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Communication about serious illness as a relational process

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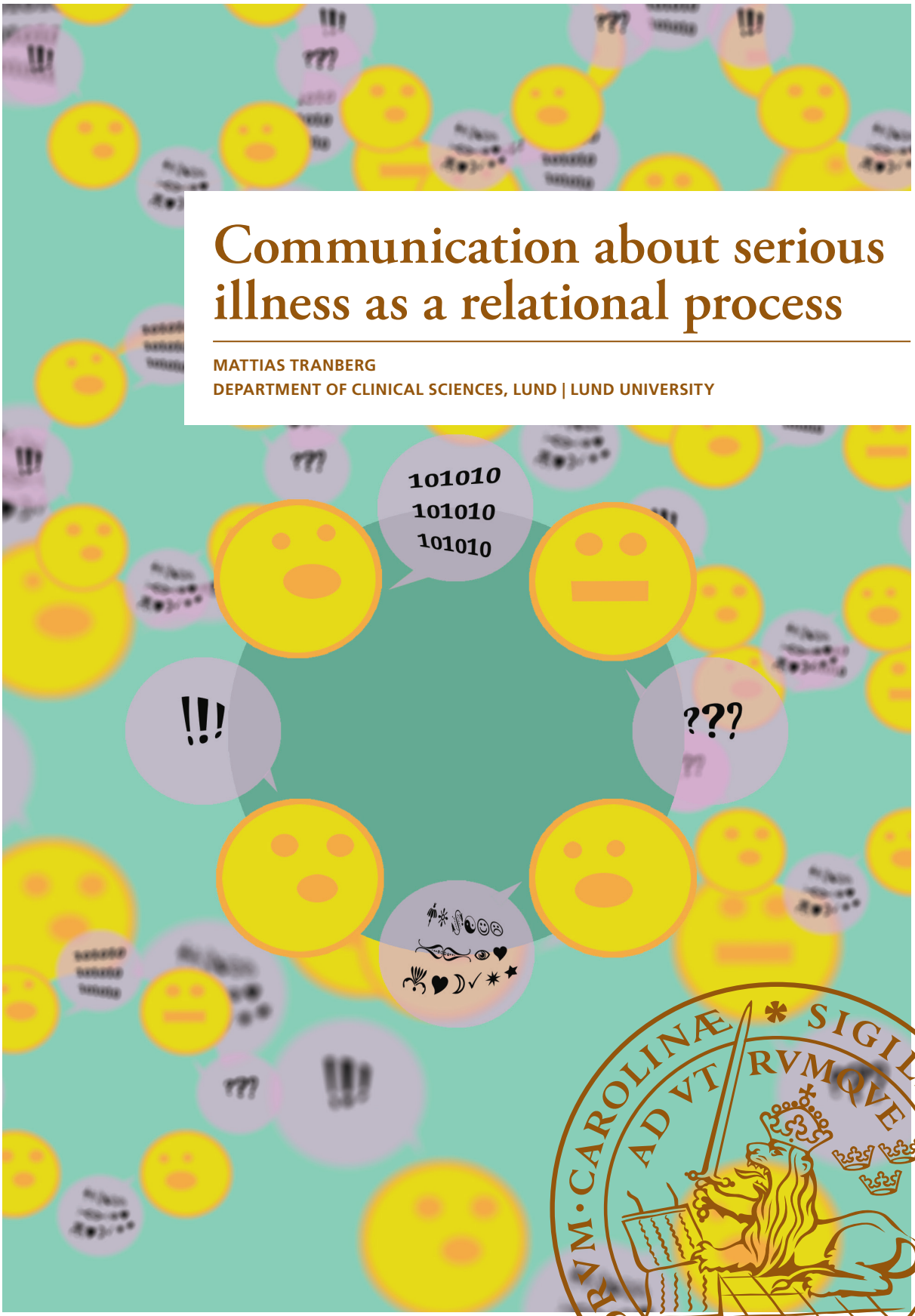

Communication about serious illness as a relational process

Communication about serious illness as a relational process

Mattias Tranberg

LUND
UNIVERSITY

DOCTORAL DISSERTATION

Doctoral dissertation for the degree of Doctor of Philosophy (PhD) at the Faculty of Medicine at Lund University to be publicly defended on 10th of February at 13.00 in Torsten Landgren Hall, Department of Oncology, Klinikgatan 5

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Abstract:

Communication about serious illness involves many parties: patients, families, friends, neighbors, and caregivers. Unfortunately, we are poorly prepared to relate to it, and talk about it. While the medical professions have become highly skilled at treating diseases, a holistic view of humans as social beings has been lost for the past centuries. In the last 40 years this has started to change, a biopsychosocial view of illness and medicine has begun to evolve, which is based on the notion that the meaning of illness for humans is highly dependent of personal values, circumstances, and relationships.

Against this background, the overall aim of this thesis is to gain a better understanding of communication about serious illness as a relational process, sourcing data from informal caregivers, medical records, patients, and physicians. Both quantitative and qualitative methods were used to collect and analyze data in four-part studies.

The results show that a lack of communication leads to feelings of loneliness, that bad news will make the patient feel less listened to, that delivering bad news is a relational process that evolves over time rather than a one-time event, and that there is a need for a more holistic view of health care that includes caregivers as well as patients and families.

Hence, it can be concluded that current communication practices need to be further developed towards a more relational approach. Also, the role of the health care providers, and their relationship to each other and patients, needs to be reconsidered.

Future studies should explore how health care can encompass social or relational contexts and discern whether it is reasonable to assume that all health care providers be excellent communicators without training or vocation, or if that should warrant special and certified skills.

Key words: Communication, Serious illness, Relationships, Process, Bad news

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To Åsa, love of my life

Table of Contents

Abstract 11
Populärvetenskaplig sammanfattning 12
List of Papers 15
Author's contribution to the papers 16
Preface 17
Context of this thesis 18
Introduction 19
The history of healing 19
Treating the whole person 19
Dividing body and soul 22
The biomedical model 23
The development of psychology 24
Psychoanalysis and psychodynamic therapy 25
Behaviorism 26
Humanistic psychology 26
Cognitive behavioral therapy (CBT) 26
Attachment theory 27
Medical psychology 29
Re-uniting body and mind 30
The biopsychosocial model 30
Salutogenesis 30
Treating the person, not the disease 31
Humans are social beings 32
Communication in health care 32
History of communication/disclosure in health care 33
Research on communication in health care 36
Rationale 39
Aims 40

Methods **41**
Ontology and epistemology 41
Participants and materials 42
Data analysis 44
Ethical considerations 46
Results **48**
Paper I 48
Paper II 49
Paper III 50
Paper IV 50
Discussion **52**
Paper I 52
Paper II 53
Paper III 54
Paper IV 55
Conclusions and clinical implications **57**
Further research **59**
Acknowledgements **60**
References **62**

Abstract

Communication about serious illness involves many parties: patients, families, friends, neighbors, and caregivers. Unfortunately, we are poorly prepared to relate to it, and talk about it. While the medical professions have become highly skilled at treating diseases, a holistic view of humans as social beings has been lost for the past centuries. In the last 40 years this has started to change, a biopsychosocial view of illness and medicine has begun to evolve, which is based on the notion that the meaning of illness for humans is highly dependent of personal values, circumstances, and relationships.

Against this background, the overall aim of this thesis is to gain a better understanding of communication about serious illness as a relational process, sourcing data from informal caregivers, medical records, patients, and physicians. Both quantitative and qualitative methods were used to collect and analyze data in four-part studies.

The results show that a lack of communication leads to feelings of loneliness, that bad news will make the patient feel less listened to, that delivering bad news is a relational process that evolves over time rather than a one-time event, and that there is a need for a more holistic view of health care that includes caregivers as well as patients and families.

Hence, it can be concluded that current communication practices need to be further developed towards a more relational approach. Also, the role of the health care providers, and their relationship to each other and patients, needs to be reconsidered.

Future studies should explore how health care can encompass social or relational contexts and discern whether it is reasonable to assume that all health care providers be excellent communicators without training or vocation, or if that should warrant special and certified skills.

Populärvetenskaplig sammanfattning

I allt högre utsträckning över hela världen, så informeras patienter ingående om sina diagnoser, och de inkluderas också i beslutsprocesser mer än någonsin. Men detta har inte alltid varit självklart och är det fortfarande inte.

Som ett resultat av utvecklingen inom medicinsk vetenskap har vårdgivarens roll kommit att handla om kommunikation i högre grad än tidigare. Tidigare fick patienter veta att de var allvarligt sjuka först när symtomen hade blivit framträdande, eftersom möjligheterna till tidig diagnos var begränsade. Numera kan många diagnoser ställas innan patienten upplever symtom. Att delge tillgänglig information är centralt inom kommunikation mellan vårdtagare och vårdgivare, och hänger ihop med principen om "informerat samtycke".

I många länder ses vårdgivaren idag som jämlik med patienten, som har rätt till information för att kunna fatta sina egna beslut. Men den bilden fångar inte att relationen mellan vårdgivare och patient i grunden är asymmetrisk, då individerna har olika mängd kunskap, olika behov och mandat. Sårbarheten som sjukdomen medför ökar patientens beroende av andra människor.

Alla sjukdomar har objektiva, subjektiva och relationella aspekter som tillsammans bidrar till den dynamiska sanningen om patientens tillstånd. När vårdpersonal inte tar hänsyn till de subjektiva och relationella aspekterna av sjukdomen utan endast fokuserar på den till synes objektiva informationen om patientens tillstånd, så reduceras sjukdomen till en mängd biomedicinska fakta. Kommunikationen blir då enbart en enkelriktad överföring av information från vårdgivaren, medan patientens röst inte blir hörd.

Konflikten mellan att skydda vårdtagaren från skrämmande information och att respektera dennes frihet är inte ett nytt fenomen, utan diskussioner om vad som är rätt eller fel har pågått sedan antiken, om inte ännu längre tillbaka i tiden. Med dualismens inträde under upplysningen blev läkekonsten till en biomedicinsk vetenskap, med fokus på att bekämpa sjukdomar. För att försäkra sig om att patienten skulle vara lydig och samarbeta blev vita lögner normen inom medicin och det blev nästan otänkbart att man skulle säga sanningen till patienterna. Så sent som 1947 hade de franska medicinsk-etiska principerna hållningen att det var legitimt att undanhålla en dålig prognos för en patient, men att man kunde avslöja en dödlig prognos för familjen om man var försiktig.

Sen kom Nürnberg-rättegångarna där det fastställdes att individen måste skyddas från medicinska övergrepp med följden att "informerat samtycke" blev det nya paradigmet för medicinsk forskning. Vid den första Internationella medicinsk-etiska konferensen som hölls 1955 fastställdes det att patienten skulle betraktas som en fri person och hade rätt att känna till sanningen. Detta visade sig dock inte vara tillräckligt för att vårdpersonal skulle förändra sina beteenden. Det var inte förrän patientens rättigheter lagstiftades år 1973 som praxis började förändras, först i Nordamerika och nordvästra Europa, för att sedan spridas vidare i världen.

De senaste åren har vi sett en stor förändring ske världen över. Förbättrad behandling har underlättat kommunikation om diagnos och symtomhantering, effektiv palliativ vård har underlättat för kliniker att ändra kurs från bot till lindring, samtidigt som man öppet kan diskutera de olika stadierna och övergången från kurativ till palliativ vård. För 20 år sedan var det mycket få länder som hade stödjande strukturer för att möta de känslomässiga och praktiska behoven hos patienter med allvarlig sjukdom, medan det numera finns utbildning och infrastruktur för stödjande vård i många länder.

Patienten har också blivit mer delaktig idag. Fler och fler länder lagstiftar om patientens rätt till information, och patienter samt närståendes engagemang i sjukvården har lett till att patienter involveras i kliniska studier som ska prioritera patienternas intressen.

Allmänhetens tillgång till information av skiftande kvalitet, genom media och virtuell kommunikation, har aldrig varit så stor som den är i dagsläget. I industrialiserade länder förväntar sig över 90% av alla personer med cancer att få veta sanningen om sin sjukdom, och att få vara delaktiga i beslutsprocessen. Även om det finns stor variation mellan individer beträffande önskemål om information och delaktighet, så visar empiriska data att individer som har blivit informerade och inkluderade i besluten fullföljer behandlingen i högre utsträckning. Runtom i världen har personer med allvarlig sjukdom i regel behov av att få prata med läkaren om sin sjukdom, för att på så vis kunna förbereda sig på det som ska komma och få försäkran om fortsatt stöd. I Sverige har vi patientlagen som säger att patienten ska informeras och vara delaktig, men att patienten också har rätt att avstå från information, och Socialstyrelsen har bestämt att det är av högsta prioritet att brytpunktssamtal vid livets slutskede genomförs.

Att vara vårdgivare idag kräver en oerhörd medicinsk-teknisk kompetens som bygger på naturvetenskapliga data, och förmåga att möta patientgrupper och individer från världens alla hörn med varierande utbildningsnivå, sociala strukturer och önskemål när det gäller information. Dessutom ska vårdgivarna klara detta med minimal utbildning och träning i kommunikation.

Min bakgrund i sammanhanget är att jag både utbildar vårdpersonal inom kommunikation och forskar på ämnet vid allvarlig sjukdom. I denna avhandling beskrivs hur det upplevs att vara närstående till en person med cancer, huruvida patienter och närstående har blivit informerade om sjukdomens utveckling och vårdens inriktning, hur patienter upplever vårdgivarens bemötande beroende på vilken information som delges vid vårdtillfället, samt läkares upplevelse av att ge ett svårt besked, eller dela med sig av allvarlig information.

Artikel I visar att många närstående upplever sig vara med-drabbade till den sjuke såtillvida att de tar på sig mycket ansvar, sätter sina egna behov åt sidan och ibland förlorar känslan av att vara en egen person i relation till den sjuke, vården och samhället.

I **artikel 2** framkommer det att många närstående och patienter hade blivit informerade flera gånger under vårdförloppet, att samtal om allvarlig sjukdom inte

bara ska vara, utan i praktiken ofta är, en process. Det framkom också att den gängse kvalitetsmätningen i dessa sammanhang var missvisande vilket försvårar kvalitetsutveckling.

Enligt **artikel 3** upplever patienter sin läkare som mindre empatisk när de har fått ett besked om att sjukdomen har progredierat (utvecklats eller om det finns nya fynd), jämfört med om de har fått ett positivt eller neutralt besked. Framför allt känner patienterna att läkaren visar mindre medkänsla och lyssnar mindre, trots att läkarna avsätter mera tid till dessa samtal. Detta kan bero på att läkaren fokuserar mer på budskapet och sig själv än på mottagaren.

Artikel 4 visar att givandet av ett svårt besked inte enbart handlar om att överföra information, utan att det är snarare är fråga om en relationell process, som påverkar såväl läkare som patient.

Sammantaget visar avhandlingen att kommunikation om allvarlig sjukdom handlar om mer än att endast förmedla biomedicinska fakta. Kommunikationen involverar också processer som löper över tid och sker i relationerna mellan patienter, närstående, vårdgivare och det omgivande samhället. Grundutbildningar i människovårdande professioner behöver därför redan från början betona vikten av mänsklig kontakt. Framtida forskning och utveckling bör fokusera på att förstärka humanismen i läkekonsten och verka för en mer holistisk syn på människan i sitt sammanhang.

List of Papers

This thesis is based on the following original publications, referred to in the text by Roman numerals:

Paper I

Tranberg, M., Andersson, M., Nilbert, M., & Rasmussen, B. H. (2021). Co-afflicted but invisible: A qualitative study of perceptions among informal caregivers in cancer care. *Journal of Health Psychology*, 26(11), 1850-1859. https://doi.org/10.1177/1359105319890407

Paper II

Tranberg, M., Jacobsen, J., Fürst, C. J., Engellau, J., & Schelin, M. E. C. (2022). Patterns of Communication About Serious Illness in the Years, Months, and Days before Death. *Palliative Medicine Reports*, 3(1), 116-122. https://doi.org/10.1089/pmr.2022.0024

Paper III

Tranberg, M., Ekedahl, H., Fürst, C. J., & Engellau, J. (Forthcoming). Physician Empathy is Sensitive to the Content of the Oncology Consultation. Manuscript submitted to journal.

Paper IV

Tranberg, M., & Brodin, E.M (Forthcoming). Breaking bad news as a relational process: Towards a holistic understanding of the phenomenon in clinical practice. Manuscript submitted to journal.

Author's contribution to the papers

Paper I

Application of qualitative techniques to analyze and synthesize study data.

Preparation, creation, and presentation of the published work, specifically writing the initial draft and revisions.

Paper II

Ideas: formulation of overarching research goals and aims.

Conducting the research and investigation process, specifically collecting data.

Application of statistical techniques to analyze and synthesize study data.

Preparation, creation, and presentation of the published work, specifically writing the initial draft and revisions.

Paper III

Ideas: formulation of overarching research goals and aims.

Application of statistical techniques to analyze and synthesize study data.

Preparation, creation, and presentation of the published work, specifically writing the initial draft.

Paper IV

Ideas: formulation of overarching research goals and aims.

Conducting the research and investigation process, specifically performing the interviews, and transcribing some of the interviews.

Application of qualitative techniques to analyze and synthesize study data.

Preparation, creation, and presentation of the published work, specifically writing the initial draft.

Preface

As an undergraduate student, I chose to become a professional psychologist for several reasons, one being that I observed that some people pursue treatment even when there is no hope. My perception was that they were motivated by a lack of better options, or a very strong fear of death. I thought that we needed psychologists who can help people adjust to time being limited and help people make the most of the time given, instead of wasting all their remaining time trying to get more time.

During my previous studies in psychology, I saw a wanted ad for a personal assistant for a dying person. I thought that it might be a good opportunity for me to gain experience, so I applied and got the job. During that time, which lasted much longer than anyone could anticipate, the person I was assisting gradually spent less time at home and more time in the unit for specialized palliative care. I got an inside view of the persons experience, and the experience of their family. I spent many days together with them in the care unit, so I also gained insight into specialized palliative care. It was heart-warming to see the different professions in action; they were available and compassionate, but to my astonishment, there were no psychologists there. As I soon discovered, that was not a local peculiarity but true for all of Sweden. I tried to get an explanation, but nobody seemed to know why.

Another observation I made quite soon was that the person I was assisting did not seem to be aware that he was dying. I asked a social worker what she thought about that, and she said that it is important to allow the patients' hope. She also asked me if I knew about the "Creative illusion" [1], which I did not. I read that book, written by a Swedish psychologist, Pär Salander, and it was a great book that I still often refer to. However, I didn't feel that it applied to this specific case, as the sick person was cognitively impaired and did not seem to have understood medical jargon like "palliative intent." It seemed to me that there was a reluctance from the health care professionals to speak clearly about the subject, which resulted in everybody except the patient knowing that he was dying. I started an e-mail conversation with Pär Salander, asking him for advice on how to proceed with psychological approaches to palliative care and research. He suggested that I contact Carl Johan Fürst and Birgit Rasmussen at the Institute for Palliative Care. We met and came to discuss communication and I decided to write my Master thesis in psychology about communication with seriously ill patients. Since then, I have remained at the Institute for Palliative Care.

Context of this thesis

The patients, informal caregivers, and clinicians studied in this thesis have been made available to me through clinicians, researchers, and educators that I met through The Institute for Palliative Care (PC). PC is a part of Lund University and Region Skåne, which focuses on research, development, and education for both general and specialized palliative care, and has a multidisciplinary team.

Within the different research projects, I have worked together with an epidemiologist, nurses, a pedagogue as well as physicians. Paper I was a joint project with the Regional Cancer Center South, with which we share facilities, and the participants were recruited by Cancer Buddies (Cancerkompisar.se) from various locations in Sweden. The patients in Papers II and III were located in Region Skåne, and the clinicians in Paper III worked at Skåne University Hospital. The Swedish Register for Palliative Care (SRPC) managed the national register used in Paper III. The participants in Paper IV were found through The Institute for Palliative Care and lived throughout Sweden.

Introduction

> The basis of medicine is sympathy[1] and the desire to help others, and whatever is done with this end must be called medicine - Joseph Frank Payne [*]

The history of healing

Since the beginning of recorded history, the art of healing has probably consisted of an interaction between a helper and a sufferer [4]. With or without the aid of a ritualized process, herbs, or drugs, the helper offered services contingent on the sufferer's unconditional belief in the healing powers of the helper or the gods the helper served. It can be proposed that for a long time, the main therapeutic agent for any remedy was psychological.

Treating the whole person

In India, the documents of *Vedas* and *Samhitas* promoted *Ayurveda* as a complete system for health care, which was provided by the gods and was written around 1000-600 BCE [5]. In Ayurveda, every human is seen as consisting of five elements (ether, air, fire, water, and earth) that form three different life energies in the body, *doshas*, and Ayurvedic medicine's focus is on achieving and maintaining a balance between body, mind, and spirit. The Caraka Samitha is considered one of the earliest preserved texts to discuss the psychological and physical causes of mental illness and stresses the importance of healthy social relationships for both mental and physical health [5, 6]

Traditional Chinese Medicine is another very old medical system. The oldest traces are from the oracle inscriptions of the Yin Dynasty (c. 1600 BC–1046 BC), where more than 20 types of diseases have been recorded [7]. Over time, medicine and witchcraft were separated, and the theories of yin, yang, and the five elements (wood, fire, earth, metal, and water) replaced the doctrine of destiny and

[1] "Sympathy" here is likely used according to Hume's notion of "sympathy", which would translate into "empathy" today [2] L. Agosta, A Delicacy of Empathy: Hume's Many Meanings of Sympathy, Revista Psicologia em Pesquisa 8(1) (2014).

[*] (p. 19) [3] W. Osler, The Evolution Of Modern Medicine, Project Gutenberg ; NetLibrary2000.

supernatural beings as causes of health and illness. In Traditional Chinese Medicine, healers aim to restore yin-yang balance by means of acupuncture, herbs, diets, or exercises such as *qigong* [7]. It does not distinguish between physical and psychological illness or between causes and treatments [8].

Greek philosophy is sometimes seen as a predecessor for the Western biomedical model, although it did have a wider, more holistic approach to disease than is the case in contemporary clinical practice. In ancient Greece, the physician-patient relationship was considered a sacred bond, *philia*, and the physician was expected to provide care with compassion and empathy.

According to legend, Asclepius was the son of the Greek god Apollo and Coronis, raised by the centaur Chiron and educated in the art of medicine [9]. Asclepius became very skilled in healing and was even able to bring people back from the dead. Many healing temples, called *asclepeia*, were established throughout ancient Greece. These temples were a place for people to come and seek both physical and mental healing. The focus was on living a healthy lifestyle, including diet, exercise, and spiritual well-being. The individual was seen as unique psychosomatic entity [10], and health came from within [11]. Dreams played a significant role in the healing process, as patients would report their dreams to priests, who would then prescribe cures based on their interpretation of the dreams. Non-venomous snakes were also an important part of the healing process and could be found in many temples. Aesculapian snakes are the serpents depicted in the symbol for medicine.

Aristotle has been credited for the first major studies on biology and psychology, which he saw as part of natural philosophy. In *On the Soul* (De Anima), he argued that the mind or soul, which was the essence of any living thing, was the link to the divine and balanced desire and reason in humans and was not distinct from the body [12].

Hippocrates is known as the father of (western) medicine, though we know very little about him, except for that he lived in Greece and gained a reputation as a writer and medical doctor. He was mentioned by both Platon and Aristotles in their writings [13, 14]. However, there are many writings attributed to Hippocrates which gives a picture of how physicians in Ancient Greece viewed disease and health. Hippocrates thought that human health was dependent on environmental factors and humoral pathology. In contrast with the spiritual and ritualistic approach of Asclepius, Hippocrates believed that medicine and healing should be based on rationalism and science, rather than spirituality and magic [9].

According to this view, everyone has a unique balance, determined by the distribution of body fluids, which expresses itself as temperament. Disease was seen as a sign that the fluids were out of balance, and treatments aimed at restoring the balance of the humors. Although few believe in humoral pathology nowadays, the words choleric and melancholy derive from Hippocrates terminology [6], and physicians around the world still abide by the Hippocratic code of ethical conduct, to *not harm*, and *always help.*

The Roman medical writer Aulus Celsus (25 BC-50 AD) was a pupil of Quintus Sextius, a medical philosopher who recommended vegetarianism, as he believed that butchering could cause a habit of cruelty [15]. Celsus was influenced by Sextius in that he developed a sense of medical mercy, although he recommended that his patients eat meat. Celsus' main, and still lasting, contribution to medicine was the introduction of the term *cancer [15]*, defining criteria for assessing head injury as well as the establishment of four distinct symptoms of inflammation: pain (dolor), heat (calor), redness (rubor), and swelling (tumor)[16].

The Greek surgeon and philosopher Galen, who lived and practiced in Rome 130-210 AD, developed the Hippocratic doctrine, and explained disease as a symptom of a pathological condition. This understanding has led medicine from the folk lore narrative of disease (mythos) to logical and rational analysis (logos) [6]. Galen wrote about human anatomy based on findings derived from dissecting animals, as Roman law prohibited human dissections [17]. Galen also addressed psychological problems and described therapeutic interventions in his work *On the Diagnosis and Cure of the Soul's Passion* [6].

The next major development came with the Persian polymath Ibn Sina, or Avicenna (980-1037), who wrote *The Canon of Medicine.* [18]. In this work, he used Galen as a point of departure, and both confirmed and criticized his predecessor based on his own observations, as well as the teachings of Islamic physicians. He introduced the concept of mental health and promoted the idea that self-esteem and emotions are essential for a patient's welfare and physical condition. He also noted that music had both physical and psychological effects on patients and advocated for the psychological benefits of breastfeeding [19]. The Canon of Medicine covered many different areas, such as cardiovascular health, tuberculosis, and rules for experimental investigation of the effects of drugs, and his work was translated into many different languages and had an authoritative status for centuries until autopsies became permitted and practiced in Europe [20].

Paracelsus, a Swiss medical doctor and theologian (1493-1541), applied the principles of alchemy to medicine and ascribed five different causes to disease: predestination, venom, astral influences, spiritual, and divine [21]. His teaching became one of the most comprehensive alternatives to the humoral system, and he went as far as to publicly burn the works of Galen and Avicenna [22]. His view was signified by the thought that illness occurred due to the individual being attacked by external influences and thus called for benevolent treatment of the mentally ill. He also suggested that the will of a patient could cause or cure a bodily disorder [23].

While Paracelsus advocated for the union of mind and body, contemporary medical doctor, and anatomist Vesalius (1514-1564) played an important role in the scientific separation of body and mind, which was a prerequisite for the epistemology of modern medicine. With the support of an enthusiastic judge, he was granted permission to dissect executed criminals [24]. His treatise *De humani corporis fabrica* disproved many of Galen's claims about human anatomy, as well as describing the structure of the brain and other organs [17, 25].

The Anatomy of Melancholy was published in 1621 by Oxford fellow and priest Robert Burton (1577-1640). It was an encyclopedia of mental illness based on scholastic philosophy of humoral pathology that enjoyed extreme popularity for several hundreds of years [26]. In it, he declares melancholy, which he used as an umbrella term for many kinds of mental illnesses, to be caused by the wrath of God, but also a result of the actions of devils, spirits, and the influence of the moon. He advised keeping busy as the best cure, along with praying to God and talking to friends [27].

In 1628 William Harvey published *On the Motion of the Heart and Blood in Animals* which proved that blood circulates through the mechanical force of the heart and disproved Galen's claim that the liver created blood, which at that time was still the prevailing theory [28]. Although his discovery was met with skepticism, it was a sound argument against the humoral system [29].

Dividing body and soul

René Descartes (1596-1650) published *Contemplation of the world* in 1633. Descartes was dissatisfied with what we would call "science" and had a particular interest in advancing medicine, as he thought that the maintenance of health was the basis for all good in life. If medicine is based on a reliable understanding of the causes of diseases and illnesses of the body and mind, we could use it to free ourselves of those illnesses [30].

Descartes resolved to find a reliable foundation of knowledge that anyone could see as reliable when examined in an unprejudiced way. He believed that if he could find something that could not be doubted, then that could be the base for the whole structure of dependable knowledge. He concluded that the only belief that could not be doubted was his own existence as a thinking being, whether anything else existed or not [31]. To him, the thinking self was distinct from the objects it was thinking about and consisted of different substance, one mental, and the other material. Therefore, a human being is a composite of two independent substances, "mind" and "body". He thought that these substances had mutually exclusive essences: "mind" had thought, consciousness and reason and "body" occupied space and had spatial properties. Bodily processes, both normal and abnormal, are physicochemical processes governed by laws of mechanics.

Physical illness could, according to Descartes' dualism, be explained "mechanistically" and should be understood as dysfunctional performance of a machine, and consequently without spiritual or moral values. Mental processes were not governed by the same laws and were thus not part of medical science [30]. This separation preserved the possibility for the Christian belief in a soul that survives the death of the body at the same time as it permitted a progressive science of the body through the study of anatomy, biochemistry, physics, and physiology [32] as well as allowing an interventionist medical practice [33]. However, despite Descartes himself being a devout Catholic and claiming that his visions came from

God, his method of doubt replaced the authority of the church with the individual's *subjectivity* as the basis of knowledge [34]. This dualism also signified a vantage point for positivism, that is, the exact natural sciences based on empirical and neutral observations and measurements [32]. Thus, the basis for a *biomedical model* of the disease was established.

The first English book on neuropsychology was probably *De Anima Brutorum*, published in 1672 by Thomas Willis (1621-1675) in which he coined the term *neurology* [35] and attributed frenzy, headache, paralysis, and other diseases to neurological disturbances. He opposed Descartes' dualism and proposed that the higher cognitive functions of humans originate from the convolutions of the cerebral cortex, based on observations of cortical malformations associated with learning difficulties [36]. He differentiated between brain disease and mental illness and recognized that the causal factors of retardation could be hereditary, congenital, or acquired [37]. His main contribution to medicine can be said to be his approach to knowledge and view of disease, led by curiosity he sought to explain the cause of disease by means of observation of anatomical and clinical correlation [36].

In 1761, Italian anatomist Giovanni Battista Morgagni (1682-1771) published *On the Seats and Causes of Disease, investigated by Anatomy*, and set the basis for modern pathology [38]. He causally explained disease as deriving from local changes in organs based on findings from 640 autopsy dissections performed by himself, and the publication included detailed descriptions and correlations with the clinical history of the disease [39]. Later contributions were made by anatomist Zavier Bichat (1771-1802), who is often credited as the founder of *histology*, even though he did not use a microscope. He described tissue structures and considered organs not to be entities of themselves, but collections of tissue. He viewed disease as specific lesions in various tissues [29].

The next fundamental step in the development of pathology was made possible by application of the microscope. Rudolf Virchow (1821-1902) came to use the microscope as a routine while performing autopsies and changed the focus from organs to cells, eventually leading to *cellular pathology* and *histopathology* [29] and the discovery that all cells come from cells, thus localizing disease ever more [40]. With the new perspective on disease, the body could be regarded as healthy, while a localized organ, tissue, or cell is sick. This allowed for the unification of surgery, which had previously been a separate profession, with medicine [41].

The biomedical model

With this new understanding of disease, the biomedical model, or *disease-centered method*, has come to dominate medicine and health care [42]. This model embraces reductionism and builds on a set of beliefs.

- All illness and symptoms arise from malfunctions in the body, that is, disease

- Diseases cause symptoms
- Health is equal with the absence of disease
- The patient receives treatment passively but is expected to cooperate.
- Mental and emotional illness is unrelated to physical functions [42]

Localization and differentiation between the health of a cell, tissue, or organ and the entire human body allowed for rapid advances in medicine, but the unity of the body was lost. First, Descartes dualism separated the mind and body, and then the body was subdivided, resulting in the development of medical specialties in the 19th century, first in Paris in the early 1840s, Vienna in the 1850s, and then in the rest of Europe and North America [43]. Specialization became a form of knowledge production, closely linked to clinical work, and by the end of the 19th century, specialties were perceived as distinct forms of medical practice [43].

The division between the mind and body persisted and increased. With the development of the medical sciences, the basis of treatment changed, and from the early 1900s, modern physicians were remade to be distinguished by administrating treatments that were solidly grounded in human anatomy, biology, and chemistry [4] and created physicians who were scientists, freed from the bounds of theology-philosophy that had shaped the profession, and left the medical profession with few tools to relieve emotional, mental, and spiritual suffering, other than treatment with the drugs of psychiatry.

The development of psychology

Psychology was first identified as a separate science by philosopher Christian Wolff (1679-1754) in his *Psychologia empirica* and *Psychologia rationalis* and was meant to be the study of the soul. The soul was seen as part of this world, but observations could not offer exhaustive knowledge. *Empirical psychology* is based on the observation of one's own mind, *introspection*, and *rational psychology* is meant to use reasoning to find the truths of the soul. For Wolff, the two methods were intrinsically linked, each informing the other [44]. Wolff was controversial and popular and consequently became the center of an academic drama that made both him and philosophy famous all over Europe. Through his influence philosophy, which psychology was part of, was taught at most German universities [45]. His work was discussed extensively by Kant [46] and psychological topics continued to be a theme among writers and philosophers, such as Schopenhauer, Nietzsche, and Dostoevsky in the 19th century [6].

Johann Heinroth (1773-1843), a German medical doctor, introduced the term *psychosomatic*, to describe illness, both mental and somatic, caused by the soul. He saw the mind as being divided into conscience, emotions/will, and basic drives. Sin

was regarded as a cause of mental illness, specifically prolonged sin, with the aim of achieving bodily satisfaction. To him, the soul and body were linked, but the soul had primacy [47]. Heinroth was of the opinion that empiricism was insufficient to understand mental illness, symptoms needed to be seen in the context of the personality and lifestyle of the individual, and required thorough philosophical knowledge [48].

Psychology broke off from the philosophical style of investigation in the second half of the 19th century. As a separate branch of human care and concern, the development of psychology as an independent field started to shape into a science, with the opening of Wilhelm Wundt's laboratory for experimental psychology in 1879 often counted as the starting point [49]. The new academic discipline was seen as a natural science that focused on quantitatively measurable aspects, such as intelligence or perceptual physiology, and utilized statistical methods. In 1887, William James founded the American Journal of Psychology, and in 1892, the American Psychological Association, which was the first association for professional psychologists worldwide. Soon after, there were laboratories for experimental psychology at universities worldwide: Tokyo, Calcutta, Buenos Aires, and Moscow [6].

Psychoanalysis and psychodynamic therapy

In 1895, Sigmund Freud (1856-1939) described the first case of a patient who was cured from physical symptoms through the "talking-cure," that is, talking with the physician Joseph Breuer about her dreams and problems, what she herself called "chimney sweeping." This approach later became known as *psychoanalysis* [50]. From the psychoanalytic view, conflicts are due to differences in conscious and unconscious wishes, which could manifest as physical illness. It is difficult to overestimate Freud's influence on Western culture, art, literature, and thought. Even though psychoanalysis is no longer seen as a subfield of psychology, it has been the basis for the development of most forms of psychotherapy, as well as cognitive psychology.

Freuds associate Sandor Ferenczi (1873-1933) is credited with developing Heinroth's concept of psychosomatics and the initial exploration of coping strategies for the patient. Together with Otto Rank, another associate of Freud, he started to emphasize the importance of the relationship between the analyst and the patient, *the therapeutic alliance*, and clinical empathy as a healing agent, as opposed to the neutral interpretation applied by Freud [51].

The Balint method is a psychoanalytic approach to the physician-patient relationship that was developed by Michael Balint (1896-1970), a student of Ferenczi, who later came to study group dynamics and eventually formed the first *Balint Group* in 1950. The purpose of Balint groups in medicine is to help health care professionals understand and cope with the emotional challenges of their work, gain insight into their own experiences, develop greater self-awareness, improve

their communication and interpersonal skills, and develop new ways of understanding and coping with the emotional demands of their work [52].

Further developments in psychoanalysis and psychodynamic therapy (PDT) include *attachment theory* and the concepts of *holding* and *containing,* all relevant to medical psychology.

Behaviorism

Experimentalist psychologists in the early 1900s began studying classical conditioning, a measurable and thus more objective way of studying both animals and humans, which led to the school of *behaviorism*. Behaviorism became the dominant paradigm from the 1920s, until the 1950s [53]. Behaviorism developed theories of operant conditioning, classical conditioning, and social learning theory and denied or ignored internal mental activity. People are thought to be completely controlled by environmental factors. Some applications of behaviorism, such as *systematic desensitization* have later been applied to medical problems, such as needle phobia.

Humanistic psychology

Some psychologists found that psychology had too much focus on dysfunction and emphasized personal growth and development over pathology. Abraham Maslow (1908-1970) believed that people could actualize themselves, provided their needs for belonging, esteem, love, and safety were met, along with the basic needs of food and shelter. Through self-actualization, they would find meaning in life [54]. Carl Rogers continued the work on humanistic psychology and developed *Client-Centered Therapy* based on the assumption that psychologists could help people self-actualize and reach their true potential. “Client-Centered” alluded to the relationship being non-directive from the stance of the counsellor, which opposed traditional analytic approaches. Rogers believed that in any helping relationship, there were conditions that transcended what school of psychotherapy or other approach the helper identified with, if they were met. The helper needed to have a genuine and honest approach, the helper needed to hold the patient in unconditional positive regard and finally the helper needed to have an accurate empathic understanding of the patient and be able to communicate that to the patient [55]. He later developed his theory with the understanding that clients were not only clients but also persons, and changed the term to *person-centered therapy* [56].

Cognitive behavioral therapy (CBT)

In the 1950s, linguist Noam Chomsky’s critique of behaviorism, George Miller’s research on short-term memory, and Jean Piaget’s theory of cognitive development

sparked the *cognitive revolution* [57]. Dr. Aaron Beck and Dr. Albert Ellis independently developed similar approaches to psychotherapy that focused on the role of thoughts and beliefs in shaping emotions and behaviors. Beck's approach, also known as cognitive therapy, focuses on identifying and modifying negative or distorted thoughts that contribute to psychological problems. Ellis's approach, known as rational emotive behavior therapy (REBT), focuses on challenging irrational beliefs that lead to negative emotions and behaviors [58]. Through hard work, patients can identify negative automatic thoughts and modify their way of thinking to change undesired behaviors. CBT has been used in many medical settings to treat anxiety, depression, chronic pain, cancer, and multiple sclerosis.

Today, CBT is widely used around the world and is considered a "gold standard" treatment for many psychological problems. It is provided in an individual or group format and may be done in person or through teletherapy. The third wave of CBT includes, but is not limited to, Meaning-Centered Psychotherapy and Acceptance and Commitment Therapy.

Attachment theory

Attachment theory is a psychological model that explains the nature of the emotional attachment between humans. It was first developed by John Bowlby and Mary Ainsworth in the 1950s. According to attachment theory, the quality of relationships that an individual has with their primary caregivers in early life can have a significant impact on their social and emotional development and overall well-being [59].

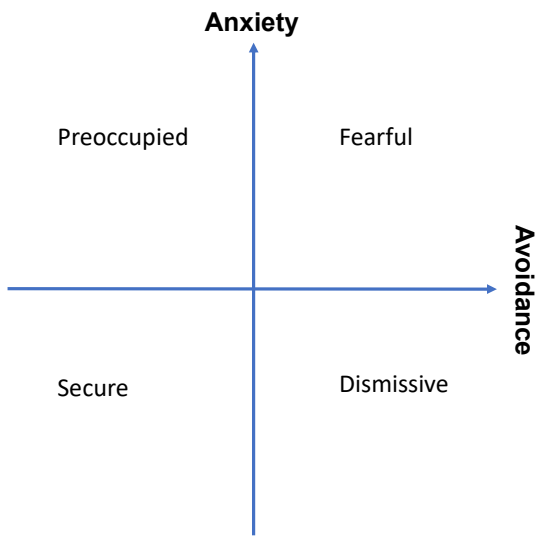

Figure 1. The dimensions of attachment styles.

For adults, attachment styles are measured in two dimensions: anxiety and avoidance. These dimensions describe how a person self-regulates emotional closeness to a contact person in emergency situations (Figure 1).

Those who have a high degree of anxiety are afraid of being abandoned or rejected and use various safety behaviors to feel safe, while those who have a high degree of avoidance distrust others and would rather refrain from a relationship that could provide security rather than risk being hurt or disappointed. A person can be high or low in both dimensions, which means that there is one secure attachment style and three insecure ones [60].

The meeting between health care provider and patient.

In health care communication, attachment theory can be used to understand how a patient's attachment style affects their interactions with health care providers, who can tailor their communication with patients in a way that considers the patient's attachment style and helps build trust and rapport. This involves actively listening to the patient's concerns and needs, providing emotional support and reassurance, and being sensitive to the patient's emotional state. By adopting an attachment-focused approach to communication, health care providers can improve patients' overall experiences and outcomes [61, 62].

A secure attachment style means that the individual has a positive image of himself and others and sees himself as valuable and others as accepting and reliable (see Table 1). People with a secure attachment style typically have good communication with their health care providers [63] and can make decisions together, called a deliberative communication style [64].

Table 1. Views of self and others according to Bartholomew and Horowitz [60].

		Model (view) of self	
		Positive	Negative
Model (view) of others	Positive	**Secure attachment** Positive view of self Positive view of others	**Preoccupied insecure attachment** Negative view of self Positive view of others
	Negative	**Dismissive insecure attachment** Positive view of self Negative view of others	**Fearful insecure attachment** Negative view of self Negative view of others

A preoccupied attachment style develops individuals with a negative image of the self, combined with a positive image of others, which is characterized by preoccupation with relationships and attempts to reach self-acceptance through confirmation from others, which shows in caregiving that they do compulsively, intensively, and independently. For these individuals, a paternalistic communication

style is recommended, that is, high involvement from the caregiver with a small amount of information-giving [64].

The negative expectations of others, in combination with a positive self-image, characterize a dismissive attachment style. A person avoids close relationships to protect against disappointment and maintains feelings of independence and invulnerability. For these individuals, leaving space for autonomy and enabling decision-making by supplying a large amount of information is recommended.

Individuals with negative images of both self and others develop a fearful attachment style, avoid social relationships, and fear closeness. Here, the health care provider needs to provide the patient with information and stay highly involved in decision making by helping the patient find their own values and needs [64].

There have been some studies on how the attachment style of a health care providers affects the relationship with a patient. The evidence for the short- and long-term patient outcomes are so far inconclusive [65], however in primary care practice, physicians' attachment style has been shown to influence patients' presentation of emotional cues [66].

Medical psychology

Medical psychology, also known as health psychology, is a relatively new field that has developed significantly over the past several decades. The origins can be traced back to the early 20th century when psychologists first began to apply psychological principles and techniques to medical settings in the treatment of shell shock after World War I, as an alternative to the biomedical interventions of hydrotherapy, massage, and electrical stimulation to try to repair what was explained as physical damage to the nervous system [67].

In the 1970s, medical psychology began to emerge as a distinct subfield within psychology, as psychologists increasingly recognized the importance of addressing the psychological and emotional needs of patients in medical settings. Since then, the field of medical psychology has continued to grow and evolve, with psychologists working in various settings, including hospitals, clinics, and other health care facilities. In clinical practice, medical psychologists use a range of evidence-based approaches to help patients manage their symptoms, improve their quality of life, and promote overall physical and mental well-being through the prevention of disease, treatment, and rehabilitation.

Another task of medical psychology is to protect patients, families, and caregivers from undesired consequences of narrow specialization of medicine; technologization; and bureaucratization of health care activities by applying a holistic view and humanistic values to health care and promoting the importance of interactions and relationships between caregivers and patients.

Re-uniting body and mind

The biopsychosocial model

The biopsychosocial model was first proposed by the psychiatrist and psychoanalyst George Engel (1913-1999) in 1977 [68]. Engel argued that the traditional biomedical model, which focuses solely on biological factors in understanding and treating illness, was inadequate. He proposed the biopsychosocial model as a more comprehensive approach that considers the interconnectedness of biological, psychological, and social factors in health and illness, which also emphasizes the importance of addressing multiple aspects of an individual's health, rather than focusing solely on one factor.

Since its inception, the biopsychosocial model has been widely adopted in the field of medicine and health care and has had a significant impact on the way health and illness are understood and treated.

Salutogenesis

Salutogenesis is a theory of health that focuses on the factors that contribute to the development and maintenance of health and well-being rather than the factors that cause illness.

The term was coined by Israeli physician and medical sociologist Aaron Antonovsky (1923-1994) in 1979 [69]. He argued that health is not simply the absence of illness but rather a state of overall well-being that is supported by a sense of coherence or meaning in one's life [70]. He proposed that health is the result of interactions among three key factors:

1. Sense of coherence: This refers to an individual's perception that their life is meaningful and manageable and that the events and challenges they face are comprehensible and manageable.
2. Stress: Stress can have both negative and positive effects on health, depending on an individual's ability to cope with and manage stress.
3. Resources: Resources refer to the internal and external factors that support an individual's health and well-being, such as social support, financial resources, education, and access to health care.

According to Antonovsky, when individuals have a strong sense of coherence and access to resources, they are better able to cope with stress and maintain their health. However, if an individual lacks coherence or access to resources, they may be more vulnerable to the negative effects of stress and more likely to develop illness[70].

The biopsychosocial model and salutogenesis are frameworks for understanding health and well-being that recognize the complex interactions between biological,

psychological, and social factors. Both models emphasize the importance of addressing these factors to promote health and prevent illnesses.

Treating the person, not the disease

> To know the patient that has the disease is more important than to know the disease that the patient has – Sir William Osler[2]

In the 1980s, the biopsychosocial model was criticized for not being operationalized in clinical practice; it was unclear how clinicians would gain the knowledge required to consider all factors [72]. Inspired by Rogers and Balint, among others, in 1986, a group of physicians from Western Ontario proposed "a patient-centered clinical method" as a new approach for implementing the biopsychosocial model. They suggested that the physician should follow the patient's interests and ask open-ended questions to explore the social and psychological dimensions of the patient.[73]

They also proposed eliciting the patient's agenda, instead of just the physician's agenda, and negotiating any conflicts [74]. The approach became one of UK's Nation Health Services' 10 core principles in 2000 [75], and in 2001 The Institute of Medicine in the U.S. recommended that all health care organizations should be patient-centered and ensure that patients' needs and values are respected and guide all clinical decisions [76]. Patient-centered care has evolved into *person-centered care* which emphasizes the importance of treating patients as individuals rather than just a diagnosis or a set of symptoms [77]. This approach is based on the belief that patients are experts in their own lives and needs and that they should be given space to tell their story and be actively involved in decisions about their own care [78]. There has been some criticism of person-centered care as it promotes the individualist image of humans and ignores that humans are relational or social beings. This view can lead to the neglect of fundamental needs and aggravate problems of social inequity [79].

[2] Sir William Osler among others made famous a modified version of a quote that may have originated with Dr. Parry of Bath. It first appeared in The Lancet in 1846. [71] G. O'Toole, It Is Quite As Important To Know What Kind of a Patient the Disease Has Got As To Know What Kind of a Disease the Patient Has Got, 2019. https://quoteinvestigator.com/2019/07/20/patient/#f+436030+1+1. (Accessed 2022-12-29 2022).

Humans are social beings

> A physician is obligated to consider more than a diseased organ, more even than the whole man - he must view the man in his world – Harvey Cushing

In the latter half of the 20th century, there was a resurgence of interest in the importance of therapeutic relationships in health care. According to Paul Gilbert (1948–), who created *Compassion-Focused Therapy* (CFT), the human brain is primarily a social brain and we are hardwired to "create caring connections" (p. 3) [80]. Research shows that the human brain has adaptations that regulate health and happiness in several systems, such as the autonomous nervous system and immune system, which have evolved to keep us in social contexts, as we are safer there [81]. Gilbert argues that we are not autonomous units, but a social species with both helpful and unhelpful social motives and we need to develop *a sensitivity to suffering in self and others with a commitment to alleviate and prevent it* [82], that is compassion, to achieve well-being.

Relationship-centered care extends the person-centered process to encompass clinician, team, organizations, and community. Health care providers work to understand the patient's unique needs, preferences, and values and aim to build a partnership with the patient based on mutual respect and trust to humanize health care, improve patient care, and strengthen interpersonal relationships [83].

The principles of relationship-centered care include:

- Personhood of both practitioner and patient matters.
- Affects and emotion have an impact on relationships.
- Relationships are reciprocal, although the patients' needs have priority.
- Maintaining genuine relationships is necessary for health and recovery, and is morally valuable [84].

Research has shown that relationship-centered care can lead to better patient outcomes, such as better physical and mental health [85], higher patient satisfaction, and improved health care experiences [83].

Communication in health care

Patient participation in decision-making was long unthinkable, and care has been based on the benignity of the performed services rather than on consensual understanding. The assumptions of the need for faith, hope, and reassurance have ruled out informed consent until modern times, and to some extent still does. It can be hard to understand why all authority has been handed to the physician, and why the physician has agreed to carry the burden of decision-making alone.

Caregivers and patients can be assumed to share the common goal of restoring the patients to well-being. What this means, however, is quite ambiguous. If a

healthy life is achieved, it is most often a multi-path goal, that is, there are different ways to get there, each with its own costs and benefits. As there are several alternatives, a common view and preference cannot be taken for granted. Consensus on the goals of care and means of getting there can only be reached through the communication[3] of caregivers and patients. The situation is complex; there is a meeting of two minds and two bodies, each with their own sometimes conflicting motivations, values, and interests, based on what they perceive to be the truth. In this age of science, the biomedical components of the truth have gained primacy in health care, at the cost of other aspects, such as the personal meaning of disease and the disease in the patients' social and cultural contexts. Bringing all the parts together seems necessary to join the art of healing with the science of medicine. These practices should be complementary to each other but require a wide range of skills and formidable efforts. To gain and hone those skills, the caregiver needs to have an interest in humanity, let go of at least a part of the advantage of authority, and engage in the challenge of listening and being moved by the patient. Many clinicians try to avoid conveying the uncensored truth and listening to patients. Caregivers and patients must learn to communicate and trust each other, which is not an easy task. Throughout history, disclosure has had the main aim of securing the patient's collaboration towards the goal that the caregiver has already decided is best for them.

History of communication/disclosure in health care

> Life is short, the Art long; opportunity fleeting, experiment treacherous, judgment difficult. The physician must be ready, not only to do his duty himself, but also to secure the cooperation of the patient, of the attendant and externals - Hippocrates [86]

In ancient Greece, the sick and the healer were united by the sacred bond of *philia*, friendship, and thus had a common interest which made shared decision-making superfluous - there was no "other" who needed explanations because both had a common goal. This meant that honest information would be counterproductive, as it deprives the patient of hope and faith, and thus could also be considered abandonment. In the Hippocratic writing *Decorum,* physicians were advised to hide most things from the patient because many patients who find out their prognosis may get worse. You should not worry the patient, not by words or appearance, you should look healthy, preferably a little chubby, you should look serious but not harsh, smell good and be friendly to everyone, everything to make the patient feel comfortable, and avoid disclosure of present or future conditions [87].

[3] The root of the word "communication" in Latin is *communicare*, which means to share, or to make common.

Despite being known as a lover of truth, Hippocrates sometimes advised slight-of-hands aimed at tricking the patient that something had been done, which his successor and commentator Galen disliked to the extent that he implied that someone else had written that [14], even though he himself made the following observation (page 75) [88]:

> I have had greater success with those patients who truly believed that they would be cured – Galen

Explanations were seen as undermining trust, as they would reveal the uncertainties built into medicine and medical science, which would place the patient in a state unfavorable to recovery. In addition to the medical legacy, the ethical legacy of Hippocratic medicine has lasted for a long time, both in Western and Arabic practice. There were few suggestions in writing on medical ethics that patients should have any participation in decision-making. The aim of conversations was limited to offering hope, reassurance, and persuading the patient to accept treatment [89]. To achieve this, the doctor needed to be authoritarian, manipulative, and sometimes even deceitful, but according to Plato, physicians were entitled to lie for noble purposes [90]. The physician-patient relationship was founded on the benevolence of the physician, and the authority of the physician was given by God [89], a notion that was reinforced by the position most physicians had as priests and monks.

The authority and standing of the physician were also factors in what information was shared. In the 13th century, the physician and theologian Arnaldus De Villa Nova urged his colleagues to promise cures to all patients but exaggerate the dangers to the patient's family. If the patient survived, the physician would be celebrated, and if they died, it would have been expected. Regardless, the physician's reputation would be preserved [87].

There has long been a perception that it is the caregiver's duty to be a shield between the sick person and pain, which includes protection from painful information, but there has also long been a longing for telling the truth and sharing responsibility with the patient. Samuel de Sorbière (1615-1670), a French philosopher and physician, discussed the idea of disclosing the imperfections of medicine as a science and the uncertainty of the outcome of a treatment to patients but dismissed the idea and instead praised the various means physicians adopted to ensure the trust and belief of their patients. He also described an imagined frank conversation with a patient where he offered three treatment options and invited the patients' input and preferences, only to reject the idea as utopian in the next paragraph [89].

The Catholic Church early condemned all forms of dishonesty and believed that the patient must be told the truth so that he could confess, receive the anointing of the sick, and avoid the purgatory [91]. As the Catholic Church's powers diminished when Europe entered the Age of Enlightenment, telling white lies became the norm.

Voltaire echoed Platon in stating that lying was a blessing when the effects were good [91].

The norm was codified by Thomas Percival (1740-1804) who wrote *Medical Ethics* (p. 19) [89]:

> A physician should be the minister of hope and comfort to the sick as far truth and sincerity will admit.

Percival did however consider the patient's needs to have priority over the physician's personal duty of veracity in the case when the truthful reply to a question asked by a patient would do harm. In such a situation, "Common principles of humanity" would demand the physician to "sacrifice that delicate sense of veracity" [89].

The first Code of Ethics of the American Medical Association reproduced all of Percival's instructions and added the following (p. 19) [89]:

> The life of a sick person can be shortened not only by the acts, but also of the words or the manner of a physician. It is, therefore, a sacred duty to guard himself carefully in this respect, and to avoid all things which have a tendency to discourage the patient and to depress his spirits.

There were those who believed that the damage that occurred if/when the patient found the truth was much worse than if it had been told the truth in the first place. At the beginning of the 20th century, American physician Richard Cabot observed that lying often undermined trust in physicians and spread to others. He thought that a more honest relationship with patients and their relatives would increase the general trust in the truthfulness of physicians, which affects the health care's ability to help the sick, as trust in health care is necessary for patients to undergo painful treatments and procedures [92]. His views were an exception to the mainstream view, and the paternalistic stance persisted until the middle of the 20th century. As late as 1954, the chairman of the Conseil de l'Ordres des Medicins in France, Louis Portes, stated the following (p. 22) [91].

> The patient be considered as a child to tame and comfort: he is a blind, suffering and passive toy.

This statement was, however, quite offensive, especially considering the Nuremberg Trials that had recently exposed the atrocities physicians had performed during World War II. The Nuremberg trials tried to restore public confidence in physicians with the Nuremberg Code, which aimed to protect the human rights of people from physicians by requiring informed consent in relation to research [93]. The outrage eventually led to a statement at the First International Congress of Medical Ethics in Paris in 1955 (p. 22) [91]:

> The normal rule is that the patient has a right to know the truth. The patient should be considered as a free person.

The process of changing habits is slow. In Donald Oken's famous study of physicians' habits regarding cancer diagnoses from 1961, 90% withheld the diagnosis from their patients and argued that they preferred not to know/have cancer. The physicians in the study thought they needed to justify telling the truth, not the other way around, and preserving hope was the top priority [94].

Paul Ramsey (1913-1988), a Christian ethicist, was credited with creating bioethics while delivering lectures at Yale in the late 1960s. The content of his lectures was published as *The Patient as Person* in 1970. He concluded that, as medical care is a joint venture between patient and caregiver, there can be no excuse to not have consent while treating another person; thus, the patient must be informed [95]. *The patient as Person* quickly became, and continued to be, a standard text in medical ethics [96].

During the 1970s, the sentiment of physicians changed, and in 1979, a study showed that only 2% of American oncologists withheld diagnoses from their patients, which signified a significant development over a relatively short period of time [97].

Since then, patients' right to information and shared decision-making has replaced the norm of paternalistic non-disclosure in industrialized countries, and health literacy has come into focus to empower patients in making decisions.

Research on communication in health care

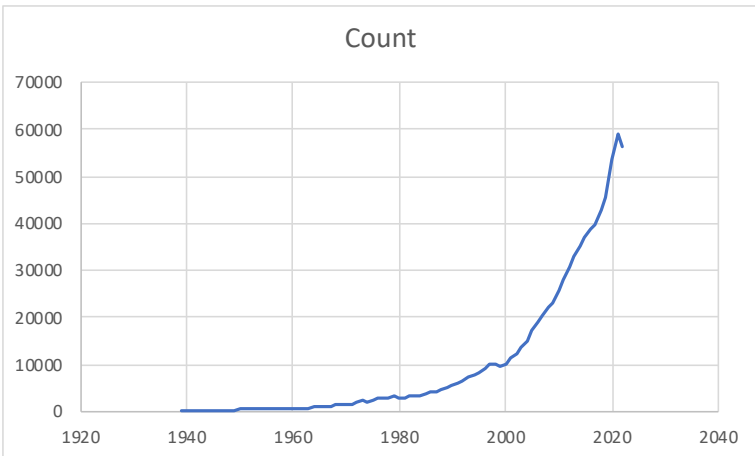

Figure 2: A search for "communication in health care" on PubMed

A search on Pubmed on "Communication in health care" reveals that the interest has increased enormously concurrently as the shift to informed consent and the

biopsychosocial model has evolved. While there are articles from the 1970s that describe communication skills training, using simulated patients and video recordings to help students learn these skills [98] it was in the 1980s that the interest in communication skills in general and the breaking of bad news in particular started.

Robert Buckman's article *Breaking bad news, why is it still so difficult?* from 1984 [99] where he defined "bad news" as "any information likely to alter drastically a patient's view of his or her future" (p. 1597), can be considered a milestone, his definition has been widely accepted since then. His understanding of the difficulties was that they related to 1) the fears physicians have of disclosing news, among them the fear of being blamed, and 2) taking responsibility for the content of the news, even though it was not in the physicians' control. In the paper, he called for greater emphasis on training physicians in the skill of talking with seriously ill patients. He also pointed out that the public's expectations that a physicians is omnipotent had changed, and that patients want information about their condition and talk about their feelings [99].

Since then, there has been much research on various aspects of clinical encounters, such as the personal qualities of the physician, patient attitudes and preferences, and communication skills, both at technical and higher levels.

Breaking bad news today

Physicians now begin conversations about serious illness earlier with their patients and continue these conversations throughout the treatment [100]. This results in reduced anxiety and depression in some patients [101]. Clinicians still struggle to discuss prognoses and respond to patients' emotions [102], and many feel that they have not received sufficient training in effective communication [103]. However, physicians often have to deliver serious diagnoses and prognoses to patients, sometimes even before the patient experiences any symptoms [104-106]. In these situations, some have attempted to minimize the unpleasantness of the news [107].

Research has shown that it is beneficial for many patients to discuss the future and how their illness may progress. It creates clarity, allows for planning, and provides families the opportunity to prepare for what lies ahead. There is also evidence that being honest with patients does not undermine trust in health care but rather increases the patient's sense of being listened to, understood, and strengthens the alliance between the patient and their physician through the patient's trust [108-110].

However, research has also shown that the recipient may blame the physician, perceive them as less empathic [111], and attribute malicious intent to them, even when they are not responsible for the situation [112]. Physicians also become vulnerable and experience anxiety, guilt, exhaustion, failure, frustration [113] and physiological stress reactions [114] when delivering difficult news.

Research on breaking bad news has led to the development of protocols [115] and guidelines for communication [116], as well as communication skills courses that

teach health care professionals how to handle emotional cues with simulated patients [117] and some that utilize ideas from improvisational theatre [118]. The *Serious Illness Care Program* is a more recent program that provides communication skills training for clinicians, preparation for patients and families, a structured guide for conversations, and customized electronic medical record modules for documentation [119].

Education and quality improvement measures have in some ways improved the way bad news is delivered. Studies have shown that health care professionals who have received communication skills training are more likely to demonstrate empathy towards their patients, but there is no evidence that these courses have an impact on physician burnout, patient satisfaction, or patient perception of communication skills [120]. The communication climate among colleagues and the responsiveness of supervisors can make a big difference to the ability to develop self-awareness and emotional skills. This ultimately affects the way patients and their families are treated [121]. Some of the topics that continue to generate much interest are empathy [122-124] and compassion [125, 126], both of which seem to be at the center of connecting with patients and families.

Empathy is defined as understanding, feeling, and sharing another person's feelings while being aware of the separation between self and others [124]. Verifying understanding with patients is a way to achieve empathic accuracy and allows patients to feel understood [127]. Empathy is believed to impact patient outcomes, such as satisfaction, compliance, trust, health status, psychological state, enablement, and self-management through three processes [128]: building a relationship through small talk and friendly gestures to establish trust, listening to what is important to the patient, showing compassion for their reactions and concerns, understanding the patient's needs, and proposing adapted therapeutics to help the patient take control [129]. Being met with empathy increases information sharing and treatment coherence, and even helps patients recover faster [130].

Compassion in health care is understood as building on empathy and taking a step further by demanding action to prevent or alleviate the other person's suffering [131]. There has been some concern about the price of compassion, empathy, and *compassion fatigue* [132, 133], recent studies have found that *compassion satisfaction* compensates for the costs of caring [134].

> Time, sympathy, and understanding must be lavishly dispensed, but the reward is to be found in that personal bond, which forms the greatest satisfaction of the practice of medicine. One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient. – Francis Peabody [4]

[4] (p. 1868) [135] F.W. Peabody, The Care of the Patient, JAMA 313(18) (2015) 1868-1868.

Rationale

Despite the enormous amount of research being conducted on communication in health care, there were many knowledge gaps at the start of this thesis. One thesis cannot address all of these; accordingly, I picked a few different but related areas to investigate in collaboration with my research team.

Informal caregivers in cancer care have been overlooked in many ways, despite considerable suffering from a holistic perspective [136, 137], and most interventions target the optimization of caring for the patient rather than their own self-care [138, 139]. Knowledge of the need for support-seeking next of kin was lacking.

Over the past two decades, the need to communicate with patients and their families about the transition to palliative care at the end of life has been emphasized by the National Board of Health and Welfare in Sweden [140] and is recognized as a highly important quality indicator internationally as well [141]. However, there was no up-to-date report of when this conversation took place, and whether it was a conversation at one time point or several conversations over time.

The ethical codes of physicians assert that they should always help and do no harm. Fear of being blamed has been a deterrent for physicians in breaking bad news [99], and medical students tend to focus on their own emotional reaction [142], but there had been no studies examining what effect the content of a consultation would have on the patients' perception of the physicians' empathy.

Despite numerous studies and interventions, such as communication skills training, the literature on breaking bad news lacks studies on the lived experience of the entire process as experienced by physicians [113]. The term itself was perceived as reminiscent of a paternalistic view of the relationship between physician and patient. Therefore, we aimed to develop and update the view of the process of sharing serious information with patients and families, as experienced by clinically active physicians.

Aims

The overall purpose of this thesis was to explore communication about serious illness as a relational process.

The specific aims were:

- To explore the lived experiences of informal caregivers in cancer care, focusing on the perceived burden and needs of individuals seeking support from an informal group for the next of kin (Paper I).

- To elucidate the pattern of communication about serious illness for patients who have died in an inpatient setting (Paper II).

- To test the hypothesis that patients would experience less empathy from the physician after a consultation with the breaking of bad news compared to a more neutral consultation. The secondary aim was to test whether the length of consultation and familiarity with the physician affected perceptions of empathy (Paper III).

- To develop holistic knowledge about the phenomenon of breaking bad news in clinical practice (Paper IV)

Methods

Ontology and epistemology

Ontology deals with the nature of being and the fundamental nature of reality. My ontological vantage point is realism. In ancient Greek, objective realism was associated with the ideas of philosophers such as Plato and Aristotle, who argued that the objects and events of the world have an objective and independent existence. In accordance with such objective realism, I consider e.g., human organs, and the physical effects of a disease, as existing independently of our consciousness about these objects. However, since this thesis is primarily based on studies of human experience, my overall ontology is better labelled as *subjective realism*. With reference to the philosophical underpinnings of descriptive phenomenology [143], this means that I am ontologically concerned with the *relationship* between the experiencing subject (e.g., patient) and the object (e.g., disease).

Because of its focus on register data, the second article in this thesis is nonetheless an exception from the principle of subjective realism mentioned above. Yet my realistic approach still applies to that study in its quantifiable object, i.e., the (objective) number and length of conversations before the patient's death.

Epistemology deals with the nature of knowledge and the ways in which we come to understand the world. In relation to subjective realism, this means that human experience is key to knowledge development. This epistemological standpoint entails *intersubjectivity*, which is the relationship between the subjective experiences of different individuals. Husserl, the founder of descriptive phenomenology, argued that intersubjectivity is made possible by the fact that our subjective experiences are structured in a similar way, and that we can communicate and share our experiences with others through language and other forms of communication. This allows us to understand and make sense of the experiences of others, and to form shared understandings and meanings [144].

In the first and fourth articles, interview data functioned as a medium for intersubjectivity between the researcher and participants. In the third study, questionnaire data filled this function, although to a limited extent because of the lacking dialogue that allows for intersubjective follow-up questions dependent on individual and context. Thus, from an epistemological point of view, questionnaires are less reliable methods to capture the common subjectivity in subjective realities (since the same concept in the questionnaire can be associated with different

meanings by the respondents). Nonetheless, the benefit of using questionnaires to collect data on experiences is that the results generate an orientation of the general state of affairs.

Participants and materials

Study	I	II	III	IV
Study design	Qualitative	Observational (review of patients' medical records)	Cross-sectional (Questionnaire)	Qualitative (Phenomenological)
Participants	28	249	186	22
Data Collection	Focus group interviews	300 patients were randomly selected from the SRPC. Extraction of data from medical records	The CARE measure (patients) Questionnaire (physicians)	In-depth interviews including questions about breaking bad news
Data analysis	Thematic analysis	Descriptive	Descriptive statistics, Mann-Whitney U, Spearman's correlation	Descriptive phenomenological analysis

Paper I

The participants in this study were selected using a specific sampling method called purposive criterion sampling, which focuses on selecting participants who meet certain criteria. In this case, the criteria were having experience as informal caregivers in cancer care and seeking support from a peer-to-peer network. The participants were recruited through email invitations and a website post by the founders of "Cancer Buddies"[5]. Groups were formed in different cities in Sweden to make it easier for participants to travel. There was a total of 28 participants: 25 women and 3 men. The average age of the participants was 50 years, and the majority were identified as partners of someone with cancer, but siblings, parents, children, and grandchildren were also represented. There were seven focus group interviews, four of which were made up of bereaved informal caregivers (including 15 participants), and three consisted of current informal caregivers (including 13 participants). The interviews began with the participants sharing their experiences and continued with the researchers asking about their needs as informal caregivers

[5] Cancerkompisar in Swedish

and how those needs were being met. All the interviews were recorded and transcribed verbatim.

Paper II

In this study, 300 people who had died in palliative care, oncology, or internal medicine in the Skåne region were selected from the Swedish Palliative Care Registry (SRPC) between 2015 and 2017. All individuals in the registry were documented to have had a "breaking point conversation"[6] at the end of life. All mentions of conversations about serious illness, including goals of care, prognosis, and conversations about dying with patients and/or their families, were extracted from the patients' medical journals.

Paper III

This study included 16 physicians and 233 outpatients from an oncology department. The inclusion criterion for physicians was that they treated patients with cancer in an outpatient hospital setting. The inclusion criteria for patients were outpatients over the age of 18 years with any type of cancer and awareness of their diagnosis. Before the consultation, the patients were approached by an assistant nurse who informed them of the study and supplied them with written information, a questionnaire, consent forms, and a stamped envelope. After the consultation, the physician placed the patient in either the "good/neutral news" or the "bad news" group, along with information on the length of visit, how well they knew the patient ahead of the consultation, diagnosis, and treatment intent. The patient rated the physician's empathy, using a validated instrument called the Consultational and Relational Empathy (CARE) measure [145, 146], and sent it to the research team by mail.

Paper IV

For this study working physicians with experience in breaking bad news were recruited among participants who had signed up for a course in communications skills training. 22 physicians in total (16 women and 6 men) gave their informed consent to participate in the study. These physicians were between the ages of 30 and 55 and were either specialists or nearing the end of their residency. All participants worked in Sweden and had expertise in a variety of medical fields including cardiology, ear-nose-head-neck, geriatrics, infectious diseases, internal medicine, neurology, neurosurgery, oncology, ophthalmology, pediatrics, palliative medicine, psychiatry, and rheumatology.

The first author conducted in-depth interviews with each participant before communication skills training. The participants were asked to describe their experiences of breaking bad news to a patient or relative, including situations that

[6] "Brytpunktssamtal vid övergången till palliativ vård i livets slutskede" in Swedish

went well and those that did not. Additional questions were asked to gain insight into participants' reactions, emotions, and reflections on the situations. All the interviews were recorded and transcribed verbatim.

Data analysis

Paper I

Here, we used thematic analysis as described by Braun and Clarke [147]. This method is considered suitable for those new to qualitative research and can be adapted to different epistemological viewpoints. The analysis focused on data from all the focus groups. The research team began by reading all transcripts of the focus groups multiple times to obtain a sense of the lived experience of being an informal caregiver. Next, the team members individually coded the transcripts, marked units of meaning, and noted how and where the participants made sense of their own experiences. These codes were compared, discussed, and developed into themes. The themes were reviewed in relation to the full text and coded extracts to ensure their validity. Finally, the themes were assembled and synthesized to form a comprehensive understanding of informal caregivers' experiences [147].

Paper II

We reviewed the documentation to identify when conversations about serious illness took place, while also categorizing the conversations according to their content. The conversations were grouped according to how long they took place before the patient's death: *years* for those that took place more than 6 months before death, *months* for those that took place between 15 days and 6 months before death, and *days* for those that took place between 0 and 14 days before death.

Paper III

The distribution of scores on the CARE measure was negatively skewed and the distribution of consultation length was positively skewed. Therefore, we used non-parametric tests to analyze the differences in the CARE measure (including the subscales "compassion/listening" and "positive/active empathy") between the groups, the level of familiarity the physicians had with the patients, and consultation length. We used Pearson's chi-squared test to check the fit between the groups in relation to physician familiarity with the patients and Spearman's correlation to analyze the relationship between consultation length and CARE measure scores. All tests were two-tailed, with an alpha level of 0.05, and included outliers in the calculations.

Paper IV

For paper IV, we chose Giorgi's application of the descriptive phenomenological method [144], which is a version of Husserl's original method modified to be useful outside of philosophy. Using this methodology, the researcher focuses on understanding the lived experiences of individuals in their daily lives and their lifeworld. In this study, the lifeworld being examined was the clinical practice of physicians meeting seriously ill patients. Ontologically, this means that we understand the physicians' lifeworld to be based on both their subjective and intersubjective experiences, and "experience" refers to both real and imagined objects, such as real patients, and imagined reactions when breaking bad news to patients.

Giorgi's approach aims to uncover the *essence* of a phenomenon, or more exactly the *general structure of* essences of the phenomenon which is constituted by its essential meanings.[144]. An essential meaning is a quality of a phenomenon which is necessary for keeping the phenomenon intact. To find the essential meanings and their constitution we investigate experiences of the same phenomenon from different participant perspectives.

To be considered a true phenomenological approach, certain steps must be followed, according to Giorgi. As the first author, I performed the *phenomenological reduction*, also called the *epoche*, which involves suspending or bracketing one's preconceptions and assumptions about the nature of the phenomenon being studied, to allow for a more objective and unbiased understanding of it. Since I study communication and lead courses where physicians are trained in breaking bad news, I had many preconceptions of breaking bad news. Thus, to perform the phenomenological reduction was a large and challenging undertaking, which was attempted by writing all thoughts and feelings about the subject before the interviews and analysis.

Furthermore, the transcripts were read in their entirety through the lens of a psychological attitude to gain a general understanding of the content. Each transcript was then analyzed individually by breaking it down into distinct units of meaning or points where a shift in the physician's described experience could be identified. The meaning units were then transformed into psychologically sensitive plain language using *imaginative variation*, which means to view the experiences of a phenomenon from different angels without being limited by preconceived notions or assumptions about what is possible or appropriate. Through this procedure, common and necessary meanings across the variations could be identified, which altogether constituted the essence of phenomenon.

In the next step, the same process was repeated with the essential meanings to discover how they were related to each other, and hence co-constituted the phenomenon of breaking bad news. At last, this constitution of meaning was integrated into a coherent description and illustration of the phenomenon [144].

Ethical considerations

In all research, ethical considerations should be made with regard to the study participants in order to avoid harm and to preserve their well-being and dignity [148]. It is the researcher's responsibility to ensure that the study participants are fully informed about the research procedure so they can give their informed consent to participate before data collection begins. The studies were performed in accordance with the principles of research ethics [149, 150] and received ethical approval from the Swedish Ethical Review Authority in Lund before starting. The researchers were aware that the processing of sensitive personal data involved a breach of participants' privacy. The primary concerns were protecting the study participants from unnecessary risks, properly handling their personal data, and ensuring that information about the studies and researchers responsible was easily accessible.

Paper I

The participants were informed about the study and the terms when they agreed to participate and signed consent forms prior to the focus group interviews.

In interview studies, it is possible that the participants may experience emotional stress during or after the interview, but this risk is considered acceptable given that they willingly agree to participate and have the option to end the interview at any time. There were several instances in the interviews when one or more participants experienced strong emotions related to the topic discussed. However, many expressed gratitude for being able to share and listen to others with whom they could identify.

In the transcripts of the interviews, we took care to protect their privacy and any identifying details were removed or substituted.

This study was approved by the Regional Ethical Review Authority of Lund, Sweden (no. 2016/363).

Paper II

This study involved a review of the medical records and registered data of deceased subjects; thus, informed consent was not obtained. For the same reason, the study was not subjected to the usual review process and was instead determined by the Regional Ethical Review Authority to not require ethics permission. However, when we needed to access medical records, great care was taken to ensure that communication regarding social security numbers was encrypted, and we were only given access to a small number of medical records at a time to reduce the risk of unauthorized individuals gaining access to the records.

This study was approved by the Regional Ethical Review Authority of Lund University (no. 2018/608).

Paper III

As giving their physician a low rating could potentially place the patient in a vulnerable position, great care was taken to protect the privacy of participating patients and physicians. The information they provided was separated from each other and from members of the research team, which could identify individual physicians based on the information they provided to the patients.

The participating physician chose an envelope with a number-series unknown to the researchers. Initially, the patient received information about the study, the consent form, and the questionnaire from the physician, who also completed a matching questionnaire. However, the Ethics Review Authority raised concerns that the patient might feel obligated to participate and that the physician might see the patient's responses, so it was decided that the patient should receive the information, consent form, questionnaire, and a stamped envelope from a nurse before their visit. The patients were told not to discuss the study with their physicians to avoid disclosing what patients participated in the study.

The patient could then take the envelope home, read the materials, ask questions, and decide whether to participate by completing the consent form and questionnaire, and returning them to the first author by mail. The patient's name only appeared on the consent form, which was kept separate from other information.

To preserve the confidentiality of the physicians, all results were reported at the group level rather than at the individual level.

This study was approved by the Swedish Ethical Review Authority (no. 2018/826).

Paper IV

Emotions and thoughts about breaking bad news are potentially sensitive subjects to talk about. Given that the participants regularly worked with seriously ill patients, and had signed up for communication skills training, we nevertheless assessed that the risk of the interview to be overly demanding was very small. Personal or otherwise identifiable data were removed immediately during transcription to protect the anonymity of physicians and patients throughout the process. For example, names, places, and years related to a physician, patient, or another person mentioned by the participant were removed from both the data material and the final product during the analysis phase.

This study was approved by the Swedish Ethical Review Authority (no. 2015/557).

Results

Paper I

For the participants in our study, being an informal caregiver to a person with cancer could be summed up by the framing theme *Being co-afflicted*, which encompassed the three main themes that emerged in the focus group interviews: *Setting aside one's own needs; Assuming the role of project manager;* and *Losing one's sense of identity.*

Setting aside one's own needs

The informal caregivers in the study described how they prioritized the needs and wishes of the sick person over their own, even though it had an impact on their well-being. Our findings suggest that informal caregivers, who are often under a lot of strain, dedicated themselves to the sick person without seeing that they themselves may also need support. Many participants reported avoiding thinking about their own needs in their situation. The experience of constantly prioritizing someone else could lead to anxiety, fear, and difficulty in relaxing and enjoying things, even when on their own. Some informal caregivers had developed depression or burnout syndrome, which in some cases was perceived as permitting them to care for themselves.

Assuming the role of project manager

The experience of being the main caregiver often required the participants to take on the responsibilities of a "project manager" throughout the course of the disease. They reported feeling responsible for managing everything related to the sick person's care, including tasks such as coordinating meals, managing medications, and making health care appointments. This role was described as lonesome, with many conflicting emotions and a resulting strain on participants. The sense of moral duty and urgency that comes with this role was seen to be like codependency for some participants.

Losing one's sense of identity

The informal caregivers described how both they and the patients underwent significant and transformative tribulations during the disease. Several participants reported feeling a loss of their own identity and feeling overlooked or unheard when accompanying patients to hospital appointments. The feeling of being invisible was

not limited to interactions with the health care staff, as many participants also reported that they were avoided by their friends and neighbors. Some informal caregivers described how they had faded away and set themselves on the side during the illness. For many, life did not return to normal after treatment ended or after their family members passed away, and they struggled to readjust.

Being co-afflicted

The recognition of being co-afflicted evolved because they had reached out and connected with others in similar situations online. As they developed trusting relationships with others, they saw what they were unaware that they were doing themselves. Through identification with others, the participants could see how the tendency to prioritize the needs of sick persons over time led them to lose their sense of selfhood. The participants said that the opportunity to join the focus group discussion and talk with others who shared similar experiences, feelings, and thoughts was a great relief and made them feel empowered.

Paper II

After being diagnosed with a serious illness, patients typically had an average of 2.1 conversations with their physician about prognosis, goals of care, palliative care, and dying.

The conversations often covered three main transitions: moving from curative to palliative treatment, shifting from disease-focused treatment to palliative care, and transitioning to end-of-life care (the conversation about dying). These conversations typically took place in the last two weeks of life, and at a median of two days before death, physicians often had separate conversations about dying with the patient's family members. From the perspective of years, months, and days, 12% had their first conversation in the years window, 46% in the months window, and 23% in the days window.

A small percentage of patients had conversations in all three time periods, and about one third had conversations in two time-windows, with the majority being at months and days. Among patients who had their first conversation in the time-windows of years, and months, respectively, two thirds (in both groups) also had a conversation 14 days before they died.

Of the reported 201 patients in the SRPC, a conversation about dying was documented in the medical records of 108 patients, and an additional 48 patients had a conversation about dying with their next of kin without the patient present out of a total of 249 reported in the SRPC. This means that there were 93/249 patients (37%) for whom we were unable to find a documented conversation about dying in the medical records. Families had conversations about dying without the patient present more frequently in internal medicine and oncology settings than in specialized palliative care.

Paper III

We invited 233 patients to participate in the study, 191 of whom returned signed consent forms and questionnaires, resulting in a response rate of 81.9 %. The response rate for the "bad news" group was 83.7% and the response rate for the "neutral/good news" group was 81.6%.

We found that patients perceived physicians who delivered bad news as less empathic than those who delivered neutral or good news. Patients who had received bad news felt that the physicians did not listen attentively and did not show as much compassion compared to patients who had received good/neutral news did. The length of the consultation had a weak but positive impact on perceived physician empathy; however, even though the bad news consultations were longer, this did not compensate for the impact of the content of the conversation. The level of familiarity between the physician and patient or continuity of care did not seem to have a significant effect on perceived empathy.

Paper IV

The essence of breaking bad news in medicine was found to be a relational process consisting of five interrelated meanings: *Becoming the bad messenger*; *Expecting the unpredictable*; *Being on stage*; *Professionally managing hope*; and *Mindfulness of the emotional relationship.*

Becoming the bad messenger

Telling patients about serious diagnoses in a compassionate way was often seen as challenging, even when the diagnosis was not necessarily life-threatening. Physicians felt a responsibility to deliver the news as gently as possible and many were hesitant to initiate the conversation because they empathized with the potential pain it would cause their patients. However, they also recognized that it was part of their job and something that needed to be done. When preparing to deliver bad news, physicians were concerned about factors such as having a previous relationship with the patient, having a family member present, having a private room, being prepared, and having enough time for the conversation. Despite the stress of these situations, some physicians still found it meaningful and fulfilling to deliver bad news effectively, as gentle, and skilled communication could make a significant difference for patients in coming to terms with their situation.

Expecting the unpredictable.

Based on their previous experiences of breaking bad news, the physicians felt that predicting the reactions and outcomes of a conversation was very challenging. Some thought family members' and patients' painful reactions were acceptable, while others worried about them, and what their own reactions would be. Many found it distressing not being sure of what the patient might feel or understood, for instance, when some patients reacted more calmly than the physician had anticipated. As a

result, the physician had to be flexible and adapt to the situation, even though this state of mind was mentally challenging.

Being on stage.

Delivering bad news was often described as a performance requiring the physician to be focused, alert, and present, without being too nervous. To do this effectively, the physicians felt they needed to be fully present, not only in their professional roles, but also as human beings. This required them to consider the entire context and adapt their relational approaches. Many physicians felt that they had to slow down, speak more slowly, use fewer words, and take more pauses. Some were also concerned about not meeting patients' expectations or being unable to answer all their questions, which could increase their distress. To focus more on the message than on the receiver, was an experience many physicians shared, and in retrospect perceived as a failure in caring for the patient.

Professionally managing hope.

One of the challenges of delivering bad news was managing patients' and families' hopes, particularly when the prospects were not good. To cope with their distress in these situations, some physicians felt the need to modify the information to leave room for hope. This could involve shifting the focus from "hope for a cure" to other goals such as maximizing quality of life. In other cases, physicians had to address unrealistic hopes gently.

Mindfulness of the emotional relationship.

Most physicians wanted to have as good a relationship with their patients as possible, but they sometimes found it difficult to combine this with the role of delivering bad news. They were concerned about the patient thinking that the physician had inflicted damage, which made it difficult to continue treating the patient. When the relationship with the patient worked well, the physician often took on the role of a fellow human being, listening to the patient's story and thoughts, and caring for them beyond their disease. This type of connection came at a cost, however, since the physicians' emotions were engaged. This effect intensified when the patients reminded them of themselves or someone close to them.

Breaking bad as a relational process.

We found that breaking bad news to patients is a complex process that involves both the content of the message and the emotional relationship between the physician and patient. It is essential for physicians to be aware of the patient's emotional state and prepare for unexpected reactions. The physician must also balance the need to provide information while leaving room for hope. This process is ongoing, as the physician must continue to navigate the emotional relationship with the patient throughout the course of the illness.

Discussion

Paper I

This study showed that informal caregivers are co-afflicted with characteristics that are similar to those seen in codependency.

Informal caregivers, often family members or friends of individuals with cancer, play a crucial role in cancer care. However, they are often overlooked by health care professionals and may not receive adequate support from the health care system. As a result, they may seek support from alternative sources such as community organizations or charities. This study showed that their experiences (which can be summed up as “being co-afflicted") can have negative effects on the caregiver’s physical and mental health, including increased risk of secondary diseases such as depression or burnout.

In this paper, we compared being co-afflicted to being co-dependent, which does have similarities. It could also be useful to examine the behavior of informal caregivers through the lens of attachment theory, which would suggest that the informal caregivers in this study may have a preoccupied attachment style. A way of meeting their unique needs could then be to not ask, but tell them, to seek support and spend time on self-care.

Understanding attachment styles, however, would not necessarily suffice to address the issue of informal caregivers’ suffering. The person-centered paradigm, which is the official stance of the health care system in Sweden, is not concerned with the well-being of family members; informal caregivers are the responsibility of the local municipality. One exception is when minors are next of kin, as that invokes the *Convention on the Rights of the Child*, which is law in Sweden since 2020 and specifically addresses children’s right to information and support in health care [151]. In the future, a relationship-centered approach might take a larger grip and treat the family as a whole.

Methodological considerations

The study was based on informal caregivers who were reaching out for support and volunteered to participate in focus groups. The sample was chosen intentionally and may not be representative of all informal caregivers. There was an imbalance in the sex of the participants, with more women than men, which may reflect the fact that women are more likely to become caregivers.

The generalizability of this study, considering the gender imbalance and selection of informal caregivers who participated in an online community, may be limited. In any case, the aim was to understand this group rather than making general claims about informal caregivers.

Paper II

We found that most conversations about serious illness occurred in the months and days leading up to the end of life, with only a small percentage of patients having documented conversations in all three time periods (years, months, and days). Guidelines recommend that these conversations occur earlier when life expectancy is measured in years or months. Communication about serious illness in the months leading up to death allows patients time to consider their options and make informed treatment decisions based on their values and priorities and is associated with less intense end-of-life medical care [152].

The analysis started by comparing the records of conversations about dying in the SRPC with the actual documentation of these conversations in medical records. We found that only 63% of the conversations recorded in the SRPC were accurately documented in the medical records, indicating that 37% of the SRPC entries had incorrect information. This suggests that medical records may not always accurately reflect clinical practice, and that there may be significant deficiencies in the documentation of conversations about dying. These deficiencies may be due to clinicians failing to document conversations with patients and families, or to health care personnel misinterpreting the transitions that the SRPC is intended to measure.

The fact that many conversations were missing led us to take a deeper look at the medical records and then we found many more documented conversations about earlier transitions. Thus, this study also highlights the challenges in accurately recording, interpreting, and categorizing conversations about transitions based on clinical notes.

Methodological considerations

The process of review and categorization was done carefully by two reviewers, but it is possible that some conversations may have been mislabeled or missed due to the subjective nature of interpretation. This shows that even in quantitative studies, there are still subjective components and interpretations, which must be acknowledged. It is our firm belief that similar results would be reproduced in other regions of Sweden by researchers using the same protocol (available on demand).

The generalizability of this study is partly limited to Sweden, as the terminology and quality register are unique to the country. The findings regarding the process of communication that takes place over years, months, and days before death most likely reflect international communication practices.

Paper III

Not unexpectedly, we found that physicians that delivered bad news were perceived as less empathic than those who delivered neutral or good news.

There are several possible explanations for this. Research points to the possibility that the physician may focus more on the message [153], and pay less attention to the patient, as a result of being afraid of the patient's reaction [112], being afraid of their own reaction to the patient's reaction, or feeling guilty because of the content of the message [154]. Other research shows that physicians may experience stress or discomfort when disclosing bad news, which can impact the empathy and communication skills [155]. It is important for patients to feel understood and cared for, not just to receive information about their illness. Patients often value listening and paying attention to their concerns as important aspects of empathy, and behaviors such as not listening or making vague promises can be particularly harmful, as can both too little and too much information [156]. This emphasizes that patients have different needs and highlights the importance of careful questioning and listening to patients' preferences to provide appropriate care.

Methodological considerations

Using questionnaires to collect data can be problematic. For example, respondents who are more educated or have stronger opinions on the topic may be more likely to complete questionnaires, which can introduce bias into the results. The high response rate from both groups in our study suggests that most of the patients were motivated to participate. However, it should also be noted that the patients might have felt obliged to give their physician a high rating, despite their participation in the study being confidential to the physician.

It would have been interesting to explore whether there were individual differences between physicians, that is, if the difference in ratings was larger for some than for others, and to investigate what made it so. However, the ethics approval stipulated that all data were reported at the group level, so we did not have that possibility.

The groups were not of a similar size, which made the power weaker than it would have been if the groups had been equal in size. As the group's results on the CARE measure as well as the length of consultation were skewed, we used non-parametric tests in accordance with widely adopted reporting guidelines for biomedical journals [157]. The results of the tests showed significant differences, but the effect would have been stronger had we used parametric tests. Because the groups had more than 30 samples each, the *central limit theorem* could have been applied. The central limit theorem states that the distribution of the sum or average of a large number of independent and identically distributed random variables approaches a normal distribution regardless of the distribution of the individual random variables [158].

Paper IV

In this study we found that breaking bad news is a complex relational process, where the physician's experience is shaped by the current and potential future relationships with the patient.

There is a significant amount of research on the topic of breaking bad news to patients; however, our study offers a more comprehensive understanding of the phenomenon by demonstrating that it involves more than just delivering the message.

When physicians inform their patients about something that may cause negative reactions, they often struggle with the task and may feel anxious, stressed, or frustrated. Our findings show that breaking bad news is a relational act, meaning that it is not possible to (subjectively) share serious information without (intersubjectively) considering its impact on the recipient, which can be difficult due to the unpredictable nature of the patient's reaction.

Being aware of the vulnerability of patients in this situation, physicians must adopt a complex mindset when breaking bad news. In our study, some physicians struggled with this complexity, and became self-conscious or overly focused on the task rather than focusing on the patient. Physicians' communication skills, medical knowledge, self-awareness, and understanding of the patient's needs all play a role for the outcome of delivering of bad news.

Physicians' emotions and feelings when discussing a patient's prognosis are often not addressed in communication skills training, which instead focuses on preparing the patient. Consequently, communication training, protocols, or guidelines may not adequately address the stress and distress that physicians may experience when breaking bad news. Without additional support and resources, physicians may be vulnerable to physical and mental distress. Therefore, medical education should help prepare physicians to break bad news to patients by introducing medical psychology into the curriculum, encouraging them to reflect on the meaning and importance of adopting a complex mindset, and how this mindset can be applied in practice.

In breaking bad news to patients, physicians must find a balance between explaining the meaning of information and leaving room for hope. At this critical moment, they feel responsible for how the patient perceives the future. Therefore, managing hope in a professional and compassionate manner is an essential aspect of the physician-patient relationship. To maintain a therapeutic relationship, physicians must consider the delivery of news and be prepared to handle various reactions from the patient. This requires a high level of self-awareness and self-control, as well as the ability to accept the unequal power dynamics between clinicians and patients and encourage the patient to express themselves within reasonable limits. However, what is considered "reasonable" appears to be subjective, and the process of breaking bad news often involves repeating the same message and potentially sharing additional negative information over time. As a

result, breaking bad news is a continuous relational process that requires a compassionate approach rather than a defensive or distant attitude.

To support the well-being of health care providers and their compassionate care of patients and families, we believe it is important to recognize a broader definition of compassion as *a sensitivity to suffering in oneself and others, with a desire to alleviate and prevent it* (p. 10) [80]. One way to do this is to allocate sufficient time and space for important conversations between physicians and patients, which can reduce the emotional strain of the task for both parties. However, this is not always possible due to constraints within the clinical organization, indicating that education alone may not be sufficient to address the issue unless the overall structure of the organization is reevaluated.

Methodological considerations

A common criticism of qualitative research is that the results are subjective, specific, and not generalizable outside the context of the study. Some responses to this suggest that one should use the terms *trustworthiness* and *transferability* instead [159]. There is a great deal of diversity within the group of physicians, and the participants in this study came from a range of specialties and backgrounds. This means that the data collected in this study represent a wide range of perspectives, which are important in phenomenological research [144]. Additionally, the study included many participants, which allowed us to reach a point where we were no longer learning new information from additional descriptions, that is, *analytical saturation*. Giorgi argues that just because something is subjective it does not mean that it is untrue, and more importantly, he proposes that when the phenomenological method is properly performed, including the phenomenological reduction and imaginative variation, it is possible to "describe an essential finding that is intrinsically general" (p. 356)[160]. Since we performed the necessary steps in the method, we claim that the findings should be applicable beyond the specific context in which the study was conducted.

Conclusions and clinical implications

I. The lived experience of being an informal caregiver for someone with cancer can be understood as being co-afflicted, similar to the concept of codependency, in the sense that they often carry a heavy burden, take a lot of responsibility, and may neglect their own needs. Recognizing informal caregivers as persons with need for support is an important step in developing humanistic relationship-centered health care.

II. Communication about serious illness between clinicians, patients, and families occurs over an extended period of time before death. We observed a pattern of conversations over years, months, and days before death. Families often had separate conversations when death was near. Using this framework may help ensure that patients and their families have the necessary information for making medical and personal decisions. The framework may also be useful for clinicians and patients in preparing for the end of life and for measuring and improving the quality of communication regarding serious illness.

III. It is important for physicians to be aware of patients' desire to be understood and recognized, and to have the skills to address emotional concerns. The results of this study suggest that either the patients' emotions are being projected onto the physician or that the physician is focused on the content of the message rather than the patient. To improve communication, physicians need time to plan and practice how to deliver difficult news, and they need support by focusing on the patient and listening to what is important to them. Training in communication skills may help physicians become more aware of their own and their patients' behaviors and emotions during consultations.

IV. The results of this study show that the essence of breaking bad news in medicine is a complex relational process that involves more than just the act of delivering information. However, the study found that, in practice, physicians sometimes had to break bad news without sufficient preparation or previous knowledge of the patient, which added unnecessary stress to an already emotionally difficult situation. To improve the process of breaking bad news, it is important to have sufficient time and continuity, and to consider the working conditions of physicians. This process can be improved by emphasizing a holistic view of humans as social beings in medical education and continuing education for clinical staff. An important

part of this training should be to develop compassion not only for the patient and their families but also for oneself.

Overall, these studies show the importance of understanding humans as social beings and that to care for the person, we need to take the person's world, ourselves, and our own world into consideration. Seeing communication about serious illness as a relational process can enhance the human connection in health care.

Further research

The development of communication about serious illness as a relational process requires a holistic approach in future research.

The Research Committee of the European Association for Communication in Healthcare recently identified future research topics: theoretical models; clarification of terminology; cultural norms, both in a wider sense and in the medical setting; and assumptions about health communication, patient outcomes, and neurological mechanisms of communication. There was also a call to widen the scope of methodologies used in communication research and link observational and experimental studies, mixed-method approaches, longitudinal studies, and diverse interdisciplinary teams with scholars from both clinical and human sciences [161].

To change practice in clinical settings, I believe work has to take place at a cultural level. I would like to be part of a cluster-randomized study where interventions aim to change the culture of a clinic, specifically how the caregivers and administrative staff relate and communicate with each other, patients, and families.

In clinical practice, communication skills are probably developed over time rather than through single events. I would like to engage in longitudinal studies to investigate which interventions are most beneficial for improving communication, strengthening relationships, and sustaining improvements. Is technical skills training with simulated patients most efficient, or should emphasis be on experiences that improve resilience, presence, and compassion?

Another path could be to investigate the role of attachment in caregiving: How does the attachment style of caregivers and patients impact the relationship, and can the caregivers' awareness of attachment styles improve the relationship?

Moreover, some clinics have assigned the task of sharing serious information to certain clinicians, who have an affinity and an interest in communication. Is that a sustainable model, how does it impact caregivers, patients, and families?

Finally, how does identity, self-awareness, and imagined expectations from others integrate with and impact patient-provider relationships, trust, shared decision-making, treatment adherence, and patient satisfaction? In relation to the psychosocial framing of this thesis, it would be interesting to compare attitudes and behaviors between health care professionals who have had medical psychology and humanities in their curriculum with those who have had a strictly biomedical curriculum.

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About the author

Mattias Tranberg is a clinical psychologist and researcher with an interest in communication, medical psychology, and palliative care. He teaches communications skills for health care providers and practices compassion-focused therapy and meaning-centered psychotherapy. This thesis investigates communication about serious illness as a relational process.

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