuals' realities are invariably influenced by the world in which they live, IPA retains that meanings are always created through interactions with others (Smith et al., 2009). Moreover, IPA has an idiographic focus that requires a detailed examination of convergences and divergences of each singular case under investigation. Adhering to Saunders' et al. (2018) point of view, this study did not pursue saturation because *"It is less straightforward to identify a role for saturation in qualitative approaches that are based on a biographical or narrative approach to analysis, or that, more generally, include a specific focus on accounts of individual informants (e.g. interpretative phenomenological analysis)"* (p. 1989). IPA was already adopted to investigate disease and care experiences in the context of complex relationship networks in which they take place (Antoine et al., 2013). Furthermore, IPA was used in several dyadic studies to investigate meanings assigned by people, individually, and in a combined form, regarding an experience lived together. Studies with a multi-perspective design adopting IPA are still quite few and recent (Orri et al., 2015; Larkin et al., 2018).

3.2. Data collection

The research was carried out in two Oncology Departments of two large hospitals in Southern Italy. In these departments, the patient is usually cared for by the same physician throughout the course of the disease. Nurses care for patients based on groups of rooms to which they are assigned on each shift. Semi-structured interviews were conducted from October 2016 to February 2017. All the interviews were conducted by the first author, in the ward where the patients were admitted. Semi-structured interviews are the most common method for data collection in IPA studies, as they elicit rich first-person account of experiences of the phenomenon under investigation (Smith and Osborn, 2008). An interview guide (see Table 1) was used flexibly to foster a natural conversation and encourage individuals to elaborate their perceptions. Language was adapted to the participants' linguistic competence. Field notes were taken to support the analysis of the interviews.

3.3. Inclusion and exclusion criteria

Inclusion criteria for patient recruitment were (1) being an adult (≥18 years) individual with a life expectancy of less than 1 year as estimated by the attending oncologist (2) Availability of at least one main caregiver (e.g. relatives or friends); (3) Availability of at least one nurse and one physician who cared for recruited patients. All the interviewed nurses confirmed to know patient's clinical data, including their reduced life expectancy. The life expectancy criterion allowed researchers to select a homogeneous sample of patients with respect to their prognosis, but it was also meant to select homogeneous subsamples of health care professionals with respect to their knowledge of the patient's prognosis. An inclusion criterion for the nurses was that they had cared for the patients recruited for at least two shifts. The physicians who cared for recruited patients were asked to participate to the study. The caregivers were selected and enrolled in the study upon indication

Table 1
Interview questions guide.

Topic	Questions for the Patient	Questions for Caregiver, Physician, and Nurse
Diagnosis and Prognosis knowledge	Please, tell me about your disease	Please, tell me about what the patient knows of his/her disease
Perspectives about communication of diagnosis and prognosis	Please, tell me about your preference on knowing your diagnosis and prognosis	Please, tell me about patient's preference about communication on his or her diagnosis and prognosis
Interactions with health professionals	Please, tell me about your talking with your physician and attending nurses about your diagnosis and prognosis	Please, tell me about your talking with the patient about his or her diagnosis and prognosis

of patients as having a significant role in their disease trajectory. A general exclusion criterion was cognitive impairment.

3.4. Participants and recruitment

Staff nurses introduced the interviewer to the patients and explained the purpose of the research. After obtaining the patient's informed consent, the other three parties were contacted to verify the eligibility criteria. If all the inclusion criteria were met, the patient entered the study. The eligible nurses were enrolled purposefully once the patient was enrolled. The patient was interviewed first, and then the caregiver. The recruited nurses and physicians were interviewed successively during working hours. All but two of the patients enrolled were hospitalised more than once during the wards in which they were recruited, and in some cases they had already been assisted by the interviewed nurse during previous hospital admissions. One of the physicians was interviewed twice because she was in charge of two patients.

3.5. Ethics considerations

The study protocol was approved by the Independent Ethics Committee of the Azienda Ospedaliero-Universitaria of Cagliari, Italy (Act n.2.27; July 25, 2016). The study complies with the principles of the Declaration of Helsinki and with the Italian Privacy Law (Decree No. 196/2003). Participants were provided with oral and written information about the purposes of the study. Participation was voluntary and confidentiality was guaranteed. All the participants were informed that they could leave the study at any time without any consequences. To preserve confidentiality, pseudonyms were used for all patients. Furthermore, to avoid traceability of single participants, we decided to carry out the sampling in at least two different healthcare facilities, without specifying each of the caregiver-patient relationships. Specific attention was given to explain the multi-perspective design of the study to all the participants.

3.6. Data interpretation

The interviews were audio recorded and verbatim transcribed, including a short description of the non-verbal aspects of the interviewees. According to the IPA standards, thematic analysis was conducted following Smith and Osborn's guidelines (2008). Thematic analysis was carried out by analysing the deep structures of the text (narratives) and the internal relations to identify patterns of meaning connection and formulate themes (Charalambous et al., 2008). In an initial phase, the researchers proceeded separately: a first step was to read each interview and take initial notes (e.g., descriptive notations, use of language, conceptual notations). A next step was to identify emergent themes, focusing on discrete pieces of the transcript and, in the meantime, taking into account the notations of the previous phase. This process allowed each researcher to develop a list of initial themes, and was repeated for all interview transcripts, proceeding from a group-unit (patient, caregiver, nurse, and physician) to another, and analysing the transcripts according to the chronological order of the interviews. Then, the interpretative possibilities were developed by weighing and comparing themes across cases, ending up with a list of cluster themes by each researcher. In the following phase, the researchers met and triangulated their findings by discussing the themes and the clusters identified in the previous phase, to achieve a consensus. To facilitate the reconciliation of the identified themes and cluster them, two strategies were adopted: (1) both interview transcriptions and field notes were used as a constant reference guide, and (2) queries about the meaning of what was said by the participants were formulated as an interpretative passage. A consensus based on coherence and distinctiveness of the clusters lead the researchers converged on two overarching themes. The applied interactive analytical process allowed the researchers to bring out interactions between the participants at group level and offers a comprehensive point of view that represents a new understanding of the phenomenon. Each of the two main themes was exemplified with excerpts from the four parties.

3.7. Rigor of the study

This study intends to respect the methodological rigour of qualitative studies by taking into account the indications by Lincoln and Guba (1985). To enhance dependability and confirmability, several audits along all the research phases have been conducted, triangulation by investigators performed, and both disclosure of challenges and difficulties of the study provided. Credibility was favoured by provision of a rich amount of interview quotes and by a constant review of the themes and clusters. The researchers were aware to look not for "*a single answer or truth, but a coherent and legitimate account that is attentive to the words of the participants*" (Lincoln and Guba, 1985 pag.21). Transferability——although limited by the culturally sensitive issue and by the idiographic trait——was fostered by sampling in two different health care organizations and by a detailed description of sample characteristics, data collection and analysis method. Moreover, the multidisciplinary backgrounds of the research team fostered a multi-side interpretation of the data. As recommended by experts (Smith et al., 2009), the researchers paid close attention to self-reflexivity about their own values and orientation, and an audit on this concern was conducted by a psychologist. This paper adhere to COREQ reporting guidelines.

4. Findings

4.1.

A total of 27 participants were interviewed. IPA studies usually focus on the detailed analysis of a few cases. However, in this study, the whole sample included four different categories of participants (7 patient, 7 caregiver, 7 nurse, and 6 physician) whose perspectives were compared. Thus, this sample size is in line with other IPA dyadic and triadic studies. A description of the participants' characteristics is presented in Table 2.

4.2.

Two main overarching themes (The "what is it?" and the "what will happen to me?" and Matching and Mismatching in Identifying the Others as Speakers) on communication related to knowing diagnosis and prognosis were identified. They are transversal to all the four parties and have a binomial feature, as it is presented below.

4.3. The "what is it?" and the "what will happen to me?"

In the participants' stories, the communication of diagnosis and prognosis seems to have two different paths of communication. Prognosis appears like a quite problematic information, a sort of further information regarding "what-will-happen-to me?" that only a few patients require, want, and receive. This difference is trackable in all the four parties and is marked by the declaration that information about the diagnosis has been given/received, but usually, information about prognosis is missing. Table 3 reports patients' statement on their current knowledge and on their will to fully know the diagnosis and prognosis, as well as the caregivers', nurses', and physicians' appraisal on patients' knowledge about the diagnosis and prognosis.

Table 2
Summary of the participants' characteristics.

	Patients (n = 7)	Caregivers (n = 7)	Physicians (n = 6)	Nurse (n = 7)
Gender	Man = 4; Woman = 3	Man = 0; Woman = 7	Man = 2; Woman = 4	Man = 2; Woman = 5
Age	63 years = 2 65 years = 1 67 years = 1 77 years = 2 83 years = 1 Average age = 70.7	35 years = 2 41 years = 1 55 years = 1 67 years = 1 72 years = 1 79 years = 1 Average age = 54.8	31 years = 1 32 years = 1 40 years = 1 42 years = 1 45 years = 1 46 years = 1 Average age = 39.3	31 years = 1 37 years = 1 38 years = 1 40 years = 1 41 years = 1 46 years = 1 59 years = 1 Average age = 41.7
School level	Primary school = 5 Secondary school = 1 Master Degree = 1	Primary school = 2 Secondary school = 3 Master Degree = 2		
Tenure			Experience as oncologist: 1 year = 1 2 years = 1 6 years = 1 12 years = 1 16 years = 2 Average tenure years = 8.8	Experience in oncological ward: 3 years = 1 7 years = 1 8 years = 1 9 years = 1 10 years = 2 11 years = 1 Average tenure years = 8.2
Cancer type	Breast cancer = 1 Abdominal cancer = 4 Head-neck cancer = 1 Lung cancer = 1			
Interview length	Minimum:12 min; Maximum: 61 min (mean = 29 min)	Minimum:13 min; Maximum: 49 min (mean = 27 min)	Minimum:11 min; Maximum: 26 min (mean = 20 min)	Minimum:18 min; Maximum: 54 min (mean = 29 min)

All the patients declare to know "what" they have in terms of disease condition, they use the word tumour to name it, and some of them describe in details the disease site and diffusion. Nevertheless, all of them talk about some missing information. This information is mostly related to prognostic issues. The will to know or to know more comes as an explicit question addressed to the physician. This is, for example, apparent in Federica's narration:

> "what she [the oncologist] has to tell me, she tells, but always without being (…) as if it were a matter of course, in a very familiar way, like if to assume that « I'm telling you it but everything will be all right, everything…» then, when I ask « Will I survive? » then, it's clear: what could she answer me? How could she know it? Obviously, I believe".

Other patients, instead, such as Gillo and Sebastiano, purposefully refrain from asking questions about prognosis to avoid information they do not desire to have.

Milena, who was diagnosed several years ago, express all her disappointment at not having received answers to her explicit questions about her prognosis.

Giuseppe, who as a teacher used to talk to people, expresses his need to talk and obtain information, even if he doesn't feel to ask questions. He says:

> "I would like to have that power that some people have (…) to be naturally inspiring, so that it wouldn't be necessary to ask them [the physicians] (…) to do like you do, as in this interview".

There is only one patient who claims to know everything, this is Letizia. She has a long disease history, thoroughly describes her illness trajectory, talks about her feelings and presents herself as a courageous person, strong enough to accept and face her destiny. Her words echo those of her caregiver, her attending nurse and her oncologist.

All the caregivers claim to know their loved one's knowledge of their diagnosis. They support their claim either by saying that they were present at the time they were told of the diagnosis, or by telling what they share with the patient. Although they feel it is right and proper for their loved one to be informed of their diagnosis, they show an ambivalent attitude towards prognosis disclosure, as they give a preeminent importance to preservation of hope and sense of reassurance for their loved one. Federica's caregiver, who declares that every patient has the right to be informed and decide, recollects of when her loved one, whom she recognizes an independent personality, asked her oncologist how much time she was left, but received a vague response:

> "She [the oncologist] probably told what she [the patient] wanted to be told. Sometimes it's important to say what the other one wants to hear, isn't it? And not « Look, there is the case that you are going to die before Christmas » what does it help? I think it is important not just to cure but to care for the patient, especially in such situations".

In Gino's and Massimo's comparison of narratives there is a discordance between the caregivers' assessment and patient's assertion. This goes along with the overemphasis on therapies' promises given by the caregivers and the patient's acknowledgment of lacking prognostic information.

The adoption of the question-answer pattern to obtain information about prognosis is reported in nurses' narratives as a communication approach applied by both physicians and patients. Generally, they experience it as peripheral actors in the scene. This aspect emerges from the story told by Letizia's young nurse. He is recalling of when a patient, who he was attending, asked to be told about his prognosis:

> "It happened I was there [in the patient's room] I had to remove a drip, when the physicians entered the room for the usual medical round, so I was just there by chance, I had nothing to do with it, to say it in brackets".

Apart from this acknowledged communication pattern, the recurring data is that many nurses admit to not knowing what the patient knows about their diagnosis and prognosis. No nurse says to directly investigate what the patient knows about the diagnosis and prognosis. Al-

Table 3
Theme 1 (The "what is it?" and the "what will happen to me?") - Comparison of Participants' Assessment in Patient's Knowledge about Diagnosis and Prognosis.

Patient name (Pseudonym) and clinic characteristics	Patient *What do you know about your disease?*	Caregiver *What does your loved one knows about his/her disease?*	Nurse *What does your patient knows about his/her diagnosis and prognosis?*	Physician *What does your patient knows about his/her diagnosis and prognosis?*
SEBASTIANO time lapse since diagnosis <6 months	I know something I don't want to know more	He knows something [Do not disclose request]	He knows partially	He's partially informed
LETIZIA time lapse since diagnosis >1 year	I know everything I want to know everything	She knows everything	She knows	She's fully informed
GILLO time lapse since diagnosis 6–12 months	I know something I don't want to know more	He knows everything	He knows partially.	He's partially informed
FEDERICA time lapse since diagnosis >1 year	I know something I want to know everything	She knows something	I ignore if she knows	She's partially informed
MASSIMO time lapse since diagnosis 6–12 months	I know something I don't want to know more	He knows everything	He knows partially	He's partially informed
MILENA time lapse since diagnosis >1 year	I know something I want to know everything	She knows something	I ignore if she knows	She's fully informed
GIUSEPPE time lapse since diagnosis <6 months	I know something	He knows something	I ignore if he knows	He's partially informed

though, Letizia's and Massimo' nurses declare some personal interest in knowing what the patient knows about his/her health condition, they refer to deduce it from conversations with patients. All nurses feel that they cannot interfere or somehow modify the patient's knowledge status because it is not required by the role. For many of them, to be a nurse justifies their ignorance about what the patient knows about his/her health condition. Giuseppe's nurse, for example, says:

> *"We do not usually investigate (…), what we are doing here is taking care of the patients from a nursing point of view (…), so we are not interested in (…) finding out what patients know, instead we pay attention to (…) avoid using words that (…) might inform them".*

Federica's nurse adds that patients do not perceive it as a nursing flaw because they show satisfaction with nursing care. She is the only nurse who reflects on the nurses' educational limits and their unreadiness to get involved in this kind of issues.

In some nurses' narrative the information about diagnosis and prognosis is presented in a sort of reverse direction: it is the patient who gives the news to the nurse. Federica's nurse says:

> "It happens quite often that the patients give you (…) the news, for instance, about a CT scan, I mean, bad news, I mean, they tell us that the disease is worsening, and …".

All physicians claim to have always informed the patient about their diagnosis by talking directly to them. Physicians refer to have followed this protocol even when relatives had asked them to limit the quantity of information to give to the patient (as in Sebastiano's case).

Information about diagnosis is presented by the oncologists as the fulfilment of a professional duty that is adjusted to each personal case by prefiguring the patient's emotional reactions. Therefore, they claim to adapt the amount of information they give according to the patient's attitude. Physicians also show to be aware of the different extent to which each patient receives and understands information. Nevertheless, no effort is reported in trying to change it, rather the question-answer pattern is referred to as a sort of silent compromise between the physician and the patient. Giuseppe's physician words recite:

> "Surely, in the case of a neoplastic patient with a stage four tumour, I can't tell them that they will definitely survive, because it would be a huge lie. That's why I usually leave it out if they don't ask me".

In short, the communication related to knowing diagnosis and prognosis is characterised by two different pathways. The common attitude of physicians is to give their patients step-by-step information, updating them on the progress of the disease. Prognosis information is presented as information available only upon specific request of the patient. Patients often make explicit their willingness to know more and to know their prognosis by asking specific questions. Nurses refer no direct interest in patient's knowledge of their diagnosis and prognosis, despite showing knowledge of related attitudes and practice.

4.4. Matching and Mismatching in Identifying the Others as speakers

Not each of the four parties recognizes the others as reciprocal speakers on topics related to diagnosis and prognosis, although all of them display reciprocal communication interactions.

Patients tend to identify physicians and caregivers as interlocutors in topics related to diagnosis and prognosis. Caregivers also display triadic communicative interactions, as they indicate patients and physicians as their speakers. Physicians present the patient as their main interlocutor, although they report to be contacted and interact with caregivers as well, especially in the terminal phase of the disease. Nurses are not acknowledged by the other three parties as speakers in communication related to diagnosis and prognosis. The nurses themselves show an ambivalent attitude: they tend to unrecognize their role, or to limit it to a generic support to patients and caregivers, but at the same time, they report many communicative interactions about diagnosis and prognosis related issues with both patients and caregivers, but not with physicians.

Fig. 1 shows communication interactions perceived by patients. The interactions with physicians are referred as mostly related to the information transmission. Despite this, Federica and Sebastiano report also the encouragements received by their oncologist, and they put these encouragements at the basis of their relationship with them. Sebastiano explains this relationship like this:

> "I got hope from the physicians. I trust a physician if he trusts me, this gives me strength (…) but if a physician says some other sort of things (…) then he lets me down".

In general, all patients talk about the presence of their relatives as an important support in communication, not just for practical help (e.g., memorizing information, familiarity with medical arguments, etc.) but also for the emotional support. Only Letizia says she prefers to

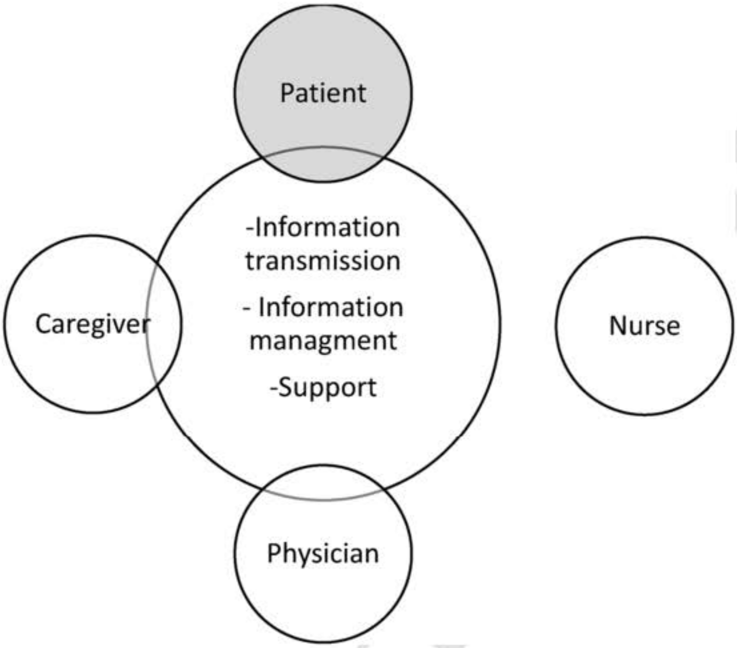


Fig. 1. Theme 2 (Matching and Mismatching in Identifying the Others as Speakers) - Patient's perspective in identifying the others as Speakers. Patients refer communication interactions regarding diagnosis and prognosis with doctor and caregiver. These interactions relate to information transmission, information management, and support. Patients do not refer communication interactions with nurses.

limit information about her health status to her relatives to avoid increasing their anxiety and worries. Sebastiano clearly admits that he has accorded to his close relatives the management of information with the physicians. In short, the information sharing with one's close relatives is presented as a natural and helpful feature by patients. This is, for example, Massimo's point about it:

> *“They always come with me: my daughter, well, one of my daughters, and my son in law (…), to be able to better understand everything, to be informed about it all”.*

Patients assert they have not discussed diagnosis and prognosis-related issues with nurses. They refer just occasional chats with nurses concerning practical assistance issues or generic words of encouragement. This way of interacting with nurses is presented by patients as normal and ordinary. They describe nurses as therapy providers, operators heavily conditioned by time constraints, task oriented and directed by physician's instructions. This is Federica's narration:

> “I have, let's say, no communication with them [the nurses]. When I come here [the ward] they take my blood (…) «Good morning!» we don't talk also because they have a lot (…)I mean (…) then, when I'm on chemo, yes, some jokes, but no more than that, just when they enter the room”.

Fig. 2 represents communication interactions from caregivers' point of view. They present themselves as the patient's support in the process of transmitting information and managing the emotional needs. This is mostly apparent when they talk about patient-physician communicative interactions: they are the ones on the patient's side when they undergo medical visits (almost all of them say they were present when diagnosis was communicated for the very first time). Moreover, they show to know what the patient was told by the oncologist and they report the patient's reaction to it. Federica's caregiver, for example, talks about a sharing she had with her loved one after a conversation with the oncologist:

> “I asked her it, but not soon after (…) I left her quite, I didn't want to rush (…) but later I told her « Do you see? Have you listened? The doctor was confident, was reassuring» and she replied « Yesss», she was in a ‘Yes’ phase, but (…) «yes, she certainly reassured me about it » In this case one should do the same thing and reinforce it”.

Caregivers also perceive themselves as receivers of medical information, and sometimes say that they receive some more information in addition to what the patient knows, particularly regarding the prognosis. They consider this additional information as an emotional overload of sorrow that they shall not pass on to their loved one.

All the caregivers say there are not communication interactions related to diagnosis and prognosis with nurses. They generally describe nurses as polite and full of patience, but report communication interactions merely related to the administration of therapies and to the practical aspects of care (how to move the patient, for instance). Many caregivers justify this absence of communication interactions with nurses by referring it to their view of the professional role of nurses, as Massimo's young caregiver does:

> “There has never been a dialogue about the situation with nurses (…) anyway: physician's word has always a different value, not to discriminate anyone, but the nurses act according to what they are told by physicians, so maybe they couldn't answer the questions we might ask them but didn't actually ask.”.

Physicians describe their communication interactions mostly as giving information to the patient. The issue of discussions on terminal care

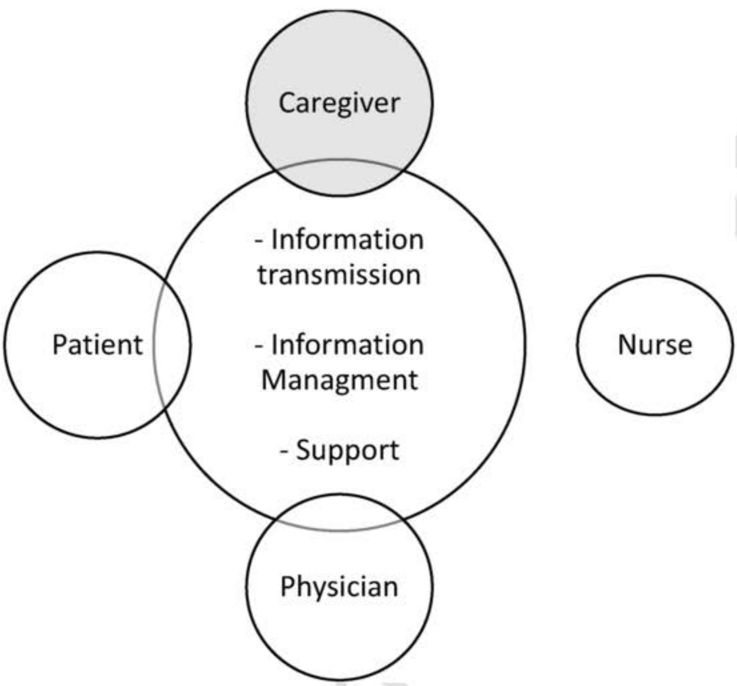


Fig. 2. Theme 2 (Matching and Mismatching in Identifying the Others as *Speakers*) - Caregiver's perspective in identifying the others as *Speakers*. Caregivers refer communication interactions regarding diagnosis and prognosis with doctor and patient. These interactions relate to information transmission, information management, and support. Caregivers do not refer communication interactions with nurses.

is reported as a constant update on clinical status and proposed therapies. There are just two oncologists, Federica's and Massimo's, who openly talk about their difficulties in dealing with the subject. Here is Massimo's young physician's narrative:

> "We often arrive to the terminal stage of the disease without knowing what the patients want. The relatives press and ask for aggressive therapies that we know to be useless and that, instead, must be considered as therapeutic obstinacy (…) sometimes patients, since they are diagnosed, tell us « Be aware, when my time comes, I don't want to be resuscitated, I don't want to be tortured! Give me some sedation and let me go in peace » But for many others we don't know, so we get to the terminal stage and (…) what happens is we ask the relatives if they want their loved one to be transferred to the hospice".

Physicians refer to interact and communicate with patients' caregivers when introduced by the patient (as shows Fig. 3). Otherwise, they describe their communicative interactions with caregivers as casual. The frequency of these occasions appears to be arranged more on the initiative of the caregivers than the physicians.

Apart from the case in which physicians received from relatives the request to omit prognostic information to the patients, physicians refer no conversation with the nurses about diagnosis and prognosis related issues. This feature is referred by physicians as standard and normal. At the question « have you discussed any issues related to the patient's diagnosis and/or prognosis with the nurses?» a physician responded with a deafening laugh and a determined denial. Nevertheless, physicians generally assure that they have a good relationship with the nurse staff and that they share all the relevant information about patient care. As an example of it, they mention the management of surgical drainage, the adoption of medical auxilia, and so on.

Similar to what the doctors say, nurses only report sporadic cases of conversations with physicians on issues related to diagnosis and prognosis. Only Sebastiano's nurse is able to report what the patient (and his caregivers) has been told by the physicians about diagnosis and prognosis, because, as she states, nurses and physicians were requested by the patient's close relatives not to talk to him about the fatal prognosis. Gillo's nurse is the only one who claims to have asked the physician what the patient had been told, yet he admits having done it out of curiosity.

Nurses report only occasional interactions with caregivers, generally related to practical care aspects. Only in Sebastiano's case his nurse recalls conversations with the caregivers about diagnosis and prognosis issues, but just as a listener and intermediary between relatives and physicians. Nevertheless, many nurses observe that, when a patient's death approaches, the caregivers ask them for their opinions and advice on how to manage care in the final stages of life. Milena's nurse describes her experience with caregivers in this way:

> "They usually ask us how it will be (the dying), how long will it take, how long will be left (…) they ask very direct questions, such as « do you think he'll make it through the night? Do I have to stay here tonight?»".

In situations like this, most nurses say they put the caregiver back to the physician to get more detailed information from them. Some nurses also say that it happens that relatives of patients approach them to vent their anger and despair. Disappointment and despair, nurses

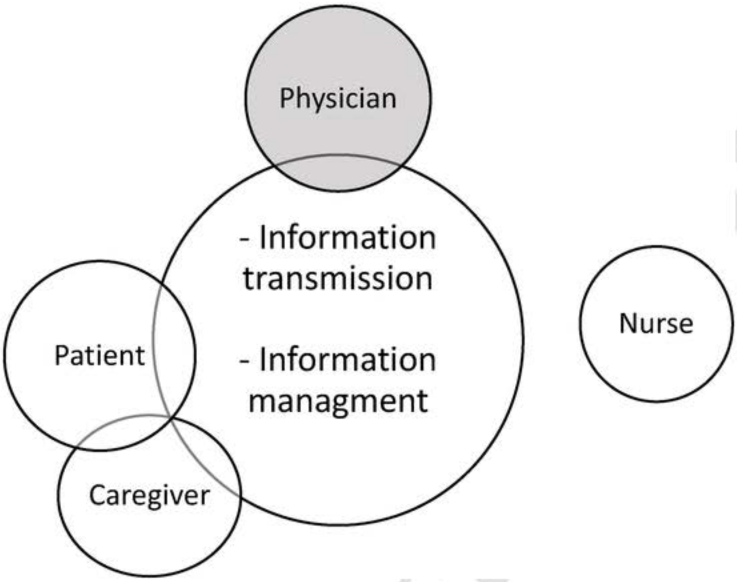


Fig. 3. Theme 2 (Matching and Mismatching in Identifying the Others as Speakers) - Physician's perspective in identifying the others as Speakers. Physician refers communication interactions regarding the transmission and management of information about diagnosis and prognosis, but he/she does not see himself/herself as a supporter of the patient.

say, that people don't dare to express with physicians because they perceive them as an authority.

All nurses present patient support as a specific role and commitment of the nurse, although most of the time they talk about it as "the only thing we can do" (please see Fig. 4). Gillo's, Milena's, Federica's and Massimo's nurses admit also feelings of discomfort and uneasiness when they are addressed by patients inquiring about their health status. Questions and comments from patients do not come as an unexpected occurrence to nurses. In fact, there are plenty of anecdotes about patients asking questions on prognosis, recovery expectancy or uttering awareness of prognosis. Giuseppe's nurse describes it like this:

> "It is very easy for them (the patients) to talk about these things whit us (…) after all, we are strangers with whom they share intimacy (…) and after all, we have the expertise".

5. Discussion

This study aims to understand communication related to the knowledge of the diagnosis and prognosis of cancer by exploring the reciprocal perspective of the communicative interactions of patients, nurses, doctors and caregivers through a phenomenological interpretive approach. By simultaneously comparing the four perspectives, our study shows how the communicative approach is experienced by the four parties, and how their reciprocal interactions are affected by it. Two main overarching binomial themes have been individuated. The first theme illustrates how communication about diagnosis is approached differently from communication about prognosis. Diagnosis is presented by physicians as a given information, by patients as a received information, and by caregivers as information received together with

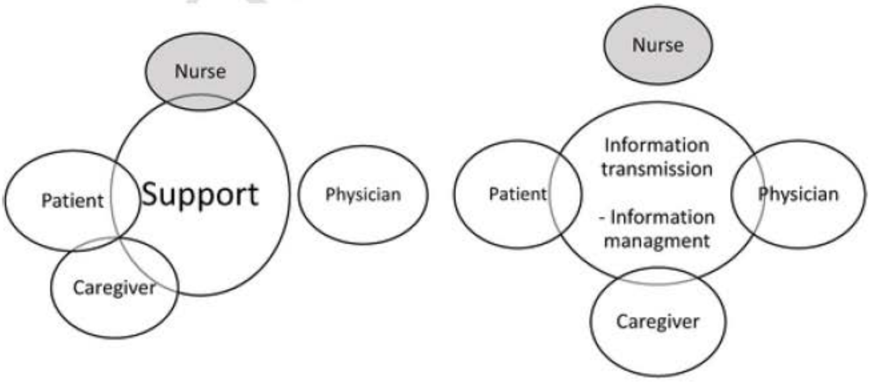


Fig. 4. Theme 2 (Matching and Mismatching in Identifying the Others as Speakers) - Nurse's perspective in identifying the others as Speakers. Nurse sees himself/herself as supporter of the patient with regard to the communication on diagnosis and prognosis, but he/she is not so stranger to what pertains to the transmission and management of information.

the patient. Patient-medical communication is established on this shared information. In reverse, prognosis is a piece of information to be requested by the patient to the physician: the question-answer pattern is adopted by physicians and reported by all the other participants. This pattern looks like a sort of replica of the so-called "collusion between doctors and patients" already described in literature (The et al., 2000): doctors do not want to pronounce a "death sentence" and patients do not want to hear it. Cross checking the interviews at group level, it can be said that the collusion appears to be a consolidated and acknowledged strategy that allows physicians to intercept in most patients their will and preference in terms of communication approach. Nevertheless, the equation "doesn't ask = doesn't want to know" remains a culturally based assumption that cannot fit all the patients (as in Giuseppe's case), and health professionals should take it into account, considering that they are invited to "*ask patients and patients' families what informational requirements are preferred.*" (Tuckett, 2004, p.508). Only in two cases, participants' assessments regarding the patient's knowledge about diagnosis and prognosis are concordant. This concordance, in one case, is prompted by the patient's open attitude and direct request of complete disclosure, in the other case is driven by relatives' direct request to not disclose prognosis. When the patient, or his/her caregivers, takes no initiative about the communication approach, the other participants seem to know less about patient's awareness and willingness to know. The two observed discordances between the caregivers' assessment and patient's assertion can be explained by the fact that physician is colluding just with the caregiver, whilst patients acknowledge not having asked——and therefore not having received——exhaustive prognosis information. Moreover, the comparison of the narratives shows that patient, caregiver, and physician have at the basis of their communication interactions the common acknowledgment that information on the cancer diagnosis has been given to the patient. On the other hand, nurse–patient communication does not ground on this shared acknowledgment, and many nurses ignore both what the patient has been told about his/her diagnosis and prognosis and what he/she knows about them. The nurses justify their ignorance by saying that communicating diagnosis and prognosis is the physicians' business. This point introduces the second theme that emerged in data interpretation. It illustrates how patients, caregivers, physicians, and nurses describe and signify their reciprocal communication interactions. Indeed, the multi-prospective design enlightens a correspondence between the nurses' perception of their extraneousness to the diagnosis and the prognosis-related communication, and the descriptions and perceptions of the nurse's role reported by the other participants. However, nurses also refer of many conversations with patients (and caregivers) about issues such as life expectancy, effectiveness of therapies, awareness of the disease, perspective of death, and so on, and define themselves as patient's (and caregiver's) supporters. This supporter role is described as being present for the patient and encouraging them, but unlike other studies (McLennon et al., 2013), staying away from corroborating or clarifying information about diagnosis and prognosis. This sort of mismatching in identifying themselves as a speaker in the communication related to diagnosis and prognosis, and at the same time the matching in interpreting the role of the nurse as an outsider in the communication related to diagnosis and prognosis should be carefully considered, as they represent the framework within which actions are performed, observed and acknowledged. In fact, anything that remains outside the frame is likely to remain unnoticed and undervalued. The phenomenon of "bad news-reverse-direction" reported by nurses (e.g., patients who spontaneously update nurses upon their clinical situation) can be a sign of a different communication need that has still to be explored and valued. Moreover, the perception of nurses' extraneousness to diagnosis and prognosis-related communication has to be addressed, in consideration of the fact that they are inevitably involved in the disclosure issue (Huang et al., 2014). Newman (2016), in her integrative review, concludes that nurses play an integral role in the process of diagnostic and prognostic disclosure, although the author suggested the need for further exploration of both physician and patient perceptions of the nurse's role. However, the nurses' sense of extraneousness to diagnosis and prognosis related communication is not an isolated finding (Helft et al., 2011). McLennon et al. (2013) already found that nurses experience uncertainty about their own role in prognosis discussions, because they did not know whether physician disclosed prognosis to patients or their families. Wittenberg et al. (2019) noticed that nurses had trouble in taking initiative and address diagnosis and prognosis related issues with patients. Georgaki et al. (2002) found out that many nurses consider their role in communicating with patients as subordinated to the physician's role.

With regard to the caregivers' role in communication process, our study shows that caregivers are still barely involved by health professionals. Although physicians theoretically recognize the importance to involve caregivers in cancer care, they find difficult to implement any structured interaction or shared communicative approach with caregivers. All the four parties have faced diagnosis and prognosis-related communication in a shared way only when relatives explicitly asked to limit the quantity of information for the patient (see Sebastiano's case). The relatives' request to limit the transmission of information appear to be the trigger of the communication flow that allow the health care professionals to approach communication in an integrated manner. Besides, only in this case caregiver was integrated in the communication process and valued by physicians as intermediary have the health care professionals approached the communication in an integrated way. Besides, only in this case caregiver was integrated in the communication process and considered as intermediary by physicians. The role assumed by family members as filters of medical information is not an unusual finding in cancer literature (Hudson et al., 2004). However, Orri et al. (2015) also found that doctors were not able to integrate family members into the care process, even though they were considered an important resource for patients' quality of life.

In this study, the comparison of the four narratives has contributed to enlighten the reasons of fragmented communication interactions. They are ascribable to a reduced capacity by physicians and nurses to involve the caregiver as a resource in the communication process; nurses' lack of awareness in what the patient knows about his/her disease; a shared difficulty in acknowledging the importance of the nurse's role in communication related to diagnosis and prognosis.

5.1. Limitations and strengths of the study

The sample of this study is quite heterogeneous with respect to participants' demographic data. This is an uncommon feature in IPA studies, although Smith and Osborn (2008) affirm that the way in which the specificity of a sample is defined can depend on the study needs. The broad inclusion criteria for this study are justified by the aim to shed light on the communication interactions between the four categories of participants. Moreover, the two sub-samples of nurses and oncologists may be considered homogeneous with respect to their knowledge about diagnosis and prognosis of their patients.

Much attention was given in performing interviews in order to preserve participants from any incidental unwanted discomfort. This has determined a broad variability in the interviews' length, mainly due to the patients' tiredness and to some interruptions during the interview (all the interviewed health professionals, except one, preferred to be interviewed during their working hour). Moreover, the interviewer paid much attention to the participants' emotional status and interrupted the interview whenever it was necessary.

The male gender is not represented in the caregiver sub-sample because the sampling procedure required the patient to indicate a caregiver significant for him/her. This has resulted in a prevalence of the female gender among caregivers. Among the recruited participants, physicians and nurses were more reluctant than patients and caregivers to participate in the study; physicians claimed restricted time to dedicate or no interest in taking part in the research. Many nurses, instead, declared not to have taken care the interviewed patient with sufficient continuity to be part in the study.

In line with all studies with an ideographic reference, generalisation is largely unfeasible and the findings of this study should be transferred with caution. Nevertheless, the simultaneous exploration of the perspectives of the four groups of participants provides additional value to the existing research and important insights that can have wider implication.

6. Conclusions

Although physicians and nurses showed a desire to adopt a communication approach respectful of patients' information and emotional needs, diagnosis and prognosis-related communication is still managed by them without a comprehensive and integrated communication approach. The multiple stakeholders (patients, caregivers, and healthcare professionals) are not always able to identify the other as speakers and they are not usually value each other as a resource in the communication process. Scarcely integrated communication interactions can hinder the acknowledgment of the patient's communication process and limit the possibility to meet his/her multiple communication needs. Furthermore, health professionals barely can detect and assess the potential impact on patients and caregivers resulting from their communication approaches.

To overcome the fragmented communication approach, it would be useful to implement joint communication training in which all the actors' perspectives are explored and addressed. Understanding how the different speakers reciprocally interact and influence each other, can help to identify potential resources and hindrance in implementing effective patient-centered approaches, while avoiding silo cultures.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Declaration of competing interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Acknowledgements

The research team would like to thank Tanya Castagna and Itziar Rey Pérez de Pipaon for their invaluable contribution in reviewing the manuscript for English language considerations.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejon.2021.101904.

Uncited References

References

Abazari, P., Taleghani, F., Hematti, S., Ehsani, M., 2016. Exploring perceptions and preferences of patients, families, physicians, and nurses regarding cancer disclosure: a descriptive qualitative study. Support. Care Canc.: Off. J. Multinatl. Assoc.Support .Care.Canc. 24 (11), 4651–4659. doi:10.1007/s00520-016-3308-x.

Antoine, P., Vanlemmens, L., Fournier, E., Trocmé, M., Christophe, V., 2013. Young couples' experiences of breast cancer during hormone therapy: an interpretative phenomenological dyadic analysis. Canc. Nurs. 36 (3), 213–220. doi:10.1097/NCC.0b013e31826429a5.

Charalambous, A., Papadopoulos, I.R., Beadsmoore, A., 2008. Ricoeur's hermeneutic phenomenology: an implication for nursing research. Scand. J. Caring Sci. 22 (4), 637–642. doi:10.1111/j.1471-6712.2007.00566.x.

Di Giacomo, P., Mariotti, A., Vignali, A., Andruccioli, J., 2012. La consapevolezza della diagnosi e della prognosi nella persona con malattia a prognosi infausta:la percezione negli atteggiamenti di un gruppo di medici e infermieri [Awareness of diagnosis and prognosis in patients with unfavorable prognosis: perception of the attitudes of a group of doctors and nurses]. Prof. Inferm. 65 (3), 143–153.

Fagerlind, H., Kettis, A., Bergström, I., Glimelius, B., Ring, L., 2012. Different perspectives on communication quality and emotional functioning during routine oncology consultations. Patient Educ. Counsel. 88 (1), 16–22. doi:10.1016/j.pec.2011.12.002.

Font-Ritort, S., Martos-Gutiérrez, J.A., Montoro-Lorite, M., Mundet-Pons, L., 2016. Calidad de la información sobre el diagnóstico al paciente oncológico terminal [Quality of diagnosis information given to terminal cancer patients]. Enfermeria clinica 26 (6), 344–350. doi:10.1016/j.enfcli.2016.07.006.

Furber, L., Cox, K., Murphy, R., Steward, W., 2013. Investigating communication in cancer consultations: what can be learned from doctor and patient accounts of their experience? Eur. J. Canc. Care 22 (5), 653–662. doi:10.1111/ecc.12074.

Georgaki, S., Kalaidopoulou, O., Liarmakopoulos, I., Mystakidou, K., 2002. Nurses' attitudes toward truthful communication with patients with cancer. A Greek study. Canc. Nurs. 25 (6), 436–441. doi:10.1097/00002820-200212000-00006.

Ghoshal, A., Salins, N., Damani, A., Chowdhury, J., Chitre, A., Muckaden, M.A., Deodhar, J., Badwe, R., 2019. To tell or not to tell: exploring the preferences and attitudes of patients and family caregivers on disclosure of a cancer-related diagnosis and prognosis. J. Global.Oncol. 5, 1–12. doi:10.1200/JGO.19.00132.

Gramling, R., Fiscella, K., Xing, G., Hoerger, M., Duberstein, P., Plumb, S., Mohile, S., Fenton, J.J., Tancredi, D.J., Kravitz, R.L., Epstein, R.M., 2016. Determinants of patient-oncologist prognostic discordance in advanced cancer. JAMA oncology 2 (11), 1421–1426. doi:10.1001/jamaoncol.2016.1861.

Helft, P.R., Chamness, A., Terry, C., Uhrich, M., 2011. Oncology nurses' attitudes toward prognosis-related communication: a pilot mailed survey of oncology nursing society members. Oncol. Nurs. Forum 38 (4), 468–474. doi:10.1188/11.ONF.468-474.

Hinchey, J., Goldberg, J., Linsky, S., Linsky, R., Jeon, S., Schulman-Green, D., 2016. Knowledge of cancer stage among women with nonmetastatic breast cancer. J. Palliat. Med. 19 (3), 314–317. doi:10.1089/jpm.2015.0133.

Hobbs, G.S., Landrum, M.B., Arora, N.K., Ganz, P.A., van Ryn, M., Weeks, J.C., Mack, J.W., Keating, N.L., 2015. The role of families in decisions regarding cancer treatments. Cancer 121 (7), 1079–1087. doi:10.1002/cncr.29064.

Huang, S.H., Tang, F.I., Liu, C.Y., Chen, M.B., Liang, T.H., Sheu, S.J., 2014. Truth-telling to patients' terminal illness: what makes oncology nurses act individually? Eur. J. Oncol. Nurs.: Off. J.Eur. Oncol.Nurs. Soc 18 (5), 492–498. doi:10.1016/j.ejon.2014.04.010.

Hubbard, G., Illingworth, N., Rowa-Dewar, N., Forbat, L., Kearney, N., 2010. Treatment decision-making in cancer care: the role of the carer. J. Clin. Nurs. 19 (13–14), 2023–2031. doi:10.1111/j.1365-2702.2009.03062.x.

Hudson, P.L., Aranda, S., Kristjanson, L.J., 2004. Meeting the supportive needs of family caregivers in palliative care: challenges for health professionals. J. Palliat. Med. 7 (1), 19–25. doi:10.1089/109662104322737214.

Innes, S., Payne, S., 2009. Advanced cancer patients' prognostic information preferences: a review. Palliat. Med. 23 (1), 29–39. doi:10.1177/0269216308098799.

Kim, C., Liang, L., Wright, F.C., Hong, N., Groot, G., Helyer, L., Meiers, P., Quan, M.L., Urquhart, R., Warburton, R., Gagliardi, A.R., 2018. Interventions are needed to support patient-provider decision-making for DCIS: a scoping review. Breast Canc. Res. Treat. 168 (3), 579–592. doi:10.1007/s10549-017-4613-x.

Lamont, E.B., Christakis, N.A., 2001. Prognostic disclosure to patients with cancer near the end of life. Ann. Intern. Med. 134 (12), 1096–1105. doi:10.7326/0003-4819-134-12-200106190-00009.

Larkin, M., Shaw, R., Flowers, P., 2018. Multiperspectival designs and processes in interpretative phenomenological analysis research. Qual. Res. Psychol. 16 (2), 182–198. doi:10.1080/14780887.2018.1540655.

Lincoln, Y.S., Guba, E.G., 1985. Naturalistic Inquiry. Sage, Newbury Park, CA.

Lopez, K.A., Willis, D.G., 2004. Descriptive versus interpretive phenomenology: their contributions to nursing knowledge. Qual. Health Res. 14 (5), 726–735. doi:10.1177/1049732304263638.

McLennon, S.M., Lasiter, S., Miller, W.R., Amlin, K., Chamness, A.R., Helft, P.R., 2013. Oncology nurses' experiences with prognosis-related communication with patients who have advanced cancer. Nurs. Outlook 61 (6), 427–436. doi:10.1016/j.outlook.2012.12.001.

Newman, A.R., 2016. Nurses' perceptions of diagnosis and prognosis-related communication: an integrative review. Canc. Nurs. 39 (5), E48–E60. doi:10.1097/NCC.0000000000000365.

Oikonomidou, D., Anagnostopoulos, F., Dimitrakaki, C., Ploumpidis, D., Stylianidis, S., Tountas, Y., 2017. Doctors' perceptions and practices of breaking bad news: a qualitative study from Greece. Health Commun. 32 (6), 657–666. doi:10.1080/10410236.2016.1167991.

Orri, M., Sibeoni, J., Labey, M., Bousquet, G., Verneuil, L., Revah-Levy, A., QualiPRO study group, 2015. Qualitative approach to patient-reported outcomes in oncology: protocol of a French study. BMJ open 5 (7), e008042. doi:10.1136/bmjopen-2015-008042.

Orri, M., Sibeoni, J., Bousquet, G., Labey, M., Gueguen, J., Laporte, C., Winterman, S., Picard, C., Nascimbeni, C., Verneuil, L., Revah-Levy, A., 2017. Crossing the perspectives of patients, families, and physicians on cancer treatment: a qualitative study. Oncotarget 8 (13), 22113–22122. doi:10.18632/oncotarget.12770.

Repetto, L., Piselli, P., Raffaele, M., Locatelli, C., GIOGer, 2009. Communicating cancer diagnosis and prognosis: when the target is the elderly patient-a GIOGer study. Eur. J. Canc. (Oxford, England) 45 (3), 374–383 1990 doi:10.1016/j.ejca.2008.08.020.

Sarafis, P., Tsounis, A., Malliarou, M., Lahana, E., 2013. Disclosing the truth: a dilemma between instilling hope and respecting patient autonomy in everyday clinical practice. Global J. Health Sci. 6 (2), 128–137. doi:10.5539/gjhs.v6n2p128.

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., Jinks, C., 2018. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual. Quantity 52 (4), 1893–1907. doi:10.1007/s11135-017-0574-8.

Shahidi, J., 2010. Not telling the truth: circumstances leading to concealment of diagnosis and prognosis from cancer patients. Eur. J. Canc. Care 19 (5), 589–593. doi:10.1111/j.1365-2354.2009.01100.x.

Smith, J.A., Flowers, P.L., Larkin, M., 2009. Interpretative Phenomenological Analysis: Theory, Method and Research. Sage, London.

Smith, J.A., Osborn, M., 2008. Interpretative phenomenological analysis. In: Smith, J.A. (Ed.), Qualitative Psychology. A Practical Guide to Research Methods. Sage, London, pp. 53–80.

Surbone, A., Ritossa, C., Spagnolo, A.G., 2004. Evolution of truth-telling attitudes and practices in Italy. Crit. Rev. Oncol.-Hematol. 52 (3), 165–172. doi:10.1016/j.critrevonc.2004.09.002.

Surbone, A., 2008. Cultural aspects of communication in cancer care. Support. Care Canc. : Off. J. Multinatl. Assoc.Support .Care.Canc. 16 (3), 235–240. doi:10.1007/s00520-007-0366-0.

The, A.M., Hak, T., Koëter, G., van Der Wal, G., 2000. Collusion in doctor-patient communication about imminent death: an ethnographic study. BMJ (Clinical research ed.) 321 (7273), 1376–1381. doi:10.1136/bmj.321.7273.1376.

Tuckett, A.G., 2004. Truth-telling in clinical practice and the arguments for and against: a review of the literature. Nurs. Ethics 11 (5), 500–513. doi:10.1191/0969733004ne728oa.

Villalobos, M., Siegle, A., Hagelskamp, L., Jung, C., Thomas, M., 2019. Communication along milestones in lung cancer patients with advanced disease. Oncol. Res.Treat 42 (1–2), 41–46 2014 doi:10.1159/000496407 Warnock C.

Warnock, C., 2014. Breaking bad news: issues relating to nursing practice. Nurs. Stand. 28 (45), 51–58 1987 doi:10.7748/ns.28.45.51.e8935.

Wittenberg, E., Goldsmith, J., Buller, H., Ragan, S.L., Ferrell, B., 2019. Communication training: needs among oncology nurses across the cancer continuum. Clin. J. Oncol. Nurs. 23 (1), 82–91. doi:10.1188/19.CJON.82-91.

UNIVERSITAT ROVIRA i VIRGILI