Bente Prytz Mjølstad

KNOWING PATIENTS AS PERSONS

A theory-driven, qualitative study of the relevance of person-related knowledge in primary health care

Thesis for the degree of Philosophiae Doctor

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Norwegian University of Science and Technology
Faculty of Medicine
Department of Public Health and General Practice,
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"In hospitals, the diseases stay and the people come and go.
In general practice, the people stay and the diseases come and go"

- Iona Heath

Illustration by Ragnhild Gjerstad.

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Norsk sammenfatning

Kunnskap om pasienter som personer. En teori-drevet kvalitative studie av relevansen personrelatert kunnskap kan ha i primærhelsetjenesten.

Det er økende dokumentasjon for at belastende livserfaring og alvorlige hendelser i livet kan være utslagsgivende for helsa, noe vi i dag har fått innsikt i bl.a. ved hjelp av moderne kunnskap om stressfysiologi. Den nye fagkunnskapen tilsier at biografisk og personrelatert kunnskap om pasienter er medisinsk relevant, men slik kunnskap har tradisjonelt blitt lite vektlagt innenfor biomedisinen; den dominerende forståelsesrammen for dagens medisinske praksis. Det overordnede formålet med dette prosjektet har vært å utforske og å identifisere hva allmennlegers personrelaterte kunnskap om egne pasienter består av, og om allmennleger vurderer slik kunnskap som medisinsk relevant. Videre å undersøke i hvilken grad pasienter som er innlagt til et kortvarig rehabiliteringsopphold validerer informasjonen fra sin fastlege med hensyn til personrelatert kunnskap, samt å utforske om denne kunnskapen ble gjort relevant under oppholdet.

Prosjektet har blitt gjennomført innenfor rammen av to typer studier; fokusgruppeintervju av allmennleger og en intervensjonsstudie på en rehabiliteringsavdeling på et sykehjem. I første del ble to grupper av allmennleger (seniorer med mye erfaring og juniorer med mindre erfaring) bedt om å diskutere i hvilken grad de har slik kunnskap om pasienter og om denne kunnskapen kan være medisinsk relevant (artikkel I). I intervensjonsstudien ble fastleger telefonintervjuet om deres pasienter som nylig hadde blitt innlagt på en rehabiliteringsavdeling på et sykehjem. Informasjonen fra telefonintervjuene ble sammenholdt med hva pasientene kunne fortelle om seg selv og sin livshistorie i påfølgende individuelle dybdeintervjuer. På den måten kunne vi utforske i hvilken grad allmennlegene faktisk hadde personrelatert kunnskap om sine pasienter. Både fastlegene - og pasientene selv- ble også spurt om hva de mente var vesentlig å legge vekt på under rehabiliteringsoppholdet (artikkel II). I artikkel III har vi sammenlignet og diskutert tre ulike perspektiver på pasientenes behov når de ble innlagt i rehabiliteringsavdelingen; 1) fastlegens anbefaling på vegne av sin pasient 2) hva pasienten selv vurderte som mest sentralt og 3) hvordan institusjonen responderte på disse individuelle behovene.

Både erfarne og mindre erfarne allmennleger som deltok i fokusgruppene vektla personrelatert kunnskap om pasienter som viktig, og identifiserte flere hindre som gjør det

vanskelig å dokumentere og overføre slik kunnskap til annet helsepersonell. De erfarne allmennlegene vektla personrelatert kunnskap om pasienter som medisinsk relevant i større grad enn de mindre erfarne legene.

De fleste av fastlegene som deltok i intervensjonsstudien var i stand til å gi en adekvat beskrivelse av pasientenes personlighet, og de hadde mye kunnskap om pasientenes yrkesliv og nære relasjoner (partner, barn). Fastlegene hadde mindre kunnskap om pasientenes interesser (hobbyer, fritidsaktiviteter), sosialt nettverk og relasjoner til foreldre og søsken. Fastlegene hadde lite eller ingen kunnskap om pasientenes barndom, oppvekst vilkår og betydningsfulle livshendelser. Noen av fastlegene ble overrasket over hvor lite de egentlig visste om pasienter som de hadde kjent i mange år (gjennomsnitt varighet av lege-pasient forhold var 15 år). De fastlegene som hadde et mer personlig lege-pasient forhold til sine pasienter var i større grad i stand til å formulere anbefalinger som stemte overens med pasientens uttrykte ønsker og behov. Pasientens ønsker og behov varierte mye, men var ofte nært knyttet til deres livsverden.

Tiltross for institusjonens intensjon om å lage individuell behandlingsplaner for pasientene, var tilnærmingen i stor grad standardisert og tok i liten grad hensyn til allmennlegenes anbefalinger og pasientenes individuelle ønsker, selv der disse lå innenfor hva som hadde vært mulig å få til på institusjonen. I avhandlingens innledning gis en historisk fremstilling av en utvikling der pasienten som person ser ut til å ha blitt borte i medisinen. Avhandlingens tre artikler diskuterer behovet for en mer fleksibel og person-senteret tilnæring til pasienter slik at helsevesenet i større grad kan gjenvinne sin ”humanitet” og bli i stand til å gi genuint skreddersy behandling som i større grad tar hensyn til pasientens spesifikke og uttrykte behov. I avhandlingens diskusjonsdel beskrives ulike tilnærminger til hvordan personen kan gjeninnføres i medisinen, herunder en humanistisk og en teknologisk variant av persontilpasset medisin, foruten narrativt basert medisin.

Kandidat/ Institutt: Bente Prytz Mjølstad, Institutt for samfunnsmedisin, Det medisinske fakultet, NTNU.

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Abstract

A growing body of research documents, that adverse life experiences can have a decisive impact on people's health. However, traditional biomedicine, the dominant perspective through which today's medical practice is conceptualized, has placed little emphasis on expert findings, such as those within modern stress physiology, indicating that biographical and person-related knowledge have medical relevance. The primary aim of this project was to explore the person-related knowledge general practitioners (GPs) had about their patients and the degree to which they ascribed medical relevance to it. We also sought to assess the importance given to person-related knowledge by patients undergoing rehabilitation, and to explore the interactions between GPs and health care personnel at a nursing home rehabilitation unit regarding the transfer of such knowledge.

The project consisted of three phases. In practice, these were carried out within the framework of two consecutive studies: first, focus group interviews with GPs and, later, a two-part intervention study at a nursing home rehabilitation unit. In the first phase, (focus group interview study), two sets of GPs (seniors with more experience, and juniors with less) were asked to discuss the extent to which knowledge about patients as persons might be medically relevant. The next two phases were carried out within the context of the intervention study. GPs were interviewed by telephone regarding the person-related knowledge they had about patients who had recently been referred to a nursing home rehabilitation unit. Information from those interviews was then compared to what the patients themselves related during in-depth interviews. In this way, we could determine the extent and accuracy of the person-related knowledge GPs actually had acquired. In the final phase of the project, we discussed the patients' needs upon admission from three perspectives: 1) the GPs' recommendations on the patients' behalf; 2) the needs the patients themselves considered most important to have addressed; 3) how the institution responded to the patients' individual needs.

Both groups of focus study GPs considered person-related knowledge about patients to be important, those with more experience attributing greater relevance to it than those with less experience. Members of both groups identified various factors complicating both the documentation of such information and its transfer to other health care personnel.

Most of the GPs participating in the intervention study could describe the personality of their patients adequately and, to some extent, their working life and close relationships (partner,

children). They had less knowledge about their patients' interests (hobbies, activities), social networks and relationships to parents and siblings. They had little or no knowledge, however, about their patients' childhood as regards either facts or conditions, or significant events or experiences. Some of the GPs expressed surprise at how little they actually knew, even about people whom they had been treating for many years (15 years was the average duration of the doctor-patient relationships).

While all the GPs were able to formulate treatment/rehabilitation recommendations for their patients, the suggestions of the physicians with more personal knowledge of their patients came closer to reflecting the needs and wishes expressed by the patients themselves. These varied greatly, often connected to the patients' living conditions and life-world.

The institution's expressed intention was to create individualized patient treatment plans. Nonetheless, those composed by the rehabilitation personnel consisted primarily of standardized elements. Even though many of the GPs' recommendations and the patients' wishes fell well within what the institution was equipped to offer, these were barely addressed by or integrated into the treatment actually provided.

All three articles upon which this dissertation is based discuss the need for a more flexible and person-oriented approach to patients. This would enable public health services to provide more genuinely tailored treatment which, to a greater extent, takes the individual patient's specific life-world into consideration.

Contents

Acknowledgments

It has often been said that the immense gift of practicing medicine resides in our being allowed to participate in the great moments of other people's lives, the better to understand our own lives and the world around us. When it comes to laying the foundation for living a good and healthy life as a human being, I have learned over the years that two vital aspects of life are: to ensure that a child grows up in a secure environment in the presence of responsible adults, and to be in good relationships with other people. In those respects, I have been very fortunate.

My parents provided me with the best possible foundation for life - a safe childhood filled with love. I was raised to have faith in myself, always encouraged to do my best and told that, through hard work, it is possible to achieve almost any desired goal.

My husband, Ole Christian, has given me the love and support I needed to go into research, having, at times, even more faith in my abilities than I did. We started our professional careers together, and we have many good memories from our time of working as companion GPs. Though we now pursue differing areas of medical interest, we still share the same understanding of what it is to provide "good medicine" and "to take good care of patients". We also agree that our three magnificent children - Solveig, Ingrid and Christian - are our greatest "achievement in life", a constant source of joy; bringing happiness into the world.

I was very fortunate to "stumble" into an academic milieu that, as I have come to appreciate over time, actually is quite unique. Allmennmedisinsk forskningsenhet (AFE) Trondheim functions at an exceptionally advanced level of scientific awareness while also providing space and permission for true creative expression to emerge, freely and without distortion. I am deeply grateful to my three supervisors, Irene Hetlevik, Anna Luise Kirkengen and Linn Getz, who, over the years, have provided me with both professional and personal support, in quite exceptional ways.

First of all I need to thank Irene. As the leader of AFE Trondheim, she took a chance on me and included me as part of the "team". Irene, you have not only been my main supervisor, but in many senses, also my mentor - always willing to advise me how best to find my way, my role in academia and my professional development. Your door has literally always been open and you have always taken your time to listen to my questions and frustrations. As my supervisor, you have been steadfast in offering encouragement and sensitive when giving criticism. Anna Luise, your pioneering research and writings have - once and for all - opened my eyes to the huge impact of adverse human experiences on people's health and disease development. Your guidance in qualitative research has been invaluable for the development and conducting of this research. Your supervision embodies for me the power of love-in-action, of nurturing the mind - and your ability to see "the pattern that connects" never ceases to amaze me. Linn, you are an everlasting source of inspiration and encouragement. Your formidable knowledge, creativity and supportive academic interest and assistance have been of paramount importance for this project. I am grateful for your gentle yet determined push during the final stage of the writing of this thesis - not letting me be satisfied with "second best".

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Being a part of the Board of the Norwegian College of General Practice has not only been an unmitigated pleasure, but made an important contribution to my professional and academic development, teaching me the art of argumentation - and reminding me of the value of seeing things from different angles.

Thanks go to my friends who still are my friends even though I have turned down many invitations recently.

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Finally, my gratitude goes out to all those who participated in this research project. This thesis is dedicated in particular to the persons whose stories form the basis of the work. Though, to protect their anonymity, I cannot mention any of them by name. I am deeply grateful to each one of them, for their time, their trust, and the openness which enabled me to glimpse the meaning within certain of their life events.

List of papers

1: Mjølstad BP, Kirkengen AL, Getz L, Hetlevik I. (2013). Knowing patients as persons: Senior and Junior GPs explore a professional resource. *European Journal for Person-centered Healthcare*, 1: 88-99.

2: Mjølstad BP, Kirkengen A.L, Getz L, Hetlevik I. (2013). What Do GPs Actually Know About Their Patients As Persons? *European Journal for Person-centered Healthcare*, 1: 149-160.

3: Mjølstad BP, Kirkengen AL, Getz L, Hetlevik I. (2013). Standardization meets stories: contrasting perspectives on the needs of frail individuals at a rehabilitation unit. *International Journal of Qualitative Studies on Health and Well-being*, 8: 21498. http://dx.doi.org/10.3402/qhw.v8i0.21498

Selected abbreviations

ACE	Adverse childhood experiences
ADL	Activity of daily living
AFE	General Practice Research Unit
APLF	Alment praktiserende lægers forening
BC	Before Christ
CDC	Centers for Disease Control and Prevention (US)
CFS	Chronic fatigue syndrome
CME	Continuing medical education
CPP	Chronic pelvic pain
CVD	Cardiovascular diseases
EBM	Evidence based medicine
EJPCH	European Journal for Person-centered Healthcare
GP	General practitioner
IBS	Irritable bowel syndrom
KOPF	Konitunerlig, omfattende, personlig forpliktende
ME	Myalgic encephalomyelitis
MUS	Medically unexplained symptoms
MUPS	Medically unexplained physical symptoms
NBM	Narrative based medicine
NEL	Norsk elektronisk legehåndbok

NFA	Norsk forening for allmennmedisin
NHI	Norsk helseinformatikk AS
NRG	Nordic Risk Group
NSAM	Norsk selskap for allmennmedisin
NTNU	Norwegian University of Science and Technology
NUD	Non-ulcer dyspepsia
OFS	Oral, facial painsyndom
OLL	Offentlige legers landsforening
PCM	Patient centered medicine
PKO	General practice consultant
PNEI	Psych-neuro-endo-immunology
PNI	Psycho-neuro-immunology
PTSD	Post-traumatic stress disorder
REK	Regional committees for medical and health research ethics
RGP	Regular General Practitioners system
TMD	Temporomandibular joint dysfunction
TWAR	Taiwan acute respiratory agent - also known as Chlamydia pneumoniae
UGP	Urogenital pain
WHO	World health organization

1 Prologue

1.1 Becoming a GP

I started my career as a doctor in 1998 after completing medical school at the University of Bergen. As newly graduated students, my husband Ole Christian and I decided to go to Northern Norway for our mandatory 1½-year internships. The meeting with rural general practice in Vadsø made such an indelible impression on both of us that, when we returned to Southern Norway after finishing our internship, we both wanted to work as general practitioners (GPs). This was in 2001, about the same time as the Norwegian authorities introduced the “Regular General Practitioners” (RGP) system[1] and we felt fortunate to be able settle in our own practice in Biri, Gjøvik. Building on our experiences in rural general practice, we started out as very enthusiastic GPs. However, the realities of working as “real doctors” turned out to be more demanding than we had expected; it was quite difficult to manage all the work in our small practice while establishing a family at the same time. After two years, Ole Christian began to work at the local hospital. Still determined to become a specialist in general practice, I continued working in the same practice during the following years. In addition to providing primary care to the patients assigned to my list, I also served as a consulting physician at a nursing home.

1.2 A professional concern conceptualized

As a novice doctor, I was very biomedically oriented, enjoying “straight on” medicine, conscientiously trying to follow all guidelines. I struggled when dealing with patients presenting diffuse symptoms; because their symptoms were less clear cut it was obviously more difficult to decide the right approach, or even to decide what was within “the scope of medicine.”[2] After some years, I noticed feeling increasingly uneasy about being a GP, especially when trying to help the growing group of patients presenting medically unexplained symptoms (MUS). I often felt incapable of explaining to these patients what is

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[1] All citizens in Norway are assigned a specific GP (a list system).

[2] During an interview in “Utposten,” a Norwegian medical journal, about “How it is to be a novice GP in the new RGP System,” I was asked about the positive and negative aspects of being a GP. My answer was that I enjoyed the same things that I had enjoyed in medical school: internal medicine and concrete biomedicine. The difficult patients were those with diffuse symptom. These I often wanted to ask, “What kind of doctor-things might I help you with?” (see Skeie I. (2003). Utpostens dobbelttime. Utposten nr.4. http://www.uib.no/isf/utposten/2003nr4/utp03402.htm).

medically unexplained; it was indeed difficult to try to reassure a patient that he/she did not suffer from any disease – while trying simultaneously not to offend the patient by questioning her/his credibility. I did not have much to offer in the strict biomedical sense, which was the only framework I considered valid at that time. Some of my patients probably left feeling disappointed by my attempts to say and do the right things. When discovering one of their names on my schedule, I often felt uncomfortable; they became my "heart sink" patients.

In 2007 I was offered the opportunity to work in the Department of internal medicine at Gjøvik hospital, and, as a part of the mandatory hospital service, I had to fulfill the requirements to become a specialist in general practice. I discovered there that the hospital doctors shared the same frustration about the above-mentioned patients. Their frustration, however, disappeared the moment those patients were discharged – in other words, were sent back to their regular GPs. This was done as quickly as possible after the investigations had ruled out that a patient was suffering from some known, organ-specific disease. After discussing the topic with some of my hospital colleagues, the head of the department challenged me to present a case of MUS during a weekly department meeting. I did that, in a slightly provocative manner, pointing to the hospital's reluctance to take responsibility for such patients. At the initiative of a senior GP present at that meeting in the role as a general practice consultant (PKO) at the hospital, this lecture resulted in me publishing a patient narrative essay in a general practice medical journal, Utposten.[3] There, I described my discomfort when trying to be a good GP for one of my patients with MUS, seeking advice from specialists without receiving any.[4] In retrospect, I see this as my first effort to conceptualize the professional concern that led eventually to this research.

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[3] Karin Frydenberg who was the general practice consultant at hospital (" Praksis konsulent" (PKO)) had at the same time an editorial post in Utposten.

[4] The patient narrative essay focused on a middle-aged woman who struggled over a long period of time with respiratory problems and fatigue following an acute lung infection with chlamydia pneumonia (at that time known and 'feared' as TWAR infection). As her GP, I referred her to several specialists but none of them could identify or document any 'real' disease, somatic or psychiatric. We tried 'experimental' treatments with limited success. On a holiday in Spain, she experienced improvement but her symptoms recurred on her return to Norway. Ultimately, she consulted a private expert on ME and finally received a diagnosis which enabled her to get a disability pension (see Mjølstad 2007).

1.3 Being a Norwegian GP at the dawn of 21st century

The same feelings of discomfort and inadequacy were shared by other GPs as well, and, I believe, have been intensifying ever since. The issue of patients presenting MUS was widely debated on Eyr, [5] an email discussion list for GPs, often in the form of relatively heated exchanges. The doctors' frustrations seemed to increase proportionately with the number of patients with unexplained symptoms. The incidence rate of patients with medically unexplained physical symptoms (MUPS) was estimated at approximately 20% of all primary care consultations in 2003 (Burton 2003). Researchers suggested that MUPS were a leading cause of sick leave (Ihlebaek, Brage, Eriksen 2007). The biomedical paradigm was not useful, neither to help doctors understand these patients' problems nor to help finding treatments to offer them (Kirkengen, Getz, Hetlevik 2007). The discipline of general practice was under pressure in many other aspects as well. The introduction of so-called evidence based medicine (EBM) had led to an increased emphasis on guidelines, both for clinical and for preventive medicine. GPs, expected to navigate within a growing body of knowledge, were in danger of experiencing information overload. Since the 1970's when the concept of a "risk epidemic" was identified as a trend in biomedicine (Skolbekken 1995), the treatment of risk factors in otherwise healthy people had become an established part of clinical practice. There was an increasing tendency for resources in primary care to be directed away from the treatment of currently ill persons in order to care for people who were symptom-free, with the aim of disease prevention (Swensen 2000).[6] The interest in risk and prevention had profound implications for clinical medicine (Getz et al 2004, Hetlevik 2004, Petursson, Getz, Sigurdsson 2009). The GPs assigned with these additional work tasks and wider responsibilities were in danger of overload as the limits of their capacities were reached (Hetlevik 1999a).

These feelings of insufficiency and discomfort forced me to start thinking more critically and systematically about the way we practice medicine, including what kind of knowledge GPs actually have about their patients. It was obvious to me that patients presenting with functional disorders, so-called MUS, were ill because of "something" and thus not able to

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[5] For more information about Eyr, see for instance, the webpage: http://mailman.uib.no/listinfo/eyr.

[6] The book, "Diagnosis: Risk" was the result of a long process of problematizing the topic of "medical risk"' from a GPs perspective.

function in the way they wanted - but the biomedical patient perspective did not provide an adequate basis for understanding why. As I wondered if something was going on in their life situations, contributing to their health problems, I realized how little I actually knew about some of these patients, who they were and how they lived their lives. It was nonetheless difficult to inquire into such things because the patients often interpreted my questions as if I were suspicious that their symptoms were "only" of psychological rather than somatic origin. Often, diagnosing a patient with a functional health problem failed to provide relief (Kirkengen 2002), but rather increased the distance between the patient and me; the person expected to give help. There were even moments when I felt that the diagnosis evoked feelings of humiliation. Such experiences further aroused my interest in academic medicine.

When we moved to Trondheim in 2007, I began to investigate how I might be able to do general practice research. An article in "The General Practitioner" supplement section of the newspaper *Dagens medisin*[7] attracted my attention. Entitled, "We must explore the relationship between psychological and somatic complaints"[8] it reported on interviews with a research group of general practitioners at the General Practice Research Unit in Trondheim (AFE Trondheim[9]) regarding patients with chronic fatigue. It made sense and inspired me to contact one of the researchers, Irene Hetlevik, leader of AFE Trondheim, who later became my main supervisor and mentor. She advised me to conceive of a research topic based on my experiences as a GP. A research project gradually developed in collaboration with my supervisors and guided by AFE Trondheim's Norwegian "Three U's" – *Undring*, which means to wonder about, positively or negatively, *Ubehag*, meaning a sense of discomfort, and *Utilstrekkelighet*, meaning a feeling of inadequacy.[10]

This thesis arises from a viewpoint within Norwegian general practice and must be seen against that background. A professional concern for the way in which we practice medicine

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[7] Dagens Medisin (Medicine today) is an independent Norwegian newspaper for the health sector.

[8] "Vi må se psykiatri og somatikk i sammenheng" (Hanger 2007).

[9] AFE Trondheim is short name for General Practice Research Unit, Department of Public Health and General Practice, Norwegian University of Science and Technology.

[10] AFE Trondheim wishes to stimulate GPs to do research in primary care by encouraging reflection upon these "3 U's" (see The Strategy document AFE Trondheim 2012. Webpage: http://www.ntnu.no/documents/10297/0/AFE+%C3%85rsmelding+for+2012.pdf/6d30e07a-dcc3-4b53-8427-64f0a9db8b14).

and an interest in what kind of knowledge GPs actually acquire about their patients has motivated my entry into research.

This specific ph.d project is rooted in professional experience accumulated over the course of years of practice, during which I alternated between functioning as a GP providing primary care to patients assigned to my practice list and, simultaneously, served as a consulting physician in a nursing home. From these two perspectives it was possible to observe that valuable *person-related* information about the patients admitted to institutional care seemed to be “lost in transition.” This observation provided the impetus for a research project wherein the paramount aim was to explore the medical relevance of person-related knowledge.

2 Introduction

2.1 Overview of this thesis

Within the framework of a three-phase project, I will present a combination of analytical, theoretical reflections and empirically-based writings on the topic, “Knowing patients as persons.” The overall theoretical framework applied is phenomenology. Qualitative research methodology has been my main research tool. The format of this thesis will therefore deviate from the format of a thesis written within a conventional biomedical context. In accordance with the traditions within humanistic sciences and qualitative research regarding transparency, I have begun this thesis by making my position explicit (see the prologue).

Since this thesis is based on conventional, Western medicine as distinct from alternative approaches to medicine (e.g. traditional, Chinese medicine), I consider it appropriate to begin the introductory chapter by defining “medicine” and discussing it as an ethical project before moving on to identifying selected milestones in the historical development of medicine. I do not have formal academic training in medical history; my main historical guide has been the renowned British historian Roy Porter’s book, “The Greatest Benefit to Mankind,”[11] in addition to consulting web-based encyclopedias to cross-check details. Obviously, Porter does not put forth any “objective” interpretation of medical history – no such interpretation exists. Nonetheless, I consider his work to be an adequate guide as he focuses on phenomena, problems and processes which I recognize as relevant and valid based on my own experience with medicine. My motivation for examining the history of medicine has been to understand how modern medicine and knowledge production developed to where it is now. One of my main questions has been: how and when did the person disappear in medicine? The more I learned about medical history, the more I discovered its relevance for my project; consequently, it became clear that this part of the introduction needed to be comprehensive. By examining history, we look for developments and events within the context of the world in which they appear. *Context* is a key word in this thesis: it is context that gives meaning to events, as nothing takes place in a vacuum.

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[11] Roy Sydney Porter (1946-2002) was a prolific British historian noted for his work on the history of medicine. He pioneered the concern with patients (instead of doctors). His book “The Greatest Benefit To Mankind: A Medical History Of Humanity” (1997) is described as “a blockbuster history from Plato to Nato” (see Obituary; Roy Porter, the Guardian 2002, http://www.theguardian.com/society/2002/mar/05/2).

Later in this chapter, I describe differing, yet parallel, developments in ways of thinking that have contributed to new insights in and approaches to medicine generally and general practice specifically. This will include contributions from anthropology, sociology and phenomenology. I also describe the development of patient-centered medicine and modern family medicine. Towards the end of the chapter, I outline some of the major challenges facing contemporary medicine and health care today, as seen from the perspective of general practice. Finally, I present a review of the literature focused on the person and person-related knowledge in medicine.

The overall purpose of the introductory chapter is to "set the scene" and show what was already known and understood when I embarked upon this project. A word about my use of references in the introduction: I became aware of several on-going trends during the early phases of my project that have led to seminal papers which sum up the issues in question. While these do not constitute the reference base for the introduction, they are introduced as footnotes as a service to the interested reader.

The introduction will lead to a discussion of the theoretical framework followed by a description of the aims of the study. In the next section, covering methods and material, I describe and discuss the methodological basis for this research project, my efforts to reach the established aims and a discussion of the legitimacy and challenges of doing qualitative research in medicine, including certain ethical considerations. In the chapter about results, I present the two studies and the three articles upon which this thesis is based. Later, a description of how the data were analyzed is presented. Finally, in the last part of the thesis, I present and discuss my research specifically. I discuss the results and relate them to relevant literature, before reflecting over implications and perspectives for the future.

2.2 The nature and goals of medicine

Human beings have practiced healing in one way or another for thousands of years. The study of prehistoric medicine (before writing was invented) has dated the perhaps oldest surgical procedure, "trepanation,"[12] the opening of the skull, to roughly 6500 Before Christ (BC). Cave paintings indicate that people believed this procedure could cure epileptic seizures, headache, and mental disorders (Porter 1997). The origin of the word medicine belongs to

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[12] Trepanation: holes drilled or scraped into the human skull. Easy accessible source; www.Wikipedia.org.

modern history and is derived from the Latin, *ars medicina*, meaning *the art of healing* (Schei 2007). According to the Merriam-Webster Online Dictionary (2013),[13] medicine is defined as:

"the science and art dealing with the maintenance of health and the prevention, alleviation, or cure of disease."

The term "biomedicine" is often used as to indicate Western contemporary medicine and is defined in the same dictionary as:

"*Medicine based on the application of the principles of the natural sciences and especially biology and biochemistry."*

The central purpose of the medical community is the alleviation of human suffering caused by illness and injury. To care for people unable to care sufficiently for themselves, and to be compassionate towards vulnerable persons, have been basic principles of medicine since the time of ancient Greece (Porter 1997). The view that the physician's task is "*to always comfort, often relieve, and sometimes to heal,*" is attributed Hippocrates, even though we do not know the actual origin of the quote. Nevertheless, Hippocrates, considered to be the founder of modern Western medicine, has left a rich medical and ethical heritage. The Hippocratic Oath, taken by generations of doctors, demanded that medical doctors maintain high ethical standards; a central rule of Hippocratic medicine was to avoid doing harm. Its principles are still important to the professional and ethical training of today's doctors, and in contemporary medical practice, as reflected in the first paragraph of the current Ethical Guidelines of the Norwegian Medical Association:

§ 1: A physician must protect human health. A physician should heal, relieve and comfort. A physician should help the sick to regain their health and the healthy to preserve it (my translation).[14]

Illness being a universal human phenomenon renders medicine and medical practice a very specific human activity. Precisely because medicine deals with human beings, morality is of crucial significance. Ethical awareness and reflection are essential elements in all aspects of

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[13] Webpage for the Merriam Webster Online Dictionary: http://www.merriam-webster.com/

[14] The entire text of the "Ethical Guidelines of the Norwegian Medical Association" ("Etiske regler for leger") can be found on this web-page; http://legeforeningen.no/Om-Legeforeningen/Organisasjonen/Rad-og-utvalg/Organisasjonspolitiske-utvalg/etikk/etiske-regler-for-leger/

physicians' professional practice, despite not always being explicitly acknowledged or even recognized. While medical research aims at producing generalizable knowledge, medical practice is about applying this knowledge to specific patients, who may or may not respond favorably. It is often stated that medicine is both a science (value-neutral) and an art (value-laden),[15] so that the choice of what ought to be done depends not only on scientific knowledge but also on questions of value, morality and interpersonal dynamics (Pellegrino, Thomasma 1981, Jotterand 2002). According to Pellegrino et al, interpretation of scientific knowledge and of relationships are two very different, but mutually important aspects of medicine indicating that medical practice entails a moral aim as its ultimate purpose (Pellegrino, Thomasma 1981). This is true not only for the clinical application of medical knowledge but also for the very "production" of medical knowledge in the first place. In other words, for all endeavors termed scientific medical research, the entire effort is one of deepening and refining our accumulated knowledge about the true nature of human beings and the human body. Medicine is consequently, at its heart, an ethical project.

However, as mentioned above, the fact that both medical research and medical practice are intrinsically value-laden activities may not be fully recognized among medical researchers and clinicians. The traditional emphasis on medicine as a profession based on factual knowledge and advanced technology can be read directly in the following quote, excerpted from the web-page for the medical curriculum at my own university, the Norwegian University of Science and Technology (NTNU):[16]

"To become a doctor, you must know the body's machinery down to its smallest cell. You must cultivate the ability to keep up-to-date in a field of knowledge that undergoes continual and furiously paced development" (my translation).

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[15] I will not go further in to the discussion of this essential topic here. Aristotle introduced a concept of knowledge that distinguishes between episteme, techne and phronesis, which I will return to in section 2.5 The nature of medical knowledge.

[16] Link to NTNU web-page: http://www.ntnu.no/studier/cmed/medisin accessed date:14.02.2014.

2.3 When did the person disappear from medicine – and how could that happen?

2.3.1 Western medicine: from Hippocrates to Descartes and Linnè

Hippocratic medicine represents a landmark in the evolution of Western medicine. Hippocrates (460-377 BC) is regarded to be the first physician who investigated the causes of diseases from what we would consider to be a scientific perspective, and in doing so he laid the foundation for the prevailing concepts of diagnosis, prognosis and treatment. Ancient medicine, as we understand the paradigm, concentrated on three components: 1) experience (empirical observation); 2) religion or magic; and 3) the speculations and propositions of philosophers. According a theory about humors (four body fluids), the normal condition (health) was defined as a balance between the body fluids and the body's environment. Any disturbance of this balance brought disease (Porter 1997). Thus, the disease was not regarded as separate from the suffering person, just as this person was inseparable from her/his actual context. The main task of the physician was, consequently, to assist the diseased person to regain her/his balance.

The medical heritage of Antiquity, with its emphasis on lifestyle and harmony, remained powerful within the Western tradition for many centuries. From the end of 16th century, however, and throughout the Age of the Enlightenment,[17] old ideas and traditional beliefs were radically challenged. This ontological and epistemological revolution continued through the 17th century and promoted scientific thought and skepticism as opposed to faith and superstition. Traditional concepts were overridden by new perspectives and the old cosmology was replaced with new models. Astronomer Nicolaus Copernicus' (1473-1543) theory of the universe not being terra-centric but rather helio-centric initiated a revolution in astronomy. Reducing the Earth to merely "another planet" represented a profound challenge of the prevailing "Earth-centered" Christian cosmology. The Scientific Revolution resulted in "an empirical turn," including for medicine, which established a different perception of

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[17] "There is little consensus on the precise beginning of the Age of Enlightenment; the beginning of the 18th century (1701) or the middle of the 17th century (1650) are often used as an approximate starting point. As to its end, most scholars use the last years of the century – often choosing the French Revolution of 1789 or the beginning of the Napoleonic Wars (1804 – 15) as a convenient point in time with which to date the end of the Enlightenment" (from Wkikipedia: http://en.wikipedia.org/wiki/Age_of_Enlightenment#Use_of_the_term).

reality. From then on, medicine was primarily informed by the natural sciences; medicine had turned “scientific” (Porter 1997).

René Descartes (1596-1650) is regarded as one of the most influential modern philosophers. Being a mathematician by training, his mechanical philosophy was strongly informed by the Scientific Revolution. According to Porter (Porter 1997, p 218):

> “*Descartes and later mechanical philosophers were determined that their ‘new philosophy’ should replace the Aristotelian cosmos of qualities and elements with one composed of particles of matter in motion obeying mathematical laws*.”

During the following years, scientific knowledge slowly ascended to the status of gold standard within academia. One of Descartes’ primary philosophical contributions is the accentuating of a dualistic concept of the human being – a heritage from ancient Greece – stating that the human mind is non-matter (res cogitans), in other words immaterial, and that the body is matter (res extensa), and that these two are not only different but also separate entities.[18] By establishing human reasoning as independent of the body, medical reasoning disconnected itself completely from religion, allowing physicians to explore the “corpse,” the dead physical body, while leaving the human “soul” to the Church. Descartes’ concept of “the body as a machine” had enormous implications for medicine (Porter 1997).

In the 18th century, the Swedish botanist and physician Carl von Linné (1707-1778) established a system for classifying living things (The Systema Naturae), which can be regarded as a precursor to the development of the modern systems for classification of diseases. Linné struggled with classifying the human species, ending up with placing humans in the animal kingdom due to humans’ ability to give birth to living offspring and to nourish these by suckling. However, what distinguished humans from other animals was their mind, indicated in the scientific name Linné attributed them; *Homo sapiens* (from Latin; meaning "the wise human"). Linné identified the essential features of Homo sapiens with the words:

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[18] Descartes’ life, person and philosophy is a complex story with many facets, but his legacy (whether this does justice to Descartes or not) is simple - dualism: mind separated from matter.

"Man, know thyself" (in Latin: homo nosce te ipsum), from the inscription on the temple of Apollo[19] (Lidén 2007).

By the late 1700s, scientific classifications had been developed further and a system for classifying diseases was in the making, based on the anatomy of the corpse. From then on such classification systems became the main route to understanding illness in human beings. Patho-anatomical descriptions of phenomena observed during autopsies were published. According to philosopher Drew Leder, modern medical thought and practice is rooted in investigations of dead, inanimate bodies the results of which are directly extrapolated to the living body, thus rendering the dead the means to explain the living (Leder 1998). Leder describes how the dead body, the corpse, became the premise for the main development of medical knowledge. This "epistemological primacy of the corpse", as Leder calls it, is still present in today's medical training, dissection of a cadaver being the entrance to knowledge about the body and an important part of the first year medical school curriculum.[20]

The French revolution (1789-1799) and its aftermaths had enormous impact on the development of Western medicine as a whole. The rise of the modern hospital began in Paris in the wake of the social change brought about by the revolution. Physicians were in charge of the hospitals which provided their salaries and medical treatment was now no longer a privilege reserved for the rich. The invention of the stethoscope by French physician Rene Laennec in 1816 marked a major step in the reconceptualization of disease and became a symbol of scientific medicine. Medicine now moved from a two-dimensional (symptoms and disease) to a three-dimensional framework (symptoms, signs and disease) as, for the first time, physicians were able to connect different types of data: symptoms and signs from the bedside clinical examination of the patient, and descriptive data of morbid anatomy found through post-mortem examination (Porter 1997). In his seminal text, "The Birth of the Clinic" (1963), the French philosopher Michel Foucault described hospital medicine as a pathology-informed medicine that attributes illness to a lesion in the human body. His term "the medical

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[19] Apollo was the Greek god of healing and medicine, of the sun and of light, and of poetry, at ancient Delphi. The Ancient Greek aphorism "know thyself" (Greek: *gnōthi seauton*) was inscribed in the forecourt of the Temple of Apollo at Delphi. See for instance: Wikipedia; http://en.wikipedia.org/wiki/Know_thyself.

[20] Today's practice of dissection in Norway is described in NOU 2011: 21."Når døden tjener livet." published by the Ministry of health and care services. See: http://www.regjeringen.no/nb/dep/hod/dok/nouer/2011/nou-2011-21/6/3.html?id=666979

gaze" denoted the medical separation of the patient's body from the patient's person (Foucault 1975).

The pathological model of disease represented a shift, moving from subjective symptoms – as reported by the patients themselves - to objective signs - as stated by physicians. This shift had profound implications for the future doctor-patient relationship, and it probably engendered a process resulting in the disappearance of the person from medicine (which I will examine later). The patho-morphological concept of disease has been maintained over the last two centuries, and it is still the dominant contemporary medical model in the Western world. The level of details within bimolecular knowledge has, however, developed tremendously, due to medical research.

2.3.2 The rise of modern medicine: hospitals and the scientific method

During the 19th century, medicine was revolutionized through major advances in chemistry and in laboratory techniques and tools. Myths about the origin of infectious disease were replaced with new theories; the germ theory for diseases. Microorganisms had already been observed through a microscope for the first time, by Dutch scientist Antonie van Leeuwenhoek in 1676. This resulted over time in the development of a new discipline; microbiology. The stethoscope was soon accompanied by other medical instruments, such as the sphygmomanometer (a device for measuring the blood pressure) and the thermometer, along with a rapidly growing repertoire of laboratory tests. The physicians' focus shifted gradually from direct human observation to measurements and recordings mediated by instruments. Data derived from physiological monitoring soon became a routine part of clinical assessment (diagnostic technology). Roy Porter notes that (1997, p 346):

"By 1900 it was becoming possible to understand a patient not by his story, nor even simply through pathological signs ascertained by the 'medical gaze', but ceaseless physiological monitoring."

This development in medical technology laid the foundation for the biomedical fragmentation of the human being into separate body parts and disease categories. This was mirrored in the training of health care professionals and the subsequent differentiation of medical specialties. Every specialist was now given professional authority over – in the sense of jurisdiction – and responsibility for "the specialty's own organ," so to speak, including the fragment of human suffering engendered by any lesion or affliction regarding this specific organ or organ-system. Step by step, the system, including the hospital both as an institution and a physical building, was divided in accordance with this model, resulting in separate departments for the various body parts and their corresponding diagnoses.[21]

A major breakthrough in epidemiology came with the introduction of statistical methods. Physician John Snow (1813-1858) in London was a pioneer in analyzing disease incidents. The famous case where he was able to prove the connection between contaminated water sources and cholera cases in London in 1854 by applying statistics is regarded as the "birth" of epidemiology. Nurse Florence Nightingale (1820-1910), known as the founder of modern nursing, was also a pioneer in the graphical presentation of statistics. During the Crimean War (1853-1856) she meticulously recorded and analyzed large amounts of data from thousands of patients - by means of statistical graphs and tables - in order to evaluate the efficacy of hospital services. Although taken for granted now, at that time this represented a new method of organizing professional thinking. As Roy Porter comments, ironically, "war is often good for medicine" (Porter 1997).

In the late 19th and early 20th century ever more sophisticated statistical analyses of data were developed, increasing the interest in data-based and statistically calculated knowledge production. The methodologies of the natural sciences were deemed to provide the most reliable and "true" knowledge, and the experimental designs utilized in laboratories rapidly took on the status of "gold standard" for obtaining evidence regarding the effects of treatment. The biomedical research paradigm now dominated as the new scientific basis for clinical medicine. (I will come back to this point later, in section 2.5 The nature of medical knowlegde).

Insulin had been extracted successfully and made available for sale in 1922, but it was the second half of the 21st century that was characterized by a rapid and remarkably varied series of medical breakthroughs. Some of the most acclaimed medical advances mid-century were the discovery of penicillin in the 1940s and the development of vaccines against various contagious diseases; the polio vaccine being probably the most significant. The first

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[21] This is mirrored in the disaggregated architecture of modern hospitals, for instance, St Olavs Hospital in Trondheim. Here, the separate clinical centers are named after their function with reference to various internal organs (the Heart Lung Center, the Abdominal Center, etc.). And quite typically, the psychiatic ward - as opposed to the other somatic wards - is located on the outskirts of the city.

pharmacological “revolution” in the 1950s yielded such important drugs as chlorpromazine (against schizophrenia) and cortisone. Documentation of a connection between smoking and several serious diseases was provided in the 1960s and regarded as important in terms of disease prevention. The development of surgical anesthesia had great impact, as did advances in radiology. The cardiac pacemaker, invented in the 1950s and representing a breakthrough in treating heart diseases, was followed by bypass surgery in 1960, the first heart transplantation in 1967, and coronary angioplasty in the late 1970s. Success was achieved in the transplantation of other organs (kidney, liver, lungs, pancreas, etc.) and these procedures soon became available and nearly commonplace. In 1953, the double helix structure of the DNA molecule was discovered, opening up for the new research field of genetics (Porter 1997). The Human Genome project was launched in the mid-1980s and the sequencing of the human genome was completed in 2003.[22] With respect to treatment, finding a cure for the childhood cancer acute lymphoblastic leukemia in the 1970s has been considered among the most significant of medical achievements, along with the first “test-tube” baby. Among the most recent pharmacological achievements, triple therapy for AIDS is often mentioned (Porter 1997).

British physician and columnist James Le Fanu reflects upon the development of modern medicine in his book, “The Rise and Fall of Medicine” (Le Fanu 1999). Here he claims that the “Golden Age” of medicine was from the 1930s until the mid-1970s, whereupon the fall of medicine began. Le Fanu analyzes a variety of factors that he believes have widened the gulf between investment and advancement. He states that medicine has faced stagnation since the 1970s due to a marked decline in medical innovation. In my opinion it still remains open to debate to what extent contemporary medicine as a whole is characterized by relative stagnation or by slow though steady advances. I will return to this topic under section 2.6 A situational analysis of contemporary medicine.

2.3.3 Bedside medicine and the development of general practice

During the 19th century, the extent and power of hospital medicine grew, eventually superseding the earlier so-called “bedside medicine.” As mentioned before, as a logical consequence of the biomedical fragmentation of the human being, hospitals were organized according to the organ or body parts in which the disease was assumed to reside (see footnote

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[22] See for instance; http://en.wikipedia.org/wiki/Human_Genome_Project

21). The view that the ideal clinician was a generalist was replaced by the ideal clinician being a specialist in one specific organ. In addition to researchers at the universities, hospital doctors became the main producers of medical knowledge, including knowledge to be implemented in general practice. GPs, however, mainly produced medical referrals to the organ specialists. As a consequence, the role of GP became subordinated to the specialists, and the GP's main task was, from a specialists' perspective, to cope with patients' trivial problems (Armstrong 1979). Gradually, the various specialities were ascribed differing ranks in the hierarchical order of organs and diseases (Album, Westin 2008):

"*Specialities associated with technologically sophisticated, immediate and invasive procedures in vital organs located in the upper parts of the body are given high prestige scores, especially where the typical patient is low or middle-aged*."

Nevertheless, outside the hospitals - in general practice - bedside medicine persisted. The difference between hospital medicine and general practice was increasingly acknowledged, and so was as a consequence, the necessity of redefining the role of the GP. Britain took the lead in this development, and the British model of general practitioner was gradually adopted and adapted to the local conditions in other countries (Stevens 1966). I will return to the more recent development and characteristics of today's general practice in section 2.4.3.

To sum up the medical history so far: During the 20th century, medicine was transformed into a profession capable of interpreting signs and diagnosing diseases, while the participation of the patient steadily decreased. The role of "modern" patient was increasingly characterized by passivity and compliance with the doctors' authority resting more on data and clinical reasoning.

2.4 Different development lines in medical thinking and practicing

Interestingly, the emergence of hospital medicine and the increasingly reductionist specialization were paralleled by the emergence of various so-called holistic movements. Waves of protests against the medical system have arisen in recent decades, some from inside medicine, but mostly from outside. A great number of 20th century philosophers, sociologists, anthropologists and physicians have challenged modern medicine's conceptual framework. For the last fifty years, parallel theoretical concepts have been developed, some of which give major inspiration, particularly to the field of general practice.

2.4.1 Perspectives on medicine: medical anthropology and sociology

Until the 1960s, medicine and medical practice had been analyzed and described mostly by "insiders," that is, by physicians or other professionals within the academic medical community. Then, sociologists and anthropologists applied the "outsiders'" look at medicine and new voices joined the academic discourse about Western medicine. In the Norwegian context, medical anthropologist Benedicte Ingstad discussed this particular field of knowledge comprehensively in the Journal of the Norwegian Medical Association (Ingstad, Skår 1982). Medical sociology and anthropology have provided significant insights not only into the social dimensions of health and health care (e.g. about causes and consequences of health disparities) but also into the organization and financing of health care. Medical anthropologists in particular have challenged the position of Western biomedicine as the steward of the "truth" about health and disease. From their perspective, Western biomedicine should be characterized as a socio-cultural system, a product of society and history, applying a scientific - in the sense of a naturalistic - framework in order to explain human bodies and classify human sickness. The book, "Biomedicine Examined," by Canadian anthropologist Margaret Lock and American anthropologist Deborah Gordon, explores the social and cultural bases of biomedical knowledge and practices through which this knowledge is constructed (Gordon, Lock 1988). British/South African physician and medical anthropologist Cecil G. Helman united the insiders' and outsiders' perspective in his close study of family medicine and general practice (Helman 1984). The same double perspective enabled American medical anthropologist and physician Paul Farmer to delineate the pathological impact of suppressive politics (Farmer 2005). Medical anthropologists like Nancy Scheper-Hughes and Margaret Lock, among others, offered constructive, and different, readings of the human body, thereby opening for different perspectives and understanding, not only of the body but also the variety of aspects of bodily ailments (Scheper-Huges, Lock 1987).

Of the many important contributions in this field, I will highlight some with particular relevance for the topic of this thesis, that of knowing patients as persons. British sociologist Nicholas Jewson and French philosopher and historian of ideas Michel Foucault, independently and in quite different terms, observed and commented on the development of modern hospitals and scientific medicine. Foucault offered an analysis of the power inherent in medicine, and of the relationship between power and medical knowledge. At the time Foucault's seminal book "The Birth of the Clinic" was translated to English, Jewson published an influential paper entitled, "The Disappearance of the Sick Man from Medical

Cosmology" (Jewson 1976). By introducing his concept of "the medical cosmologies," Jewson aimed to depict how developments in medicine are linked to or spring out of existing dominant ideas in particular societies at particular times. In this perspective, medical knowledge production reveals its socio-cultural roots or sources. Briefly, Jewson identified and named several "cosmologies." In the first of these, the "person-oriented" cosmology, which had existed before the Age of Enlightment, the patient was conceptualized as a holistic entity, upon whose personal attributes each medical decision was based. At that time, doctors were dependent on their patients not only for diagnosis and management of illness, but also economically. The next cosmology, informed by scientifically grounded and increasingly specialized medical knowledge, was termed "object-oriented." During this period, the balance of power between doctor and patient underwent a change since the control of medical knowledge now passed from the patient to the clinician. Hospitals became the centers for the new medical profession, the site for scientific research, and the source of the physicians' salaries (Waddington 1973).[23] Jewson's third medical cosmology, "laboratory medicine," emerged toward the end of the 19th century. Now, the patient became the object of medical practice, and diseases were reduced to being merely "physical-chemical processes." This period and practice brought forth what Foucault (1975) termed the new "clinical gaze," reflecting the transfer of power from the de-personalized patient to the professional doctor.

A fourth medical cosmology - "surveillance medicine" - has been proposed by David Armstrong, professor of medicine and sociology at King's College, London. According to him, "surveillance medicine" emerged during the 20th century, inaugurated by the incipient observation of apparently healthy populations (Armstrong 1995). Diagnostic labels such as hypertension and diabetes were reconceptualized as risk factors, foreboding future health-related events.[24] Armstrong points out the introduction of new diagnostic technology as the driving force (Armstrong 1995) associated with the rise in "identified" risk factors

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[23] Sociologist Waddington describes how the structure of the doctor-patient relationship that emerged in Paris was of a radically different kind, with the doctor assuming the dominant role, due to the shift from observation to examination. Examination gave the doctor access to the patient's (naked) body, and to information that was considered private, explaining why the relation changed so dramatically. From being expected to meet the patients' needs and comply with their wishes like "a gentleman," the doctor became professional empowered – by professional judgment – to define the problem at hand and even ignore the wishes of their patient.

[24] The Framingham Heart Study was a milestone in 1960-61, defining hypertension, elevated cholesterol and smoking as the main risk factors for cardiovascular disease (CVD).

(Skolbekken 1995). The concept of risk factors has dissolved the distinction between norm and deviation, blurring the presumably dichotomous variables “health” and “disease.”[25]

This development has been conceptualized as “medicalization,” a process by which common human conditions and problems come to be defined – and subsequently “treated” – as medical conditions. The process termed medicalization was identified and problematized by sociologists,[26] among them, Irving Zola (1935-1994), who delineated its implicit social control by means of medical authority expanding into domains of everyday life (Zola 1972). The inherent impact of medicalization to the change of norms and definitions, was a gross expansion of illness. The number of patients diagnosed with common conditions such as diabetes and hypertension increased steadily along with rising numbers of what were called “the worried well”[27] (Porter 1997). The clinical management of risk and risk intervention has grown into a complex and comprehensive task, engendering a variety of dilemmas for the GPs. Its theoretical underpinnings are contested, as has been extensively elaborated by, among others, Norwegian and Nordic scholars[28] (Skolbekken 1995, Hetlevik 1999b, Getz 2006, Broderson, Hovelius, Hvas 2009). The Norwegian term, “*risikant*”[29], for a person at risk was introduced in the early 1990s by Jostein Holmen, Norwegian Public Health researcher and one of the founding fathers of HUNT (the Health Research Study of Nord Trøndelag County) (Holmen 1994).

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[25] As commented on by Per Fugelli, Norwegian professor of social medicine and former GP, everyone can now be considered to ‘be at risk’, and the target of modern public health can easily end up striving for the Utopian Zero-vision; the belief that it is possible to remove all risk and disease from society (Fugelli 2006).

[26] Sociologist Ivan Illich and his book “Medical Nemesis” were central to this movement (see section 2.6.3.)

[27] The expression “the worried well” denotes healthy people who worry about falling ill. As far as I know, the term was coined by Sidney Garfield in an article published in Scientific American in 1970 (see Garfield 2006).

[28] This field has developed over the years. See, for instance, the article by Skolbekken about the “Risk-Epidemic” (Skolbekken 2010) or the thesis by Petursson about the validity and relevance of prevention guidelines for general practice (Petursson 2012).

[29] The term “to be a person at risk” (Norwegian: *risikant*) describes a person who feels healthy, but who has one or several risk-factors for developing disease or for dying prematurely.

2.4.2 The subjective turn: psyko-neuro-immunology and phenomenology

While, as delineated above, the biomedical patient has been conceptualized as a "de-personalized" human being, great activity unfolded within basic research areas such as endocrinology, immunology, and neurophysiology, aiming at exploring the responses, in the human organism, to different kinds of strain. Even though the interest in the relationship between mind and body has been a consistent theme since the beginning of modern medicine, it was not until the last 20 years that research managed to reveal the interrelatedness between strain, behavior and health.

In the 1970s, American psychologist Robert Ader (1932-2011), among others, proposed a theory about how the human mind could significantly affect the ability of the immune system to fight disease. Ader is considered to have coined "psycho-neuro-immunology" (PNI) as a field and also to have founded the journal, "Brain, Behavior and Immunity".[30] Even though the theory was met with skepticism initially, it has since been applied and studied in many medical specialties, not only psychiatry. Researchers in this field have focused on exploring the interaction between the central physiological adaptive systems – initially, the immune and central nervous systems. When broadening the scope of types of strain, researchers within psychology and sociology also were included. Gradually, these increasingly multidisciplinary activities resulted in a growing and documented recognition of: the significance of lifetime experience for lifetime health of the human organism. The study of PNI investigates the interaction between psychological processes and the nervous and immune systems of the human body, and has later developed in to psycho-neuro-endo- immunology (PNEI) (Irwin 2008).[31]

Since experience as a phenomenon is inextricably connected with an experiencer, the human *subject*, absent as it had been from biomedical research for at least a century, was now seen to be relevant to comprehensive research on human health conditions. Consequently, human lifetime experience acquired medical relevance. This fact necessitated a framework appropriate for the exploration of experience as a strictly subjective, personal matter. Such a

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[30] Regarding Robert Ader, see, for instance: http://www.urmc.rochester.edu/news/story/index.cfm?id=3370

[31] In addition to research groups that have connected psychology, neurology, endocrinology and immunology, other researchers in recent years have contributed from natural science/humanistic research, which have relevance for the understanding of how lifetime experiences can be linked to the maintenance of health or development of diseases (Getz, Kirkengen, Ulvestad 2011).

framework is provided by the European philosophical tradition called “phenomenology.” As will be evident later, phenomenology – a philosophy and a methodology – holds fundamental relevance for this thesis. Here, a brief historical sketch of the philosophy will be given, while phenomenology as a methodology and a method will be discussed in the chapter, Theoretical Framework.

The modern phenomenology, elaborated by German philosopher Edmund Husserl (1859-1938) from preceding philosophical schools, most known among these being German philosopher Georg Hegel’s (1770-1831) phenomenology, represented an anti-reductionist position (Hegel 1972). It was guided by an imperative formulated as “Zu den Sachen selbst,” a call for approaching phenomena of the human lifeworld (Husserl’s term “Lebenswelt”) - among these, human experience - in a manner as free from predefined categories and presuppositions as possible. Consequently, phenomenology provides a frame for exploring lived experience as opposed to theory, and of complexity as opposed to oversimplification. Likewise, phenomenology opens space for sensitivity to processes as opposed to a premature focus on the outcomes of a development, intervention or observation.

Husserl's thoughts were revolutionary in several ways, most notably in the distinction between “natural” and “phenomenological” modes of understanding[32]. He broke with the positivist stance of his time, claiming that experience is the source of all knowledge. Varying views were evolving within the phenomenological tradition whose direction, later on, was impacted by, among others, Martin Heidegger (1889-1976), Hannah Arendt (1906-1975), Hans Jonas (1903-1993) and Maurice Merleau-Ponty (1908-1961). Generally speaking, however, phenomenology as a philosophy focused on what human beings can perceive and how phenomena appear to human consciousness. The Stanford Encyclopedia of Philosophy offers the following recognized definition of phenomenology:

“Phenomenology is the study of structures of consciousness as experienced from the first-person point of view. The central structure of an experience is its intentionality, its being directed toward something, as it is an experience of or about some object. An experience is

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[32] Interestingly, Husserl in his early years studied mathematics and obtained his PhD in 1883 with the work “Contributions to the Calculus of Variations” before he devoted his attention to philosophy (from Wikipedia).

directed toward an object by virtue of its content or meaning (which represents the object) together with appropriate enabling conditions."[33]

Phenomenology emphasizes the notion of the humanities as being different from the natural sciences and thus requiring a different approach. The differences arise both at ontological and epistemological levels. Ontology refers to our assumptions concerning the nature of being and reality; epistemology relates to assumptions about the nature of knowledge.[34]

Within the Norwegian context, the work of philosopher and essayist Hans Skjervheim (1926-1999) was central to the critique of positivism within philosophy and the social sciences. He was concerned about the limits of the (natural) scientific framework for our understanding of socio-cultural and lifeworld phenomena, warning against the dangers implicit in objectifying human subjectivity, an approach which he characterized as, "an epistemological mistake" (Skjervheim 1992, 1996). Psychologist Steinar Kvale (1938-2008) engaged primarily in the implications of phenomenology, hermeneutics and dialectics for psychology and education. In his work, he examined the role of the interview in the research process (Kvale 1983). Phenomenology has inspired various Norwegian health professionals, in their clinical approach as well as in their research (Thornquist 1994, Martinsen 1996, Kirkengen 2001).[35] Phenomenology has been applied to a range of philosophical problems within a variety of disciplines. In the present thesis, however, I will concentrate on drawing attention to the contribution of phenomenology to medicine and the study of illness, and in particular to the phenomenology of the body.

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[33] Open access to the Encyclopedia has been made posible by a world-wide funding initiative. An easy available source: http://plato.stanford.edu/entries/phenomenology/

[34] In Merriam-Webster Online Dictionary (2013) epistemology is defined as: "the study or the theory of the nature and grounds of knowledge especially with reference to its limits and validity." Ontology as: "a particular theory about the nature of being or the kinds of things that have existence."

[35] A more recent publication of importance to the field of applied phenomenology is: Kirkengen AL. The Lived Experience of Violation: How Abused Children Become Unhealthy Adults (Patterns in Applied Phenomenology). Zeta books, Bucharest, 2010 (Kirkengen 2010).

2.4.3 Development of patient-centered medicine and modern family medicine

Patient-centered medicine

By the late 1950s, new ideas were arising from within the profession itself. One of the most significant of these movements is called "patient-centered medicine" (PCM), emphasizing a patient-centered approach in a consultation - as opposed to being doctor, hospital or technology-centered. In this model, the patient's narrative, as it is told during the consultation, is given more value, and the social and psychological context of the presented problem is explored further, than in a biomedical model. The approach is actually rooted in humanistic psychology, and the American psychologist, Carl Rogers (1902-1987), is considered to be its originator. Originally, Rogers developed this theory as an approach to the therapy situation, initially calling the therapy, "non-directive," then, "client-centered", and ultimately, "person-centered" (Rogers 1957). Roger's theory was based on the fundamental assumption that human growth occurs when individuals confront problems and struggle to master them. During this struggle, they develop new views about life and new ways to deal with problems. From this perspective, life is a lifelong process of moving forward creatively. Rogers believed that the principles he was describing could be applied in a variety of contexts and not just in psychological therapy settings, as has later been noted by Norwegian physician and scholar Linn Getz (Getz 2004).

In 1964, Michael Balint (1896-1970), a Hungarian psychoanalyst, introduced the concept of patient-centered medicine. Balint was critical towards the ways of understanding and communicating with the patient which were dominant at that time. He was the first to mention that the symptoms presented by patients might not always be their "real" reasons for seeking assistance. Balint also introduced the expression, "the drug doctor," to denote the powerful therapeutic effect of the doctor as a person (Balint 1964).

Some years later, another model was theorized by the American psychiatrist George L Engel (1913-1999). In an article in Science in 1977, he claimed that there was a need for a new medical model, and then launched the bio-psycho-social model in support of the patient centered method (Engel 1977). Engel used Systems Theory to propose a model for a new and integrative way of thinking about disease.[36] The model asserts that doctors must incorporate biology, psychology, social influences, and data into the clinical process, acknowledging these as components of the complex causes and aspects of disease development and treatment, and should take all these factors into consideration when deciding which treatment to choose (Engel 1980).

Development of general practice/ family medicine

Ian R. McWhinney (1926-2012), an English/Canadian physician and academic, is acknowledged as one of the founders of modern family medicine. In the late 1980s, he developed and defined the concept of family medicine as a distinct, field of practice, as well as an academic discipline. His model is now basic to the training of family physicians/GPs, with McWhinney's, "Textbook of Family Medicine" (published in 1989) being one of the seminal texts in the field (McWhinney 1989a)[37]. Fundamental to his patient-centered approach is the long term doctor-patient relationship and the trust that patients place in their doctor. He also emphasizes the importance of the doctor becoming familiar with their patients' life stories (McWhinney 1997):

"Family medicine does not separate disease from person, or person from environment."

Since the concept of PCM was launched, referrals to patient-centered clinical care have spread rapidly throughout medicine, and the term currently holds an honored status in policy documents. General practice/family medicine is included in the medical curriculum of universities, especially in Western Europe.[38] In Norway, general practice is one of three main domains taught in medical school, with internal medicine and surgery being the other two. There has been a particular focus on the communication theories in PCM, which are now being taught at many medical universities. GPs are often engaged to train medical students in

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[36] Anthropologist, Gregory Bateson is the most influential and earliest founder of System Theory in social sciences (see Wikipedia http://en.wikipedia.org/wiki/Systems_theory_in_anthropology). Systems theory in medicine is defined as: "a holistic medical concept in which the human patient is viewed as an integrated complex of open systems rather than as semi-independent parts. The health care approach in this theory requires the incorporation of family, community, and cultural factors as influences to be considered in the diagnosis and treatment of the patient" (see Mosby's Medical Dictionary, 8th edition. © 2009, Elsevier).

[37] "A textbook of Family Medicine" was a greatly expanded successor to McWhinney's acclaimed "An introduction to Family Medicine" published in 1978.

[38] In regions of Eastern or Southern Europe, it is still possible today to graduate from medical school without being exposed to a general practice/family practice curriculum (see Brekke et al 2013).

communication skills (Silverman, Kurtz, Draper 1998), which is part of the curriculum at all four Norwegian universities (Gude et al 2003).

Norwegian general practice: development of ideology and clinical practice

In 1977, the two Norwegian general practice associations (APLF and OLL) formulated a vision for good general practice moving toward the year 2000.[39] Their acronym, KOPF, stood for the ideal that primary care and general practice be: "Continuous, Comprehensive, Personalized and Binding."[40] The Norwegian College of General Medicine (NSAM/NFA) has been a driving force in the professional development of general practice in Norway since its establishment in 1983, representing the academic avant-garde of Norwegian general practice and providing valuable contributions to the professional debate, particularly during the 1990's.[41] NSAM's "Risk project" (1994-1998) was intended to stimulate critical thinking and debate regarding the concept of medical risk (as delineated previously). The project, resulting in an anthology entitled "Diagnose: Risiko," is still informing the debate in the field (Swensen 2000). When EBM was introduced, the college opened a discussion concerning "the concept of knowledge" in medicine (Kirkengen, Jørgensen 1993). Linked to the introduction of the Regular General Practitioner System in Norway in 2001[42], NSAM formulated "Seven Principles of General Practice" (2003), representing core values and contents for assuring good standards of professional general practice (see illustration of the poster: "Plakaten", Figure 1). [43]

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[39] The Norwegian abbreviations are: APLF for "Alment praktiserende lægers forening"; OLL for "Offentlige legers landsforening"; NSAM for "Norsk selskap for allmennmedisin"; NFA for "Norsk forening for allmennmedisin."

[40] KOPF is the Norwegian acronym for: "Kontinuerlig, Omfattende, Personlig og Forpliktende".

[41] One of the first Norwegian "witness seminars" about medical contemporary history took place in 2008. The topic was the introduction of general practice/family medicine as a university discipline in Norway and the professional development over the years. Twenty-six people regarded to be prominent historical witnesses to the development of general practice as a university discipline were present. Remarkably, the contribution of NSAM was barely mentioned. See Evensen SA, Gradmann C, Larsen Ø, Nylenna M. (red.) (2009). Allmennmedisin som akademisk fag, Michael, 6:11–126.

[42] The RGP System was introduced in 2001, and a patient list scheme was established for the entire population. The main objectives of the reform were to improve access to GP services, facilitate more stable patient/GP relationships and to ensure equity in the use of health care services for the entire population.

[43] "Seven Principles" (Plakaten): honor the doctor-patient relationship; do what is most important; give most to those who need most; use words that promote health; invest in continuing education, research and professional development; describe practical experiences; take the lead" (my translation). "7 teser for allmennmedisin" was published in The Journal of the Norwegian Medical Association in 2003. The poster is available at: https://legeforeningen.no/Fagmed/Norsk-forening-for-allmennmedisin/Fagdokumenter/Syv-teser-for-allmennmedisin/

SJU TESER

FOR ALLMENNMEDISIN

En oppsummering av NSAMS tenkedugnad 2000- 2001.

Vår samtid anno 2001 preges av økende muligheter for medisinsk behandling, men også av kommersialisering og medikalisering, rettighetstenkning og økt forbrukerbevissthet.

En ny beskrivelse av faget **allmennmedisin** i fastlegeordningen skal

- KLARGJØRE LEGENS ANSVARSOMRÅDER
- FREMME FORSVARLIG BRUK AV MEDISINSK TEKNOLOGI OG MEDIKAMENTER
- GI BASIS FOR INNHOLD I GRUNN-, VIDERE- OG ETTERUTDANNING
- SKAPE REALISTISKE FORVENTNINGER TIL HELSETJENESTEN
- SIKRE FAGLIG IDENTITET OG TRYGGHET FOR LEGEN.

1 **HOLD LEGE-PASIENTFORHOLDET I HEVD!**

Allmennmedisinens sentrum er lege-pasientforholdet. Det viktigste er det personlige møtet og dialogen med pasienten over tid.

2 **GJØR DET VIKTIGSTE!**

Allmennpraktikerens hovedoppgaver er diagnostikk og behandling. Legen er
- **fortolker av pasientens symptomer og plager**; skiller ut de som har behandlingstrengende sykdom, og forskåner pasientene fra urettmessig å bli behandlet som syke
- **veileder og lærer**; hjelper pasienten til å forstå sin situasjon og hvordan den kan mestres eller lindres
- **vitne og ledsager**; følger pasienten og hans nærmeste gjennom sykdom og lidelse.

3 **GI MEST TIL DEM SOM HAR STØRST BEHOV!**

Forventningene til allmennmedisinen overstiger både ideelle og praktiske muligheter. Allmennlegen må organisere hverdagen slik at det blir rom for de pasienter som har størst behov for hjelp. Allmennlegen må også ta hensyn til behandlingskostnader; hvis flere behandlingsstrategier er like effektive, skal allmennlegen velge det billigste slik at ressurser som spares kan komme andre til gode.

4 **BRUK ORD SOM FREMMER HELSA!**

Allmennlegen skal gi pasienten tro på egen mestring av hverdag og helse. Allmennmedisinen skal utvikle et språk som begrenser fokus på risikotilstander og medisinbruk med liten nytteeffekt.

5 **SATS PÅ ETTERUTDANNING, FORSKNING OG FAGUTVIKLING!**

Fagutøvelsen skal baseres på dokumentert viten, praktiske ferdigheter og erfaringsbasert kunnskap. Faget skal utvikle begreper som knytter sykdom og lidelse til relasjoner og gi en forståelse av hvordan livet setter spor i kroppen. Medisinsk etikk skal beskrive hvordan respekten for menneskets verdighet er en forutsetning for helbredelse.

6 **BESKRIV PRAKSISERFARINGENE!**

Å forebygge sykdom og uhelse er ofte et spørsmål om å endre samfunnsforhold. Legen skal systematisere og dele sin kunnskap med forvaltning og politikere om sykdoms- og lidelsespanoramaet i sin populasjon.

7 **TA LEDELSEN!**

Allmennlegen skal ta aktivt ansvar for å sikre god samhandling mellom aktørene i helse- og sosialtjenesten. Allmennlegen skal bidra til at spesialisttjenester prioriteres til dem som har størst behov. I samhandling med andre helsearbeidere må allmennlegen arbeide aktivt for at faglige ressurser utnyttes optimalt. Som leder av legekontoret må legen sørge for at medarbeiderne får utvikle faglig og personlig kompetanse.

NSAM

Norsk selskap for allmennmedisin

The Norwegian College of General Practitioners

Figure 1 The poster “Seven principles of General Practice”. (“Plakaten” med “7 teser for allmennmedisin”). Reproduced with permission from NFA.

In a 2009 report from the Norwegian Medical Association, future aims for primary care services moving towards the year 2020 were anchored in the three keyword terms, “Trust - Safety - Accessibility.”[44]

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[44] The Norwegian title of the rapport is: “Tillit-Trygghet-Tilgjengelighet”. Statusrapport om styrking av allmennmedisin og fastlegeordning frem mot år 2020. Available at: http://legeforeningen.no/PageFiles/15792/TILLIT%20-%20TRYGGHET%20-%20TILGJENGELIGHET.pdf

The first Norwegian textbook of general practice, “Allmennmedisin. Fag og praksis”, was published in 1991 (Berntsen et al 1991) and described the GP’s role and ways of working. The book was soon included in the medical curricula of all Norwegian medical faculties, a tangible sign that general practice was now considered a university discipline. It remained in use until 2003.[45] In 1997, the first comprehensive Norwegian textbook of general practice “Allmennmedisin” was published. It described symptoms and diseases, as well as the *clinical* work of general practice. It was an important contribution to the overall improvement of clinical work in general practice (Hunskår 1997).[46]

In summary: At the beginning of the 21st century, general practice is acknowledged as an essential part of the medical curriculum in most Western European universities, and training in PCM is widespread and compulsory. The concept of patient-centeredness, however, holds different connotations for different scholars. Historically, very little seemed to happen regarding this issue until around 2011 when *the person* reappeared in the medical discourse, initiated by The International Journal of Person-centered Medicine.[47] The present project developed during a period that can be considered a relative lull in the professional and conceptual development of this particular topic. In section 2.9, I will return to the more recent developments and the reappearance of the person in medicine.

2.5 The nature of medical knowledge

Modern Western medicine is grounded in the scientific concepts of the human being and the human body. That is, it is linked to two different cultures: the humanities, and the natural sciences. Michael Loughlin, a British philosopher, elaborates how the Cartesian division of reality into an inner and an outer realm becomes problematic when applied to human complexity. The outer realm is, by definition, something that can be objectified while the inner realm is strictly subjective. As the relationship between these realms is not self-

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[45] ”Festskrift til Allmennlegeforeningens 75 års jubileum.1938-2013.” Available at: http://legeforeningen.no/yf/Allmennlegeforeningen/Publikasjoner/Festskrift-til-Almmenlegeforeningens-75-ars-jubileum/

[46] The 2nd edition of the textbook included a presentation of the ideology of general practice (Hunskår 2003), and the 3rd edition includes discussions of the theoretical framework of medicine (Hunskår 2013).

[47] Miles A, Mezzich JE. (2011). The care of the patient and the soul of the clinic: person-centered medicine as an emergent model of modern clinical practice, International Journal of Person Centered Medicine, 1(2): 2007—22.

explanatory, human beings become "problematic entities" (Loughlin 2013).[48] Loughlin writes:

> *"Descartes and his philosophical followers had to reassemble the world they had divided into subjective and objective realms, so as to make sense of human life and practice. Having made a strict division between proper scientific evidence as the 'base' for medical practice, and all of the human, 'subjective' features of the clinical encounter, including the judgment of practitioners and the perspectives and values of patients, contemporary theorists of medicine are then confronted with the problem of how to 'integrate' these essential features in order to make sense of the reality of clinical practice."*

This problem of integration has been depicted as an imbalance, a difference in length - or rather, length and strength - of the biomedical and the humanistic "legs" of biomedicine; this is characterized by the dominance of the natural sciences over the social sciences and the humanities in medical knowledge production. Striving for a better balance between these traditions has been posited as desirable (Hetlevik 2004, see illustration, Figure 2), although not "automatically" resulting in an integration of the kinds of knowledge typical for these fields.

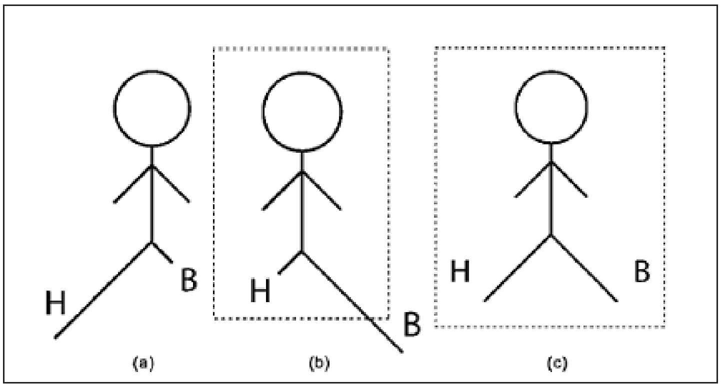

Figure 2 Medicine used to be based on humanistic (H) science (a). In contemporary medicine, the biomedically based content (B) seems to be greater than the practical possibilities (b). A better balance between H and B is needed (c) (Hetlevik 2004). Reproduced with permission from Scand J Prim Heath Care.

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[48] This reference had not yet been published when I started my project, but highlights the epistemological challenge in an excellent way.

The schism between, “The two cultures,” a term – and popular shorthand – coined by British scientist and novelist Charles Percy Snow (1905-1980) in 1959 (Nylenna 2000) still represents an unresolved problem and a persistent challenge, despite the recognized relevance of such a process for medicine (Ulvestad 2001).

2.5.1 Knowledge traditions in medicine

Theoretical and practical knowledge

The history of science relies on a dichotomous knowledge tradition, distinguishing theoretical from practical ways of knowing (Molander 2002). In contrast to the traditions of the biomedical paradigm, wherein knowledge is regarded as accumulated, objectively true facts, practical knowledge traditions do not separate knowledge from the knower, from the acting subject who manifests “knowledge-in-action” and “knowledge-in-use.” These ways of knowing, based on participation and dialogue, are characterized by being fundamentally “tacit”; they are difficult to articulate as they involve skills and competencies that are inherent in practices, in ways of doing. Furthermore, they are characterized by a cognizance of processes, contexts and/or situations; the knowledge thus acquired cannot be separated from it application since it was gained through experience rather than formal training (Cheetham, Chivers 2005, Henry 2010). These are the words of Swedish philosopher and physiotherapist Hildur Kalman (Kalman 1999):

“Linguistically, 'to know' is a state verb. Superficially, it describes only a state, not an activity. […] To know is to have a disposition to perform successfully either some kind of action (= knowing how), or to perform some kind of true assertive speech act (= knowing that). Basically, knowing is an activity.”

This kind of distinction between theoretical and practical knowledge has it origins as far back as ancient Greece (around 400 BC) with philosopher Plato’s definition of knowledge – episteme – as true, justified beliefs. Philosopher Aristotle acknowledged two practical forms of knowledge (knowledge-in-action): techné, denoting skills and the ability to do something, and phronesis, a form of practical sense whose aim is to enhance humans’ well-being (Strand, Schei 2001).

Another distinction - between tacit and explicit knowledge - is also frequently applied and widely used. The term “tacit knowing” was first introduced into philosophy in 1958 (Personal knowledge) by Michael Polanyi (1891-1976), a Hungarian-British philosopher of science (Polanyi 1958).[49] In a later work, “The Tacit Dimension,” he explored the topic further,

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[49] A commonly used example of tacit knowledge is facial recognition. ‘‘We know a person’s face and can recognize it among a thousand, indeed a million. Yet we usually cannot tell how we recognize a face we know, so most of this cannot be put into words.’’ (Polanyi 1967)

concentrating it into the now almost iconic phrase, “we can know more that we can tell” (Polanyi 1967). According to Polanyi, all knowledge - not only that which cannot be expressed verbally – is rooted in tacit knowledge in a highly specified sense of that term: tacit knowledge is described as “know-how” (embodied knowing), as opposed to “know-what” (facts) or “know-why” (science). Transfer of tacit knowledge requires personal contact, interaction and trust. Polanyi’s emphasis on trust as basic to knowing the world was also at the core of Kalman’s reflections about trust as an epistemological category. On that background, she examined the possible impact of shattered trust – resulting from destructive experience – on knowing and relating (Kalman 1999).

Some contemporary scholars (Nordenstam 1983, Molander 1999) even advocate a tripartite typology, comprised of both theoretical knowledge and practical knowledge plus praxis knowledge, denoting an established, consensual way of doing. The Norwegian terms depict these three as: a claim or statement (påstandskunnskap); a skill or competence (ferdighetskunnskap); and, a familiarity or acquaintance (fortrolighetskunnskap). These ways of knowing, however, seem interdependent and are at times so indistinguishable that they more likely refer to interrelated aspects than to discrete categories.

Reidun Førde, a Norwegian physician and professor of medical ethics, has emphasized the following elements in clinical medical work as having had strong tacit components: medical/clinical experience (including practical skills); the physician’s accumulated “subjective” knowledge (e.g. personal knowledge about patients); and, clinical reasoning (Førde 1993).

The current knowledge base in general practice

Over the years, many scholars have attempted to characterize the basis for knowledge in general practice, a clinical discipline demanding complex competence and skills (De Vibe et al 1997, Roksund 1998, Holtedahl 1998, 2002). GPs’ work takes place at the intersection of people and medicine, and general practice as a discipline, more than others, traditionally uses both the humanities and the natural sciences as points of reference. Although the latter seems to gain ever more dominance, traditional biomedical knowledge represents only a part of the knowledge base upon which GPs need to rely when encountering the variety of problems for which patients actual seek medical help (Roksund 1998, Gulbrandsen, Hjortdahl, Fugelli 1997). In an article in Utposten in 1998, Stensland & Bærheim, Norwegian GPs and current professors in general practice, refer back to Nordenstam and Molander’s tripartite typology

(Stensland, Bærheim 1998). They outline different sources of knowledge in the clinical work of GPs as follows: Firstly, GPs relate to theoretical or propositional knowledge, typically articulated in written texts. Next, GPs need clinical skills, acquired through practice which cannot be learned from a text -although the learning process itself may be systematized into texts, e.g. descriptions of how to measure blood pressure. Finally, GPs rely on praxis knowledge, representing an accumulated and condensed familiarity with various phenomena. These authors regard tacit knowledge as a skill in the sense of learning to recognize faces "at a glance," joined with the history of the person, or transferring theory into practical action. Tacit knowledge is seen to be learned primarily by "reflection-in-practice" (Schön 1983).

2.5.2 The origin of evidence-based medicine

So-called "evidence-based medicine" (EBM) has been a powerful and influential movement within medicine and health services over the last 20 years.[50] It is of fundamental relevance to the topic of this thesis, and I will therefore elaborate on the topic in the following section.

Originally, the movement was motivated by the intention to improve medical practice by basing clinical decisions on available research evidence rather than on tradition and the expert opinions of leaders within the profession.[51] The concept was introduced by Sackett, Guyatt and Cochrane, who began using the term during the 1990s.[52] The first definition of EBM was that it was "a systematic approach to analyze published research as the basis for clinical decision making." Over the years, the definition has changed to the more formal one of EBM as "the conscientious and judicious use of current best evidence from clinical care research in the management of individual patients" (Sackett et al 1996). One fundamental principle of EBM is that it posits a hierarchy of evidence to guide clinical decision making. Randomized controlled trials (RCTs) are considered to result in evidence that is regarded as being of the

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[50] My first meeting with EBM was as a medical student in the last year of medical school. In particular, I remember a lecture about how to treat tonsillitis where one of the GP teachers claimed that he, in accordance with up-to-date research, had stopped giving antibiotics to people with streptococcus tonsillitis since studies had shown that only very few hours of decreased suffering were attained. I still remember our astonishment at the GPs' confidence in research and our worry about changing well-established treatment.

[51] The concept of evidence is widely debated. One common definition when discussing scientific evidence is that it consists of empirical observations and experimental results that serve to support, refute, or modify a scientific hypothesis or theory. The EBM movement evaluates quality and the strength of the evidence in relation to which scientific method has been applied (see http://en.wikipedia.org/wiki/Evidence).

[52] Archie Cochrane, a British physician, began advocating the use of systematic reviews in medicine and emphasized the use of evidence from RCTs as these were considered to provide more reliable information than other sources of evidence. The Cochrane Collaboration is named in his honor.

highest quality and to provide the strongest evidence. Another important principle of EBM is that evidence alone is not a sufficient basis for making clinical decision; it should be considered along with the preferences and values of the individual patient and also be based on the clinical expertise of the physician or healthcare professional.[53]

Technology has played a large role in the advancement of EBM, and computers, databases and the Internet have facilitated the collection and easy access to large amounts of data. The development of systematic reviews and thereby the possibility to synthesize rapidly growing bodies of evidence have been essential in EBM. The Cochrane Collaboration was formed in the early 1990s to organize medical research information in a systematic way. Today meta-analysis and systematic reviews have become the basis for clinical guideline formation, health technology assessment and comparative effectiveness reviews, all of which are used increasingly in making health policy and reimbursement decisions. The Norwegian branch of the Cochrane Collaboration has its base at the Norwegian Knowledge Centre for the Health Services which was established in 2004.[54] The main stated purpose of the institution is to promote effective, accessible, safe and equitable health care quality through the generating, summarizing, evaluating and disseminating of research based knowledge.

Even though many consider EBM as one of modern, Western medicine's greatest achievements, one which is now being implemented across the world, several scholars have been critical to this development. The Journal of Evaluation of Clinical Practice edited by British professor Andrew Miles has a long tradition of examining the assumptions and implications connected to EBM.[55] Norwegian geriatrician Torgeir Bruun Wyller is one of several Norwegian scholars who have acknowledged that EBM is based on a good idea, but one that has gone astray; he points out that the most extreme developments move in the direction of what he coins as "vulgar cochranism" (Wyller 2011).

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[53] Gordon Guyatt, one of the leaders participating in developing EBM acknowledges that in the beginning there was little focus on patients' preferences (see for instance the editorial by Smith & Rennie in BMJ entitled: Evidence-based medicine – an oral history, BMJ 2014; 348g371).

[54] In Norwegian: Nasjonalt Kunnskapssenter for helsetjenesten.

[55] Webpage for The Journal of Evaluation of Clinical Practice: http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1365-2753

2.5.3 Medical decision making

As mentioned earlier, an important contribution to the process of establishing common ground for Norwegian GPs was the 1997 publication of the comprehensive textbook in clinical general practice (Hunskår 1997). Another important contribution in that regard was the 1999 launch of the first edition of the Norwegian Electronic Medical Guide (Norsk elektronisk legehåndbok) (NEL). NEL is an updated, web-based medical decision support tool for physicians and other health professionals in Norway, tailored for busy GPs and often referred as to a "point-of-care tool." Ninety-five percent of Norwegian GPs are subscribers.[56] In addition, Norwegian GPs can access the Norwegian Electronic Health Library (Helsebiblioteket), a publicly funded, online knowledge service providing free access to point-of-care tools (e.g. UpToDate, BMJ Best Practice), The Cochrane Library, guidelines, systematic reviews and major scientific medical journals, etc. The Norwegian Knowledge Centre for the Health Services hosts Helsebiblioteket, which is publicly funded by Norway's national budget and the four regional health authorities.

To sum up, within general practice, the practice of medical decision making has gone through a fundamental change during the last 30 years. The basis for making decisions has shifted away from established clinical traditions (subjective judgments and reliance on textbooks, opinions of authorities and clinical experience), towards a formal application of evidence based medicine on large patient groups and in accordance with guidelines.

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[56] By 2014, NEL is by far the most widely used medical decision support tool in Scandinavia. The Danish edition of NEL (Lægehåndbogen) was launched in 2011 and the Swedish edition (Medibas) in 2013. From 2007 to 2010, NEL was available free-of-charge to government-approved health professionals in Norway. In 2009, the publisher Norsk helseinformatikk AS lost a competitive bid so that by 2011 NEL once again became a subscription-based electronic encyclopedia.

2.6 A situational analysis of contemporary medicine

2.6.1 Public health - and the role of medical progress

Since it is impossible to disentangle the person completely from the wider societal context to which she/he belongs, I will now present a situational analysis of some aspects of contemporary medicine, beginning with public health. My point of departure will be the rhetorical question; "has medicine mattered?" This question was also the starting point for Thomas McKeown (1912-1988), a British physician and medical historian, when he wanted to examine the role of curative medicine for public health during the past two centuries (McKewon 1976). Disappointingly, he concluded that the contribution of modern medical interventions accounted for only a small part of the historical fall in mortality (known as the McKeown thesis). The decline and retreat of some of the major infectious epidemics of the 19th century actually seemed to have started before specific treatments were available. For instance, tuberculosis began to disappear even before Koch discovered the tubercle bacillus in 1882 and the mortality graphs for many fatal contagious diseases started declining before antibiotics were marketed or vaccines introduced. Of course, the picture is not black and white; vaccination against polio, for example, does seem to have been of great importance to public health, as acknowledged by McKeown.[57] The reasons for the retreat of epidemics have been hotly debated, and are bound to be complex. The improvement in overall standards of living, including better nourishment and hygiene, along with a less impoverished population, are among the factors that probably have contributed to generally improved health, together with increased resistance against infections (Porter 1997).

Over the years, health economists and policy analysts have attempted to assess the contributions of explicit individual medical care to health improvements. Increased life expectancy and quality of life are often used as outcome benefits. It is, of course, difficult to estimate with precision what increase in life expectation can be attributed to specific treatments. Public health advances are often credited with adding about twenty years to the life expectancy during the first half of the 20st century (Bunker 2001). While McKeown only was able to attribute 1-2 years to advances in medicine (McKeown 1976), Bunker has

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[57] There also seems to be little disagreement about the fact that many of today's vaccines are important and cost-effective health interventions to improve especially global public health by preventing infectious diseases (e.g. tuberculosis). The importance of improvement in poverty levels is acknowledged as essential, as well. There is also a strong focus on development of new vaccines against e.g. human immunodeficiency virus (HIV).

estimated that about half of the increased life expectancy since the 1950s (7 ½ years) can be attributed to medical care (Bunker 2001). Approximately 25-55 % of the fall in CVD morality has been attributed medical intervention (the Capewell studies - see for instance Unal, Critchley, Capewell 2004, Capewell et al 2010).

In a review of Le Fanu's previously mentioned book, "Rise and Fall of Medicine," Richard Horton, editor in chief of the Lancet, elaborated on this perspective under the title, "How sick is modern medicine?" (Horton 2000). He claims that medicine owes a great debt to chance, pointing, for instance, to the fact that most of cancer treatment drugs were simply stumbled upon. He also calls attention to what the US Centers for Disease Control and Prevention (CDC) regard as the "ten great public health achievements" of the 21st century: vaccination, motor-vehicle safety, safer workplaces, control of infectious diseases, declines in deaths from coronary heart disease and stroke, safer and healthier foods, healthier mothers and babies, family planning, fluoridation of drinking water, and recognition of tobacco as a health hazard.[58] He comments on this as follows (Horton 2000):

"*Compare these simple social milestones with those feats of technical discovery celebrated annually since 1901 in the Nobel Prize in Physiology or Medicine. All but a few distinguished laureates have come from the laboratory rather than the clinic, and few prize winners reflect the tradition of Public Health."*

2.6.2 Social determinants of health

One of the dominant features connected to the health conditions of all industrialized countries today, also as an extensive global phenomenon, are the social gradients in health and disease. In Norway, the relationship between socioeconomic conditions and life expectancy is mirrored in the life expectancy difference between districts in Oslo; if we compare districts with the lowest and the highest life expectancy there is a 7-9 year difference (Berntsen 2013). The German physician Rudolf Carl Virchow (1821-1902) is not only considered to be "the father of modern pathology"[59] , but also one of the founders of social medicine (Porter 1997). He was an impassioned advocate for social and political reform, stating that:

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[58] http://www.cdc.gov/about/history/tengpha.htm

[59] Virchow is credited with many important discoveries. His most widely known scientific contribution is the cell theory. The discovery that an enlarged left supraclavicular node is one of the earliest signs of gastrointestinal

Footnote continues on the next page

“*Medicine is a social science, and politics is nothing else but medicine on a large scale. Medicine, as a social science, as the science of human beings, has the obligation to point out problems and to attempt their theoretical solution: the politician, the practical anthropologist, must find the means for their actual solution....The physicians are the natural attorneys of the poor, and social problems fall to a large extent within their jurisdiction.”* [60]

Virchow’s considerations regarding the importance of improving the health of the many instead that of the few, are still relevant. Earlier mentioned, physician and anthropologist Paul Farmer argues that promoting the social and economic rights of the world’s poor is the most important human rights struggle of our times. The same social forces that give rise to epidemic diseases (e.g. HIV and tuberculosis) also shape the risks for human rights violations. In his book “Pathologies of Power; Health, Human Rights, and the New War on the Poor,” he quotes Virchow (Farmer 2005):

“*For if medicine is really to accomplish its task it must intervene in political and social life. It must point out the hindrances that impede the normal social functioning of vital processes, and effect their removal.”*

Michael Marmot, professor of epidemiology and public health at University College London, has conducted ground-breaking public health studies which provide valuable insight into the sources of social inequalities in health. Marmot, as the principal conductor of the Whitehall Studies of British Civil Servants, documents that, even among middle-class people, social gradients in mortality and morbidity run from the bottom to the top of a hierarchical structure (Marmot, Shipley, and Rose 1984). The Whitehall Study I (established in 1967) had a profound impact on our understanding of the role of social inequality in disease development. The main findings of this study were that CVD mortality increased in a graded manner with decreasing employment status, even after being adjusted for the effects of income, education and traditional risk factors - such as smoking - on health. The association between low socioeconomic status and high CVD mortality has later been confirmed by numerous studies. Twenty years later, the Whitehall Study II (established in 1985) documented a similar

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malignancy or lung cancer (Virchow's node) is attributed to him and he is also known for elucidating the mechanism of pulmonary thrombo-embolism, coining the terms “embolism and thrombosis” (Porter 1997, wikipedia).

[60] Appearing on November 3rd, 1848, in the weekly journal, ”Die medizinische Reform.”

gradient in morbidity, not only for CVD but other major diseases and causes of death (Marmot et al 1991). The main findings in this study were that high job strain and low perceived control at work increased the risk of death, demonstrating the global impact on health of social situatedness.[61]

The Inverse Care Law, introduced by Julian Tudor Hart in The Lancet in 1971, has been a key issue in the debate about health inequality. Hart, who was a general practitioner in a poor area of Wales, claimed in that article that (Hart 1971):

"The availability of good medical care tends to vary inversely with the need for it in the population served."

Socio-economically deprived populations experience difficult access to and poor quality health services more often than do affluent groups, despite their suffering from multiple external disadvantages. In short, ample documentation testifies to the fact that those in most need, actually receive the least.

2.6.3 Challenges in health care services: society

In "The Rise and Fall of Modern Medicine" (Le Fanu 1999), Le Fanu outlines four paradoxes of modern medicine that have arisen despite the celebrated advances of medicine: the disillusioned doctors, the worried well, the soaring popularity of alternative medicine, and the spiraling costs of health care. Roy Porter comments on this development as follows (Porter 1997, p 12):

"*Alongside [the phenomenal progress in medicine], major chronic and psychosomatic disorders persist and worsen – jocularly expressed as the 'doing better but feeling worse' syndrome – and the basic health of the developing world is deteriorating."*

A rising awareness of the limitations of the fragmented biomedical concept of disease has been paralleled by an increasing awareness of the need for a different view of the human body, of health and of disease. The renaissance of herbal medicine and the flourishing market for so-called "alternative medicine" (such as homeopathy, naturopathy, etc.) also indicate that a growing numbers of people are dissatisfied with the help they are being offered. Alternative

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[61] See for instance: http://www.ucl.ac.uk/whitehallII/), which was set up to address this topic specifically.

medicine traditions label their approaches as holistic, although none of these can document a scientific underpinning for that claim. Still, more than half of the Norwegian population seeks treatment by “alternative” practitioners - and 60-80 % of those doing so state that they have benefitted from their services (NOU 1998:21).

Good intentions – unintended side effects

During the last 50 years, a dramatic growth in technical capabilities and resources devoted to medical care has been observed. Logically, one would expect a corresponding improvement in health care while negative side effects of this development would be more unexpected. In the following, I will elaborate on the more unintended side effects of modern medicine.

Since Zola introduced the term “medicalization” in the 1970s, attention to this problem has increased within the research community. Along with Zola, Ivan Illich (1926-2002), an Austrian philosopher and social critic of modern Western medicine, was one of the first to utilize the term. In his seminal paper, “Medical Nemesis,” Illich addressed the limitations of modern medicine, arguing that a medicalization of the human lifeworld might cause more harm than good by turning many people into lifetime patients (Illich 1974). He introduced the notion of “iatrogenic disease,” illness caused by medical treatment or examination. Medicalization has also been called “disease mongering,” a pejorative for widening the diagnostic criteria of illness in order to expand the markets for those in the business of selling medical treatments, strongly supported by the pharmaceutical industry (Moynihan, Heath, Henry 2002).

In an article in the Norwegian medical journal, Utposten, in the 1990s, Eivind Meland, currently a professor of general practice in Bergen, attempted to raise the awareness of health professionals’ moral responsibility and to urge the Norwegian population not to allow themselves be taken over by the health services (Meland 1995). He composed a warning label stating that: “Health care institutions may be dangerous to your health: You risk being labelled with a diagnosis you do not deserve. You risk being made unnecessarily helpless. Your capacity to care for yourself risks being destroyed” (see illustration in Figure 3, my translation).

Å søke helsevesenet kan være
HELSESKADELIG

Du risikerer å få en diagnose du ikke fortjener.
Du risikerer å bli unødig hjelpeløs.
Egenomsorgsevnen kan bli ødelagt.

HELSETILSYNET

Figure 3 Showing the warning label for health institutions (Meland 1995). Reproduced with permission from Utposten.

Twenty years later, Fisher & Welch published a paper about the problematic side effects of the growth in medical care with the subheading: “How might more be worse” (Fisher, Welch 1999). The authors identified three essential pathways by which more medical care may lead to harm; more diagnosis, more treatment and more for the physicians to do. More medical care may lead to harm because more testing might also result in detecting not only “real” diseases but also “pseudo-diseases.” The consequences of lowering thresholds for treatment include more diagnostic labelling and more medical treatment. Simultaneously, the physician might be distracted as to prioritize which issues are of greatest concern for the patient. The development in today's health care system is not sustainable, neither practically nor economically, producing galloping costs, yet less health (see graph in Figure 4) (Fisher, Welch 1999, Getz 2006).[62, 63]

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[62] At one of the keynote lectures at the first Nordic congress of general practice in Copenhagen in 1979, the Norwegian GP Christian Borchgrevink discussed the risks and downsides of medicalization, showing a graph of how more might become worse. The graph looked very similar to the one presented by Fisher et al twenty years later (Sigurdsson 2013).

[63] The focus on the potential harms of medical care begun in the 1970s and culminates in our time with international conferences entitled, for example, “Preventing Overdiagnosis” and with prestigious medical journals like JAMA publishing a series of articles entitled, “Less is More.” This development was, however, not overt at the start of this project in 2008/2009.

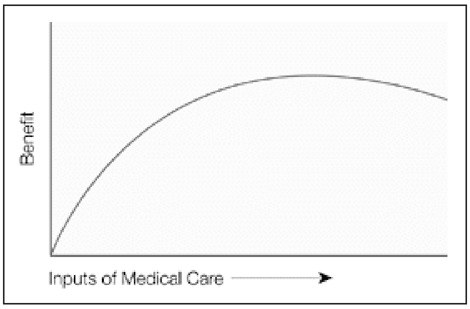

Figure 4 Showing how increased costs do not correlate to increased health (Fisher, Welch 1999). Reproduced with permission from JAMA.

2.6.4 Challenges in health care services: general practice

Three contemporary, recurrent challenges for health care services from a general practice point of view can be described through three M's: medically unexplained symptoms, medical risk and multi-morbidity.

Medically unexplained symptoms: Medicine is facing wide-ranging challenges concerning the so-called medically unexplained symptoms (MUS). Lack of adequate objective findings have led to an extensive production of medical acronyms in an attempt to create order. One of the first was NUD (non-ulcer dyspepsia) a descriptive "term" for abdominal ailments without detectable ulcers in the stomach or duodenum. Irritable bowel syndrome (IBS) is another example. The current number of acronyms referring to the digestive system has reached several hundreds. Ailments in other body parts have received similar descriptions, e.g. chronic pelvic pain (CPP), urogenital pain (UGP), oral, facial pain syndrome (OFS) or temporo-mandibular joint dysfunction (TMD), chronic fatigue syndrome (CSF/ME), etc. Each of these presently used acronyms, however, refers to a problem which is still poorly defined. As a consequence, all studies of these health problems may be heavily biased. The results are difficult to apply in a consistent manner for clinical health service practitioners.[64]

Medical risk: Medicine is part of the modern industrial and technological society where risk assessments have been well integrated for a long time. However, it is in principle impossible in medical research to limit the identification of risk factors that could be associated with future disease. Choosing a level for intervention has major implications for the size of the "at

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[64] Members of the research group at AFE Trondheim have explored the theoretical underpinnings of the field. They state that (Eriksen, Kirkengen, Vetlesen 2013): *"... the medical method, criteria, observations and requirements of evidence together with a disproportional focus on medical diagnostic naming represents a possible barrier to an understanding of such symptoms.*"

risk" population and for health care service resources, both human and economical. Several scholars have explored this field (Skolbekken 1995, Hetlevik 1999b, Getz 2006), and some of these also join the Nordic Risk Group (NRG) of researchers and GPs from the Nordic countries. The group promotes critical thinking within the field, and they published the book "Vården skapar ohelse" in 2009 ("Medical care creates ill health") (Broderson, Hovelius, Hvas 2009).

Multi-morbidity: General practitioners experience that a large percentage of their patients suffer from co- and multi-morbidity, a term denoting that medical risk, established organic diseases with or without symptoms, functional disorders and/or mental diseases are present in the same person. This is confirmed in population studies showing the clustering of diseases.[65] Multi-morbidity will become a growing problem in aging Western populations since it is older people who tend most often to present more than one disease. Traditionally, each disease is supposed to be treated in a particular, defined manner in accordance with specified guidelines. In cases of multiple diseases in one individual, multiple guidelines are expected applied, often not easily combined.[66] The resulting mix of drugs, termed poly-pharmacy, can compromise the patient safety. This has been a topic of concern during the recent years, particularly concerning frail old people with multiple diseases. Multi-morbidity along with age-related changes in drug interactions and secretion represent great challenges for providing optimal drug therapy to the elderly, whether they live at home or in an institution. The home-nursing services delivered by the municipalities are crucial partners for GPs and have an important role to play in primary care. Different models and care pathways have been developed to ensure adequate follow-up of chronically diseased patients in primary care; most of these models are highly disease-oriented and developed by specialists.[67]

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[65] Barnett et al published an article in 2013 in The Lancet about the distribution of multi-morbidity in relation to age and socioeconomic deprivation in Scotland (Barnett et al 2013). Tomasdottir et al found that 60 % of the participants above 60- years of age in the HUNT Study (Helseundersøkelse i Nord-Trøndelag) had two or more chronic diseases (Tomasdottir et al 2014, in press).

[66] The major effort in the fight against chronic disease has unintentionally created individual disease "silos," individual diseases apparently isolated from each other. This becomes reinforced by specialist groups, pressure groups, patient organizations and clinical guidelines (Parekh, Barton 2010).

[67] In a recent study, the disease-based care pathways for older patients were found to be neither feasible nor sustainable in primary care. A patient-centered care pathway that could meet the needs of multi- morbid patients was recommended (Røsstad et al 2013).

2.7 Future challenges for providing health care to the elderly

As the research of this thesis deals with frail elderly people in a rehabilitation unit, I will discuss some of the challenges regarding providing health care to the elderly. The growth of the aging population, often referred to as “a wave of elderly people” or “the silver tsunami,” is expected to impact large parts of the Western world, due mainly to the combination of high post-World War II birth rates, low death rates and increasing life expectancy.[68] In Norway, the group aged 67 or older is expected to more than double before 2060, from 0.6 million to 1.5 million people. Likewise, the number of very old people, those over 80, will probably triple in the same period (Brunborg, Texmoen, Tønnessen 2012). The increase in size of the aging population challenges the welfare state financially as well as practically. The society will spend more money on pensions and on health care, and simultaneously experience a considerable shortage of skilled workers. The main topic becomes how to meet the need for care among the elderly who, in the future, will not only be more numerous but also probably different from those of past generations. Today’s elderly are generally in better health and function at a higher level for longer than old people did before. They probably also have higher expectations as to the quality of care, being used to a high standard of living. Prognoses for future health service consumption are ambiguous. So also are prognoses for the likelihood of changes in disability-free life expectancy. In Norway, strong emphasis is currently placed on providing home-based care to elderly and frail people. Most of these remain at home until they reach a critically low level of cognitive and/or physiological functioning, at which point the likelihood of being admitted to an institution increases substantially (Gaugler et al 2007).

Nevertheless, as the older population increases, more elderly and frail people are likely to find themselves “in transit” between home and institutions. Most Norwegians are assigned to a specific GP (list system), a system intended to assure continuity of care. When the patient is transferred from her/his home to a nursing home/rehabilitation unit, the institution formally requests the assigned GP to provide essential medical information about this patient as to diagnoses, current medication, etc. Currently, no formalized standards regulate what type of biographical and contextual information should ideally follow patients to (or from) health care

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[68] The Norwegian terms are “Eldrebølgen” and “ Sølvtsunami.” See for instance: “Forbered deg på sølvtsunamien” http://e24.no/kommentarer/spaltister/forbered-deg-paa-soelvtsunamien/20092789

institutions. After admission to the nursing home/rehabilitation unit, the patient's treatment is transferred to the consulting physician (a GP or, less frequently, a specialist in rehabilitation medicine or geriatrics), who is connected to the institution.

2.8 Biologically embedded lifetime experiences

Research in the field of medicine and associated disciplines has recently deepened our understanding of the connections between people's former and present life conditions and their health. This new knowledge confirms how important it is to consider the individual's health in a lifetime perspective and to take socio-cultural, relational and personal aspects into account. This recognition does not come as a surprise to experienced clinicians, especially not GPs. What is rather new, however, is the soundness of the biomedical, empirical evidence.

While serving as the GP in a small mining and fishing community, Bugøynes, in the northernmost county of Finnmark in the 1960-70s, the Norwegian GP Anders Forsdahl made certain groundbreaking observations of the influence of poor living conditions on people's future health. His clinical observations were hardly accidental since, according to most health and social welfare parameters, the county of Finnmark historically has been the most disadvantaged area of Norway.[69] Forsdahl found a correlation between infant mortality and premature mortality due to CVD among adults, in the same birth cohorts (Forsdal 1977). On the basis of these observations, he formulated a hypothesis regarding the relationship between poor living conditions during childhood and important risk factors for CVD in adult life, later well-known as the Forsdahl-Barker Hypothesis.[70]

Twenty years later, another pioneer, Dr. Vincent Felitti, Head of the Department of Preventive Medicine at Kaiser Permanente in San Diego, US, investigated the reasons for the high dropout rate among patients who had been successfully losing weight in an obesity

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[69] In addition, the population in this part of Norway suffered disproportionally during World War II. When the German forces withdrew during the autumn of 1944, they applied the "Scorched Earth" policy. More than ten thousand dwellings, schools, hospitals and some churches were destroyed, as well as most of the fishing boats. About two thirds of the population was evacuated to Southern Norway by force (see, for instance, this webpage: http://www.finnmark.no/page.jsp?id=138&lang=en).

[70] Forsdal found a correlation between the county mortality rates among men aged 40-69 in 1964-67 with the county infant mortality during childhood and youth in 1896-1925.Today this generic finding is known as the Forsdahl-Barker Hypothesis, appreciating Forsdahl as the original source of this groundbreaking idea, and Barker as a later developer of it, (demonstrating the same relationship between inadequate nutrition in the fetus and risk of disease at the age of 50-60.)

program.[71] By accident, and much to his surprise, he learned that many of the "drop-out" patients had histories of childhood abuse or neglect.[72] Researchers at the Centers for Disease Control (CDC), among these Dr. Robert Anda, recognized the significance of these clinical observations and, in 1992, a large, epidemiological study was established, known as the Adverse Childhood Experiences (ACE) Study. The first wave of the study was conducted at Kaiser Permanente between 1995 and 1997, in collaboration with the CDC. More than 17,000 participants - a typical middle-class American population with health insurance - participated in the study and responded to a detailed questionnaire on adverse childhood experiences. Each participant was given a score according to the total number of event categories experienced.[73] One of the first major findings was a dose-response association between ACE scores and morbidity in adult life (Felitti et al 1998). Since then, the ACE study has provided extensive scientific documentation of the clinical relevance of traumatic childhood experiences. The key findings have been that adverse childhood experiences are vastly more common than previously acknowledged, and that they impact powerfully on adult health a half-century later. Currently, more than 60 original publications from the ACE Study's retrospective and prospective sub-projects are available. Numerous epidemiological studies now document strong associations between stressful lifetime "events" and poor health in general, and exposure to e.g. childhood adversity, integrity violation and loss of significant others in particular.[74]

Over the last 15-20 years, research activity has increased at the interfaces between the disciplines of psychology, immunology, endocrinology, microbiology and the neurosciences. Advanced research has recently shown how persistent taxation of human adaptive stress responses can lead to malfunction. The phenomenon is called "allostatic overload" (McEwen 1998a, b). Briefly explained, strong and/or persistent threats to an individual's existence and integrity eventually lead to exhaustion of the body's flexibility. Such chronic, adaptive

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[71] Kaiser Permanente is an integrated, managed care consortium in the United States.

[72] Felitti is reputed to have said to patients planning to drop out of the project: "Before you guys eat yourselves to death - could you please explain to me what all this is about?"(Personal report, Dr. Anne Luise Kirkengen.)

[73] The ACE Score attributes one point for each category of exposure to: child abuse and/or neglect; emotional or physical neglect; emotional, physical or sexual abuse; living with an alcoholic, mentally-ill or criminal parent/ household member; loss of a parent due to divorce/ separation; witnessing a parent being treated violently (score of 0 to 10). The higher the score, the greater the exposure, and greater the risk of negative consequences.

[74] The Adverse Childhood Experience study (ACE study) from San Diego, the Whitehall 2 study from London and The Dunedin Study from New Zealand, to name the most "acclaimed" studies.

disorders appear to contribute to the development of many major diseases. The model of allostatic overload may also help to explain the observed patterns of co-morbidities that have been registered.

2.9 The patient as a person in medicine

I now return to general practice and patient-centered medicine. I will present a résumé of literature regarding this thesis' main topic, "Knowing patients as persons," based on the references existing prior to the current project. As I have mentioned: in footnotes, I will refer to results from work that was being done as this project progressed. The most recent developments in this field will be discussed later in section 8.4.

I will begin the discussion of this topic with previously mentioned quotes from two outstanding and influential people within modern medicine and general practice, Ian McWhinney and Iona Heath.[75]

"Family medicine does not separate disease from person, or person from environment."

"In hospitals, the diseases stay and the people come and go. In general practice, the people stay and the diseases come and go."

Both phrases underline that *the person* is of crucial importance within general practice. Why might that be? As mentioned earlier, general practice is perhaps the only branch of medicine defining itself in terms of the relationship to the patient as a person (De Vibe et al 1997, Holtedahl 1998). "Background information" about a particular patient – that is, knowledge beyond what is strictly medical – is inevitably accumulated when serving as a GP for the same person over time, whether intentionally or not. This kind of knowing can be termed "*person-related knowledge"* since it represents the physician's view of this patient *as a person*. At the same time – and as a result of practicing as a primary care doctor over many years – GPs seem to gather "*experience-based knowledge"* of how it is, in general, to live a life. Some scholars have described this kind of knowledge as "knowledge of human nature,"

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[75] Ian McWhinney, as mentioned earlier, was one of the founding fathers of modern family medicine. Iona Heath is a prominent figure in British general practice. She has worked as a GP in inner-city London for over thirty years and was President of the Royal College of General Practitioners (RCGP) from 2009 to 2012. She is the author of many articles and papers about general practice and also writes a regular column for the British Medical Journal (BMJ) where she comments on topics of current interest.

denoting the resources and strategies people mobilize to regain or improve their health (Rudebeck, Mattson, Lynö 2000, Schei 2001).

As also mentioned earlier, the now documented interrelatedness between strain and poor health does not come as a surprise to experienced GPs. GPs' acknowledgement that life's strains leave their mark is in accordance now not only with age-old wisdom but also with the latest empirical research. Numerous epidemiological studies have documented the interrelatedness of stressful lifetime "events" and poor health. However, no calculations of "average" impact of pre-defined life events at the group level can suffice to elucidate the subjectively and inter-subjectively (socio-culturally) constituted meaning inherent in human experiences. An approach based on predefined categories does not explain *why* and *how* events presumed to be "the same" – and, as such, expected to have the same impact – nonetheless affect different individuals in a different manner. A way to explain this might be found in the comprehensive body of knowledge linking personal experience – a subjective phenomenon – to human health and disease. Theories regarding chronic distress, for example, and work linking various scientific disciplines, such as psycho-neuro-immunology (PNI, as mentioned earlier), now document the impact of a person's biography, lifetime experiences, interpersonal relationships, and lifeworld on her/his biology, that is, on that person's physiology and bodily functioning (Kemeny 2009).

Current medical practice has no formally authorized tradition for appraising, gathering, and transferring personal, biographical knowledge, not even within the context of the front-line medical care provided by GPs. Some biographical information is noted customarily in patient medical records, but this is primarily demographical data (gender, civil status, occupational status, and housing), referred to as belonging to the category of information, "familial/social."[76] In general practice as well, patients' records are typically and primarily comprised of biomedically relevant data about the patient, such as medical history and status, list of medications, etc., and only rarely such biographical information as life history, salient events or experiences, or significant relationships. For instance, in a 1997 survey regarding GPs' knowledge of a range of psychosocial problems among their patients, Norwegian physician and researcher Gulbrandsen, found that doctors' knowledge of their patients'

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[76] Patient medical records are intended to provide an overview of the patient's medical history as well as to ensure documentation of compliance with professional or governmental regulations.

psychosocial problems ranged from 53% (stressful working conditions) to 19% (history of violence or threats) (Gulbrandsen, Hjortdahl, Fugelli 1997).
As mentioned previously, my personal clinical experience showed that knowing patients as persons could help me to understand their particular circumstance, e.g. a sudden deterioration of health. I had also experienced the benefits of being familiar with the patient's lifeworld, personality and ways of being and thinking, including her/his values and preferences. This familiarity had proven crucial to exercising "good" doctoring. Initially, it seemed difficult to spell out precisely what this knowledge was about since it was, in a sense, tacit and thus not easily shared with other colleagues or other health personnel. Nonetheless, my co-researchers, a group of experienced GPs, found such experiences both recognizable and evocative.

At the start of the project, as we struggled to grasp this kind of knowledge appropriately, we circumscribed it as: "GPs' general knowledge about how it is to be a human being and live a life." Professor and GP Edvin Schei had emphasized "knowledge of the human nature" earlier as an important clinical competence (Schei 2001).[77] According to Schei, the biomolecular and technical aspects of illness and health are overemphasized in medical training, with little attention being paid to the phenomenological aspects. The acquisition of "knowledge of the human nature" to create a sound basis for independent and appropriate judgment, is left to chance in today's medical training (Schei, Gulbrandsen 2000).

Physician and philosopher Eric Cassell, author of several books on moral issues within medicine and on the nature of suffering, has been concerned with the fragile person and person-related knowledge in medicine for many years.[78] This content is rarely an explicit part of physicians' professional knowledge, as he claims in one of his books, under the sub-heading, "Who is this person" (Cassell 2004 p 155):

"( ) the fact that to know what people are is also to know what they are not, will not and could not be. What kind of knowledge is this, and where does it reside?"

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[77] In 1998, my last year of medical school at the UiB, I recall Schei, one of my teachers in general practice, telling us of his plan to initiate what he called a "Filosofisk Poliklinikk" (FP) (Philosophical Out-Patient Clinic). This was not actually a place for patient treatment, but a serie of monthly public debates concerning medical education, humanities, and the biomedical professional culture. The aims of FP are to enhance awareness of humanistic topics in medicine, to encourage public debate about medical ethics and to stimulate reflection. (See for instance http://www.uib.no/isf/people/edvin.htm)

[78] In 2010, after this project was initiated, Cassell published an article entitled, "The person in medicine" where he gave a concise, developed description of what he regards a person to be (see Cassell 2010).

Gradually, the concept "knowing patients as persons" crystallized as a way to capture the essence of what we seeked to explore while also bearing witness to the rapidly growing evidence of how lifetime experiences and existential circumstances impact on health and disease (as described under the earlier section on embedded life experience). The accumulating documentation of the mutually interrelatedness and salience of human biology and biography was particularly relevant to patients suffering from ill-defined and/or complex health problems (Kirkengen 2001).

I eventually discovered that concerns about medicine becoming narrowly scientific and impersonal had been raised as early as in the beginning of 1900s. One of the first physicians to articulate this was British physician Francis Peabody (1881-1927), who worried that physicians were in danger of forsaking the patient for science (Peabody 1927). This resonated with Canadian physician and humanist William Osler (1849 -1919),[79] who later wrote:

"The good physician treats the disease, but the great physician treats the patient."

According to Porter, the patient-as-a-person movement was initiated in the decades after 1900 with a doctrine influencing primary care (Porter 1997 p 682):

"*Medicines would not help much - though these would still be given - but the psychological support of the doctor would. The physician had to be trained to see the patient as a person and not a disease; a sympathetic, caring manner was therapeutic in itself.*"

Among the earliest texts on this issue of which I am aware is a 1934 article in The Canadian Medical Association Journal by A.H. Gordon entitled, "The Patient as a Person." The author comments ironically on his own title as follows (Gordon 1934):

"The title itself is trite to the point of banality, for what else could a patient be but a person? The answer is that in the progress of our art the case of illness may by almost imperceptible stages pass from being a person, through the stages of being a problem, and end in being regarded as so much material."

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[79] William Osler, considered the founder of modern medicine, changed medical training by insisting that students learn at the bedside, seeing and talking with patients. His best-known quote is probably: "*Listen to your patient, he is telling you the diagnosis,*" which emphasizes the importance of taking a thorough history. (See for instance: http://en.wikipedia.org/wiki/William_Osler#cite_note-Tuteur-2).

In the same paper, he also comments on what shapes a person:

"What a man or woman is today is, among other things, the sum of what he (or she) has been thinking in the years or decades gone by, and these are the things that have given him (or her) shape as a 'person'" (my supplements in ( )).

This description fits well with the work of Cassell. In one of his most renowned books, "The nature of suffering and the goals of medicine (1991)," he emphasizes ethical issues that arise because clinical medicine is theoretically rooted in pathology and science, and not in the people's experiences and their lifeworld. According to him, a wise doctor knows that the problem with modern medicine is that it has no bearing on people and lived life since its focus is merely on the diseased organ. Cassell is adamant about the significance to doctors of knowing their patients as a person. In some of his earliest writings, he reflects on what characterizes a person – a person is always in a relationship with him/herself and other persons, has several roles in relation to other persons, and always has a past. He states that (Cassell 2004, p 156):

"To know that illness, one must know something of the person. To know the person, one must know something of the narrative."

And further (Cassell 1985, p 108);

"The story of an illness - the patient's history - has two protagonists who are intertwined; the body and the person. By careful questioning, it is possible to separate out the facts that speak of disturbed bodily functioning - the pathophysiology that gives you the diagnosis. To do this, the facts about the body's dysfunction must be separated from the meanings that the patient has attached to them. Skillful physicians have been doing this for ages. All too often, however, the personal meanings are then discarded. With them goes the doctor's opportunity to know who the patient is."

Several Norwegian, humanistically-oriented GPs have addressed similar topics in different ways. John Nessa, an experienced GP with an interest in psychiatry, psychotherapy, philosophy, and language, has emphasized that talking with patients is medical work. In his doctoral thesis, "Talk as medical work," he explored how patients and doctors actually communicate (Nessa 1999). He has also examined how GPs respond to patients' general life problems, discovering that many GPs are frustrated by the fact that many patients seek medical help for what the GPs define as “non-medical problems” (Nessa, Schei, Stensland 2009). As referred to earlier, Norwegian physician and researcher Pål Gulbrandsen examined what GPs actually know about their patients' social context (Gulbrandsen 1997, 1999). He found that, although the doctor obtains little systematic information, he/she usually gathers salient information over time. Most GPs are aware that the patient's social context matters. The British GP Iona Heath has challenged physicians to include social risk factors more systematically in their medical histories (Smeeth, Heath 1999). Social factors are probably equally important to disease as biological factors, she says; therefore, physicians must find simple and non-stigmatizing ways to secure information about unemployment, economic hardship, poor living conditions, and social isolation.

3 Theoretical framework

The theoretical framework of a thesis relates to the philosophical basis on which the research rests. Generally speaking, theoretical frameworks inform our thoughts and assumptions about phenomena we encounter, yet often in an unrecognized and non-reflected manner. The more familiar things are to us, the less we are inclined to reflect upon how we came to know what we actually know. Our own prejudices are “hidden” from us since they are a result of how we have learned, in the process of socialization, to understand the world. What we take as given is a consequence of the norms and rules we use to orient ourselves in the world. This is also true for professional orientation, including that of researchers being a result of socialization during training and practice.[80] Consequently, researchers need to clarify their standpoint, their epistemological frame, and their way of knowing.

The paramount aim of the present project was, as previously mentioned, to explore the medical relevance of person-related knowledge. The exploration was to be from the vantage point of the GP, which means someone socialized into a biomedical understanding of human beings and human bodies. However, those intending to approach patients as persons need a frame of reference which includes the aim of safeguarding these patients’ status as equal subjects (as opposed to objects). Phenomenology was therefore chosen as the overall framework for this thesis, as guiding philosophy, methodology and method. As a philosophy, phenomenology focuses on understanding the experiencing human being using first person accounts as a direct source of knowledge about how it is for this particular person to live her or his life (see section 2.4.2). As a methodology, phenomenology has been introduced into medical research as a means for describing and gaining insight into how human beings experience their lifeworld.[81] As a method, it helps us to explore, in a systematic way, the subjective and inter-subjective realms of lived experiences in order to understand the meaning and significance these hold for the individual person(s). Such is the framework for the present study, springing from, as briefly mentioned in the prologue, the professional observation that

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[80] Historian of consciousness Donna Haraway, among others, says that it is impossible to see from "nowhere" or see from all perspectives and therefore be objective. The act of appearing to see everything from nowhere is by Haraway described as “the God-trick” of science (Haraway 1988).

[81] The terms “methodology” and “method” are often used inaccurately and without differentiation (see for instance Gorman 2011). By “methodology,” I refer here to the theoretical analysis of, and principles associated with, a branch of knowledge; “method” is used here to refer to the techniques and procedures employed in gathering, structuring, and analysing the data engendered by the research question.

valuable knowledge about patients admitted to institutional care seems to get “lost in transition.”

3.1 Ontology and epistemology

In order to make the process of how phenomenology was applied as the theoretical framework for this thesis transparent, it is essential to clarify the ontological and epistemological rationale for the research, with reference to the questions: what is the nature of the phenomenon at hand; what do we want to know about it; and, how should this inquiry be conducted? With reference to this particular study, relevant reflections are:

What is the phenomenon to be studied? The main phenomenon of interest here is the GP’s experience of knowing patients as persons. What does this experience actually involve? To what extent do GPs acquire such knowledge? Are they aware of this kind of knowledge? If they are, to what extent do they ascribe medical relevance to it? And, finally, in a rehabilitation setting, is this kind of knowledge regarded as important and/or medically relevant by the patients themselves and by health personnel?

What can we know about this phenomenon, and how might such knowledge be constituted? Experience is a strictly subjective phenomenon since it always is about something, for someone, one specific person, in a particular situation in the sense of one specific context. Experience is therefore inextricably linked to a subject, and each experience is informed by and integrated with previous experiences (Vetlesen 1994). This is valid both for the person in the role of patient and the one in the role of doctor. Researchers aiming at exploring and reflecting upon such subjective phenomena as human experience in the context of medicine and medical practice would be well-advised to choose phenomenology as their theoretical framework (Kvale 1983, Mishler 1986). Investigating human experience as communicated in the form of first person accounts involves an exploration of systems of values and of symbols as they are conceptualized and expressed in language, spoken or written. This demands competence both in language (linguistics, semiotics) and in interpretation (hermeneutics) (Kvale 1983, van Manen 1990, Mishler 1986, Ricoeur, Thompson 1981). The principles of hermeneutics, focused on identification of the structures of meaning, help establish a common ground of understanding among participants in social discourses and for discourse analysis. Consequently, the application of a phenomenological framework involving hermeneutical principles and linguistic tools is well-suited to exploring and reflecting upon human experience within medicine and medical practice. The methodological perspective of phenomenology facilitates entering the interviewee's world of subjective and personal experiences without disturbing the context in which these manifest (Kvale 1983, van Manen 1990, Mishler 1986, Ricoeur, Thompson 1981).

Research based on first person accounts acknowledges subjective experience as being a valid source of knowledge (e.g. in relation to medicine). Such an approach makes it possible to understand the phenomena of the human lifeworld. It allows insight into the significance of events and relationships for individuals as well as groups. It allows an understanding of the particular and inter-subjectively established meanings attributed to these events and relationships. Such an exploratory approach to socioculturally constituted value systems is based primarily on dialogues between the researcher and selected individuals, or on conversations with groups of people. In these conversations, the researcher may take the role of active participant, facilitator, moderator or participant observer, depending on the intended degree of guiding to be done. Consequently, the nature of this role has to be acknowledged in the reports of talks and discussions. Regardless of the form of interaction, however, it remains evident that the researcher is involved in the process of producing and collecting the research material, beginning the interpretative, and in a certain sense the analytical, endeavor from the outset. Consequently, the researcher needs to make her or his theoretical position and framework of understanding transparent, in an explicit and detailed manner (Kvale 1983, van Manen 1990, Mishler 1986).

3.2 The lifeworld and the lived body

The subjective world of human life and experience has no ascribed place within the naturalistic bio-medical research perspective, where objectification and standardization are key concepts. The human lifeworld (originally Lebenswelt) is, however, a central concept within phenomenology, comprised of the objects around us as we perceive them as well as of our experience of our bodily self and of our relationships to fellow human beings. According to phenomenology, experiencing, perceiving, learning, and, consequently, knowing, is only possible through the body. All experience is based on bodily being. One's experience is always perceived first bodily and only then interpreted. French phenomenologist Maurice Merleau-Ponty considered the body to be the primary site of knowing of the world, the means by which all other objects are made available to us; he conceptualized "the lived body" as a corporeity of consciousness, as opposed to the dualist "cogito" of Cartesian ontology

(Merleau-Ponty 1989). He stated that the body and that which it perceives are intertwined and cannot be separated. In other words: as human beings we cannot separate ourselves from our perceptions of the world.

Norwegian phenomenological physiotherapist Eline Thornquist advocates applying the concept of the lived body as a way to understand illness. She asserts that the history of a human being is reflected in body posture, movement and reaction patterns. To regard the body as a purely physical phenomenon, detached from life, deprives people of the opportunity to develop meaning and prevents them from understanding their own "bodily symptoms" (Thornquist 1993). The body may also express experiences that people cannot immediately communicate with words; such bodily knowledge may even be unavailable to the persons themselves. The work of Norwegian GP and professor of general practice Anna Luise Kirkengen has provided insight into how extreme human experiences such as childhood sexual abuse are inscribed in the body (Kirkengen 2001). Such embodiments of violation experiences are informed by the situated logic inherent in the specific experiences and thus may not correspond to scientific logic and rationality. Consequently, such subjectively informed violation embodiments risk being misinterpreted by the health care system and diagnosed as functional disorders or "medically unexplained symptoms." Kirkengen's findings expose the unique logic of assault embodiment thus rendering the path from violation to sickness comprehensible.

Applying a phenomenological approach when meeting patients in clinical practice involves accepting the other person as an integral human being, and acknowledging the living body as the locus of expression of lived life, history and meaning. Implicit, also, is the acknowledgment of the health care professional as a person and fellow human being. Norwegian GP Eli Berg has shown that being a clinician who was open to perceiving the connections between bodily expression and life experiences enabled her to help patients gain insight into the relationship between their present illness and their previous adverse experiences, which facilitated their recovery from chronic illness (Berg 2005).

3.3 A methodology for studying the particular

Qualitative studies were "invented" originally within the social sciences, especially within sociology and anthropology, and the phenomenological approach has contributed to the development of qualitative methods in important ways. Most researchers applying such methodologies aim at studying phenomena in their natural setting, striving to develop insight into and understanding of the meaning systems into which people allow them to inquire. This demands accurate and detailed description and interpretation. A major problem within the field of qualitative research seems to be the mixed discourse arising during attempts to legitimate the choice of a non-numerical, that is, a qualitative approach (Giorgi 1994). Arguments derived from the methodological principles of phenomenology may blend with criteria from the positivist tradition; some "qualitative" researchers tend to seek legitimacy for their research by means of "quantitative" criteria. Thus they jeopardize the qualitative methodology as well as nourishing the common objection to qualitative research as being a superficial presentation of "common sense" facts already known in advance. They also strengthen the common assumption that the most appropriate application of qualitative methodology is a pilot study for exploring a new field – before doing "proper" quantitative studies. Kvale discusses the problems arising from researchers' attempts to interpret the social world by means of the mathematically constructed universe while being amateurs at addressing the linguistically constituted world (Kvale 1996). The most common qualitative research method is the semi-structured and open-ended interview, which demands a highly attentive and skilled listener. Similarly, conducting focus groups requires facilitation skills and flexibility, in addition to the ability to stand back from the discussion so that group dynamics can unfold in their own right.

The central distinction between quantitative and qualitative research methods is: quantitative research is based on deduction (moving from the general to the particular), relying strongly on numbers and regarded as a means for obtaining objectively collected data; qualitative research, meanwhile, is based on induction (moving from the particular to the general), relying mainly on narratives, written or spoken, and regarded as a means for obtaining subjective accounts. According to McWhinney, one goal of science is to identify generalities whereas qualitative research is the "study of the particular" (McWhinney 1989b).

4 Aims of the study

The paramount aim of the project presented in this thesis was to identify and explore what GPs' knowledge of their patients as persons consists of, and whether GPs consider such knowledge to be medically relevant. Furthermore, we aimed at exploring the extent to which patients themselves consider such knowledge important, especially for the purpose of rehabilitation. Lastly we sought to explore the interaction and communication between GPs and staff members of a nursing home concerning the health problems of the elderly in their common care.

This was done in three phases in which the above mentioned aims are embedded:

1. In the initial phase, two groups of GPs - “senior” with more experience, and “junior” with less - were invited to reflect upon and discuss the potential significance of knowing the patients assigned to them as persons. The core questions were whether GPs had information about their patients beyond their traditional “biomedical” knowledge and, if so, whether they considered such knowledge to be medically relevant. The impact which the extent of the GPs’ professional experience had on their knowledge of and communication about the patient as a person was evaluated as well.

2. Thereafter, we explored the kind of person-related knowledge GPs *actually* had about their patients by comparing the information provided by GPs to the narratives offered by the patients themselves.

3. Finally, we compared and discussed three perspectives on the patients’ needs and aims when admitted to a rehabilitation unit, specifically: 1) what GPs recommended on behalf of their patients; 2) what the patients themselves considered central to their own functional improvement; and, 3) how the institution responded to these individual priorities.

These three phases resulted in papers 1-3 (see page 12, List of papers). In practice, each of these three phases was organized in two consecutive parts. The first part involved focus group interviews with GPs, the second part involved telephone interviews with GPs and in-depth-interviews with patients at the nursing home rehabilitation unit.

5 Methods and Material

5.1 Methodological reflections and choice

The intention of the present project was to elucidate and explore the significance and medical relevance of knowing patients in primary care as persons. Our main interest was to understand how professionals regard and relate to two types of knowledge conceptualized not only as different, but also as being of unequal medical significance: on the one hand, biomedical knowledge about human bodies and bodily malfunctions and diseases, and on the other hand, relational and personal knowledge, accumulated during repeated encounters with their particular patients. This defining focus on descriptions of and discussions about ways of knowing indicated that language was to be of central interest as well as the central means of inquiry.

Language, a primary means of communication between humans, is inextricably bound to context. The implicit and explicit meaning of what has been said in encounters between people cannot be separated from the situation and the persons involved. Every encounter involving two or more people is an encounter between subjects who interpret, produce, and convey meaning within their personal, experiential horizon. Communication is not the transfer of information but the exchange of messages that are heard and interpreted, and the meaning “sent” is not necessarily identical to the meaning “received.”

According to the rules of hermeneutics, the central domain of which is meaningful phenomena, both human activities and their results are appropriate objects for interpretation since they are never self-explanatory and unambiguous. French philosopher Paul Ricœur (1913-2005) is best known for combining phenomenological description with hermeneutics, in particular his elaboration of the concept of “philosophical hermeneutics.” German philosopher Hans Georg Gadamer stressed that humans, as historical and social beings, never understand directly, nor without certain premises or presuppositions (Gadamer 1989). Understanding texts, objects or actions always requires the awareness of the given premises of the person who interprets and seeks to understand them. Our understanding is fundamentally limited by our historical situation – our situatedness as persons. Due to this, persons entering into a dialogue introduce their differing “horizons” into this situation. A dialogue with the intention of providing insight into another’s “world view” is consequently a source for learning and an arena for understanding – talking together changes the persons involved.

Talking together means to find a shared point of departure, to probe one's own presuppositions and to open up for a different view. From this perspective, Gadamer highlights human talk - dialogues, conversations and discussions in groups - as attempts to change or to engage personally, to share a realm of meaning. He describes this kind of openness as being vulnerable, non-defensive. Consequently, a real dialogue or conversation is characterized by its participants surpassing their own horizon, allowing themselves be led by others in an atmosphere of mutual trust (Gadamer 1989).

This kind of activity may result in the "melting of horizons," a Gadamerian term for the process of widening our primary understanding so that it can melt into that of another person, or into a text, and becoming broader and enriched. This implies a dynamic process, a movement towards something different and new when compared to the starting point of the interpreter; it indicates that dialogues and talks are "productive," not only in the sense of speech-on-tape or transcript-as-text, but as change and understanding, as perceiving, learning, and embodying. The kind of understanding that is at stake is by no means unilateral but always double: a possibility of understanding the other and a means of understanding oneself. In talking with others we meet - and face - our presuppositions and our prejudices. Therefore, implicit in the productivity of talking and reading may also be the acknowledgment of a necessary subsequent change of opinion, position or point of view. We are, actually, moved by talking about things of personal concern. Gadamer underlines that the very process that creates a new understanding begins when something matters to us, when something impresses us and challenges what we take for granted or as a given (Gadamer 1989).

The issues inspiring the present project involved a challenge to a professional dogma which assigns different significance to different kinds of knowledge, and the recurring professional experience of discomfort linked to this difference. The professional "presupposition" – that being socialized into biomedicine involves a primary reliance on objective knowledge – was often and repeatedly challenged by a different, though equally professional, experience in particular professional situations: the sense that something of undeniable significance was lacking. This experience of unease, this challenge to the secure professional horizon itself, was what "mattered" and made an impression, in a Gadamerian sense. Therefore, entering into dialogues and conversations with fellow professionals and patients alike, albeit in varying ways, presented itself as the appropriate form of inquiry.

The methodological framework for the research material was designed to address the need that the voices of three groups could be heard - GPs, patients, and staff - within differing settings and to differing degrees of detail. Within these different communicative spaces, various types of knowledge and experience could be voiced, heard, and documented. GPs' reflections about their professional experience concerning ways of knowing patients in general, as well as their valuing of these kinds of knowledge, could unfold in a collective setting. However, encounters between a particular patient and that person's doctor had to be framed as a dialogue. Rather than stand alone, this dialogue would, in turn, provide the opening for the researcher's face-to-face talks with patients. These, again, involved talking at a location and in a mood colored by the fact of the patients' being in a transition, too incapacitated to remain at home yet hoping to return there once their condition had improved. Finally, encounters with members of the nursing home staff, including the observations included in the field notes as well as the materials collected regarding each of the nine patients' individual process of referral and rehabilitation, emerged in settings determined by the established routines and structures of the institution, over which the researcher had no influence as regards duration or frequency.

5.2 Ethical considerations of particular relevance

5.2.1 Approaching vulnerable persons when the aims are scientific

For this part of the project (the intervention study as described later), we wanted to approach persons who were admitted to a special unit in a nursing home for the purpose of rehabilitation. For most patients, being in transit, shifting between their home and an institution, involves increased vulnerability. Though the transition might be necessary it may not be desirable; the fact that it is thus voluntary only in a limited way can contribute to an increased sense of neediness and helplessess.[82] In elderly people, cognitive impairment, which may be the temporary result of acute illness, is not always acknowledged. When elderly, frail and ill people are being moved to an unfamiliar environment, however, their risk of experiencing impaired cognitive functions rises sharply (Neerland, Watne, Wyller 2013). This needs to be taken into consideration when asking for a patient's informed consent since such

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[82] From an anthropological perspective, being in transit ("in between") is seen to represent a particularly vulnerable situation. Various scholars in a number of fields have written about the concept of "liminality" (from the Latin, līmen,, meaning "a threshold").

impairment clearly affects the person's ability to understand information in general, and the details implicit in participating in a research study in particular. Likewise, persons residing in institutions and dependent on others' care might feel pressured to participate in research, or might fear that, were they to decline, the staff might lose interest in caring for them (see section 5.5 Ethical formalities, regarding how we ensured and safeguarded the rights of the patients participating in study).

5.2.2 Qualitative interviews with vulnerable persons

Approaching people for research purposes in such a vulnerable situation demands that the researcher behave in a way that elicits trust. Showing respect, a prerequisite for gaining such trust, is the most salient prerequisite for developing insight into the meaning a situation holds for the particular person. For an encounter within the frame of a medical institution to be characterized by equality, the researcher must be aware of potential issues of asymmetry, not only in terms of knowledge and authority but also of power. When conducting qualitative research interviews, the establishment of a trusting and respectful interpersonal participant-researcher relationship is essential to gaining access to "rich data." This involves a delicate ethical balance; building sufficient trust with the aim of coming close enough to gather thick descriptions while at the same time taking adequate precautions to make sure that the patients do not feel their integrity to be violated.[83] According to qualitative researchers Guillemin and Heggen this is ethically challenging (Guillemin, Heggen 2009):

"It is a paradox in qualitative research that often the best data come at the expense of participants revealing something deeply personal about themselves."

The authors emphasize that to be a trained and ethical researcher you must know more than just the ethical codes and what is required in order to qualify for official approval, which they refer to as "situated research ethics" (Guillemin, Heggen 2012):

"Rather, researchers need to develop their ethical awareness, perception and judgment, and their capabilities to reflect and act when actually in the field."

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[83] "Thick descriptions" is a term that was used by anthropologist Clifford Geertz to describe his own method for doing ethnography (Geertz 1973). A thick description of human behavior would be one that explains not just the behavior but also its context, so that the behavior becomes meaningful to outsiders.

Consequently, the most demanding task for the researcher is to aim to conduct a non-suppressive dialogue, a talk between equally ranked persons. As sociologist Ann Oakley underlines, this implies that phenomena such as mutuality and reciprocity are at stake (Oakley 1984). According to her, to come close to people while researching social and relational matters requires the researcher's personal involvement. She states that such personal involvement does not constituted a dangerous bias but, rather, is the condition under which people come to know each other and to admit others into their lives (regarding the topic of what is appropriate to ask, see paper 3). Experience with being a GP might prove to be a valuable resource when conducting qualitative research, including as regards to these particular ethical aspects (Jaye 2002). For example, being accustomed to "containing" patients stories as an "emphatic witness" might increase the likelihood that interviews are carried out in a sensitive way. Also, the competence of a professional listener may contribute to providing relief and initiating the process of change which promotes healing (Frank 1998). The aforementioned realities connected to performing research with people at vulnerable junctures makes it irrefutably evident that the ethics guiding such a project cannot and must not be limited to considerations focused on competence or the formalities of "informed consent." As ethics are deeply woven into the very structure of this project, it could only be performed within an ethically guided epistemology.

5.3 Study design

5.3.1 The larger research project

The aim of the research project was to explore the perceived medical relevance of person-related knowledge in general practice as well as at the interface between primary care and institutional care. The design of the project was comprised of three phases.

The data collection was divided into two parts. In the first part, two groups of GPs were invited to reflect upon and discuss the general and potential significance of knowing their assigned patients as persons (referred to from now on as "the focus group study"). The second part consisted of a step-wise intervention at the interface between GPs and a nursing home, exploring how the caretakers communicated and valued knowledge about their patients as persons (called "the intervention study"). Data from the focus group study formed the basis for a exploring how senior and junior GPs appraised knowledge about patients as persons in general (the first phase, leading to paper 1). In addition, the GPs in these two groups provided input that proved important to shaping the final design of the subsequent intervention study (see section 6 Summary of results).

In the intervention study (second and third phase, leading to papers 2 and 3), each GP (not identical to those participating in the focus group study) was interviewed about her or his assigned patient in need of short-term rehabilitation in a nursing home. The intervention study was designed to explore the transfer of knowledge about patients as persons between caretakers. Here, we examined what GPs *actually* knew about their patients as persons as compared to the narratives offered by their patients themselves (paper 2).

In the third phase, (leading to paper 3), we compared and discussed views of patients' needs and aims as seen from three different perspectives: 1) those emerging from the GP-interviews; 2) those emerging from a double set of patient interviews; and, 3) those found in the official records kept by the unit's residential physician and the staff members during the patients' rehabilitation at this unit.

5.3.2 The focus group study

Settings

The focus group study was conducted in an urban setting in central Norway in 2008. We selected GPs from pre-existing groups assuming that their familiarity with each other would allow them to reflect more openly on types of knowledge that are rarely discussed in formal medical-academic contexts. The Norwegian Continuing Medical Education program (CME) for GPs made it possible for the researchers to approach ongoing local groups. Our selections were made to fulfill our intention to explore our topic with GPs grouped according to length of professional experience and degree of post-graduate education.

Participants

Group 1 – Senior GPs

The first CME group consisted of seven highly experienced GPs representing a collective total of 168 years of clinical practice (mean 24 years), all of whom were specialists in general practice. The ages of the six men and one woman ranged between 41 and 65 years (mean 53 years). All the seniors had previous and/or current experience as consulting physicians in nursing homes. The group had met regularly (2-8 years of participation) prior to inclusion in the study. The group was self-directed in accordance with the formal CME framework, and the members alternated as chairpersons and organizers.

Group 2 – Junior GPs

The second CME group consisted of five less experienced GPs, all of whom were working toward fulfilling the mandatory requirement for specialist training, namely two years of group participation in a highly structured program. They represented a collective total of 15.5 years of practice (mean 2.5 years). The two men and three women were between the ages of 31 and 38 (mean 33 years). Four juniors had previous and/or current experience as consulting physicians in nursing homes. They had met every fourth week for the five months prior to this study, under the guidance of an authorized tutor, a senior GP.

Interview Settings

Written information was provided prior to the group interviews, which were held where the groups usually met: group 1, in a meeting room at the office of one of the doctors, group 2, in a meeting room at NTNU. I opened both group interviews by recounting a vignette from a scientific article regarding an actual patient.[84] The story highlights that confabulation, a phenomenon seen in dementia, can be framed as a social and discursive event; as such, it is most appropriately interpreted and responded to by people, in this case health care professionals, who are sufficiently familiar with the particularities of a patient's personal background (Örulv, Hydèn 2006). Then, with reference to "memory work," a method for

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[84] The narrative is about Martha and her friend Catherine, both diagnosed with Alzheimer's disease and living in a nursing home. The two ladies overhear some of the staff saying that it is time to serve coffee. They interpret this to mean that they are supposed to arrange a coffee party, and they begin to think about and discuss how to organize this. Later on, the staff sets the table and the coffee is served. The staff then leaves the room to make a report. The residents now all begin to behave as if this were a real coffee party; they converse and enjoy their coffee – all except for Martha, who seems to have interpreted the situation differently. She has obviously taken the role of hostess of the party, a role she has played many times in her live as she comes from a family where hospitality and generosity were important values. When Gertrud, one of the residents, suddenly leaves the "party" with a foreign "visitor" (Gertrude's son) Martha is offended, both because the "visitor" didn't sit down to have coffee with them and because Gertrud was so impolite as to leave without saying goodbye. Martha tries, unsuccessfully, to hold on to them. Returning to the table, Martha explains to the other "guests" that the "visitor" could not join in because he had already had his coffee at home. In the strict medical sense, Martha is now confabulating (referring to a conversation that did not happen). If one puts this episode into context, however, taking into account Martha's self-perception as a care-giving person and an attentive hostess, the apparently meaningless act becomes meaningful (Örulv, Hydèn 2006).

exploring shared memories of specific events[85] (Haug 1987), I asked the GPs: “Does this narrative remind you of any of your patients?”

The semi-structured guide for the ensuing focus group discussions included the following topics:

1. Do GPs have other kinds of knowledge about their patients than biomedical knowledge?
2. If so, what is this “other” knowledge about?
3. Do GPs distinguish biomedical knowledge from this “other” kind of knowledge?
4. If so, how is this expressed in their discussions of their patients?
5. To what extent are doctors aware of this “other” knowledge in professional settings?
6. To what extent do doctors attribute medical relevance to this kind of knowledge?

Finally, participants were asked for advice concerning the eventual role of GPs in the intervention study, the next phase of the research project. The responses that emerged focused primarily on the most practical and informative way to approach the GPs in order to elicit their knowledge about their patients. They also addressed potential ethical problems linked to the exploring and reporting or recording of the person-related knowledge about patients which their GP had provided.

The GP groups were encouraged to conduct their discussions as they usual did; I did not actively intervene except when asking for ad hoc validation or when offering an online-interpretation, that is, seeking confirmation from the interviewees that I had understood them accurately (Kvale 1983). I kept notes, particularly on the interactions among participants and their group dynamics (Morgan 2010, Wilkinson 2004). The interviews were both audio and video taped (the video tape served mainly as a safety device in case of failure of the audio tape or of problems in distinguishing the voices of the participants while transcribing). The

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[85] The method called “memory work” was developed by the German feminist and sociologist Frigga Haug. Its basic concept is to bring together people who have lived at the same time in comparable sociocultural settings (for example, being a teenager in post-war Germany in the 1950s) and then open up for discussions about topics of common interest. Addressed in lay terms and presented as a memory or an experience, these can be shared with the others and form a common ground for discussion (Haug 1987).

senior GPs selected a chairman for their group meeting but the junior GPs decided not to; they were certain they would not encounter any difficulties in keeping order despite the planned absence of their experienced, formal tutor.

5.3.3 The intervention study

Settings - Research site

This study was conducted at a rehabilitation unit of an urban, Mid-Norway nursing home with 32 single rooms for patients undergoing short-term rehabilitation (two to three weeks). The staff included consulting physicians, nurses, physiotherapists, occupational therapists and nurses aides. The service provided was based on an interdisciplinary approach involving multiprofessional cooperation, keeping shared protocols but separate records. In principle, records were data-based, but the various professional groups used different software systems as well as paper records. Information about the patients which was considered essential was made accessible to all the professional groups. To be admitted, the patient her-/himself (or family members) had to apply to the Health and Welfare Agency in the municipality responsible for granting permission (self-referral). Accessible health information from the patient's GP and the community home care services was obtained and evaluated. If a patient had been hospitalized recently, the discharge letter was obtained.

An entry procedure was carried out, typically a dialogue with a nurse aimed at identifying the patient's needs. The "mapping tool" included a checklist for creating the "patient care plan" as well as a questionnaire. The checklist contained a schedule indicating the sequence of treatment measures and the distribution of tasks among staff members. The questionnaire addressed the following topics: actual health problems, mobility, activities of daily life (ADL), family relations, social behavior/functioning, housing conditions, and the patient's own rehabilitation expectations and goals. The nurse was mandated to delineate appropriate aims for the patient's stay, resulting in a description of a primary goal, which then was differentiated into secondary goals. Finally, an individual rehabilitation plan was delineated, designed to take into account all the information gathered.

Research design and data collection

Only patients who had been admitted directly from their homes were considered for inclusion. Also, only patients who had seen the same GP for more than two years were included. Those patients who were judged capable of giving informed consent were invited by the staff to participate, based on a pre-formulated invitation. Once the patient had consented, the head nurse at the unit contacted me. I introduced myself to the patient, asked for permission to contact her/his regular GP for further information. Once that permission had been granted, I phoned the doctor to request consent to discuss her/his knowledge regarding that patient as a person. More detailed information about the study was telefaxed to each GP's office along with a copy of the patient's signed consent. Once a GP gave consent, a 10 to 15-minute telephone interview was scheduled with her/him to take place within three days. The two main issues discussed during this interview were the GPs' personal knowledge about the actual patient (see Figure 1, paper 2 regarding the topics included in the interview guide), and the GP's reflections concerning the most salient needs of this patient with regard to her/his rehabilitation.[86]

Each patient interview was conducted face-to-face and took place in the patient's own (single) room at the rehabilitation unit to avoid distractions and ensure privacy. This first interview with the patient was held shortly after the interview with the respective GP, typically within the first week (mean 5 days), and lasted approximately one hour. The departure point for these interviews was a condensed version of the information obtained previously which the GP had authorized the first author to share with the patient. The patient was encouraged to correct and/or deepen this information. In addition, the GP's explicit proposal as to the central aim of the rehabilitation process was discussed with the patient. Finally, the patients were asked if there was any of the information disclosed that they did not want to be passed on to the consulting physician at the nursing home (interview guide, see Appendix 1).

Integrating these two sources, I wrote a paper-based, biographical record, as detailed below, including a description of the patient as a person, the GP's proposals and the patient's explicit wishes as to her/his current rehabilitation. As the patient and I had agreed, I handed this record over, personally, to the staff member(s) responsible for the care of this patient, to one

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[86] The two main questions: 1) What can you tell me about patient NN as a person that might have relevance for this stay; 2) What are your recommendations for this particular patient with regard to her/his rehabilitation stay.

of the three consulting physicians and/or one of the nurses, while verbally outlining the most salient topics. These meetings took place at the end of the first or the beginning of the second week of the patient's stay (mean 9 days), depending on when the consulting physician was present. The staff members were asked to take these biographical records into consideration when determining the patient's rehabilitation plan and when providing the patient's daily care. A second interview with every patient, regarding her/his appraisal of the entire period, was typically conducted on the day of discharge. The main issue addressed was the degree to which the patient's stated wishes or expressed needs as articulated in the biographical record had been taken into account during their stay.

The biographical records

The biographical patient record contained a description of the patient as a person, the advice of the GP, and the explicit wishes of the patient regarding her/his actual rehabilitation.[87] Only information which the patients had agreed to have included appeared in this record. The information they did not want me to forward to the staff at the unit were typically of a highly sensitive nature, e.g. private details regarding personal relationships. All patients were invited to read their biographical record (or to have me read it to them aloud) for correction and acceptance of the final version. Patients B, C, G, H suggested small changes, typically concerning the date of an important life event and/or the wording of descriptions of their social network.

Field notes

I recorded detailed and comprehensive notes regarding each of the patients included in the project from the moment they consented to participate and during my frequent visits to the unit during the entire period of data collection. I also noted all my contacts and interactions with the GPs, and I recorded their responses during these telephone interviews in detail. The notes about my encounters at the unit included reports after having talked with staff members and participated in unit staff-meetings concerning these patients. The notes also included observations, comments, and reflections linked to the interview settings and the interactions

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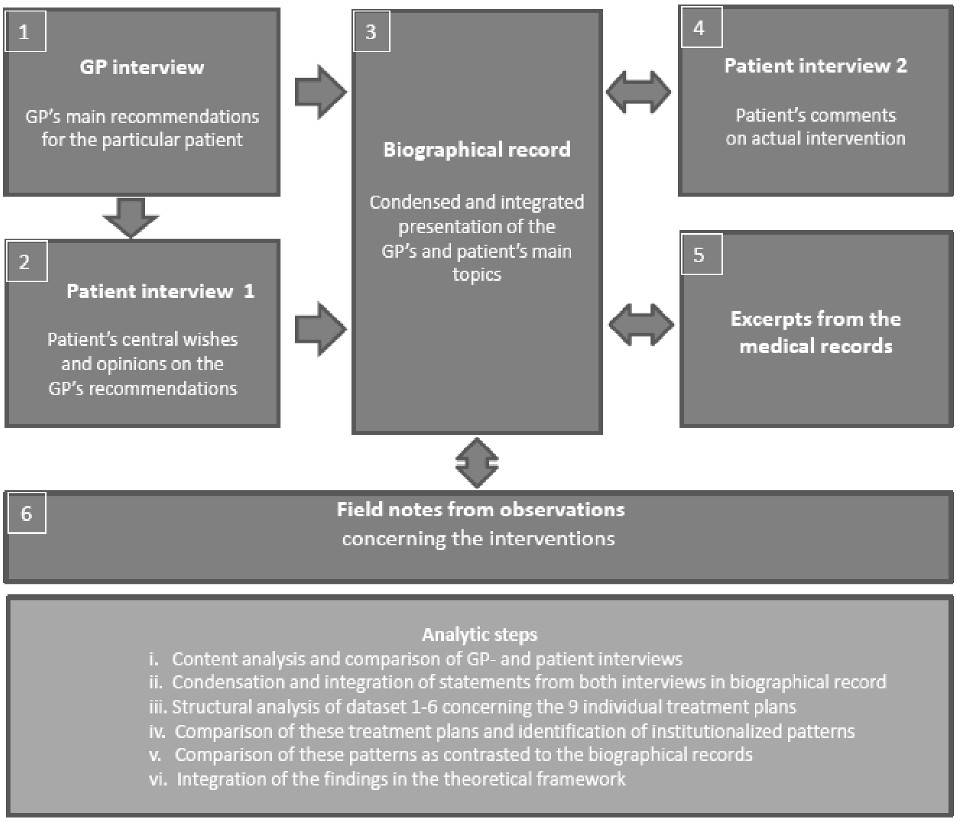
[87] The biographical records typically started with a short description of the patient's present health problem and reason for requiring rehabilitation. It then consisted of two major parts: 1) A description of the patient as a person focusing on the topics of social background (upbringing) and education/occupation, personality, relationship with family, social network/interests and important life events; 2) A description of the most important needs of the patient along with a description of the patient's own wishes and the GP's recommendations for this particular rehabilitation stay.

with staff members. Finally, I collected excerpts from the patients' electronic and paper-based records (including staff members' notes). Thus, the complete material consisted of: GP interviews, patient interviews (1 and 2), biographical records, excerpts from the medical records, and the field notes (Figure 5, reproduced from paper 3).



Analytic steps

i. Content analysis and comparison of GP- and patient interviews
ii. Condensation and integration of statements from both interviews in biographical record
iii. Structural analysis of dataset 1-6 concerning the 9 individual treatment plans
iv. Comparison of these treatment plans and identification of institutionalized patterns
v. Comparison of these patterns as contrasted to the biographical records
vi. Integration of the findings in the theoretical framework

Figure 5 The components of data material (1-6) and description of the analytic steps (i-vi). Reproduced from paper 3 with permission from EJPCH.

Patients and staff had consented to me having access to the participants' complete medical records. The head nurse of the unit obtained these records, and I was allowed to use one of the offices at the unit for taking my notes. I was, however, not given any access to information about other patients than those included in the study, or about any other aspect of the unit's policies, nor was I a regular observer of everyday routines or procedures. Though focus was not on observing organizational or structural aspects or interaction among staff, as such, my field notes and reflections did address interactions with staff members and the interview settings, including information gathered from my frequent visits at the unit. These sources provided me with a situational understanding of the unit's "inner life."

Participants

Patients invited to participate in the study had arrived from their homes and expected to return to them after rehabilitation, their relationship to their current GP had lasted for more than two years, and they were judged competent to provide informed consent. Eligible patients were added consecutively. Professional information about the GPs (age, number of assigned patients, number of doctors sharing their offices) was compiled from official registers.

The recruitment started in February 2010 with the last participant being enrolled in April 2011. In this period, 25 eligible patients were admitted to the rehabilitation unit directly from their homes, i.e. not from other institutions or hospitals. Sixteen of these patients were not included in the study due to administrative lapses (6), patient incapacity to grant consent (4), patient refusal to participate (3 patients and 3 GPs). The remaining nine patients and their respective GPs – six men and three women in both groups (patients and doctors) - were enrolled consecutively. The mean age of the patients was 64 years (44-94 years) and that of the doctors was 51 years (34-61 years). The mean duration of the doctor-patient relationships was 15 years (3-25 years). Seven patient-and-doctor pairs were of the same gender (five male and two female pairs). The participating patients had differing primary diagnoses with the exception of two whose main diagnosis was multiple sclerosis. All patients' central purpose for admission was rehabilitation. For patient B, D and H, an additional aim was providing their usual caretakers with a period of needed relief (see Table 1, reproduced from paper 2 with permission from EJPCH).

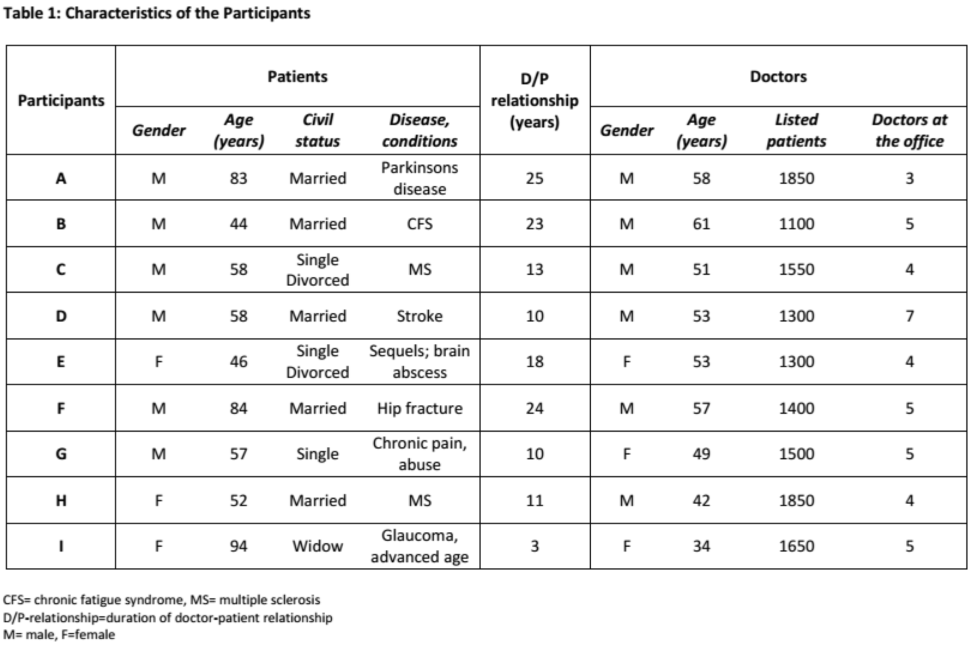


Table 1: Characteristics of the Participants

Participants	Patients				D/P relationship (years)	Doctors			
	Gender	*Age (years)*	*Civil status*	*Disease, conditions*		*Gender*	*Age (years)*	*Listed patients*	*Doctors at the office*
A	M	83	Married	Parkinsons disease	25	M	58	1850	3
B	M	44	Married	CFS	23	M	61	1100	5
C	M	58	Single Divorced	MS	13	M	51	1550	4
D	M	58	Married	Stroke	10	M	53	1300	7
E	F	46	Single Divorced	Sequels; brain abscess	18	F	53	1300	4
F	M	84	Married	Hip fracture	24	M	57	1400	5
G	M	57	Single	Chronic pain, abuse	10	F	49	1500	5
H	F	52	Married	MS	11	M	42	1850	4
I	F	94	Widow	Glaucoma, advanced age	3	F	34	1650	5

CFS= chronic fatigue syndrome, MS= multiple sclerosis
D/P-relationship=duration of doctor-patient relationship
M= male, F=female

Table 1 Showing the characteristics of the participants in the intervention study. Reproduced with permission from EJPCH.

5.4 Data analysis

5.4.1 Phenomenology and hermeneutics

The basic aim of phenomenology is to approach a phenomenon, “die Sache,” without presuppositions in the sense of predefined categories. This implies that a researcher, while exploring or interrogating certain conditions, situations, features or circumstances in the human life-world, is obliged to, and must strive to, be as open-minded as possible. In the methodological literature, this stance or state of mind has been termed the “bracketing” of one’s own presuppositions or prejudices. While acknowledging this aim, the researcher needs to be aware of that she or he cannot pretend to be “without” any preconceptions, nor can understanding be achieved without considering one’s own position and horizon. This implies an obligation to clarify one’s standpoint, in a literal and philosophical sense. It is also widely accepted in the phenomenological tradition that it is an advantage for the researcher to be experienced and competent within the realm of interrogation. At first glance, these claims may seem contradictory, yet they reinforce each other when combined: being skilled but not judgmental, being familiar but not partial, being knowledgeable but not dogmatic, and being well-informed yet willing to correct or change one's own point of view.

Transferred to the realm of medical research, a phenomenological approach allows the researcher to acknowledge that subjectivity is not only unavoidable but is, in fact, the very precondition for understanding. Implicit here is the researcher's ability to understand a fellow human being in the role of a patient and the patient's ability and opportunity to put words to her or his own experience and state of mind. Despite having been socialized into the habit of relying on and prioritizing the third person "voice" - the voice of biomedicine - in all professional matters and contexts, within a phenomenological framework the medical researcher gains access to the first person voice - the patient's experience. With this chosen framework, no claim of objectivity or value-neutrality has validity. The aim of such an effort is not to define and explain natural facts but to gain insight into and understand social phenomena.

As in other fields, including in medical research, the first person voice is present in language, whether written or spoken, in talk, whether in dialogues or conversations and discussions in groups, and in texts, whether derived from talk, dialogue or conversation.

Here, we enter the field of hermeneutics, a domain consisting of or comprising meaningful phenomena. Hermeneutics is the theory of text interpretation, or, more precisely, as defined by Merriam Webster:

"*the study of the methodological principles of interpretation."*

Phenomenology becomes hermeneutical when its method is applied for the purpose of interpretation rather than "pure" description of human experience, as, for example, in Husserl's transcendental phenomenology (van Manen 1990, 2011). Hermeneutic-phenomenology has both descriptive and interpretive elements; Martin Heidegger, Hans Georg Gadamer and Paul Ricoeur are among the foremost representatives of this tradition. Hermeneutic rules and principles are directed towards facilitating a direct investigation and description of phenomena as these are experienced and spelled out by human beings, to aid in understanding these experiences, rather than explaining them with as regards to cause. Among the basic aspects of hermeneutic phenomenology are pre-understanding, dialogue and interpretation, in accordance with Heidegger's thesis that all human awareness and description is interpretive. Gadamer (Heidegger's student) elaborated hermeneutic phenomenology further by exploring the role and nature of language and human conversation – through which our prejudices and preconceptions emerge (van Manen 1990, 2011). Ricoeur's contribution to this tradition is grounded in his view of the mutual interrelatedness of phenomenology and hermeneutics. He insists that human awareness is always directed toward something that is meaningful, but that this implicit meaning does not offer itself at "face-value," so to speak. Rather, it demands interpretation since nothing can be without a historical or situational context. Ricoeur examines how human meanings are deposited and mediated through myth, religion, art, and language. He elaborates in particular on the narrative function of language, on the various usages of language, such as storytelling, and on how narration and temporality interact. He explores the ultimate return to the question of the meaning of being, the self and self-identity, utilizing the practice of phenomenological reduction and writing to understand the forms of life (van Manen 1990, 2011). This implies giving voice to human experience just as it is (Jardine 1990).

5.4.2 Analyzing qualitative interviews

There are a variety of approaches to analyzing qualitative data, though these have some analytical elements in common, e.g., the de- and re-contextualization of data (Starks,Trinidad 2007). As already acknowledged, the applied theoretical framework and methodology for this thesis is phenomenology, and our analytical approach has been inspired by Kvales phenomenological-hermeneutical canon (Kvale 1983, 1996). According to Kvale, there exists "a continuum between description and interpretation," for example, in documents or texts derived from a qualitative research interview, performed face-to-face between a researcher – the interviewer – and an informant – the interviewee. Typically, such interactions are not based on predefined questions and preformulated options for answers, but rather on talks structured to cover a limited range of topics.

Kvales steps of analysis

Kvale has outlined six possible steps of analysis and interpretation, depicting the continuum of interpretative activity termed "interview" in this tradition (Kvale 1996). These steps do not necessarily appear in this order.

In the *first step*, the researcher relates to how the interviewee spontaneously describes certain aspects of her or his life-world without any special interpretation, neither on the part of the interviewee nor of the interviewer.

In the *second step*, and based on this description, the interviewee might find new meanings in her or his own experience, or discover new relationships to other phenomena or aspects, without any direct input from the researcher.

In the *third step*, and while talking together, the interviewer may attempt to interpret or condense the perceived meaning of the interviewee's description by offering this to the interviewee for validation or differentiation. Such an ad-hoc validation – or "on-line interpretation" to use Kvale's term – represents an aspect of an ongoing hermeneutic process, the effort of making meaning of each other's words and phrases while talking together. Consequently, the researcher does not "obtain" an interview or "collect" interviews for building a research material. The researcher is, in fact, already involved in the act of bringing forth this material. The dialogue comes to an end when the issues at hand have been explored exhaustively, documented, either by means of the researcher's written notes or in a transcript of an audio or video recording. How these documents are transformed into textual material to be analyzed will be described in the following chapter.

In the *fourth step*, the transcribed interviews are interpreted by the researcher(s). This includes the analysis proper, involving three analytical levels to distinguish between self-understanding, common sense understanding, and theory.

The *fifth step* of interpretation would be another interview with the same person – that is, introducing the results of the complete analysis during a follow-up interview and offering the interviewee the opportunity to correct or supplement it.

A possible *sixth step* would involve the possibility that the interviewee takes action based on insights gained during the interview(s). This would demonstrate the potentially liberating or therapeutic effect of the interaction termed a "qualitative interview" (as already touched upon in the ethical section and in paper 3).

Steps one through five were applied in the analysis of all the interviews with the patients included in the intervention study (Kvale 1996).

An excerpt from the second interview with patient B, a response evoked by the interviewer's perception that the patient hesitated when asked to talk about childhood experiences, provides an example of "on-line-interpretation":

I: [Referring to our previous talk] I sensed that your childhood and while you were growing up was an especially sensitive topic to talk about. I don't know if you agree with that? (Pause) I got the feeling that you wanted to hold back a bit there. And that you had good reasons for doing that.

Patient B responded by elaborating on the topic, explaining that he was afraid that certain childhood experiences would be used against him. This response lead to a second set of questions, seeking to clarify whether the issue of "trusting people" might be what was at stake:

I: Is this something that you feel you can't share with anyone – because you're afraid that people might use it against you? Does it have something to do with trust?

Patient B agreed, and recounted an episode when a doctor included information about his childhood, including inaccurate facts about his alcoholic father, in a medical report. He later felt as if the information were being used against him.

Regarding the application of the fifth step in Kvale's canon, the interpretations and analyses of the interviews were not reintroduced directly into a follow-up interview. Instead, they were reformulated, condensed and included in the patient's biographical record. These were then read and approved by all interviewees, a few of whom made comments correcting details, before being handed over to the staff.

Analytical levels ad modum Kvale

In addition to the phases mentioned above, the analysis of all types of interviews included in the research material (individual face-to-face with patients, individual by telephone with GPs, and focus groups) was also differentiated into three levels, as according to Kvale's hermeneutical canon (analysis proper) (Kvale 1983). At the first level of interpretation – that of *self-understanding* – the researcher attempts to envision and understand (and formulate) how the interviewees themselves understand the issues they thematize or explore. At the second level – that of *common sense* – the interpretation aims to critically appraise what is being said by using general or "public" knowledge (common sense). This involves a two-fold approach, focusing first on the content of the statement (object oriented) and then on the person making the statement (subject oriented). At the third level, the interpreter or researcher applies a theoretical understanding, that is, integrates the interpretation into existing theories in the field of interest or exploration. Validation of these interpretations is achieved by consulting various groups: the interviewees validate our reading of their self-understanding; the shared perceptions of the group which Kvale refers to as “the general public” are the source for validating our critical understanding based on common sense; finally, the research community is invited to appraise how we have integrated our analyses into relevant theories (see also section 9 Discussion of method).

5.4.3 Transcription

Since no single format could be applied to all possible settings, transcription may be done in many ways. Mishler points to an important, though often ignored, reflection on transcription in general: the task of transcribing speech into written text is only a partial representation of speech, just as initial recordings (audio or video) are themselves only a partial representation of “what actually” occurred (Mishler 1986). Some features accompanying speech, such as body language and the situational context of the interview, are always lost, first through their reduction from interaction to documentation, next in the “transformation” from talk to text. Being particularly aware of the potential impact of these “lost” details made me a keen recorder of detailed field notes during the entire project.

When choosing the mode of transcription one has to consider the theoretical premises and practical conditions of the actual research project. One consequence was my decision to transcribe all the audiotapes myself, which provided me the necessary flexibility to quickly and seamlessly follow all the steps and phases comprising the course of each of the nine complete interventions. In addition, the intense and repeated listening involved in transcribing provided me with new and/or deeper insights, which I could then bring to the next interviews I transcribed. Another important benefit concerns the potentially sensitive nature of the data when addressing personal, salient life events. I found it important to assure the patients that only a very limited number of people – only me and my supervisors – would have access to the tapes or read the coded transcripts, while their identity was known only to me. This decision, I believe, contributed substantially to the framework of trust and confidentiality which guided the entire project, and which was explicitly underlined in the consent form.

All the interviews in this study (the group interviews and the individual telephone/ face-to-face interviews) were audiotaped and then transcribed verbatim into Norwegian. The transcription of 833 minutes of audiotaped talk in the intervention study alone yielded 301 typed pages.[88] Choices concerning the mode of description were adapted to reflect the different settings. The transcriptions of the focus group interviews, defined as material for discourse analysis, needed to allow for micro-level scrutiny as to language, syntax and metaphors, as outlined by Jonathan Potter, British professor of discourse analysis (Potter 2004). Consequently, all paraverbal features as well as overlapping speech were noted in the transcripts; the length of pauses was noted and differentiated as to either hesitation or silence; the voices were commented on regarding rise or fall in volume or tone; the variations in the tenor of laughter were noted; and emphasized words or sentences, stuttering or stumbling were all marked (an example is given in excerpt 1 in paper 1). The interviews in the intervention study were also fully transcribed, but with less nuances of expression since not being material for discourse analysis.

5.4.4 Analyzing the data from the focus group study

Our intention with this study was to explore the usually “unspoken” types of knowledge inherent in professional contexts, namely GPs’ knowledge about patients as persons. The GPs who met in groups were invited to discuss the potential medical relevance both of acquiring knowledge about their patients as persons and, in certain circumstances, of sharing that knowledge with other health professionals. We were interested in “what” the GPs spoke about and “how” they spoke about those things. In other words, we were not only interested in the content of their conversation but also in how they interacted while reflecting on the actual topics. Simultaneously, we were interested in the impact of length of professional experience on the GPs knowledge and communication about the patient as a person versus the patient as a biomedical entity. All decisions regarding how to conduct the focus group interviews and how to safeguard an appropriate analytical approach were guided by these overriding interests.

As described in paper 1 (under the section Interview settings), the focus group interviews were organized to stimulate “natural talk” in the groups. Participants were encouraged to discuss these issues in the way they usually discussed their scheduled or selected topics, in other words, they were to feel free to follow their familiar format (e.g. choosing a chairman or not). My role as a researcher in these talks was primarily to initiate the discussion by setting

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[88] Transcribing 1 minute of tape usually takes about 10 minutes. That is 8330 minutes or 138 hours of transcription time.

the agenda – through telling a story – and thereafter refrain from actively intervening in the discussion except for ad hoc validation or on-line interpretation, if needed. Clearly, knowing that one is being observed does have an impact. For the participants to be as unaffected by the presence or actions of the observer as possible, the participating researcher interfered only minimally so that the groups could speak as "naturally" as possible – as opposed to "artificially," as is documented in the transcripts (see also Interview guide, Appendix 1).

We applied two different yet mutually enhancing analytical approaches to the same material. Using Kvale's phenomenological-hermeneutical analysis, we explored the impact of the GP's professional experience on their appraisal of knowledge of patients as persons (as explained in paper 1); we used this same phenomenological-hermeneutical method also to analyze the data from the intervention study.

Then, using a discourse analysis, we investigated how professional experience, or more precisely, the extent of that experience, informs the GP's appraisal of various types of knowledge and structures within the medico-political realm. The term discourse analysis is used in many different ways, but a general understanding of the term is that it denotes the analytical study of language *in use*. One definition is:

"the study of linguistic relations and structures in discourse."[89]

Discourse analysis has evolved within disciplines such as psychology, sociology, philosophy and linguistics. Discourses can be analyzed on different levels. A micro-level analysis addresses detailed elements of spoken language in specific contexts (e.g. the dialogue/interaction between doctor and patient in a consultation), while studying discourses at the macro-level (e.g. the Foucauldian studies of the relationship between power and knowledge) addresses language and ideology in society. According to primary care researchers Shaw and Bailey, discourse analysis is particularly relevant to family practice research because it (Shaw, Bailey 2009):

"focuses on interaction, looking beyond the literal meaning of language. It lends itself to studying the complexities of day-to-day family practice, helping to unpack taken-for-granted (and often revered) ideas and practices."

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[89] From Merriam Webster Online Dictionary (2013).

We have used Ricoeur's reflections on discourse as a speech event to guide our analyses (Ricoeur, Thompson 1981):

"discourse is an exchange of messages utilizing language, taking place between specific speakers, at a specific moment, in a specific context."

In our analysis of the focus group transcripts, we aimed at exploring the relationship between speech and meaning by utilizing sets of indicators, each of which referred to the way in which senior and junior GPs addressed the "subject" – the medical significance of knowing patients as persons. We defined indicators and then looked for similarities and differences. At the first analytical level, we looked at how these were expressed in structures and at the second analytical level how they were expressed in wording and phrases. On the micro-level, we examined language, syntax, and metaphors, inspired by Potter, who defines discourse analysis as (Potter 2004):

"an analytic commitment to studying discourse as texts and talks in social practices."

The third analytical level involved braiding together the results of the two different analytical approaches (phenomenological-hermeneutical analysis and discourse analysis) to achieve a meta-perspective (see Figure 6 for overview of the analytical approach, reproduced from paper 1 with permission from EJPCH).

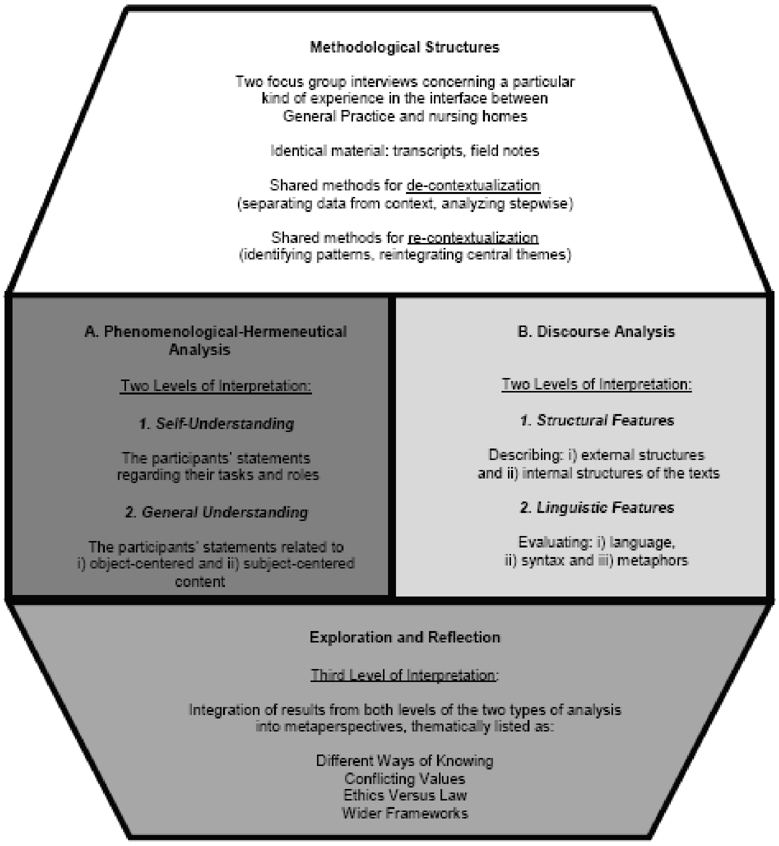

Figure 6 Overview of the analytic approach. Reproduced from paper 1 with permission from EJPCH.

5.4.5 Analyzing the data from the intervention study

We had two aims when analyzing the data from the intervention study:

1) To explore the respective GP's knowledge of her or his patient as person by comparing the information the GP shared with the researcher with the narratives offered by the patient in question (analyzing nine pairs).

2) To compare the GP's proposed aims for the patient's rehabilitation to the patient's own stated wishes, and then to compare the GP's proposals and patient's wishes to the actual treatment plan developed by the staff at the rehabilitation unit.

The results regarding the first aim (paper 2) were grounded in an analysis following Kvale's tri-level phenomenological-hermeneutical model, focusing mainly on analytical levels 2 and 3. The point of departure for the analysis was a comparison of the GPs' statements regarding their patients as persons with the patients' own statements, which permitted the GPs' familiarity with the various aspects of each patient's life to be assessed.

The analysis of the second aim (paper 3) was also inspired by Kvale's canon as described above. The results were based on the previous analysis of the two kinds of texts presented and discussed in paper 2 (telephone interviews with GPs and first interviews with patients). They were then supplemented with three additional types of texts: excerpts from the medical records, the biographical records, and the second interviews with the patients. This phase of the project represents a comparison of three different voices (Mishler 1986) (for further details see the section Analysis and Figure 6 for analytical steps in paper 3).

5.5 Ethical formalities

Both studies in this project were submitted to the Regional Committee for Medical Research Ethics (REK), Mid-Norway, and conducted according to the Helsinki Declaration. Since the first study (focus group interviews with two groups of GPs) did not involve direct research of patients, biological material or personal health information, approval from REK was not required (personal communication REK Mid-Norway). The protocol for the intervention study, including the letters of invitation (to patients, GPs and health personnel at the rehab unit, respectively), were evaluated by the REK committee and approved (approval date 07.05.2009). REK emphasized in their approval letter that only patients capable of giving informed consent could participate in the study and that the evaluation of the patient's ability to do so should be performed by the health personnel at the rehabilitation unit (and not the researcher). This decision was made due to the vulnerability of the group and to ensure and safeguard the right of the patient to deny participating or withdrawing from the study, without any explanation.

The intervention study was conducted in accordance with the study protocol; the head nurse herself evaluated if a potential participant was capable of giving an informed consent and also made sure that the first request to the patient was carried out by a rehabilitation unit staff member. Information was given, both orally and in writing. The fact that four patients were excluded from participating in the study due to their incapacity to give consent, and that another three refused to participate (see paper 2) indicates that this was done in an acceptable manner.

The health personnel participating in the study all gave their informed consent to participate. Details regarding the procedure for inviting the GPs and the health personnel at the rehab unit can be found in paper 3. Three GPs chose not to participate in the study (even though their patient had given consent), but none of the health personnel at the rehab unit declined.

The study was also approved by the Norwegian Social Science Data Services (NSD) which handles the statutory data privacy requirements for the research community in Norway. The date of approval was 15.04.2009.

6 Summary of results

6.1 Synopsis of papers

6.1.1 Paper 1

Knowing patients as persons. Senior and Junior GPs explore a professional resource.

Mjølstad BP, Kirkengen AL, Getz L, Hetlevik I. (2013). *European Journal for Person Centered Healthcare,*1: 88-99.

This paper presents the findings from the first part of our research project the overall aim of which was to explore the medical relevance of person-related knowledge about patients. Our point of departure was the awareness that, over time, GPs seem to accumulate knowledge about their patients' personal lives, whether intentionally or not. Our own clinical experience indicated that biographical knowledge about the person could be crucial to understanding the circumstances of a sudden deterioration. In addition, we were attentive to a growing and comprehensive body of scientific evidence documenting the impact of lifetime experience and existential circumstances on human health and disease development.

Aims and objectives

The aim of this study was to explore whether GPs have medically relevant professional knowledge about their patients beyond "proper" biomedical knowledge. More specifically: we explore the extent to which GPs gain knowledge regarding the personal lives of their patients. Next, we wanted to explore how GPs judge the medical relevance of such person-related knowledge, and whether senior and junior GPs judged it differently. Finally we wanted their advice concerning the possible role of GPs in our planned intervention study, a subsequent part of the project.

Material and Methods

With the aim of collecting broad and comprehensive material, we recruited two groups of GPs as different as possible from each other with regard to their professional experience (senior and junior GPs). In total, twelve GPs participated in two focus group interview discussions of the medical relevance of acquiring and sharing knowledge about patients as persons. As documented in the transcriptions, these interviews revealed that the two groups of GPs differed significantly in the way they addressed the actual issues. Due to this, we decided to perform a double-layered analysis of our material, exploring both content with regard to experience, and language with regard to discourse.

Results

Both GP groups agreed as to the obvious lack of emphasis on person-related knowledge within the health care system. They identified several phenomena as interfering with documenting such knowledge systematically and sharing it intra-professionally. The groups differed considerably, however, when it came to the degree of their emphasis on such knowledge. Senior GPs attributed more importance to person-related knowledge than did junior GPs while displaying much more verbal authority and professional independence. Discussing the topic at hand, the groups' ways of talking also differed: the seniors' discourse was dominated by ethical considerations while the juniors focused on legal arguments.

6.1.2 Paper 2

What do GPs actually know about their patients as persons?

Mjølstad BP, Kirkengen AL, Getz L, Hetlevik I. (2013). *European Journal for Person Centered Healthcare*, 1: 149-160.

The second and third papers present our findings from the second part of the present project: an intervention study at a rehabilitation unit in a nursing home. As described in the first paper, the twelve participating GPs in the focus group study were confident that they possessed medically relevant knowledge about their patients' life-world relating, for example, to patients' rehabilitation. In the project's second phase we explored the knowledge GPs *actually* had about their patients as persons, as outlined in this second paper, through comparing information provided by GPs with narratives offered by patients.

Material and Methods

The GPs of the nine patients included in this study (different doctors than those participating in the focus group study) were interviewed by phone regarding their patient who recently had been admitted to the rehabilitation unit at the 'study' nursing home (see also 6.2). Subsequent face-to-face, in-depth interviews with these nine patients, using their GP's report as the point of departure, served both to validate this information and to provide a starting point for further inquiries into the patients' life stories. The transcripts of these interviews were analyzed within a phenomenological-hermeneutical framework.

Results

We found that the GPs were familiar with their patients as persons to varying degrees. Most of the GPs were able to characterize the personality of their patients comprehensively, and they had acquired substantial knowledge about the patient's occupation and closest family relationships. The GPs tended to be less familiar with their patient's interests, hobbies, social network and relationships to parents and siblings, and least familiar with the patient's childhood, upbringing and social background. Some GPs reacted with surprise or even embarrassment when becoming aware of potentially significant "knowledge holes" regarding a patient whom they had known for many years.

Our analysis also identified the following: Despite the variety of patient ages and cause(s) for admission, we discovered a fairly homogeneous pattern concerning the categories of conditions or details of a patient's biography and life-world that the GPs were familiar with. The issues most frequently elicited by the GPs can be categorized as "biomedical knowledge," which coincides (not surprisingly) with the types of information doctors are trained to inquire into and to record. A corresponding pattern concerned under-communicated or missing topics, primarily issues traditionally defined as "private," "intimate" or "sensitive" and often considered either inappropriate to broach and/or irrelevant to the medical problem at hand. These patterns reflect the fact that doctors are dually socialized, both as medically trained professionals and as culturally socialized fellow human beings.

Although the GPs participating in the initial focus groups claimed to be knowledgeable about their patients as persons, the GPs included in the intervention study had, in fact, very limited knowledge about that particular patient, which limitations were obviously informed by both professional and social structures. These findings may, as well, mirror the well-documented discrepancy between doctors' ways of thinking (attitude, point of view) versus their ways of doing (actual practice).

Conclusions

In this study, we documented limitations of GPs' knowledge about their patients as persons. A long-term doctor-patient relationship seems, on the one hand, to enable GPs to identify and spell out their patients' personal characteristics. It does not, however, ensure that the GPs accumulate knowledge of a biographical nature which, particularly during transitions to other caretakers, might prove most salient to their patients' health and treatment.

Implications:

We believe these findings to have relevance both for clinical practice and medical education, but further research and reflection is needed before formal changes in current practice are to be recommended.

6.1.3 Paper 3

Standardization meets stories: Contrasting perspectives on the needs of frail individuals at a rehabilitation unit.

Mjølstad BP, Kirkengen AL, Getz L, Hetlevik I. (2013). *International Journal of Qualitative Studies on Health and Well-being*, 8: 21498.

In the third paper, we describe and evaluate the intervention in the rehabilitation unit; that is, the implementation of person-related knowledge (a biographical record) about patients admitted to this rehab unit. We compare GPs' proposed aims communicated to the researcher during telephone interviews and patients' proposed aims for the institutional care as expressed in face-to-face interviews, with the actual treatment plan developed by the unit's staff.

Material and Methods

Nine Norwegian GPs were interviewed about one of their patients who had recently been admitted to a nursing home for short-term rehabilitation. A successive interview conducted with each of these patients aimed both at validating the GP's information and exploring the patient's life story. The GP's opinions regarding treatment and the patient's biographical information and treatment preferences were condensed into a biographical record which was then presented to the nursing home staff. The transcripts of the interviews and the institutional treatment measures were compared and analyzed within a phenomenological-hermeneutical framework. In this paper we compare and discuss: 1) GPs specific recommendations for their patients; 2) the patients' own wishes and perceived needs; and, 3) whether and how this information was integrated into the institution's interventions and priorities.

Results

Each GP made rehabilitation recommendations which included statements regarding both the patient's personality and life circumstances. GPs who had developed a personal, long-term doctor-patient relationship formulated recommendations more in accordance with the patients' own preferences than did the GPs who were less familiar with their patients' lives. Despite their physical and/or mental impairments, every patient was able to delineate, coherently and in detail, her or his specific needs for rehabilitation. A wide variety of issues were at the core of the patients' actual needs, the specificity of which mirrored fundamental particularities of their individual life-world. Certain wishes could easily be integrated into the institutional program while others seemed to go beyond the scope of the institution's repertoire.

A comparison of the GPs' recommendations and the patients' wishes on the one hand and the actual rehabilitation scheme on the other revealed a series of minor and major mismatches. The nursing home staff made an individualized selection of therapeutic interventions based on pre-defined and standardized treatment approaches, yet without personalizing these.

Conclusions

We found that the institutional voice of medicine tended to override the voice of the patient's life-world; that is, patients' stories were subordinated the institution's routines. Consequently, and despite the institution's best intentions, the staff's efforts to provide appropriate rehabilitation in every case was, to some extent, jeopardized.

Implications

We propose a closer collaboration between the GP and the institution aimed at eliciting and exploring information specific to the context of every particular patient. Furthermore, we advise the development of a more flexible and person-oriented conceptualization and application of patient care plans, more genuinely and precisely tailored to allow for the "best possible approach to this specific person's life-world."

6.2 Results not published in the papers

Both GP groups participating in the focus group study were asked for advice concerning the eventual role of GPs in the intervention study, regarding both the most appropriate way to approach GPs and the potential ethical problems linked to exploring person-related knowledge. As discussed in paper 1, both groups associated medico-ethical consideration with the various types of knowledge being discussed.

Confident of the significance of person-related knowledge, the seniors said they would not hesitate to relate such knowledge, provided the patient had given consent (or, were the patient incapable of consenting, with the consent of the patient's next of kin). As the nature of this knowledge is tacit and not easy to articulate in written language, they felt that the best way to transmit it would be verbally, ideally in a face-to-face encounter between the GP and the health personnel at the nursing home. Being realistic about the time constraints in primary health care, however, a phone call would be considered a good alternative.

The junior GPs, on the other hand, said they would be hesitant to share their subjective experiences of the patient with an unknown colleague calling from a nursing home, though they clearly acknowledged the potential medical relevance of this knowledge. Their primary concern, as described in paper 1, regarded the risk of being criticized for basing medical advice on their personal (subjective) judgments. Both groups of GPs mentioned that some patients might object to having information about their personal situation be transmitted, and thereby risking to prejudice the health personnel they met and to deprive them of an opportunity to make a new start, to "turn over a new leaf" (e.g. hoping to avoid stigmatization by not having their "old" alcoholism mentioned to new health personnel).

Conclusions

The initial study documented that GPs' reflections and decisions were strongly impacted by experience, leading them to become increasingly oriented towards solutions adapted to each patient's life circumstances. We propose using the term "situated gaze" to conceptualize experienced GPs' purposeful application of person-oriented knowledge.

7 Key findings

This thesis has shown:

The more clinical experience the GPs acquired, the more they appraised biographical information about their patients as being relevant to their medical tasks; experience enhances the professional's awareness that a person's life-world is highly relevant to his or her health. From a theoretical perspective, this finding indicates that experience over time motivates and enables GPs to emancipate themselves from the conventional "biomedical gaze" (in the Foucauldian sense), focused on the patient's disease, to apply a "situated gaze," that is, a way of viewing the diseased person that includes his or her specific life-world.

Data from a small group of fragile patients provided many narratives with clear relevance to their health situation and the rehabilitation process, as documented in research literature.

It is possible to compile and compose a biographical overview (a biographical record) that patients can agree to and can accept having handed over to other health professionals.

The staff at the institution explicitly stated a willingness to receive the biographical information and to give it their consideration. It was not apparent in practice however, that the rehabilitation plan designed for these patients had been influenced by the information provided. Despite the institution's stated ideal of creating a personalized plan for each patient, the patients were, for the most part, required to adapt to the institutional routines.

The patients did not object to the research being conducted during their stays, but nor did they express surprise or disappointment for the lack of impact which their biographical "declarations" had on the treatment they were actually offered.

All three papers in this thesis revolve around a vision of a more flexible, comprehensive and person-oriented way to conceptualize and apply treatment and care, one which is more genuinely and precisely tailored to suit each particular person's highly specific life-world characteristics.

8 Discussion of results

In this thesis, I began by defining and discussing medicine as an ethical project. I drew the conclusion that, as medicine is a specifically *human* activity aimed primarily at preventing, alleviating and curing disease in *human beings*, morality is of the utmost significance. This is certainly so for medical research and knowledge production as well. In the following section, I will discuss the results of this thesis from a variety of wider perspectives, summarized according to key findings. Many more topics could be discussed in relation to this project; I have selected some.

As I explored the history of medicine, I noticed that the person had "disappeared" from mainstream medicine when the patient became the "object" of medical practice and as diseases were conceptualized as mere "physical-chemical" processes (section 2.3). As already mentioned, several scholars have commented on medicine becoming narrowly scientific and impersonal. Our empirical findings are in accordance with those comments in the sense that the human life-world was not actually taken into account in the medical/clinical settings of the present study. The experience of our research team suggests that this has relevance for contemporary biomedical practice in general given the rapidly accumulating evidence that adverse lifetime experiences are related to a variety of health problems. Thus, a move toward a more comprehensive view of human health and disease is needed, one which takes into account the diseased person's biology, lifetime experiences, and socio-cultural context.

In the meantime, the individual clinician may perceive the field of medicine as simply continuing its long tradition of being both humanistic and person centered as noted by (Miles, Asbrigde 2014):

> *"We fully expect that some clinical colleagues will assert that our contention that health care should return to its humanistic basis – and urgently so – advances nothing new or is even* <u>unnecessary</u>*. They will claim that their practice is already "fully person-centered" ("what other kind of care can there possible be?")*

Nevertheless, many powerful forces are pulling in the opposite direction - away from a humanistic medicine. Our findings provide an anchor for the claim that the currently observed crisis in medicine, with its expensive and endlessly expanding technology, is not only a crisis of care, compassion and trust but also and essentially *a crisis of knowledge*. This is not to be interpreted, at its core, as an issue merely of quantity, as in "not having enough knowledge."

Rather it involves a two-fold inadequacy: first, *an inadequate knowledge production* due to a reluctance to identify the shortcomings of traditional medicine's concept as to what constitutes knowledge about the human body; second*, an inadequate knowledge implementation* due to a reluctance to apply the growing and increasingly solid body of knowledge about the interrelatedness of biology and biography. This will be the starting point for my reflections in the general discussion of my results.

As this project approached its completion, we were witnessing what might be considered a renaissance for the person in medicine. Various movements aiming to reintroduce *the person* into medical research, training and clinical practice, however, are clearly based on quite different ways of understanding the concept of the person in medicine. "Personalized medicine" comes in at least two very different variants: *a hi-tech version* and *a humanistic version*. I will pick up the topic about "the person in medicine" from where it was left in the introduction (section 2.9), and comment on these contemporary attempts to re-personalize medicine. Finally, I will reflect upon what might constitute a more adequate knowledge base for general practice, one which would represent a more genuinely person-oriented approach, and discuss whether narrative based medicine might be part of the answer.

8.1 De-personalized health care; frustrated patients and health personnel

Historically, Cartesian dualism "served" medical research well in certain important ways. By separating the scientific from the metaphysical realm, this framework enabled the dead human body to be considered an acceptable object of scientific exploration without being obstructed by the church. The view of the body as a complicated machine, and the development of the anatomical-clinical method, led to a significant increase in knowledge about the body (anatomy), its function (biology, physiology) and diseases (pathology, microbiology etc), which, over time, also contributed to major advances in medical practice, as described previously. In many ways, the universalist medical concept of "disease" as an entity that can be diagnosed on the basis of certain criteria regardless of either context or person has often proved to be an efficient way of conceptualizing health problems.

However, the systems of classifying diseases according to their general features separated the disease from the diseased person and this biomedical framework left many complaints and health problems inadequately explained. The predominant biomedical view of the body as an "advanced machine" has led to an increasingly dominant mechanical approach to medical research and clinical practice. As the earlier mentioned Norwegian GP and scholar John Nessa commented, the main danger inherent in the concept of the body-as-a-machine is the risk of regarding the body as *merely* a machine (or even *nothing but* a machine) (Nessa 1993). "The body-as-a-machine" model also promotes the perception of the body as a closed system with no interaction with the environment (Thornquist 2003).

A main critique of modern medicine's Cartesian heritage is that it hampers a more comprehensive and integrative approach to health care and renders biomedicine de-personalized, fragmented and overspecialized. According to philosopher Drew Leder, Cartesian dualism even "fractured the language of the self, [so that] many theories remain caught in the dilemma of hyphenated disjunctions (body-mind)" (Leder 1998).

Patients, health professionals and health care administrators alike express frustration with the obvious shortcomings of the health care system. But neither frustrations nor reminders are necessarily signs of a genuine awareness within the profession regarding that those problems have their roots in the dualistic theoretical framework. Nobody, nowadays, would openly profess support for dualism, yet dualism is implicit in biomedicine as well as being inherent in Western culture and languages. Hospitals for mental diseases are typically segregated from hospitals for somatic diseases, and the architecture of modern, somatic hospitals reflects the organ-divided structure of the medical "map" of the human body, assigning the various organs, when diseased, to different floors or even buildings.

Patients report their frustration when encountering a fragmented heath care system, especially in hospitals. Per Fugelli has transformed his personal experiences of being a cancer patient into widely acknowledged and debated texts. After meeting 37 different hospital physicians during his cancer treatment, he coined the ironic concept of "Disposable Doctors" ("Engangs-leger"). He criticizes current specialist health care for being far too fragmented and advocates that all patients receiving hospital care ought to have their own hospital doctor, parallel to having their own regular primary care doctor.[90]

How patients experience the health services represents a very important aspect of the quality of the health services. In a 2013 report, the Norwegian Knowledge Centre for the Health Services presented the results of a large-scale national survey among somatic inpatients in

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[90] See for instance http://www.dagensmedisin.no/nyheter/motte-37-leger-under-kreftbehandling/

Norwegian hospitals during 2012. Several problem areas were identified, particularly the preparations patients received prior to admission and prior to discharge from the hospital (Bjerkan et al 2013). Half of the patients were dissatisfied with information concerning what problems might arise during their hospitalization, and then what to do in case of relapse after discharge. Poor or insufficient collaboration between the hospital and the patients' regular GPs was reported by 40 % of those surveyed, although it was a stated goal of the latest reform in Norwegian Health Care, the Coordination Reform (effectuated from 01. January, 2012).

In 2013, a group of Norwegian physicians initiated a protest action, "Health Service Action ("Helsetjeneste aksjonen") (Wyller et al 2013), motivated by the clinicians' rising discomfort with the organizational structures emerging within the Norwegian health care services over the last years, especially the ever-increasing bureaucratization and use of New Public Management (NPM). Using such slogans as, "Person First" ("Menneske først") and "Care for Every One" ("Omsorg for den enkelte"), they proposed that NPM be replaced by a new ideology for health care (Wyller et al 2013).

So-called "holistic" and "bio-psycho-social" approaches are criticized by some for adapting to the biomedical paradigm and for attempting to hide an essentially dualistic and reductionist model beneath a layer of psychological and social perspectives. As discussed in paper 3, a predictable consequence of debating the lack of dimensions is to add yet another hyphen – such as addressing the existential and spiritual realms of human lives by attaching the word "spiritual-" to the "bio-psycho-social" model. According to Thornquist, dualist biomedicine has led us astray, since it ignores *the body as a source of knowledge and a field of expression of experiences from the human life-world* (Thornquist 2003).

In summary: It can be claimed that modern advances in medicine are primarily a triumph of scientific and technological advances, but not so successfully translated into advances in patient care (within a humanistacally oriented framework). Medicine's tendency to see patients as objects - as complicated machines - need to be fixed (Miles, Asbrigde 2014).

8.2 Inadequate knowledge production?

8.2.1 Evidence based medicine meets primary care reality

General practitioners, as other health professionals, are expected to act in accordance with EBM which is currently regarded to be the theoretical basis for all health care services. The assumption, on which EBM is based, is that it is possible to produce knowledge with general validity for all individuals who share the same basic epidemiological characteristics of the research group from which the data came. Usually, medical research examines the relationship on the group level between a treatment intervention and a disease outcome, with emphasis placed on what is considered objective and measurable. In this process, the uniqueness of each individual is eliminated by means of randomization in order to make the groups one seeks to compare in the study as “similar” as possible, based on the idea that subjectivity is an interference and causes biased results. For example, the investigating and measuring of the effect of a new drug is performed by determining whether a group of treated patients achieves more favorable results *on average* as compared to the average effect experienced by a “similar” but non-treated group. In epidemiological studies all aspects regarding the person – except for the exposure studied – are tried corrected for as confounding factors.

Physicians and health personnel are challenged to “adjust” this general knowledge and apply it appropriately to specific patients (e.g. according to guidelines). The task is demanding since this condensed type of knowledge does not at all indicate precisely who may or may not respond favorably. It is, in fact, debatable, whether it is right to consider this kind of knowledge “universal” in the sense of being valid and transferable to all patients having a limited number of characteristics in common with the study group (e.g. age, sex). As social psychologist Tor-Johan Ekeland commented, the “average” patient does not actually exist in clinical practice (Ekeland 2007). The effect of each drug is studied separately, in clinical trials which systematically exclude patients presenting co-morbidity, or those belonging to certain age groups; consequently, that drug’s effectiveness when administered along with other, equally separately tested drugs (poly-pharmacy) remains undocumented. Many patients, especially the elderly, most often suffer from several different diseases and/or health problems (I will return to discuss multimorbidity as a challenge) (Tomasdottir et al 2014).

The debate about EBM is often heated. Norwegian philosopher Harald Grimen (1955-2011) called for a more sober analysis of how the evidence based approach can best fit in and be used (Grimen 2009). He argued that there are some parts of medical practice where, obviously, it is important to focus on what constitutes effective interventions.[91] For medicine this will mean: what is documented as having an effect in terms of clinical trials (efficacy). In other areas, however, the EBM approach may not fit as well, and may lead to undesirable forms of standardization and impair judgment in clinical practice. According to Grimen, one area of medicine where there the use of the so-called "evidence based approach" is clearly limited, is in areas where so-called "client-therapist" interactions are significant. In these fields of medicine, there is no point in instituting specified procedures. Psychotherapy is one such area where "the client-therapist" interaction is shown to be of particular importance; there is little evidence that specific technical differences of the various forms of psychotherapy are more important than the factors they have in common.[92] It takes time, effort and money to search for more or more recent, information, in accordance with the procedural recommendations of EBM. It is essential to analyze when, in fact it makes rational sense to seek out more information versus when to rely on clinical experience.

8.2.2 General practice needs an adequate knowledge base

General practitioners typically work with patients over time, providing continuity of care; the doctor-patient relationship is regarded as crucial. General practice needs to have a knowledge base wherein valid approaches to people's suffering over time may be found. In addition, it should facilitate GPs' ability "to do what is most important," "to give most to those with the highest needs," and, "to use a health-promoting language," in accordance with the principles of general practice (page 40, footnote 43).

General practice is characterized by personal doctor-patient relationships which continue over time - sometimes over the course of an entire life - in which the GP has the opportunity to

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[91] Obviously, there is a great difference between considering what type of hip replacement is best suited for treating hip osteoarthritis versus deciding which treatment is most effective for prolonged depression.

[92] The debate about this topic has been called *the Dodo bird debate* – referring to *the Dodo bird verdict* claiming that all psychotherapies regardless of their specific components produce equal outcomes. Psychologist Rosenzweig who coined the Dodo bird verdict terminology, borrowed the phrase from Alice in Wonderland, where the Dodo Bird - when asked to decided who had won a race where nobody had care to measure how fare each person had run, nor how long - said that: "Everybody has won and all must have prizes." (See for instance Wikipedia; http://en.wikipedia.org/wiki/Dodo_bird_verdict).

follow patients' health conditions through different phases in life.[93] GPs certainly need conventional biomedical knowledge about the human body's different parts in health and disease, but this kind of knowledge is not sufficient. Human knowledge, self-understanding and insight into the relationships between environment, life events and health are equally important for being a good GP. Knowledge of this kind, however, is rarely discussed in main stream medical education and research at the universities. The knowledge base that GPs are expected to master and act upon is created primarily in hospitals and research institutions, far away from the GPs reality. That type of knowledge tends to provide answers to question that GPs are not as concerned with and not the answers they need most. Cross-sectional knowledge of statistical relationships within selected groups is often difficult to apply at the individual level. We must work to develop a better scientific description of reality, one that addresses the knowledge that is central to general medical expertise and integrates the clarifications gained through experience.

To a certain extent, the major challenges in general practice mentioned previously - the growing number of patients defined with medical risk, MUS and multi-morbidity - may be seen as artifacts of the way we currently conceptualize disease and produce knowledge. Contemporary medical research focuses mainly on objectively observable, group-based and fragmented knowledge, while the impact of subjectivity and of personal lifetime experience on disease development is rarely taken into account. The growth in the number of human beings suffering from MUS (pain, fatigue and "functional" disorders) may, in fact, reflect a "dysfunctional" medical theory (Kirkengen 2002, Eriksen, Kirkengen, Vetlesen 2013). The dominant explanatory models of biomedicine - the body as a complicated machine and linear causality models for disease development - are obviously not sufficient to provide adequate explanations. People suffer from subjective symptoms, but the somatic investigations do not reveal any underlying disease.[94] Neither the biomedical terminology nor its descriptive

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[93] Returning to the quote from Iona Heath: "In hospitals, the diseases stay and the people come and go. In general practice the people stay and the diseases come and go."

[94] A systematic review on "Chronic fatigue syndrome (CFS / ME)" from 2006 concluded that: "CFS/ME is a condition that breaks with traditional dualism of diseases; as either 'somatic' or 'mental.'" For further information see; http://www.kunnskapssenteret.no/publikasjoner/diagnostisering-og-behandling-av-kronisk-utmattelsessyndrom-myalgisk-encefalopati-cfs-me Diagnostisering og behandling av kronisk utmattelsessyndrom/ myalgisk encefalopati (CFS/ME). Rapport fra Kunnskapssenteret Nr 9–2006.

definitions has succeeded in clarifying the classifications in terms of applied diagnosis. The growing number and diversity of medical acronyms (see section 2.6.4) does not help.

All definitions of medical risks are based on epidemiological studies. The risk definitions (the measurement levels on which GPs are supposed to act) are detailed in clinical guidelines to be used in general practice. In principle, the indicators associated with future diseases are unlimited within medical research. There has, however, been little debate within the biomedical community about the pragmatic and ethical ramifications of this activity. For example, the 2007 European guidelines for management of arterial hypertension would, if applied in a strict manner, overburden and thus destabilize the Norwegian healthcare system (Petursson et al 2009). Non-adherence to clinical guidelines within general practice is well documented; GPs who do not adhere to guidelines may have valid reasons for not doing so (Hetlevik, Getz, Kirkengen 2008).

Medical doctors are trained traditionally to focus on separate diagnoses. This approach, supported by the biomedical disease classification systems and clinical guidelines, has been criticized as being “a silo approach” (as mentioned earlier – see footnote 66 p 55) (Parekh, Barton 2010). Chronic illnesses and diseases have a tendency to cluster in the same person as co- and multi-morbidity, and are often multi-factorial, indicating complex origin/ causation and explanatory models (Barnett et al 2012). The well-documented social gradient in health indicates the existence of “causes behind the causes” (Marmot, Shipley, Rose 1984), such as poverty, unemployment, violence, etc. A new causal perspective on clusters of diseases and co- and multi-morbidity may be found in how the accumulation of various stressors over time might lead to dysregulation of the individual’s physiological adaptive systems (allostatic) (McEwen 1998a,b).

8.3 Inadequate implementation of new relevant knowledge

As mentioned earlier, a growing body of knowledge documents associations between subjective phenomena (such as stressful lifetime events) and poor health. A conventional biomedical approach cannot explain, however, why such experiences, statistically estimated to have an equal impact, affect individuals differently. To understand the impact of a person’s subjective experiences on that person’s physiology and function is crucial.

As discussed in all three papers, empirical knowledge accumulated in the last three decades, shows that a person’s life-world experiences have a direct impact on that individual’s body down to the sub-cellular level (Getz, Kirkengen, Ulvestad 2011, Tomasdottir et al 2014). It has been demonstrated beyond doubt that relational and social matters are of general medical relevance (Blackburn, Epel 2012, Danese et al. 2009, Friedman et al. 2012, Grunewald et al. 2012, Kiecolt-Glaser, Gouin, Hantsoo 2010, Surtees et al. 2011). This body of knowledge is crucial for an appropriate medical comprehension of human sickness. Nevertheless, and as commented upon in paper 2, we recognize that neither this evidence nor its adequate professional interpretation and implementation have as yet been integrated into mainstream practice. For instance, and as mentioned under the section about EBM, it is clear that the evidence upon which current clinical guidelines is built is highly selective, with a strong bias toward de-contextualized biomedical measures, characterized by many simplifications. The reference list of the previously mentioned 2007 European guidelines for management of arterial hypertension, for example, includes 825 references, none of which discusses psychosocial risk factors (social determinants of health), even though there exists considerable documentation of their relevance to CVD (Petursson 2012).

We uncovered a pattern in the missing aspects in the GPs' knowledge of their patients: these related primarily to issues traditionally defined as "private," "intimate" or "sensitive." Interestingly enough, a growing body of consistent evidence indicates that precisely these "untouchable" matters in clinical encounters do, indeed, hold medical relevance and ought to be discussed. As pointed out in key findings, neither health professionals nor patients in the intervention study were surprised that, when treatment plans were drawn up, the biographical knowledge was not taken into consideration. As I see it, patients are so used to be treated in an impersonal way by health professionals that they probably do not expect to have any impact on their own treatment plan.

8.4 A contemporary renaissance for the person in medicine

For many years, clinical medicine has harbored a tension between "universalism" and "specificity". Having studied social implications of genetic research in humans since the late 1990s, sociologist Richard Tutton[95] claims in his paper, "Personalizing medicine: futures present and past," that (Tutton 2012):

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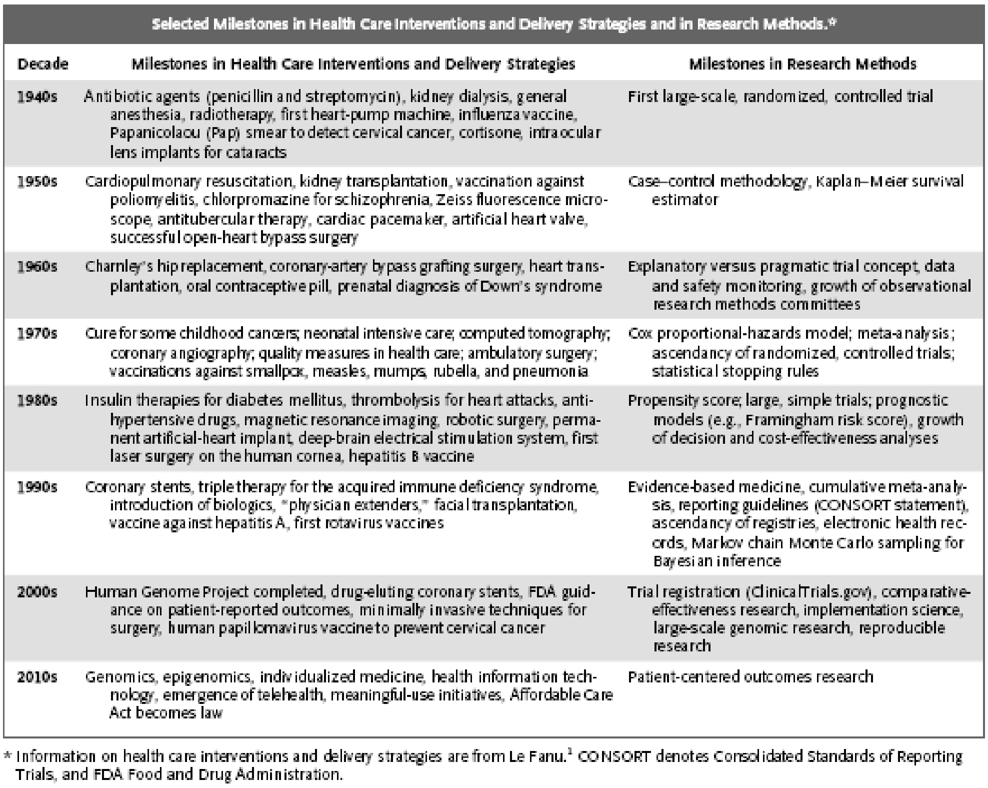
[95] Since the late 1990s Richard Tutton has been studying, among others topics, the social implications of human genetics research.

“*…there have been different historical forms of “personalization” over time which have been defined very much in relation to the tension between “universalism and specificity” in Western medicine.”*

Health care and medical research approaches have advanced and developed since EBM was introduced in the 1990s. Two important emerging movements have evolved challenging the "old" EBM approach with its dominant belief in generalized group-based knowledge as the only significant knowledge. One important movement is the so-called “personalized medicine” *(the hi-tech version of personalized medicine)*, which springs from the idea that the individual is unique, including in a strictly biomolecular and metabolic sense. As opposed to applying the group-based knowledge of EBM, tailor-made individual treatment is preferred. Another emerging direction argues that EBM has led to a reductionist and fragmented, depersonalized medicine; a philosophical, humanistic medicine *(the humanistic version of personalized medicine*) is emphasized instead.

Health care interventions have also changed dramatically over the years. An overview of selected milestones in health care interventions and in research methods, published in New England Journal of Medicine in 2012, highlights that EBM (the group-based approach), “invented” in the 1990s, is now being eclipsed by newer approaches. Based on 2010’s genomics, individualized medicine and person-centered outcomes research (connecting research results to patients’ health care needs) is regarded as the most appropriate approach (see Figure 7) (Gabriel, Normand 2012).



Selected Milestones in Health Care Interventions and Delivery Strategies and in Research Methods.*

Decade	Milestones in Health Care Interventions and Delivery Strategies	Milestones in Research Methods
1940s	Antibiotic agents (penicillin and streptomycin), kidney dialysis, general anesthesia, radiotherapy, first heart-pump machine, influenza vaccine, Papanicolaou (Pap) smear to detect cervical cancer, cortisone, intraocular lens implants for cataracts	First large-scale, randomized, controlled trial
1950s	Cardiopulmonary resuscitation, kidney transplantation, vaccination against poliomyelitis, chlorpromazine for schizophrenia, Zeiss fluorescence microscope, antitubercular therapy, cardiac pacemaker, artificial heart valve, successful open-heart bypass surgery	Case–control methodology, Kaplan–Meier survival estimator
1960s	Charnley's hip replacement, coronary-artery bypass grafting surgery, heart transplantation, oral contraceptive pill, prenatal diagnosis of Down's syndrome	Explanatory versus pragmatic trial concept, data and safety monitoring, growth of observational research methods committees
1970s	Cure for some childhood cancers; neonatal intensive care; computed tomography; coronary angiography; quality measures in health care; ambulatory surgery; vaccinations against smallpox, measles, mumps, rubella, and pneumonia	Cox proportional-hazards model; meta-analysis; ascendancy of randomized, controlled trials; statistical stopping rules
1980s	Insulin therapies for diabetes mellitus, thrombolysis for heart attacks, antihypertensive drugs, magnetic resonance imaging, robotic surgery, permanent artificial-heart implant, deep-brain electrical stimulation system, first laser surgery on the human cornea, hepatitis B vaccine	Propensity score; large, simple trials; prognostic models (e.g., Framingham risk score), growth of decision and cost-effectiveness analyses
1990s	Coronary stents, triple therapy for the acquired immune deficiency syndrome, introduction of biologics, "physician extenders," facial transplantation, vaccine against hepatitis A, first rotavirus vaccines	Evidence-based medicine, cumulative meta-analysis, reporting guidelines (CONSORT statement), ascendancy of registries, electronic health records, Markov chain Monte Carlo sampling for Bayesian inference
2000s	Human Genome Project completed, drug-eluting coronary stents, FDA guidance on patient-reported outcomes, minimally invasive techniques for surgery, human papillomavirus vaccine to prevent cervical cancer	Trial registration (ClinicalTrials.gov), comparative-effectiveness research, implementation science, large-scale genomic research, reproducible research
2010s	Genomics, epigenomics, individualized medicine, health information technology, emergence of telehealth, meaningful-use initiatives, Affordable Care Act becomes law	Patient-centered outcomes research

* Information on health care interventions and delivery strategies are from Le Fanu.[1] CONSORT denotes Consolidated Standards of Reporting Trials, and FDA Food and Drug Administration.

Figure 7 Selected milestones in health care interventions and delivery strategies and in research methods (Garbriel, Normand 2012). Reproduced with permission from N Engl J Med. Copyright Massachusettes Medical Society.

8.4.1 The hi-tech version of personalized medicine; a hopeful vision?

The term “personalized medicine”[96] is most often associated with the hi-tech version of personalized medicine – a much heralded “revolution” in biomedicine that envisions the individual patient as the central focus of future healthcare. The meaning attributed to the term *personalized medicine* varies widely, and no single definition has been agreed upon as yet. Many other terms, such as *genomic* medicine, *stratified* medicine, and *precision* medicine are frequently used as synonymous with *hi-tech personalized* medicine.[97] If one takes into account what constitutes personhood (I will soon return to the common definition), it is debatable whether or not it is correct to refer to a “person” here. Regardless of this, there is obviously something rhetorically appealingly about referring to the person.

Whatever definition is selected, a distinct feature of the vision of personalized medicine is likely to be its capacity to integrate complex information from multiple data sources and to generate valid algorithms to help support health and predict/prevent disease among all citizens. A decade after the human genome was decoded, the various “-omics”[98] aim to translate achievements from the basic sciences into clinical and public health applications. So far, some success with individualization of treatment has been achieved, e.g. tailor-made chemotherapy for some types of cancer. However, the initial expectations and promises linked to genomic medicine remain largely unfulfilled. By now, the chase for “omic” data as the true mirror of individual health has ironically been dubbed, “Narciss-omics”, alluding to the mythological Narcissus who, falling in love with his own beautiful reflection in a pool falls into it, literally, and drowns. Hence, “Tailor-made medicine or Narciss-omics” is the telling title of a paper written by Norwegian physicians reflecting on the potential and unintended side effects of such a development (Ræder, Moelven, Njølstad 2012).

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[96] To my knowledge, the term “personalized” was first coined in the context of genomics, and applications of genetic information currently play a major role in the discourse related to personalized medicine.

[97] Several international foresight analyses exist regarding personalized medicine, for example: “Forward Look: Personalised Medicine for the European Citizen - towards more precise medicine for the diagnosis, treatment and prevention of disease.” http://www.esf.org/fileadmin/Public_documents/Publications/Personalised_Medicine.pdf.

[98] The neologism “omics” refers to a field of study in biology ending in -omics, such as genomics, the study of the genomes (the genetic material) of an organism, proteomics, the study of the proteom (the entire complement of proteins– and metabolomic the study of the metabolome (the chemical processes involving metabolites) (see Wikipedia; http://en.wikipedia.org/wiki/Omics)

The theoretical anchor for this development is provided by so-called systems medicine, the application of systems biology to medical research. Systems medicine has been inaugurated as a strategy for understanding the complexity of chronic non-communicable diseases in the 21st century and as an appropriate way to combat these (Bousquet et al 2011). The authors define systems medicine as follows:

"The 'systems medicine' concept, which takes a holistic view of health and disease (...) aims to tackle all components of the complexity of non-communicable disease."

Words like "holistic" and "person-centered" are typically considered words of honor in general practice. GP and Professor Richard G. Roberts, former president (2011-2013) of the World Organization of Family Doctors (WONCA), is co-author of the above article, along with 64 systems biologists.The authors' shared vision includes the following prophecy;

"…in 10 years or so, each patient will be surrounded by a virtual cloud of billions of data points."

Such masses of data generated by high-throughput technologies will be challenging to manage, visualize, and convert into improvements in patient outcomes, let alone to communicate to the patients in a comprehensive, appropriate, and comprehensible manner (Vogt et al 2014).[99]

8.4.2 4 P medicine in tomorrow's general practice?

The acronym "4 P" denotes a special vision for future health care as being Predictive, Preventive, Participatory, and Personalized. The stated aim of its proponents is to prevent future disease development by means of early, tailored interventions for persons identified as being at risk. Early diagnosis and screening clearly have an important place in this scenario. Implicit in the 4P vision is the promise of a cheaper yet more efficient health care linked to the argument that early diagnosis contributes to better treatment control and that prevention is less expensive than treatment (Bosuquet et al 2011).

Some reflections on each of the 4 Ps:

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[99] Henrik Vogt, phd candidate and member of the same research group that I belong to (General Practice Research Unit) is working with a phd-project where one of the aims is to advance an understanding of the strengths and limitations of systems medicine as a framework for primary health care. The title of the project is: "Systems medicine as a theoretical framework for primary care – a critical investigation".

Predictive: As mentioned earlier, medical research has for decades produced so-called risk factors expected to predict future diseases in currently healthy persons (section 2.6.4). A relatively elevated blood pressure was the first of these "factors" to be introduced within the health care system on a large scale. Definitions of "normality" are central to defining margins denoting risks. Any consensus distinguishing what is normal from what deviates involves a normative process, introducing both potential error but also normativity into (presumably) value-neutral science. Norms may be negotiated and manipulated, even more so when a deviance invites a pharmaceutical correction – identical with economical interests – or when a lowering of thresholds increases the number of potential patients. The problems connected to definitions of norm and deviation will most certainly remain within the 4P approach, or may even increase due to the non-transparent and complex nature of these new sources of information (Vogt, Getz, Hetlevik 2014).

Preventive: Prevention is only possible if prediction leads to appropriate and effective changes. In principle, such changes can occur in two ways on an individual basis: either a person changes his/her way of living, based on correct and well-founded information, or the risk factors (e.g. elevated blood pressure, elevated cholesterol) are "changed" in the sense of being modified/altered by means of medical technology, typically via specific medications. Both types of change may result in effective prevention, in other words risk reduction. In general practice, motivating patients to change their life style by means of information about risk has, however, not proved successful.[100] Therefore, most "changes" have been achieved through introducing and prescribing an increasing number of preventive medications, both in general practice and in specialist medicine, although effectiveness of preventive medication in populations is much less known than efficacy in clinical trials.

Participatory: To participate in decisions aimed at creating change requires fulfilling crucial premises. The participants need to understand the impact of either "being me, living as I have decided to do" or "me being changed by means of lifestyle or technology". They need to agree upon potential gains. And they need to share an understanding of "causes". In this

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[100] The problems with preventing and treating obesity can serve as a good example here. In addition, it is documented that life-style intervention in high-risk individuals in Norwegian general practice did not succeed (Swensen E, Reiten T Eriksen O. (1994). Intervensjon i en risikogruppe for hjerte- og karsykdommer i Seljord og Kviteseid. *Tidsskr Nor Lægeforen* 114: 3458-3462), neither has it been proven successful in international literature (Ashenden R, Silagy C, Weller D. (1997). A systematic review of the effectiveness of promoting lifestyle change in general practice. *Fam Pract*, 14: 160-17).

connection, it is crucial to consider that the medical concepts regarding causality and risk are not only contested and abstracted but are also part of a knowledge regime endowed with great authority. Few patients dare to challenge either these concepts or this authority. The literature documenting that the elements of risk prediction and risk reduction are poorly understood is also overwhelming; this applies to patients, doctors, health politicians and researchers alike (Hetlevik 1999b). Another essential aspect of the concept 'participatory' is that all persons/patients shall share their data on relevant electronic platforms for the benefit of society (Bosuquet et al 2011).

Personalized: The new "image" of Personalized within the 4P systems medicine can easily be dismantled as being "more of the same", as contributing to an even more fragmented knowledge production. Previous conditions will be maintained as long as the human organism is treated as no more than a collection of biological components:

"'Systems biology' in current practice is not easy to distinguish from old-style reductionist biochemistry applied on an ever-larger scale" (Cornish-Bowden 2006.)

8.4.3 Humanistic versions of personalized medicine; person centered medicine

As touched upon in the introduction under section 2.4.3 Development of PCM, ("The person in medicine"), the professional development within family medicine and in general practice almost came to a standstill after the bio-psychosocial model was introduced in the 1970s and the patient centered approach in the 1980s. One exception, however, seems to be the development of narrative based medicine (NBM) which occurred parallel to the development of PCM (Kalitzkus, Mathiessen 2009). NBM appears both compatible with and in line with the patient centered approaches[101] as both aim at bringing the patient as a subject back into medicine.

As also mentioned briefly in the introduction, "the person" reappears in the medical discourse in 2010, initiated by The International Journal of Person Centered Medicine through its

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[101] Greenhalgh and Hurwitz pointed out that the meaning of narratives in the physician-patient interaction becomes apparent in those subjective, patient-oriented encounters, especially in Balint groups (Greenhalgh, Hurwitz 1999).

Editor-in-chief, professor Andrew Miles.[102] Internationally, Miles is renowned for advocating a change in the global EBM debate, away from increasing reductionism grounded in population-based, aggregated biostatistical data, and towards embracing the complex and personal aspects of medicine.

In a paper in 2011, Miles and Mezzich review the latest development in biomedical clinical practice in detail (Miles, Mezzich 2011). They describe the emerging signs of a crisis in modern medicine, engendered by the predominance of technological cure over human care in clinical practice. The authors describe two parallel developments in the realms of “cure” and “care” respectively: the growth of evidence based medicine EBM and that of person-centered care.

In the same year, the late Barbara Starfield (1932-2011), professor of Health Policy and Management at John Hopkins University, published an article about *person*-focused care. In her work, Starfield provided major scientific underpinnings for the vital role primary care must play in any rational, balanced, effective and compassionate health care system. Instead of care which focuses on diseases, she promoted “person-focused care”, which she defined as being, “based on accumulated knowledge of people, which provides the basis for better recognition of health problems and needs over time and facilitates appropriate care for these needs in the context of other needs” (Starfield 2011).

The American doctor and philosopher Eric Cassell (mentioned in section 2.9) also continued his conceptual exploration of person-centered medicine and developed theories about the person in medicine. In 2010, he published a paper including the following description of a person, of what actually constitutes personhood (Cassell 2010):

“A person is an embodied, purposeful, thinking, feeling, emotional, reflective, relational, human individual always in action, responsive to meaning, and whose life in all spheres points both outward and inward. Virtually all of a person’s actions - volitional, habitual, instinctual, or automatic - are based on meanings. Persons live at all times in a context of ever present relationships in which a variable degree of trust is necessary both to others and in the self.”

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[102] Professor Andrew Miles is Editor-in-chief of two medical journals and one of the initiators of The European Society for Person Centered Healthcare. The Society is based on the observation that, as health care has become more scientific, it has also become increasingly depersonalized and inhumane.

A phenomenological framework conceptualizes “the person” as being capable of creating and conveying meaning, informed by incorporated lifetime experiences together with relevant others, and a fundamentally relational and social human being. According to Cassell, a person has a past and a future, and both are part of the person who is present at that moment. A person is able to love, in both the deepest and the shallowest of ways. Every person has a spiritual life, a dimension greater than the person her-/himself. Some people only select words from within religious contexts, but spirituality is also implicit in loving others and in connections or phenomena greater than the person, such as belonging to a profession or a nation (Cassell 2010).

How could these characteristics of a person be termed or even integrated into medical contexts? How might one think about or spell out the relationship between person and disease? Cassell says (Cassell 2010):

“Sickness and its manifestations are inextricably bound up with the phenomenon of meaning. Everything that happens to people; objects, events, relationships, every sight and sound, everything that happens in or to the body is given meaning. Meaning has cognitive, physical, emotional, and spiritual aspects. Thus, meanings have an impact on every dimension of persons. Meaning is the medium, the intervening agency, which unites all aspects of sickness and its impairments with the sick person. In other words, people do not act because of events, things, circumstances, or relationships; they act because of their meanings. The importance of the centrality of meaning is that meanings can be changed and with the change in meaning the patient’s reality is changed.”

The discussion about how to reintroduce “the person in medicine” is still at its beginning and is constantly evolving. Internationally, new humanistic models have been developed for nursing and for long-term patient care, promoting “personhood” (person centered nursing) (McCormack et al 2012). In March 2014, the European Journal for Person Centred Healthcare devoted their entire issue to person centered health care and the discussion of the concept of person centered medicine including contributions from twenty scholars/ authors (Miles, Asbrigde 2014). In July 2014, the first World Conference on the topic will be arranged in Madrid, Spain.

8.5 Towards a person centered health care: might narrative medicine be part of the answer?

I will now return to NBM, as mentioned at the start of this section. In its modern Westernized form, NBM evolved as a consequence of a "narrative turn" in the medical field in the late 1980s.[103] Listening to the patient narrative/story has always been a vital part of medicine, but with the development of modern medicine, objective "facts and findings" have been deemed more reliable. With NBM, the patient narrative was again regarded as an important resource for understanding the individual, patient-specific meaning of illness. There exist different forms of NBM; as regards its special relevance for general practice, NBM represents both a particular attitude towards patients and doctoring and a special form of physician-patient communication.

For several years, British GPs have been exploring whether a narrative approach might make sense in primary care (Greenhalgh, Hurwitz 1999, Launer 2002). The narrative approach is neither a substitute for nor an alternative to conventional evidence, nor does it stand in opposition to it, as emphasized by John Launer, a British GP interested in narrative based primary care (Launer 2002):

"Primary care lies at the crossroads between the world of stories and the world of facts."

NBM had its start within medical humanities and is related to person centered medicine. The NBM movement aims at restoring humanity and moral engagement to medical work, to counterbalance EBM.

Listening to patients' stories – not only with the aim of acquiring information in order to determine the proper diagnosis and/ or treatment, but also to contribute to reworking and "improving" the story – old stories can be exchanged with new ones. According to John Launer (Launer 2002):

"A narrative based approach sees the search for better stories, and the attempt to provide these, as the basis of all the work that is done in primary care."

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[103] The term Narrative Based Medicine (NBM) was coined to mark its distinction from Evidence Based Medicine (EBM); in fact, NBM was promulgated to counteract the shortcomings of EBM.

The concept underlying the narrative approach can be summarized as follows: we construct our view of reality by telling stories. NBM reasserts the importance of lived experience, and the expression of that experience.

Even though NBM is related to PCM, there are some important differences. Traditionally, PCM does not emphasize that the doctor try to understand the total life situation of the patient in front of her/him. PCM focuses primarily on “how the case looks from the patient’s perspective” in order to facilitate effective consultations[104] and improve adherence to treatment plans. The patient centered model of the consultation is, to a large extent, a skills-based approach. The approach emphasizes that the physician should take an interest in four axes - which is typically referred to in Norwegian contexts as the 4 F's of the patient: *Forestillinger* (interpretations of symptoms, what is imagined), *Forventning* (expectations, what is anticipated), *Følelser* (feelings, concerns) and *Følger* (consequences). Questions to ask to investigate these axes might be: “What is the reason for your visit?” “Have you thought of any possible reasons for your symptoms?” “Is there something specific that you want me to do about this problem?” “Do you have any concerns regarding your symptoms?” And: “How does this affect your daily life?” As I see it, one way to describe the PCM approach is that it allows the physicians to “peek” into aspects of the patient’s life-world, as if through small keyholes. A fifth F is suggested; *Forutsetninger* - referring to the patient’s living conditions and the resources and opportunities available to him or her (Hunskår 2013).

Humanistic medicine, the basis for both PCM and NBM*,* represents a concept of humanity in which human beings are recognized as self-reflective and meaning-seeking. It becomes increasingly clear that the fact that human beings are self-reflecting has actual biological implications. Phenomena such as trust and hope[105], relatedness (Holt-Lunstad, Smith, Layton 2010), guilt and shame (Dickerson et al 2004) and disempowerment (Marmot 1991) are biologically relevant to an extent unknown in other species (although animals display rudimentary equivalents).[106]

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[104] PCM aims at increasing the probability that the patient’s actual reason for initiating contact is dealt with, and that fewer misunderstandings arise.

[105] The phenomenon called placebo can be seen as representation of this category (trust and hope).

[106] It has been shown that the biological profiles of male monkeys change according to their change in status within a hierarchical system. (See the Baboon study: http://healthland.time.com/2012/05/22/baboon-study-shows-why-high-social-status-boosts-health/)

Traditionally, NBM has not concerned itself with the interaction between biology and biography, although this reciprocal interrelationship has been suggested; rather, the goal has been to develop health personnel's empathy and communication skills. However, as I see it, the relevance of NBM extends beyond issues of empathy and respectful interest. The postulate here would be that meaning-making has biological correlates, as for example, recent neuro-imaging studies indicate impact of psychotherapy on the brain. Narrative competence might thus have far greater relevance as it fits the emerging complex disease models. Knowledge of how narratives can be inscribed in human biology is growing and integrating knowledge from the fields of psycho-nevro-endocrino-immunology research, as mentioned earlier (see section 2.4.2).

8.5.1 Narrative competence

In addition to acknowledging the subject's right to voice her/his own experience, the listening professionals must also deepen and refine their empathic abilities if they are to understand what they hear. Narrative competence, that is, the empathic ability to recognize relevant patterns in other human beings' life stories, can both be learned and taught (Charon 2004). At the same time, it is of paramount importance neither to reduce empathy to being merely another instrumental skill (Macnaughton 2009), nor to confuse it with sympathy or identification. Empathy, as understood within the phenomenological tradition, particularly as elaborated by scholar Edith Stein, means to appraise another person's "otherness" (Frank 1985). This crucial 'open-mindedness' on the part of the medical professional is echoed in Richard Baron's seminal paper entitled, "I can't hear you while I'm listening" (Baron, 1985). French philosopher and psychiatrist Pierre Janet (van der Kolk, van der Hart 1989) has traced the detrimental impact on health when people attempting to come to grips with their own experiences are prevented from telling and being listened to, particularly experiences that involve existential upheaval. The work of, among others, American social psychologist James Pennebaker has demonstrated the benefits to health of formulating a narrative, including the impact that it has on reducing stress and physiological overtaxing (Pennebaker 2000).

According to Launer, many practitioners will instinctively recognize "good" stories, in terms of involving a definitive shape, clarity and closure (Launer 2002). There is probably, however, a long way to go before a theoretical framework is developed that helps us recognize and conceptualize the patterns of clinically relevant stories in the midst of everyday "talk".[107]

Scholars/researchers within the field of general practice have suggested that in a broader perspective, NBM represents a way of thinking or attitude grounded in an understanding: that human beings are biologically created to formulate stories; that stories affect us; and, that we all have the opportunity to be co-creators when the stories are told and interpreted (Getz, Hvas 2013). NBM, compatible as it is with complex disease models, is expected to increase in importance in the future.

Currently, knowledge of how narratives may be thought of as inscribed in the body is growing. A traditional biomedical research approach has already proven beyond doubt that some biographical events generally have a significant impact on health, e.g. the death of a child or caring for a chronically disabled close relative. A systems-oriented framework for thinking is emerging, one which is based on the inseparability of the body and the mind, and on human beings as essentially relational creatures. The human genome and the immune system respond to impressions and experiences. As we apply narrative reasoning in relation to biology, we encounter the field of biosemiotics; English anthropologist Gregory Bateson, a pioneer in systems theory, and also a precursor of biosemiotics, is known for the concept: *"the pattern that connects"*. To reach deeper and ever more subtle levels, we need to uncover and work with personal stories and their meaning for life; we need to approach "life projects" in ways that require sophisticated analyses.

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[107] Experienced colleagues describe an explicit moment of recognition when the patient's narrative puzzle comes together. Some even say that they react physiologically (goose-flesh). Typically the patient also shows physical signs of emotional engagement in such instances (sighs, tears in their eyes, etc).

9 Discussion of method: evaluation of the soundness and validity of the study

Before moving to the final paragraphs of this thesis, which deal with Implications and Future perspectives, I will now discuss methodological aspects of this project.

9.1 Evaluating qualitative research

There exist numerous criteria for the systematic assessment of the soundness of qualitative methods, but there is a lack of consensus among qualitative researchers as to the criteria to apply. Some qualitative researchers claim that the terms *validity* and *reliability*[108] are not applicable to qualitative research, arguing that it does not make sense in qualitative research to be concerned with "truth" or "falsity" of an observation with respect to external reality. They recommend that the idea of discovering "truth" through measures of validity and reliability be replaced with the idea of *trustworthines*s, focusing on establishing *confidence* in the findings. According to Kvale, *"validity means whether one has in fact investigated what one wished to investigate*" (Kvale 1983). When applied to the present project, one may ask: Do the findings at the core of our initial questions and our presentation constitute a valid condensate of the aspects or phenomena we have encountered and inquired into?

Standards for judging the quality of qualitative research may be described in the terms of *rigour, credibility, and trustworthiness.* A set of *criteria for rigorous qualitative research* has been proposed by Norwegian researcher and professor in general practice, Kirsti Malterud: the research question should be clearly stated, there should be an adequate presentation of background/ context and an accurate description of the material. The analysis should be thorough and well-documented. Important factors such as reflexivity and transferability should be discussed (Malterud 2001).

When evaluating qualitative research one must also consider that a variety of qualitative approaches exist (Starks, Trinidad 2007). Some of these allow proximity to the empirical data and result mainly in "pure" descriptions; others are theory driven and consequently more

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[108] *Validity* and *reliability* are traditional criteria for jugding quantitative research. *Reliability* is concerned with the accuracy of the actual measuring instrument or procedure; *validity* is concerned with the study's success at measuring what the researchers set out to measure. *External validity* refers to the extent to which the results of a study are generalizable or transferable. *Internal validity* refers to the rigor with which the study was conducted.

explicitly analytical and interpretative. Striving to reach a deeper understanding of a phenomenon in order to unfold any implicit features or structures requires a multi-level analysis and involves an integration of the findings in relevant theoretical frameworks. This means that the researcher chooses one (or a few) specific perspective(s), leading to conclusions which, consequently, represent only a few of a variety of possible interpretations. According to Kvale this kind of plurality of interpretations is not only legitimate but, in fact, unavoidable in a process of exploring ambiguous phenomena such as language, human relationships, or systems of values (Kvale 1983). Therefore, it is crucial to report all parts of the process and of the argumentation as explicitly as possible so that the soundness of both the exploration and the interpretation can be evaluated by others. Kvale acknowledges and emphasizes Ricoeur's definition of validation as a discipline involving argumentation – comparable to how courts interpret the law; it is always possible to challenge an interpretation (Kvale 1983, 1996).

In the following section I will present considerations concerning the quality of the present qualitative research, including a discussion of the study's design, material and method, the credibility and trustworthiness of the results, touching finally upon reflexivity and transferability.

9.2 Reflections regarding design, method and material

In general: The strength of our project lies in our choice of analytical framework and the variety of methods; this enabled us to collect and explore different and complementary types of material, representing different voices from a very particular "place" in the health care system, namely the interface between patients' homes, their providers of primary care, their GPs, and a health care institution. The richness of our material has already been presented and elaborated on in the three papers underpinning the present thesis.

The focus group study: Here, the main purpose was to gain insight into GPs' familiarity with their patients in the sense of knowing them as persons. The second aim was to validate the researchers' clinical experiences that this kind of knowledge is often useful and medically relevant for general practice. An additional purpose was to elicit useful input for creating the best possible design for the intervention study. The size of the focus groups, respectively five and seven participants, is generally regarded as appropriate for this purpose (the optimal size of groups depends on the topic to be discussed) (Fern 2001). In general, focus group interviews are deemed a quick and convenient way to gather data from several people. That was also our experience; the group interaction (regarded as part of the method), and the group discussion encouraged the GPs to clarify and explore their views in ways that might be harder to achieve in individual interviews. Our choice to engage with preexisting groups, so-called “naturally occurring” groups, worked well. Our contention that the difference in the extent of the GPs’ professional experience was the key to understanding the differences we noted in the groups’ discussions, has to take group history and dynamics into account (See Paper 1). According to Fern, the number of groups to involve depends on the purpose and complexity of the research questions; in general, between two and eight focus groups are suggested as the optimal number. By involving two groups in our study who represented opposite poles of a conceivable scale as regards motivation, age, experience, directedness, and familiarity among the members, we acquired both rich accounts within each group and covered a broad spectrum of opinions and statements. Giving both groups a wide timeframe may also have facilitated a phenomenon described by Fern: the length of the group discussion is sometimes more important than the number of sessions because the unique or creative thoughts often seem to come late in the discussion (Fern 2001).

The intervention study: The design of the intervention study allowed us to explore what salient biographical knowledge about their patients as persons GPs actually had acquired, and to identify divergent perspectives on the needs of frail individuals admitted to a rehabilitation unit. The study also yielded insight into how the wishes and needs of the patients were informed by their specific lifetime experience and everyday life-world, providing nuanced information about the complexity of their rehabilitation process. The trustworthiness of our results is reflected in the fact that the information presented by the patients very often matched what we were told by the GPs.

Even though the participants were included in the study consecutively, as opposed to strategically (which was impossible in the actual setting), and even though the research team was entirely dependent on the staff members for delivering invitations to the eligible patients, (see Paper 2), we nevertheless succeeded in obtaining a sample of informants that represented a wide diversity as regards to age, degree of disability, chronic health problems, actual needs, personal preferences, and experiential backgrounds. In our view this variety and diversity, (apart from the common denominator functional loss), as well as the types of data material collected for each of these, counterbalanced the low number of participants.

As per our protocol, we had intended to include up to 15 patients along with their GPs. However, the period of data collection lasted longer than planned due to internal problems at the nursing home. We were unprepared for the considerable "loss" of eligible patients as a consequence of the staff's dispositions, and we also were taken by surprise that some of the GPs chose not to participate despite their patients' wishes and their having been granted permission to talk freely with the researcher. Of course, we had no possibility to elicit their reasons. However, after one year, the point at which we decided to stop any further inclusion of participants, the data that had been generated from the nine included pairs of patients and GPs proved to be very informative. It represented a satisfying range of age, gender and diagnoses, and included several "thick descriptions" – in the sense of anthropologist Clifford Geertz – with regards to life circumstances as well as traumatic experiences from prior encounters with the health care system (Geertz 1973).

Telephone interviews: While references to methodological considerations involved in carrying out telephone interviews are scarce in the research literature, a frequently applied approach in research based on randomly selected informants involves answering pre-formulated questionnaires. The comparison of phone conversations with informants versus face-to-face interviews has not been discussed extensively as regards qualitative studies, probably because this method is not used frequently. Telephone interviews offer the advantage over face-to-face interviews of allowing the respondents to feel more relaxed and able to talk more freely (because "unseen") and, as a consequence, to disclose sensitive information more easily (Norvick 2008). A considerable disadvantage, however, is the loss of nonverbal and contextual data (e.g. absence of visual cues), and possible distractions due to activities in the participant's environment – although such distractions may happen when talking face-to-face as well. Telephone interviews also tend to be kept short as compared to in-person interviews. In our study, this phenomenon turned out to be an advantage as it facilitated the inclusion of busy GPs; it was much easier to make an appointment for a short telephone interview than it would have been had we aimed at meeting the GPs in person. I experienced a remarkable openness on the part of the participating GPs when interviewing them by phone; most of them talked freely, disclosing even very sensitive information. In only one of the GP telephone interviews did I encounter some of the reported disadvantages, such as bewildering pauses and delayed responses to my questions, making me wonder whether there were "distractions around". However, during the course of the interview I understood that the GP was actually busy reading the patient's records in order to find the correct answers to my questions.

The limited time frame for telephone interviews (10-15 minutes) with the GPs might have had an impact on their capacity to fully articulate appropriate recommendations for their patients. On the other hand, GPs are quite familiar with reporting or recalling medical date in settings with time constraints. In addition, this relative time limit might bode well for the transferability of the results, since precisely such constraints exist in real clinical practice. It is also possible that even better results might be achieved in future studies or clinical routines by preparing the GPs for this role as "consultant" to patients in transit, as described in Paper 2.

Detailed and comprehensive field notes, utilizing excerpts from the medical records, contributed valuable insight into the institution's routines. Nonetheless, consistent observations of the interactions among staff members and/or additional interviews with them might have yielded deeper and perhaps more differentiated insights into the rationale informing their actions.

9.3 Reflections regarding the credibility and trustworthiness of the study

Reflexivity is often mentioned in relation to the evaluation of qualitative research, and is defined as (Malterud 2001):

"An attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process."

To be able to judge the credibility and trustworthiness of a study, an honest and informative account of how the researcher interacted with the subjects in the field (in addition to how the study was conducted) is necessary and will strengthen the reader's confidence in the findings/ conclusions. Consequently, transparency is regarded as important in several ways.

Firstly, the *transparency* of the research process as such is important to ensure an accurate evaluation of the quality and trustworthiness of the work, enabling the readers to judge if the results are reasonable or not. Since the researcher is the main "instrument" in a qualitative study, her/his personal and professional experiences (those with relevance for the research project) must also be accounted for (Hallberg 2013). Methodological transparency regarding the process of analysis is also regarded as important due to the wide range of methods within qualitative research. Regarding this particular research project, I have aimed for transparency in all these levels: I have been open about my position as a researcher, as noted in the prologue (including my personal and professional experience); I have described the theoretical framework for this research; and, I have described my methods and mode of analysis as thoroughly as possible.

9.4 Reflections regarding my roles in this project

Participating observer: The paramount intention of the entire project was to explore the significance of knowing and encountering patients who are in transit between their own homes and nursing home, as persons. This aim demanded adherence to an epistemological framework allowing for first person accounts. The subsequent face-to-face, in-depth interviews with the patients were framed to allow highly personal issues to be elicited. The condensate of these talks, mediated to the staff of the nursing home in the form of a biographical record, and validated by the patient, was strongly informed by a mutual exchange of opinions and interpretations intended to safeguard the patients' best interest. In this setting, my own contribution (as the researcher) to and involvement in every step of the research process was obviously of great significance. My previous experience as a GP and a consulting doctor in a nursing home had given me insight into the unique dynamics of patient transit, and likewise, into the patients' special vulnerability during this process. I had gained an understanding of the importance of adequate information being exchanged between caretakers "at both ends", so to speak.

My main challenge was to maintain a proper balance between proximity and distance, and between the levels of information, interpretation, analysis, and theoretical anchoring. As described in the literature, the continual movement among these levels of the research process as a whole seemed to take on the character of a spiral – from gathering basic data in different roles and encounters, to transcription, interpretation, intermediate analysis and discussions with co-researchers, to theoretical framing of aspects or phenomena, and, finally back again to talk with patients and staff, recording, interpreting, and analyzing. In short: the way of doing research in the present project rendered the researcher a most significant research instrument.

Interviewer: Clearly, the interpersonal skills of the interviewer matter, not only to be able to establish trust, which is central premise for access to first-person accounts, but also to have the kind of sensibility necessary to grasp both the content and the meaning of what the interviewees are saying. As already mentioned, it might be highly advantageous to be an experienced GP when performing research interviews. I would also add that my role as a teacher in communication skills for medical students had made me familiar with how to listen attentively, to respond flexibly, and to formulate opening questions. It has given me experience with paraphrasing, that is, with reflecting back to the interviewee what has been said in order to confirm or elaborate the meaning of statements or stories. Also, I have learned to be observant, to pick up para-verbal or non-verbal cues and subtle signs, such as facial and other bodily expressions, and changes in pitch or tone of voice.

9.5 Transferability

It is often discussed whether results derived from qualitative studies can be generalized, whether or not this is a stated goal. Research in general aims at producing knowledge of interest for a wider circle than just the participants and the researchers involved. Within qualitative research, transferability to similar groups under similar circumstances is often a reasonable claim.

The GPs who participated in the focus groups during the first phase of this project claimed to be knowledgeable about their patients as persons. Although a different group of doctors participated in the later part of the study, the findings indicate that physicians' knowledge is, in fact, limited, and that the patterns of those limitations are shaped both by professional and social phenomena. Our findings may also be seen to illustrate the well-documented discrepancy between doctors' ways of thinking (attitude, point of view) and doing (actual practice) (Hetlevik 1999b). The wider generalizability of the research findings is open to debate. It may be argued that an important limitation in the focus group study is that we only conducted one group interview with each of the two categories (junior and senior). As validated through our personal experience as clinicians and clinical teachers, we assert, nonetheless, that the documented difference between the two discourses represents relevant observations and interpretations.

As regards the transferability of the results from the intervention study to other similar groups, the individual situations of study participants as well as the routines at other institutions will, obviously, differ. However, based on our clinical experience, neither the range of patients nor the nature of the institution appear as unusual.

10 Implications and future perspectives

10.1 Person-centered health care seen in light of scientific responsibility

“*Investigatores mementote vos generis humani veritatis speciem effingere*”[109]

If we consider the empirical findings from this project in the context of the historical development of modern medicine, there is reason to claim that human beings’ lives are not actually taken into consideration in mainstream, contemporary, Western medical thought and practice. The ever-increasing evidence that adverse lifetime experience is related to health problems would indicate that medicine ought to address this: any comprehensive overview should, in addition to the biomedical approach of health and disease, include the person’s past and current life stressors, as well as social and cultural situation. Optimal treatment of a person’s health problems has to be based on an understanding of the whole person in his/her context.

While I see considerable room for immediate improvement, some issues clearly require a more fundamental theoretical rethinking. There is need for general improvement to be made in the understanding and conceptualization of *why, when* and *how* health personnel best can take human beings’ lives into consideration. We need to change the way we think about disease and health, leaving the prevailing biological machine metaphor behind us. This applies to people in general, health personnel and, last, but not least, to researchers.

Ethical considerations beyond the ethical formalities of research (which typically involve informed consent and avoidance of causing harm) are usually omitted from medical research, probably because the common belief shared by most scientists is that “science” and “scientific facts” are value-free or value-neutral (objective) and “intrinsically good”. The presuppositions about the nature of human beings and humanity that are implicit within current medical research – the underpinnings of the current process of knowledge production – are often taken for granted, without the question of whether or not they are ethically tenable having been examined.

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[109] This Latin statement is posted on the wall of the General Practice Research unit in Trondheim. The English translation is: “*Researchers! Remember you are creating mankind’s definition of reality.*”

It is not surprising that the theoretical perspectives and commentaries of the researcher as an interpreter receive little attention, given the presupposition within natural science that a single objective truth actually exists and can be identified. If we acknowledge, however, that research is a creative activity and that knowledge always emerges from the interaction between a research tradition, an experiencing subject and a perceived object/phenomenon, then the researcher's assumptions and preconceptions, choices and judgments can become the focus of scientific and ethical attention in new ways (Thornquist 2003).

According to a Nordic group of researchers (Forssèn et al 2011) this common characterization of science as objective and neutral is not only misleading but also wrong: *"scientific practice is value-laden, uncertain, open-ended and embedded in complex contexts."* Under the heading, "Rethinking scientific responsibility", they argue that researchers should acknowledge that they are co-responsible for the wider consequences of both their research focus and the applications of their findings (Forssèn et al 2011). They present a method for meta-reflection that might lead to more transparency when critically reflecting on the possible consequences of research projects. Examples of important questions to increase such transparency are: what tradition has fostered this research idea; who designed the study; what constraints influence the design (time limitations, accessible methods, etc.); who will fund it and for what reasons; and, ultimately, how will these aspects influence the project? An explicit analysis of such "upstream" elements might place the research in a wider context and reveal influences that are often downplayed or ignored. In a discussion of "downstream" elements the researcher should reflect upon the possible consequences of her/his findings; for the individual, the health care system and for the society.

Traditionally there has been more emphasis placed on "doing" (in the sense of creating new, original data) than on "thinking" (which should represent the basis of all academic work and its merit) in medical science, as discussed by Getz, Kirkengen and Hetlevik in the 2008 paper with the telling title, "Too much doing and too little thinking in medical science!" (Getz, Kirkengen, Hetlevik 2008). Concerns for practical feasibility and the "manageability" of hypotheses and analytic approaches often take precedence over clinical relevance when research projects are being planned. In contemporary academia, where "production" is paramount, scientists are no longer encouraged to follow demanding and somewhat unfamiliar path and run a greater risk of not hitting the target ("delivering") on time. The authors emphasize that innovative and analytical thinking about existing data may be just as important and valuable for medical progress as is doing empirical research. They quote the 1915 Nobel laureate in physics, William Bragg:

"The important thing in science is not so much to obtain new facts as to discover new ways of thinking about them."

Researchers and the research community must ensure a sound ethical framework for research, aiming not to constrain it but to foster its relevance. Implicit in this are new discussions to raise, as part of the analysis of research ethics. When evaluating the quality of research, we are accustomed to thinking in terms of methodological elegance and integrity. When evaluating research ethics, we must also include theoretical assumptions, asking for example whether the research idea and the chosen methods do justice to the nature of human beings. Thus, in order to plan and conduct proper research, medical researchers need to be knowledgeable regarding the theory of science and not only its methodology and methods.

The willingness to ask critical questions about medicine's role in society is also important (Førde 2003). Such scrutiny is of higher relevance now than ever before given the current discussions of phenomena such as over-diagnosing and over-treating. To what extent, and precisely how, do the health care services actually contribute to increased morbidity, despite their good intentions?

The research community needs to understand that they are the stakeholders, involved in the creating of a reality, of what is to be considered "true" in medicine. Knowledge is not value neutral, nor is the production of knowledge. There is a tradition in academia to shift the blame to the pharmaceutical industry and the media whenever research results are misinterpreted or exaggerated. Actually, the fragmentation and linear thinking which dominate contemporary medical research provide a perfect scientific glove for the pharmaceutical industry to put its hand (commercial products) into. Researchers must bear their share of the responsibility for the realities that emerge from the projects in which they involve themselves.[110] Also, the research community has a responsibility to raise their awareness about other issues as well, such as the potential for harm connected with contemporary medicine.

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[110] Further discussion of the topic of scientific responsibility can be found in Getz' thesis 2006.

10.2 Clinical medicine in the future

Based on what I have just discussed, I must conclude that, before we proceed at full speed with the "implementation" of person centered medicine, we must pause and consider the theoretical underpinnings for that way of thinking about and practicing medicine. Clarification of the conceptual and epistemological basis for person centered health care will not come overnight. Professor Andrew Miles, mentioned earlier, has formulated a thought-provoking warning: when it comes to developing a theoretical framework for person centered health care, we must avoid making the same mistakes and epistemic errors of EBM (Miles, Asbrigde 2014):

"Whereas EBM proceeded to develop methods (ill-conceived in general philosophical and methodological terms) to accelerate the transfer of research into practice without an adequate epistemological basis, person-centered healthcare must at all costs – and as we have emphasized in this article – avoid the same destiny as EBM within the History of Medicine."

And further;

"We need to safeguard medical theory in terms of how it understands the person of the patient and thus to return to medicine and healthcare more broadly a more accurate understanding of what constitutes clinical practice."

Among the important questions to be asked are: What constitutes person centered health care and what is its essential meaning? How does it differ from patient centered health care and how are we to understand it, and practice it? What are its pitfalls? What will be the consequences and costs to society of such an approach? A huge challenge stands before us: to develop a theoretical framework, one which is scientifically comprehensive and sound while also supporting and building on the indisputable skills of experienced, dedicated clinicians – rather than clashing with them, as is so often the case.

I will end this chapter envisioning the future of clinical work with patients and presenting my hopes for the future of medical clinical practice.

In the coming years, I hope that we succeed in changing the way we (as a society) think about disease and illness, and that the medical profession goes beyond considering "man as a machine" to develop a scientific and comprehensive perspective on the human being. As general practice is the only medical specialty focusing on "the whole person", during the entire course of a life and even across the generations, I believe that GPs are particularly suited to move this development forward. My hope is that, on a scientific basis, we will be able to develop more effective humanistic models of care than those currently available. I hope that health professionals will be trained and prepared to respond to the subjective experiences, unique biographies, identities and life projects of their patients when the situation calls for it. To reach this goal, we must do away with the myth that subjective experience cannot be trusted in a discipline based on science. This, however, will require that health professionals receive proper education in "integrative" thinking and methods of contextualization. I hope we can lay to rest the discussion of whether or not it is damaging to the patient to talk about difficult experiences. We could then begin to discuss how the good clinician may allow the patient to lead the way toward a deeper understanding of the weave of connections existing in the subtle matrix of biology and biography, molecules and meaning – without jumping to any conclusions and with full respect for the person's integrity.

I hope that, in the future, we will come to understand more about what characterizes a meaningful patient story as regards health, how and when to elicit personal stories, how and when to communicate that information without compromising patient privilege. We will need then to find a suitable place for these in our everyday medical practice, while also paying appropriate attention to standardization whenever relevant.

I hope that it will soon become common knowledge that every person's life experience holds a unique meaning and impact for that individual, that every person is diseased in his/ her own way. I do realize, however, that very many powerful forces in and around medicine point in the opposite direction of the vision I have presented for the future. Modern medicine may not even have the ability to recover its humanism. I choose, however, to trust that it can.

11 Closing remarks

Let me conclude the discussion of my thesis by returning to my motivation for entering into research, which arose from a professional concern with the development of medicine and how we practice it.

The present study has shown that the two groups of GPs that were studied were more or less convinced of the relevance of person-related knowledge, depending on their level of clinical experience and maturity. Furthermore, approaching as few as nine patients in a vulnerable life situation ("in transit") due to ill health and hardly able to care for themselves, revealed life stories which, according to scientific evidence, have high relevance to health. Many of the GPs involved in the project had acquired little knowledge of their patients' stories, despite telling me that life experiences matter. They did not seem to be aware that there was, in fact, so much more to be known, had they only asked – and listened. Though this worries me, I do see cause for hope, as described above. Thus, what worries me even more is that the patients themselves did not expect to be treated like persons; they seemed to know in advance that, as much as their stories mattered to them, they did not matter to medicine. Not only doctors need to develop, but also the patients, and the general public. After having witnessed the emergence of so many powerful stories in such powerless patients, I feel there is no way back. I can never again look at a patient without thinking of a story.

Gregory Bateson commented (Bateson 1979):

"But I come with stories – not just a supply of stories to deliver to the analyst but stories built into my very being."

Research confirms this. Our study has shown that, when we are open for stories and even request them, we find them, stories that matter - quite literally, as they have biological impact on bodies.

Many consider it to be common knowledge that life experiences impact the body. Actually, however, mainstream medical thinking has yet to acknowledge adequately, much less address, the implications and consequences inherent in the massive quantity of research confirming the connection between adverse lifetime experiences and disease. Some major cognitive awakening is needed so that this "common knowledge" informs common practice and research. Medical practitioners must recognize at last that the fragmented knowledge production on which their field rests must be changed.

To meet the aim of developing a coherent and responsible approach to person-centered medicine within general practice, time and thought must be invested. It would be risky to rush ahead without a plan, without having thought the matter through, as Bateson says, adapting a line of poetry (Bateson & Bateson 1987):

"*Where angels fear to tread, fools rush in.*"

We must strive to restore to the human being its position as a subject and not merely an object of medical thought and practice. Let us hasten slowly, but still move forward, steadily.

12 Epilogue

During the period of working with this thesis, I have also been teaching medical students how to communicate with patients, mainly during the first and second years of their studies at NTNU, but also during their sixth and final year. The curriculum in general practice includes 6 weeks of in-service training ("praksis utplassering"), during which the students have to record a video of an actual consultation with a patient. The final year students are required to pass a "video evaluation", an oral examination involving the presentation of their patient consultation video plus participating in a discussion with their fellow students, in the presence of two tutors (teachers).[111]

In one such session during which I served as a tutor, a male medical student presented an excerpt from his videoed consultation with a man suffering from post-traumatic stress disorder (PTSD). The student did not know the patient but had received information from the discharge report that the patient had been diagnosed with PTSD and was now supposed to start treatment with psycho pharmacy. According to the discharge report, "*the patient should not be exposed to deep conversations or therapy regarding his traumatic experiences*" by the GP.

As soon as the video of the conversation between the young male doctor and the middle-aged male patient begins, one immediately has the impression that they both are somewhat introverted types. The young doctor manages, masterfully, to create a safe and trusting atmosphere and the patient, without any sign of feeling challenged, begins to tell openly about the trauma that he has been through and to explain about the trouble this has given him. The young doctor carefully explores the patient's medical history and learns that the patient's sleeping problems involve his awakening at a certain time every night. When the doctor wonders about the reason for this, the patient explains that he wakes up every night at three minute past four o'clock because his body is in "alarm". The doctor wonders again; what the reason for this might be, and the patient explains that this is the precise time of the accident in which he had been involved. The patient also explains how particular perceptions – such as dripping water or a certain odor – can trigger flashbacks. The body seems to remember the trauma. [This is when I get goose bumps on my arms.] The young doctor goes further and

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[111] The patients being videoed will have given advance, written consent to the consultation being used for teaching and professional development. Some details have been changed to protect confidentiality.

explores the patient's suicidal thoughts, and the conversation flows smoothly. The doctor then goes on to ask about the patient’s home conditions and to determine that the patient has a lot to worry about at home as well. His wife is mentally ill and threatens constantly to kill herself: “*a classic example of the result of abuse,”* according to the patient. Every day, when he comes home and puts his hand on the doorknob, he wonders: “*What will meet me when I open the door today? Has she finally made good on her threats – has she hung herself in the stairway*?”

As a tutor I wondered; what was it that should not have been explored in this narrative?

12.1 Scenes from a nursing home

The field notes have been crucial in this project capturing what otherwise might have been overlooked or forgotten. I have channelled some of my impressions of what I observed at the unit into the poems below under the heading, “Scenes from a nursing home” – inspired by the reflections Anna Luise Kirkengen included in her thesis entitled, “Inscribed bodies”. I owe Anna Luise a debt of gratitude for having made me aware that what a tape recorder picks up is not sufficient to produce a transcript that reflects situational understanding.

The Old Harley Davidson Biker

I was passing through the hallway when I caught sight of him;
The 'old biker'
Sitting in a chair by the wall
Dressed in worn-out jeans and a leather vest
A cup of coffee in his hand, crossed legs
Just sitting there still, watching
His much older fellow patients doing exercise to music
The constantly smiling female instructor
Demonstrating movements in time to the music
The music sounding somewhat familiar
And then I recognized it:
old old third-rate country music
The old biker looked like he was just bored stiff
I kept on walking

The Old Lady and the Funeral

I was going to visit her in her room
Surprised to find her lying on the bed
With closed eyes, her hands folded
On her bedside table, a funeral announcement
the Bible and a list of hymns
It was an hour of devotion
The funeral of her dearest brother
Not being able to attend
She was lying there in her room
Picturing the funeral to herself
Singing the hymns quietly inside
Participating in her own way
It was an hour of devotion
So I quietly left the room

A Poet with Unbearable Pain

He told me he was a poet writing a book

But not able to do so now, forced to lie still on his bed

With skin as white as the sheets surrounding him

Almost blending in with the bedclothes

His body was skinny and small; looking weak and fragile

But the look in his eyes – surprisingly strong and vital

His pain was almost unbearable

But he still eagerly wanted to talk

Because talks, he said

Could alleviate more than painkillers

So we talked

He revived and propped himself up on his elbow

When I was leaving the room, I stopped by the door

Turned and looked back

Now I could barely catch sight of him

Once again enveloped in sheets – blending in

"A heralded suicide" was to be the title of his book

The Poet had told me

The Sea Captain

Who could have imagined:

The old man with trembling and unsteady hands

Bent over and bowed walking slowly along the corridor clinging to his walker

He used to be a solid steady captain of super oil tankers in distant oceans

Which need 4000 meters to stop on the open sea

The distinctive features of Parkinson's disease and old age blinded me

I saw a patient, not the person

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14 Appendix

Intervjuguide 1:Telefonintervju av fastlegen

Introduksjon: ”Din pasient er nylig innlagt til et korttidsopphold her på X sykehjem”.

Spørsmål 1: ”Hva kan du fortelle meg om denne personen som kan være av betydning for dette oppholdet?”

Spør spesifikt om følgende tema (”Kan du beskrive”):

- pasienten som person
- bakgrunn; familie, yrkesliv, interesseområder, hobbyer
- betydning av/ forholdet til nære relasjoner
- sosialt nettverk (venner, naboer, familie etc)
- personlighetstrekk som kan være av betydning når man skal gi omsorg og behandling
- livshendelser som kan være av medisinsk betydning

Spørsmål 2: ”Hva tror du som fastlege at sykehjemmet best kan bidra med i denne situasjonen?”

Intervjuguide 2: Dybdeintervju av pasienten

Introduksjon: ”Jeg har nå snakket med fastlegen din på telefon og han/ hun har fortalt meg en del om hvordan han/ hun kjenner deg som person. Jeg ønsker å drøfte med deg om noen av disse opplysningene kan være viktig for sykehjemslegen å kjenne til når behandlingsopplegget ditt skal utformes”. (Gjennomgang tema for tema).

Spørsmål 1: ”Fastlegen beskriver deg som en person som….”

a) bakgrunn; b) sosialt nettverk; c) nære relasjoner; d) personlighet

For hvert tema spørres: ”Hva tenker du om dette?” *Pasienten kan korrigere opplysningene*.

Spørsmål 2: ”Tror du at det kan være viktig for sykehjemslegen å kjenne til noe av dette som fastlegen har fortalt om deg som person?” *Pasienten er med på å definere hva som er medisinsk relevant.*

Spørsmål 3: ”Fastlegen mener det også kan være viktig for sykehjemslegen å kjenne til at ..”

e) livshendelser; f) andre forhold som har betydning

”Hva tenker du om dette?”

Spørsmål 4: ”Tror du det kan være viktig for sykehjemslegen å kjenne til noe av dette som fastlegen har fortalt om viktige hendelser i livet ditt?”

Spørsmål 5: ”Vi har nå snakket om det som er særpreget for din person og ditt liv, og som vi tenker kan være viktig å ta hensyn til når behandlingsopplegget ditt skal utformes. Er det noe av det vi har snakket om som du ikke ønsker at sykehjemslegen skal få kjennskap til?”

Intervjuguide 3: Evalueringssamtale med pasienten ved utreise

Introduksjon: ”Du skal nå reise hjem etter å ha vært her på X sykehjem i 3 uker. Du har deltatt i et prosjekt der man har forsøkt å ta hensyn til hvem du er som person og hvordan livet ditt har vært til nå”.

Spørsmål 1: ”Kan du fortelle om hvordan du har opplevd dette?”

Spørsmål 2: ”Tror du det har vært nyttig for deg at opplysninger fra fastlegen din ble innhentet på denne måten?”

15 Papers I-III

Paper I

European Journal for Person Centered Healthcare Vol 1 Issue 1 pp 88-99

ARTICLE

Knowing patients as persons: senior and junior general practitioners explore a professional resource

Bente Prytz Mjølstad MD[a], Anna Luise Kirkengen MD DrMed[b], Linn Getz MD PhD[c] and Irene Hetlevik MD DrMed[d]

a PhD Student, General Practice Research Unit, Department of Public Health and General Practice, Norwegian University of Science and Technology (NTNU), Trondheim, Norway
b Professor, General Practice Research Unit, Department of Public Health and General Practice, Norwegian University of Science and Technology (NTNU), Trondheim and Institute of Community Medicine, University of Tromsø, and Senior Researcher, Centre for Health Promotion, Akershus University Hospital, Norway
c Professor, General Practice Research Unit, Department of Public Health and General Practice, Norwegian University of Science and Technology (NTNU), Trondheim, Norway and Landspitali University Hospital University of Iceland, Iceland
d Professor, General Practice Research Unit, Department of Public Health and General Practice, Norwegian University of Science and Technology (NTNU), Trondheim, Norway

Abstract

As part of a research project exploring inter-professional communication in Norwegian healthcare, junior and senior general practitioners (GPs) participated in focus group interviews regarding the medical relevance of acquiring and sharing knowledge about their patients as *persons*. The transcripts were interpreted using phenomenological- hermeneutical and discourse analysis. Both GP groups expressed concern over the lack of emphasis on person-oriented knowledge in the healthcare system and pointed out factors which interfere with the documentation and sharing of such knowledge. Senior GPs attributed more importance to person-related knowledge than did junior GPs while displaying considerably more verbal authority and professional independence. The seniors' discourse was dominated by ethical considerations while juniors focused more on legal arguments. Our study documents how, with experience, GPs' reflections and decision-making become more oriented towards solutions adapted to each patient's life circumstances. To conceptualize expert GPs' purposeful application of person-centered knowledge, we propose the term "situated gaze."

Keywords

Discourse analysis, epistemology, lived experience, person-centered medicine, person-centered primary healthcare, phenomenological-hermeneutical analysis, primary health professionals, qualitative research

Correspondence address

Dr. Bente Prytz Mjølstad, General Practice Research Unit, Department of Public Health and General Practice, Norwegian University of Science and Technology, PO Box 8905, 7491 Trondheim, Norway. Email: bente.mjolstad@ntnu.no

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Introduction

General Practitioners (GPs) and Family Physicians (the designation of primary healthcare doctors varies internationally) typically work with patients over time. Such continuity of care, providing repeated encounters between doctor and patient, often engenders a doctor-patient relationship based on mutual trust [1]. The GP becomes familiar with the patient as a *person*, that is, the patient's life history and relationships, both in illness and in health. This situated knowledge of particulars [2], comprising both general aspects of human life and particular aspects of an individual patient, is of a different kind than the general and abstracted knowledge of biomedicine. Representing subjective phenomena [3] and, as such, defying standardized interpretations, this type of knowledge is rarely included in the scientifically grounded knowledge production of biomedicine.

After alternating roles of GP and consultant physician in a nursing home over the course of several years, the first author (BPM) became concerned about the consistent lack of emphasis on information about the lives of patients contacting the healthcare system, for example, elderly and chronically ill people in transition between their homes and a nursing home. This observation provided the impetus for a research project, led by our research group whose members collectively possess 90 years of clinical experience providing primary care. Our point of departure was the awareness that, over time, whether they intend to or not, GPs accumulate knowledge about patients' personal lives. The research project was divided into 2 phases. In the exploratory phase, 2 groups of GPs were invited to reflect upon their ways of knowing about "their" patients' personal lives. The consequent phase will consist of an intervention into the interface between GPs and a nursing home, emphasizing communication among caretakers of their knowledge about patients as persons. Here, we present the findings from the focus group study, based on a comparison of the impact of professional experience on the GPs' knowledge and communication about the patient as a person *versus* the patient as a biomedical entity.

An appropriate framework for research into the realm of human experience is provided by phenomenology, a European philosophical tradition concerned with the human life world and with human experience. Phenomenology was developed by Husserl and further elaborated by Heidegger, Sartre, Merleau-Ponty and Levinas, among others. The tradition, as a philosophy, aims at understanding the experiencing human being in the first person, as a direct source of knowledge about how it is to lead a life. As a methodology, it has been introduced into psychological [4,5], pedagogical [6] and medical research [7] as a way to gain insight into and, to describe, how human beings experience their life world. Utilizing first person accounts, the method helps explore the subjective and inter-subjective realms of lived experiences in order to learn the meaning and significance they hold for the individual person(s). The method is grounded in the presumption that an equity exists between researcher(s) and informant(s); this perspective helps assure that the research conducted will be context-sensitive, as open as possible and not limited by the presuppositions of the researcher [5-7].

Investigating human experience as communicated in the form of first person accounts involves an exploration of systems of values and of symbols as they are conceptualized and expressed in language, spoken or written. This demands competence both with language (linguistics, semiotics) and with interpretation (hermeneutics) [5-8]. The principles of hermeneutics, focusing on identification of the structures of meaning, help establish a common ground of understanding among participants in social discourses and for discourse analysis. Consequently, the application of a phenomenological framework involving hermeneutical principles and linguistic tools is appropriate to the exploration of the ways doctors present their professional knowledge about patients as persons and how they evaluate the medical relevance of this particular knowledge.

Biomedicine, the basis of contemporary Western healthcare systems, is a body of knowledge grounded in a framework based on detached observation and objectivity [9]. Foucault has termed this view of the human body as a natural object as "the medical gaze" [10]. The history of science employs a dichotomous knowledge tradition separating the theoretical from the practical, establishing "a sharp distinction between facts and values" [11]. This distinction constitutes the natural sciences as a realm of value-neutral objectivity; values themselves are posited as residing outside science, within the realm of human subjectivity. These premises allow the production of scientific knowledge to be viewed as separable from its application.

In contrast to the biomedical paradigm, practical knowledge traditions see knowledge as inseparable from the subject, as "knowledge-in-action" and "knowledge-in-use". These ways of knowing, based on participation and dialogue, are characterized by being fundamentally "tacit"; they are difficult to articulate as they involve skills and competencies that are expressed as practices, as ways of doing. Furthermore, they are characterized by familiarity with processes, contexts or situations, with knowledge that cannot be separated from its application and that is acquired through experience rather than formal training [12,13].

Gradually, the concept of the mindful body [14] has emerged from increasingly convergent research within a variety of disciplines revealing the impact of life experience on human health and disease [15]. Several epidemiological studies [16-18] document strong associations between stressful lifetime experience and poor health. However, calculating the impact of pre-defined events as average at the group level does not adequately address the potential range of subjectively and inter-subjectively (socio-culturally) constituted meanings inherent in human experiences. The approach provides no explanation of how experiences may be categorized as having equal impact and yet affect individuals differently, which can limit healthcare professionals' capacity to identify, appraise and address the health impact of existential experience and may ultimately lead them to employ medical interventions that prove ineffective, counterproductive or even harmful [19].

An experience is always about something, for a specific person situated in a given context; inextricably linked to a subject, each experience is informed by and integrated with previous experiences [20]. This is valid both for a person in the role of patient and in the role of doctor. The GPs' familiarity with particular patients, acquired over time and in varying situations [21], presents issues which go beyond general professional ethics: knowing what is right and good to do not only in terms of medical approaches, but for this patient in this situation. Information derived through this "deontological" way of knowing [22] may be difficult to articulate in the accepted language of biomedicine and as a result may not appear in medical records, even when deemed medically relevant.

Methods and materials

The study was conducted in an urban setting in central Norway in 2008. We selected GPs from pre-existing groups assuming that their familiarity with each other would allow them to reflect openly on kinds of knowledge that are rarely discussed in formal medical-academic contexts. The Norwegian Continued Medical Education program (CME) for GPs made it possible for the researchers to approach ongoing local groups. The 2 groups chosen differed the most from each other as regards professional experience and educational history.

Group 1 - Senior GPs

The first CME group consisted of 7 highly experienced GPs, men and women, all specialists in general practice and represented a collective total of 168 years of practice (mean 24 years). They had met regularly (2-8 years participation) prior to inclusion. The group was self-directed within the formal CME frame, with members alternating as chairpersons and organizers.

Group 2 - Junior GPs

The second CME group consisted of 5 less experienced GPs, men and women, all had worked toward fulfilling the mandatory requirement for specialist training of 2 years of group participation and represented a collective total of 15.5 years of practice (mean 2.5 years). They had met every fourth week throughout the 5 months prior to the study, guided by an authorized tutor.

Interview Settings

Written information was provided prior to the group interviews, which were held where the groups usually met. The first author (BPM) opened both group interviews by recounting a vignette from a scientific article regarding an actual patient. The story underlined how the phenomenon of confabulation in dementia is a social and discursive event and therefore best understood and addressed by healthcare professionals who are familiar with that patient's personal background [23]. Then, making reference to "memory work," a method for exploring memories of specific events [24], BPM (the first author) asked the GPs: "Does this narrative remind you of any of your patients?" A structured guide for the ensuing focus group discussions included the following topics:

1. Do GPs have professionally relevant knowledge about their patients beyond biomedical knowledge?
2. If so, what is this "other" knowledge about?
3. Do GPs distinguish biomedical knowledge from this "other" kind of knowledge?
4. If so, how is this expressed in their discussions about their patients?
5. To what extent are doctors aware of this "other" knowledge in professional settings?
6. To what extent do doctors attribute medical relevance to this "other" kind of knowledge?

Finally, participants were asked for advice concerning the eventual role of GPs in the intervention study, the second phase of the research project.

Initially, the groups were encouraged to conduct their discussions as usual; BPM (the first author) did not actively intervene except to ask for *ad hoc* validation or offer an online-interpretation, that is, seek confirmation from the interviewees of her having understood them accurately [5]. BPM kept notes, particularly on the interactions among participants and their group dynamics [25,26]. The seniors selected a chairman for their group meeting, but the juniors decided not to; they did not foresee having difficulty keeping order despite the planned absence of their experienced, formal tutor.

Transcription

The group interviews were audio taped and transcribed, *verbatim*, into Norwegian by the first author. Paraverbal and non-verbal elements were noted in parentheses. Overlapping speech was written as sequential voices. The transcripts and field notes constitute the material of the present study.

Analysis and interpretation

To suit the aim of our study, namely to address and explore an otherwise unspoken kind of knowledge in primary care [27], we applied 2 different yet mutually enhancing analytical approaches to the same material. By means of a phenomenological-hermeneutical analysis [5,7,28], we explored the impact of the GPs' professional experience on their appraisal of knowledge of patients as persons. This analysis focused on what the doctors talked about and treated as relevant. By means of a discourse analysis, we explored how professional experience informs the GPs' appraisal of various types of knowledge and structures within the medico-political realm. This analysis focused on how the doctors worded their views and professional standpoints (see Figure 1).

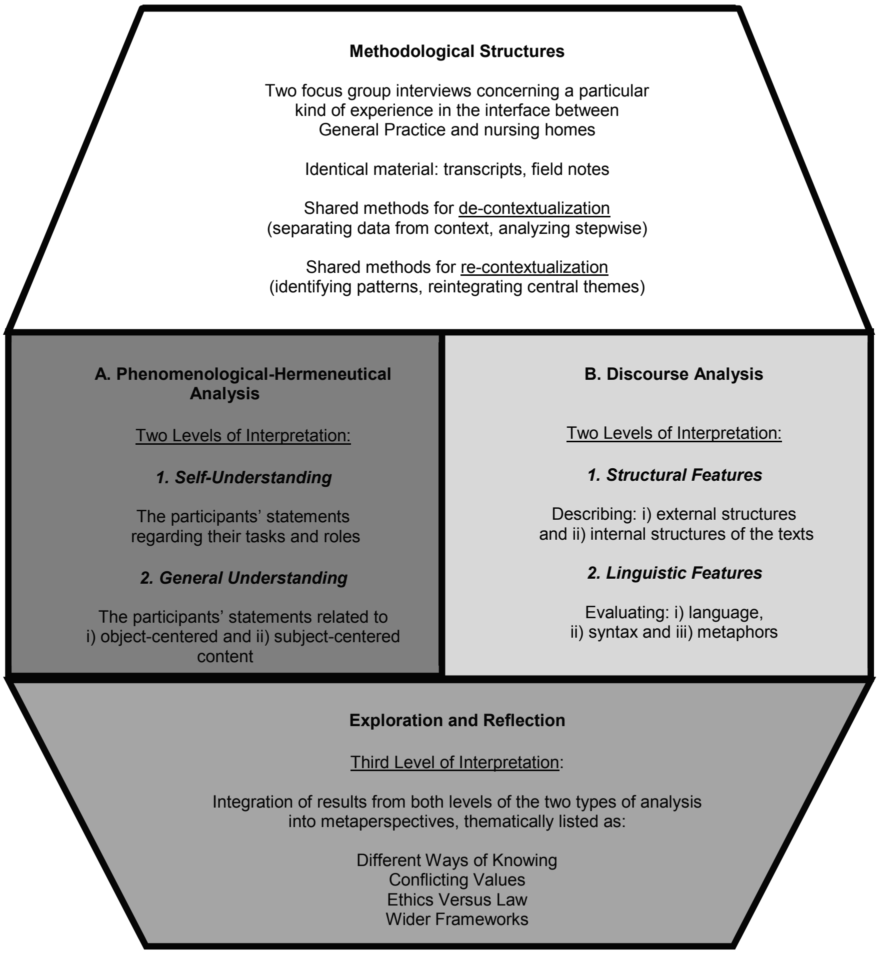
Phenomenological-Hermeneutical Analysis

Our phenomenological-hermeneutical analysis comprised interpretation on 3 levels [5]. The first level concerned the GPs' statements about their self-understanding in relation to their professional tasks and societal roles. The second level dealt with the GPs' general understanding of their professional experiences as expressed in their accounts of specific topics, both professional and societal and what these accounts revealed about the speakers. Then, in order to deepen our insight into the interplay between professional and socio-cultural phenomena, we integrated the results from both levels of the 2 types of analysis to form a third analytical level. This integration of our findings, first with each other and then together into a wider framework, provided a meta-perspective from which to examine the connections between experience, judgment and action.

Discourse Analysis

We used Ricœur's reflections on discourse as a speech event to guide our discourse analysis: discourse is an exchange of messages utilizing language, taking place between specific speakers, at a specific moment, in a specific context [8]. In this study, exploring the relationship between a speech event and its meaning involved an exploration of sets of indicators, each of which

Figure 1 Overview of 2 analytic approaches and how they diverge and converge



refers back to senior and junior GPs addressing their "subject": the medical significance of knowing patients as persons. These explorations were based on speech transformed into text, which constituted the first step of interpretation and abstraction. As these texts were already de-contextualized, they were regarded as autonomous.We describe and compare indicators of similarities and differences in the first level of the analysis as they are expressed in structures and in the second level of the analysis as they are expressed in linguistics. On the micro-level, we examine language, syntax and metaphors, inspired by Potter who defines discourse analysis as "an analytic commitment to studying discourse as texts and talks in social practices" [29]. At the third level here, as with the third level of the phenomenological-hermeneutical analysis, we integrate the results from both levels of the 2 types of analysis in order to achieve a meta-perspective.

Research Ethics

The encounters occur on the basis of voluntary participation of competent individuals who have consented to sharing both verbal and written information. The research protocol was submitted to the Regional Committee of Medical Research Ethics, but formal approval was not required.

Results

Part A: Phenomenological-Hermeneutical Analysis

Interpretation based on the doctors' self-understanding

The first level of inquiry revealed that all GPs refered to themselves as competent agents in roles and functions defined by 3 types of professional relationships.

Firstly, their relationships with their patients. These were characterized by knowledge which increased over time, thus improving the GPs' capacity to identify patients' contextual and individual needs; this was expressed implicitly in the growing number of patient histories and their increasing level of detail. These relationships involved closeness and mutual trust, which, according to the doctors, are deemed to be prerequisites for providing the best possible care.

Secondly, the relationships with colleagues and other health professionals. These were described as complex and affected several aspects of the GPs' professional role. Although GPs defined themselves as sources of salient knowledge about their patients, they often experienced their input being devalued by colleagues in specialist care when cooperation or communication was required.

Thirdly, their relationships to institutions of the health bureaucracy. This was exemplified by The Norwegian Labor and Welfare Service (NAV) [30], described as being only minimally oriented toward integrating the GPs' knowledge of patients as persons. The doctors reported a discrepancy between the formally stated support for the GPs' role as crucial to bureaucratic procedures concerning individual patients *versus* the limited influence they actually have in most cases. As one of the senior GPs articulated explicitly, they feel trapped "as hostages in this damned role."

Interpretation based on general understanding - the object-centered approach

The second level of inquiry indicated that the GPs knew many of their patients' personal backgrounds and social relationships very well. This familiarity assisted them in making appropriate and satisfactory assessments in specific situations.

The doctors identified structural phenomena prohibiting their salient knowledge of patients as persons from being considered in medical contexts: a) electronic patient records are not designed to accommodate or nuance this kind of knowledge; b) a "standard" consultation, as defined by the reimbursement system, does neither encourage GPs to have in-depth dialogues with a patient presenting complex health problems, nor to create a comprehensive record of the patient's history and life circumstances; c) GPs lack an adequate and authoritative professional terminology in which to articulate the medical relevance of this knowledge; d) lingering social taboos make it difficult to approach sensitive information; e) limitations derive from issues of confidentiality both in terms of patient information and third party interests; f) there is no system for routinely involving a patient's GP during admission to and discharge from nursing homes.

The experience of being marginalized may result in GPs refraining from passing on knowledge to which they attribute significance. They acknowledged, however, that such passive resignation is likely to contribute to further marginalization of medically relevant personal knowledge about patients.

The GPs also discussed contexts where a lack of knowledge about patients as persons has an impact. A patient who appears needy and dependent during an office visit may present quite differently during a house call. A temporary GP substituting for a doctor well-acquainted with a certain patient's life story may experience difficulties, especially if what is known about the patient through experience has not been noted in the written records. GPs with the responsibility to sign nursing home death certificates for patients with whom they are unfamiliar may find that written records lack not only medically and socially relevant information, but also the simplest biographical information, such as the patient's occupational history.

Interpretation based on general understanding – the subject-centered approach

The doctors questioned the impact of external, non-medical structures on their professional actions, for example, their communities' political priorities. They did not, however, explore why they refrained from challenging or opposing these systems. They did not perceive themselves as influential and therefore saw their responsibility for these priorities and their outcomes as limited.

The GPs recognized sources of conflict within the system and indicated that they often found themselves involved in what they termed the patients' "fight with the system". They made it clear that stakeholders and decision-makers ought both to adopt a more holistic perspective and to practise flexibility when that is obviously indicated. They admitted that such conflicts tax their personal energies and lead to "exhaustion", inclining them to choose the "easy way" in order to manage their daily workload. They were aware that such adaptive strategies might appear as docility or disinterest when seen from outside; deeper explorations, however, demanded more time and commitment than they had at their disposal. This encouraged pragmatism, despite the GPs' explicitly stated wish, emphasized by expressions of indignation and hints of professional disobedience, to spend their time, effort and competence in more appropriate and productive ways:

> "When we feel exhausted during office hours, we all know that we regress. We don't explore any more, we act . . . You stop all explorations because these obligate you so much more." (S1)

> "It takes its time - you need perhaps, let's say, to change your course - yet it's much easier just to get things done - just act, in a way." (S2)
>
> "Say, we cut out one dialogue-meeting [30] a year and rather use this time for following one of our patients to a nursing home - just make a small revolution here." (S3)

Part B: Discourse Analysis

Structural Features – external

A comparison of the 2 interview transcripts showed external, structural differences: (a) the length of the texts (26 pages for seniors *versus* 13 for juniors); (b) the duration of the discussions (87 *versus* 53 minutes); (c) the number and length of coherent narratives from individual participants; (d) the duration of thematically distinct reasoning; (e) the course of the debate as reflected in shifts: in turn-taking, breaks, hesitations and in sections with overlapping speech & (f) the frequency and extent of the researcher's (BPM) verbal contributions.

Further differences relate to: the seniors' starting immediately after the introduction; the substantive nature of their contributions; how numerous and detailed their narratives were; how wide the range of associated topics they opened which led to new arguments and issues; the absence of pauses in the flow of their talk and the infrequency of the researcher's interventions.

In contrast, the juniors: hesitated long before responding to the introductory story; related few narratives of considerable length; expressed themselves briefly; failed to introduce new topics on an associative basis, adhering primarily to themes inherent in the opening vignette; fell silent frequently and often asked for further guidance.

The juniors' discussion was characterized by very orderly turn-taking. Even without the leadership of a chairman, there was almost no overlapping speech. The seniors' talk, in contrast, was at times mutually interruptive, which, on a few occasions, interfered with the researcher's attempts to ask validating questions. These findings are supported by field notes such as, "a heated discussion with much intense engagement among participants; competing for the opportunity to speak; many hands up". None of these phenomena were observed during the juniors' interview.

Structural Features – internal

Our subsequent comparison of internal structures reinforced the impression of inter-group differences on this level in addition. The seniors repeatedly developed their own topics. They discussed these extensively, in thematically oriented debates characterized by differing or opposing opinions, challenging each other for clarity and they did not hesitate to have their views and arguments validated or rejected. The juniors, in contrast, adhered closely throughout their conversation to the core medical topic introduced by the researcher: a patient's dementia accompanied by, in medical terms, confabulations. The juniors did not introduce thematically related topics during their discussions and never overtly disagreed. Instead, they tended to talk together repeatedly in pairs, in separate and harmonizing dialogues, apparently seeking one another's support for, or confirmation of, their own views. These dialogues might reflect doubts as to having comprehended the "task at hand" correctly. This assumption was supported in the documentation: the juniors lead a circular discussion, the result being that, towards the end of the interview, the researcher felt obliged to repeat parts of the introduction and again clarify the purpose of the interview.

Linguistic Features – language

After having been introduced to the opening narrative, a participant in each group responded by volunteering a narrative based on personal clinical experience. The internal consistency, details and plot of both narratives confirmed that the narrating doctors had grasped the core of the introductory story and its purpose as intended by the researcher. Despite this consensual interpretation, the talk in the groups led in different directions, representing opposite perspectives. The seniors added 2 similarly detailed stories to the first narrative, introducing other themes relevant to the topic, "concepts of knowledge," which they had been asked to discuss. The juniors returned instead to the introductory narrative and discussed "dementia" as an issue and as a practical, clinical challenge, rather than relating examples from their own experiences with patients.

The groups also differed in relation to the use of concepts and definitions. The seniors acknowledged and accepted the stated definitions of "knowledge of human nature" and "knowledge of patients as persons," and seemed to take the medical relevance of such kinds of knowledge about patients as given. The juniors seemed uncertain of how to understand the concepts and how to value these kinds of knowledge. While the seniors used indicative language and referred to shared categories and unifying concepts (e.g., types of relationships and their significance), the juniors used tentative formulations and described a variety of constellations separately or episodically.

Linguistic Features – syntax

The speech of the 2 groups differed syntactically and conclusions may be drawn from the patterns of these differences regarding the levels of participant's self-confidence *versus* insecurity, their certainty *versus* uncertainty. While the seniors tended to utter complete sentences and to present coherent arguments, the talk of the juniors was characterized by frequent incomplete sentences, interpreted as demonstrating the speakers' need to search for proper terms or adequate words. The juniors made their statements hesitantly, often correcting themselves. Also, they frequently used modifying particles and phrases, rendering their statements less convincing and trustworthy. Extensive use of the plural and of impersonal rather than personal pronouns, of the passive form rather than the active and of tentative rather than indicative formulations, all contributed to the impression that the juniors felt a need to safeguard themselves by "moderating" and "generalizing" their statements and through maintaining personal distance.

> "Because - the thoughts that you have in your head - in a way that - you don't have - you don't know the truth - can't be sure that this is the truth. It's a little bit like - others have to be or become familiar with the person themselves - that's the way you're thinking." (J2)

> "I believe that they - at least when the patient has been there for a while - they in some way have to - and when the staff or the health personnel is stable - so you get - yes - it's secondary information then - what I have is a lot of - it's been through a filter already - but - I think this is useful anyway." (J1)

Linguistic Features – metaphors

The talk of the juniors differed from that of the seniors also in relation to the use of metaphors and associative language. Although the seniors utilized various clichés, they conveyed special traits of specific patients and characteristics of local circumstances through the use of powerful metaphors inspired either by medical technology or the doctor's and patient's life world. In other words, they used "lyrical elements" similar to fiction or poetry. Metaphorical language is used to give life to professional experiences with specific patients and therapeutic situations. It is also used in comprehensive descriptions of collaborations between the levels of the healthcare system and of communication with the healthcare bureaucracy. The talk of the juniors contained almost no metaphorical or associative language. Their statements were dominated by a professionally informed vocabulary and medico-specific terminology. They were thematically oriented toward a limited spectrum of the situations encountered during the daily work of general practice and in interactions with other agencies or stakeholders in the healthcare system.

Exploration and Reflection

What follows is an integration of the 2 strands of inquiry, phenomenological-hermeneutical and discourse analysis, relating them to theoretical frameworks relevant to the similarities and differences elaborated so far and identifying the values upon which the texts are based.

Different ways of knowing

Both groups spent most of the time exploring different ways of knowing as these apply to everyday general practice settings. These included regular encounters with patients as well as interactions, collaborations and communications with other agents in the healthcare systems representing both specialist institutions and the health bureaucracy. The groups acknowledged the relevance of discussions of various knowledge traditions increasing their awareness of the premises underlying their own professional actions. They carried on several discourses, both as intertwining strands and as strands they followed separately. All of these were closely connected to self-experienced, concrete, daily tasks and realistic challenges in their professional lives. The discourses related to the biomedical *versus* the humanistic, the theoretical *versus* the practical, the objective *versus* the subjective and the ethical *versus* the legal. Both seniors and juniors associated medico-ethical considerations with the various types of knowledge in discussion. Thus, different ways of knowing and their various ethical aspects were at the core of both groups' conversation.

The seniors were confident and quite unambiguous about the special significance of knowledge about patients as persons. They perceived an implicit necessity to communicate this knowledge, in addition to strictly biomedical information, to professional colleagues in general, but especially when elderly patients are admitted to nursing homes:

> "I'm sure that when talking about the patients I really know best, I would manage within only 30 minutes, to communicate some of this 'software-knowledge' to those who need it, which would give them a fantastic platform to build on." (S2)

> "We use assessments all the time. It's done with a lot of knowledge and - for that matter - with a lot of wisdom. There are no other professionals within the healthcare system that could do this with the same degree of wisdom. Not necessarily because we are that wise, but because everybody else is so concerned with following the rules. That's what we are good at: to act in accordance with rules, but still manage to be flexible and adaptive and make wise decisions." (S7)

The juniors were also convinced that they held relevant and significant information about their patients as persons. But they obviously struggled with how to document and manage this knowledge and with whether it was appropriate to record it - it was based on their own accumulated experience with each patient and, as such, was subjective knowledge and therefore not "medical" in the strictly traditional sense:

> "You have a lot of information about matters which you choose not to record; for instance about alcoholic parents. You just record it as 'difficult childhood' without any further details." (J2)

> "Things that you experience regarding [the patient's] personality, characteristics and manners - it would be almost insulting to record - because it is subjectively acquired knowledge, which has nothing to do with medical diagnosis, treatment and assessment." (J1)

The juniors were clearly not accustomed to framing the social or relational aspects of their professional experiences. They were aware of encountering them on a daily basis and acknowledged the impact of their patients' life world on their own professional acts:

> “You may record ‘family conflict’ or something very ‘small’ - and then you actually know about her family and the importance of childhood experiences on present health problems.” (J2)

The juniors experienced a conflict between the obvious relevance of knowing patients as persons and their professional training which often attributes validity only to objectively acquired knowledge. This mirrors the ongoing debate in the philosophy of science and in medical epistemology concerning the traditional dichotomy between a normative *versus* a naturalist concept of health and disease [31]. The juniors were bewildered about the basic criteria for professional conduct and reasoning. They worried that they might encounter problems if they take a stance that is not solidly anchored in authoritative, professional knowledge; in other words, in objective, biomedical knowledge. Feeling committed to this knowledge tradition, they perceived that their own, subjectively acquired knowledge about social or relational aspects of a patient’s life, has no legitimate place in the formal transfer of information.

> “If I’m going to give a nursing home a summary of [my knowledge] about a patient, it would be about diseases. I would not pass on information concerning things like sick leave due to a conflict at work or in the family or feeling depressed. I regard this as social knowledge about the patient - which has not developed into disease.” (J2)

> “I have to say, though, that I draw my own conclusions, when I experience patients my own age visiting the doctors’ office frequently. Of course, now and then you’ll think that this has to do with something more than just the somatic disease. But you don’t record these thoughts! Nevertheless, these thoughts could be of important medical relevance to recognize how the patients experience the disease, the discomfort. It’s obvious that the next caretaker would benefit from having the assessment you have done there: Is this hypochondria or is it real?” (J5)

Juniors seemed to presume that the dividing line between the objective and the subjective was identical to the line between what is relevant and what is not. The seniors had a different perspective:

> “Now we’re discussing the concept of medical relevance beyond what we traditionally consider this to be; like measuring the blood pressure to be 160/80 [mmHg]. If things were that simple it would be easy! But then you have all these other circumstances ‘surrounding’ both the blood pressure and the diseases and the complaint about headaches and stomach aches . . . One of my patients has still not recovered from his son-in-law killing himself driving a car; the accident made him become ill - he is diseased by it . . . You won’t be able to find it on a CT scan, that he still feels bad about it.” (S5)

Conflicting Values

Implicit in the discourse about what kind of knowledge is defined as objective, valid and real, as compared to what kind of knowledge is defined as subjective and inter-subjective, is a discourse about values. Both juniors and seniors were unambiguous as to their professional obligation to administer and use the knowledge they have acquired and have access to, as best they can. The GPs expressed a strong and fundamental sense of responsibility. It was their central ambition to judge and act on the basis of knowledge that is correct and to apply this knowledge in a proper manner. They showed a clear awareness of professional and legal frameworks. The groups voiced diverging opinions, however, as to what should guide their decisions within these given frameworks. They also disagreed as to the fundamental appropriateness of the framework upon which the mandate of the medical profession and a doctor’s clinical practice rests.

Taking a critical stance toward the very framework of the discipline of medicine, the seniors did not ask: “What is correct to do?” They appeared oriented primarily toward ethics: “What is right to do?” They explored in detail the structures steering their work, which of their tasks the political and administrative forces would have them prioritize, as opposed to which tasks the doctors themselves would prioritize had they the power to decide. Here, they described an area of conflict revolving around various obligations, including mandatory participation in certain meetings:

> “It is always extra, extra, and extra - but I feel the need to say: Enough - now we have to prioritize. Are we going to participate in yet another dialogue meeting requested by NAV [30] or in a meeting at the nursing home? On the one hand you have a really sick person - on the other a healthy person struggling with a problematic life situation. Try to balance these two against each other. And I believe that it strengthens our legitimacy as doctors if we are able to clarify that we actually do belong with the diseased person, emphasizing the kind of knowledge that only we as GPs are able to provide.” (S2)

> “Just return to those old ethical rules of ours; there is something about ‘effort where the suffering is greatest’ and especially those persons on the brink of becoming incompetent, close to losing their overview. But what we are instructed to do - is to use our time as GPs to negotiate between employer and employee in a conflict far away from the issue.” (S7)

The seniors perceived themselves as managers of knowledge also regarding their own contribution to medical record documentation. They were aware that producing these (usually electronic) documents may challenge them to draw a line between what other agents or third parties may rightfully demand access to and what they themselves may consider inappropriate for disclosure:

> “I have told you the story about when I was accused of malpractice in connection with a woman who died of cancer. It [the accusation] was not related to incorrect

> medical treatment, but her husband held that misconception and demanded access to her patient records. Because I refused him access, I was reported to the police, to the public prosecutor and the Director of Public Prosecutions. I even denied the police access unless they reached a verdict. And the background for this was that this woman [the patient] had been expressing for years that her main problem in life was her "husband from hell". Consequently, I repeatedly recorded: 'The same complaint as always - her husband is pestering her to death!' I could not give this husband access to her journal - that would definitely be contrary to her interests." (S5)

One of the seniors related the condensed and anonymous story about a patient who had been raped. After the violation, she had developed chronically recurring urinary tract symptoms, but without any objective findings to confirm a bacterial infection. The information about the assault, however, was not given to the doctor by the patient herself but, in confidence and without her knowledge, by her husband - who was convinced of the significance of the rape experience to his wife's chronic illness. The senior argued for both a specific medical intervention (prescribing antibiotics to "treat" or relieve her symptoms, although not appropriate in strict, medical terms) and for communicating this treatment strategy to doctors in charge of this woman's care in the future, as they will most likely encounter the same "unexplainable" (from a traditional, biomedical perspective) complaints:

> "But it still matters for her [life] - and with regard to her welfare - even when I am not responsible for her follow-up - I think it is important that the consulting physician at the nursing home actually understands and knows about this - without necessarily bringing it up face-to-face with the patient herself." (S2)

Ethics *Versus* Law

Through various self-experienced, practical examples, the juniors also explored how best to reconcile concepts of knowledge, medical documentation, mandatory tasks or acts, with professional values or, rather, they explored how these issues may be in conflict with each other and therefore a source of daily disputes. The juniors' main concern was to record professional choices or advice in ways that rendered them unassailable and which limited their legal risk, as expressed in the excerpt below from one of the previously mentioned separate dialogues:

Excerpt 1 Conversation between two junior GPs

J2: Yes, and then you don't record: 'The patient is dull, does not stick to agreements - better to make a regular appointment'. You don't record things like this, it has to be acceptable - because - well you know – the patient has a right to read her medical record.

J5: Yes - and that was what I recorded in the journal: 'Today the patient came late for her appointment - she was so and so late. Did not seem to understand that she then had to wait for 1½ hours - to avoid delay for other patients who were on time'.

J2: Mm, mm [signaling agreement].

J5: But this is a patient with - a kind of special diagnosis and – sometimes I actually do record things like this.

J2: And it's a kind of defense or evidence for the future - let's say – if she would want to complain about your treatment that day.

A concern about being open to blame or accusations based on professional judgments or choices also informs a debate about investigations conducted by other professional agencies regarding one's "own" patients. Here, the juniors displayed considerable insecurity, expressed as hesitating or even refusing to expose their personal opinions, particularly in settings where these might be entered into medical documents as their professional utterances:

> "I guess I would have been a little bit reluctant to submit some of my subjectively acquired experiences with the patient - because there probably is more than one answer - and the thought of someone recording this somewhere - that could be a bit unpleasant." (J1)

> "You know, when referring a patient to a psychiatric ward - I often experience that the doctor in charge calls me to get some more information - and then I feel it natural to tell my candid opinion. But I always emphasize that this is my opinion. It may be incorrect - or a subject for a discussion." (J4)

The juniors evidently shared a need for adhering to guidelines which are normative for their professional practice. The following narrative makes explicit an underlying preoccupation with avoiding potential accusations or lawsuits in the wake of situations characterized by professional doubt or conflict:

> "When we are talking about being quoted and being responsible, I actually have experienced that in connection with a case involving a child - that my talk with the emergency clinic was forwarded. They [referring to health personnel at the clinic] articulated some kind of concern about the child of a female patient - and I probably said that I had also had the same thought. That was all I ever said! . . . Experiencing a thing like this makes you skeptical about what kind of knowledge you forward to other people. You know, it was just one of those 'gut feelings' - only an intuition about being skeptical towards her [the patient/ mother].

> And I think it is the same as if they call you from the nursing home asking like that - I think I would have been more reserved." (J2)

Wider Frameworks

A clear difference emerges from the inquiry in the 2 strands of group-discussions based on the same questions. The key to understanding this difference is the extent of professional experience in the sense of accumulated knowledge of a particular kind. Professionals from the same field within the healthcare system, namely General Practice, display discourses that reflect opposing social theories. After presenting numerous examples of applying the medical gaze as a "situated gaze" in similar ways, characterized by closeness to the patient and by insight into lived life, the doctors' perspectives then seemed to diverge: the more experience they had, the more critical they were. The doctors as groups, as social systems, enter a wider debate and a more profound discourse, one that has been delineated by philosophers [32]. At the core of this debate is the question of how social systems secure change or maintain basic structures. Habermas [32] proposes a theory of emancipation by means of conflict-oriented critical stances furthering disclosure and of identification of suppressive structures. Luhmann's theory, on the other hand [32], propounds consensus as a means to establish, re-establish and maintain social systems, as exemplified by the healthcare system.

Within this wider frame, our analysis indicates what may, at first, appear to be a paradox or to contradict commonly held beliefs: the seniors are the more "rebellious". That is, in a field in which one experiences the impact of lived life, for better or for worse, the seniors more overtly voiced a demand for emancipation from both an ontology and an epistemology suppressive of life world knowledge. Thus, accumulated, lived experience - termed in other traditions than the biomedical as "Wisdom" - may supersede legal frameworks. The aim of achieving an accurate understanding, related to one instance of a phenomenon, by focusing on the human life world and on systems of personal values (as in the humanities), may take precedence over the aim of finding a correct explanation, generalizable to other instances of the phenomenon (as in the natural sciences). The professional value of clinical experience with patients over time may seem like "common sense" knowledge, but has recently been highlighted in relation to quality assessment by Starfield [33] who argues for a more "person-focused primary care" as do Miles and Mezzich in broader terms for medicine and healthcare in general [34-36].

Reflections on Validity

Kvale emphasizes that Ricœur describes validation as a discipline involving argumentation - comparable to how courts interpret the law; it is always possible to challenge an interpretation [5,37]. A validation of our argument, that the key to understanding the differences between the 2 group discussions is the extent of the GPs' professional experience, must take differences in group history and dynamics into account. The seniors have explicitly chosen to stay together and mature as a group and have known each other for years whereas the juniors were randomly assigned to their group through a waiting-list process and had known each other for only 5 months. These differences might have influenced the discussions and interactions to accentuate the senior GPs' ability and willingness to discuss more freely and openly, as compared to younger colleagues. Still, as also validated through our personal experience as clinicians and clinical teachers, we (the authors) believe that the documented differences between the 2 discourses (seniors and juniors) represent valid and professionally relevant observations and interpretations.

In accordance with the traditions of phenomenological-hermeneutical research, we have made our position explicit and have aimed for methodological transparency. We have integrated the findings using relevant theoretical frameworks to unfold their implicit aspects, well aware that our reading represents only one out of several possible interpretations.

Conclusions and Implications

In this study, we have analyzed how 2 groups of GPs, with contrasting amounts of clinical experience, appraise the medical relevance of knowing patients as persons and of sharing such knowledge in interactions with other health professionals. Both groups were concerned about the lack of emphasis on person-oriented knowledge within the healthcare system in general. The senior GPs, however, were less ambiguous and displayed more authority and independence than the junior GPs. They also displayed a higher intensity of personal engagement, verging at times on professional rebellion. Their arguments were typically grounded in ethics and were critical toward "formalism", while those of the junior GPs referred more often to formal rules and regulations.

Our study allows us to claim that accumulated experience with patients in continuous therapeutic relationships motivates and enables GPs to emancipate themselves from the "biomedical gaze" (in the Foucauldian sense), focused on the patient's disease, to apply a "situated gaze," a way of viewing the diseased person that includes his or her specific life world. This situated gaze transcends scientific detachment and acknowledges the impact of socio-cultural context on health and disease. Implicit in this finding is a considerable epistemological challenge. Indeed, the medical community - including the educational system - cast in the naturalist framework of biomedicine, needs to revise its prevailing concept of knowledge by integrating ways of knowing that more adequately address the clinical tasks within medicine.

Acknowledging the impact of socio-cultural context as a valuable source of knowledge about patients should receive greater emphasis in medical training in general and in General Practice in particular. GPs are the entry point into the healthcare system in many countries and provide the arena offering continuous care to chronically diseased persons, people who are deeply dependent on their needs being accounted for and their best interests being safeguarded.

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The authors declare no conflicts of interest with respect to the authorship and/or publication of this article.

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Paper II

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ARTICLE

What do GPs actually know about their patients as persons?

Bente Prytz Mjølstad MD[a], Anna Luise Kirkengen MD DrMed[b], Linn Getz MD PhD[c] and Irene Hetlevik MD DrMed[d]

a PhD Student, General Practice Research Unit, Department of Public Health and General Practice, Norwegian University of Science and Technology (NTNU), Trondheim, Norway
b Professor, General Practice Research Unit, Department of Public Health and General Practice, Norwegian University of Science and Technology (NTNU) Trondheim; Institute of Community Medicine University of Tromsø & Senior Researcher, Centre for Health Promotion, University Hospital Akershus, Norway
c Professor, General Practice Research Unit, Department of Public Health and General Practice, Norwegian University of Science and Technology (NTNU), Trondheim, Norway & Staff Physician, Landspitali University Hospital of Iceland, Iceland
d Professor and Leader, General Practice Research Unit, Department of Public Health and General Practice, Norwegian University of Science and Technology (NTNU), Trondheim, Norway

Abstract

Background and Aims: Life experience and existential circumstances have an impact on health. Within medicine, however, the significance to patient care of person-related, biographical knowledge receives only rudimentary emphasis and its substantial theoretical underpinnings are inadequately understood and infrequently applied. This study explores the types and extent of some Norwegian general practitioners' (GPs') person-related knowledge, exemplified by patients on the GPs respective lists who are currently in a state of frail health.

Methods: Nine GPs were interviewed regarding one of their patients who had recently been admitted to the rehabilitation unit of a nursing home. Subsequent interviews with the individual patients served both to validate the GPs' information and as a starting point for further inquiry into patient life stories. Interview transcripts were analyzed within a phenomenological-hermeneutical framework.

Results: Most GPs were able adequately to characterize the personality of their patients and had acquired substantial knowledge about their occupation and closest family relationships. The GPs tended to have less knowledge regarding patients' interests, hobbies, social network and their relationships to their parents and siblings. They had the least knowledge about patients' childhood, upbringing and social background. Some GPs reacted with surprise or embarrassment when becoming aware of potentially significant "knowledge holes" regarding patients whom they had known for years.

Conclusions and implications: We document limitations to healthcare professionals' eliciting of knowledge about their patients as persons. A long-term doctor-patient relationship seems to enable GPs to identify and articulate their patients' personal characteristics. It does not ensure that the GPs will accumulate knowledge regarding those biographical facts or experiences that, particularly during transitions to other caretakers, might prove most salient to their patients' health and treatment. We believe the findings to have relevance both for clinical practice and medical education, but further research and reflection is needed before formal changes in current practice are to be recommended.

Keywords

Comparison of interviews, GP-patient relationship, information transfer among caretakers, patients as persons, patient transfer, person-centered medicine, primary care, qualitative research

Correspondence address

Dr. Bente Prytz Mjølstad, General Practice Research Unit, Department of Public Health and General Practice, Norwegian University of Science and Technology, PO Box 8905, 7491 Trondheim, Norway. E-mail: bente.mjolstad@ntnu.no

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Introduction

A growing and increasingly detailed and comprehensive body of scientific evidence documents that lifetime experiences and existential circumstances have a significant impact on human health and disease development [1-8]. Currently, however, there exists within the field of medicine only a rudimentary tradition for gathering, transferring and emphasizing such person-related, biographical knowledge, even in the first line of medical care which is served by general practitioners (GPs). The theoretical understanding of the significance of such knowledge has not yet been thoroughly explored [9-14].

We have recently documented that experienced Norwegian GPs claim to accumulate substantial knowledge over time about their patients as persons. Though they consider such knowledge to be medically relevant, they often find it difficult to formulate and record, both for the immediate patient record and for potential transfer to other actors and institutions in the healthcare system [15].

A concrete situation in which the transfer of such patient-related knowledge lacks a formal channel for emphasis, despite its potential relevance, is when an elderly and/or otherwise frail individual is being transferred temporarily to a nursing home for rehabilitation. In Norway, as in many Western societies, the increasing number of aging and elderly frail people poses a major challenge to the public health system. Even though today's elderly are in better health and function at a higher level than those of previous generations, the cognitive and functional impairment and multiple chronic diseases [16] which often accompany old age are likely to result in an increasing proportion of the population ultimately requiring extended primary healthcare services. According to national surveys, most Norwegians prefer to live at home rather than in a nursing home for as long as possible [17]. By prioritizing home-based, primary care, the government seeks to reduce or postpone individuals' need for long-term facilities. Most elderly people living at home function well and can take care of themselves, often with the support of family members and/or municipal home-visit services. Yet, an acute disease or sudden change in life circumstances may critically impair functioning such that short-term rehabilitation and/or a temporary stay at a caretaking nursing home [18,19] become necessary. Most likely, an increasing proportion of the elderly will periodically find themselves "in transit" between their home and an institution. An efficient exchange of relevant knowledge about the patient between the patient's local healthcare provider and the temporary caretaking institution is a prerequisite if rehabilitation during these transitions is to be successful. All citizens in Norway are assigned a GP; this family doctor could be expected to play a central role in the exchange of such information.

Frequently, GPs serve as consulting physicians in nursing homes and, consequently, often participate both in the rehabilitation of disabled and/or chronically ill people of different ages and in the end-of-life care of frail, elderly people [20]. A nursing home doctor (GP or geriatrician), however, particularly one working in more densely populated urban settings, rarely has previous knowledge about patients admitted for rehabilitation.

Medically relevant knowledge, according to the traditional view informing the biomedical basis of contemporary Western healthcare systems, utilizes observable and measurable variables. These facilitate the objectification of bodily functions and symptoms based on the current, established classification systems for diagnosing somatic and mental diseases. Within this natural science framework, human subjectivity, the patient's world of personal experiences, values and relationships, is rarely assessed or treated as relevant [21].

The comprehensive body of knowledge linking the subjective phenomena of personal experience to human health and disease draws upon a variety of scientific disciplines, including, among others: stress research, psychoneuroimmunology, genomics and telomere research. The emerging evidence affirms the impact of someone's biographical experience - her/his interpersonal relationships and human life-world - on that person's body, both its physiology and its functioning. This attests to the fact that mind informs matter. Or, put more concisely: *the evidence shows that mind matters* [6-8].

In other words, knowledge about "the biological body" in a purely physical and biomolecular sense, might not suffice to capture the essence of a person/patient's functional breakdown or to permit an appropriate characterization of her/his actual needs. To accomplish those goals, knowledge about "the lived body" (the person's embodied life) needs also to be attributed relevance.

Motivation for this Project

For several years, the first author of this paper alternated between working as a GP, providing primary care to the patients assigned to her practice list and serving as a consulting physician in a nursing home. From these 2 perspectives she was able to observe that information about the personal lives of patients admitted to institutional care seemed to be "lost in transition." Typically, the GPs' referrals included *biomedical knowledge about the patient* (a medical history and status, list of medications, *etc*.) but only rarely *biographical knowledge about the person* beyond strictly demographical data such as gender, civil and occupational status (e.g., life history, salient events, significant relationships, *etc*.). In her role as GP, the first author experienced repeatedly how central relevant biographical knowledge could be to understanding the circumstances surrounding a sudden deterioration of health. This observation is supported by the writings of the late Barbara Starfield, an authoritative, international primary healthcare researcher [22].

The overall aim of the larger project to which the present study belongs is to explore the medical relevance of person-related knowledge. The project consists of 3 consecutive phases. In the initial, exploratory phase, 2 groups of GPs were invited to reflect upon and discuss the potential significance of having knowledge about their assigned patients as persons. The participating GPs in that study were confident that they possessed medically relevant knowledge about their patients' life-world, for example, in the case of admission for rehabilitation [15]. In this second part of the project, as outlined in this paper, we explore the knowledge the GPs *actually* have about their patients as persons by comparing the information the GPs share to the narratives offered by the patients themselves. In a third paper, in preparation, we will compare GPs' proposed aims for their patients' institutional stay (as communicated to the researchers during telephone interviews) with the actual treatment plan that the staff of the rehabilitation unit eventually developed.

Theoretical Framework

A combination of phenomenological and hermeneutical principles (interpretations) [23-25] provides a research framework well suited to exploring and reflecting upon human experience within medicine and medical practice, investigating what GPs know about their patients as persons and comparing that to the patients' own account. The methodological perspective of phenomenology facilitates entering into the interviewee's world of subjective and personal experiences without disturbing the context in which these manifest. Since an investigation of human experience as communicated through first-person accounts involves an exploration of value systems and of symbols as they are conceptualized and expressed in language, both spoken and written, the researcher is well served by being conversant with hermeneutics.

For our conceptual differentiation of a "patient" from a "person," we have relied upon Eric Cassell's definition, distinguishing a philosophically-based state of personhood from the social role of patient, one which is imposed by disease and defined by pathology-oriented biomedicine [26]. According to Cassell, a person is "an embodied, purposeful, thinking, feeling, emotional, reflective, relational, human individual always in action, responsive to meaning and whose life in all spheres points both outward and inward. Virtually all of a person's actions - volitional, habitual, instinctual or automatic - are based on meanings" [27]. Since meaning and personhood are mutually constituted, statements about persons are statements about values and social phenomena.

Method

The present study was conducted at the rehabilitation unit of an urban nursing home in central Norway. The recruited patients had been admitted for a short-term stay (2-3 weeks) due to some impairment to their ability to function in their home setting. Potential participants, deemed competent to grant informed consent, were identified by the unit staff, told about the existence of the study and, finally, asked to sign written consent forms. Only then did the first author contact those patients' regular GPs to request their own agreement to participate in the study.

Once both the patients and GPs formal consent had been obtained, the first author scheduled a 10-15 minutes' telephone interview with the GP, focused on the topic: "*What can you tell me about patient NN as a person that might have relevance for this stay?"* The GP interview was structured (see interview guide, Figure 1), audiotaped and transcribed, *verbatim*, by the first author. A face-to-face interview was conducted with the patient shortly after the GP interview, lasting typically for one hour. Each patient interview began with the first author presenting a condensed version of the information that their GP had shared with the researcher and granted explicit permission to share with the patient. The patient was encouraged to correct, deepen or supplement this information immediately. Field notes commenting on interview settings and interviewees' nonverbal and/or paraverbal responses (voice tone, pitch and pacing) completed the data sets for each of the study's patient/GP participant pairs.

The Regional Committee for Medical Research Ethics for Central Norway approved the overall project, including the present study. All participating patients and GPs received written information and supplied, as required, their signed, informed consent prior to being included.

Figure 1 The topics of the interview guide. The order of the topics varied among the interviews

What can you tell me about this patient as a person – with relevance for this stay?

- Personality
- Relationship to immediate family (spouse, children, partner)
- Occupation - working life
- Life events (significant/ important for health/ illness)
- Interests - Hobbies (leisure activities)
- Social network - friends, acquaintances
- Relationship to parents and siblings
- Social background – childhood, upbringing (origin)

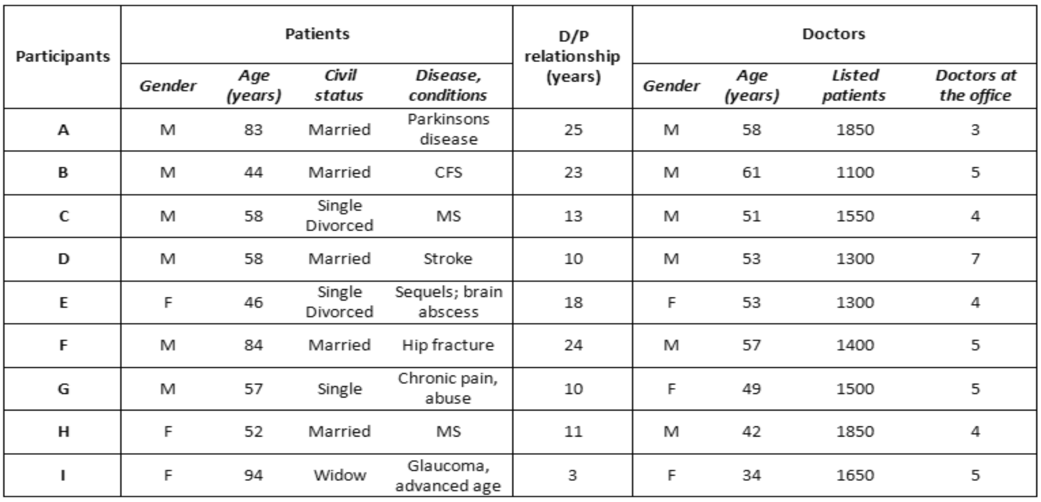
Participants

Patients invited to participate in the study were living at home, were expected to return to their homes after rehabilitation, whose relationship to their current GP had been ongoing for more than 2 years and who were competent to provide informed consent. Eligible patients were added consecutively. Professional information about the GPs (age, number of assigned patients, number of doctors sharing their offices) (Table 1) was compiled from official registers.

Analysis

In a previous study [15] we focused on what, in general, it is like to be a GP who knows her/his patients' biography and especially when cooperating with other parts of the healthcare system. In the present study, we investigate more concretely what person-related knowledge GPs actually tend to have. We found it relevant to exemplify this by focusing on patients on the GPs' lists who were currently in a vulnerable state of health, documented by the fact that they had been admitted for rehabilitation. Our analytic approach is inspired by Kvales' tri-level phenomenological-hermeneutical analysis. The findings in this paper involve primarily his second and third analytical level. Level 2 involves interpretations based on general understanding and common sense; this is double-layered, being both subjectively and objectively focused.

Table 1 Characteristics of the participants



Participants	Patients				D/P relationship (years)	Doctors			
	Gender	*Age (years)*	*Civil status*	*Disease, conditions*		*Gender*	*Age (years)*	*Listed patients*	*Doctors at the office*
A	M	83	Married	Parkinsons disease	25	M	58	1850	3
B	M	44	Married	CFS	23	M	61	1100	5
C	M	58	Single Divorced	MS	13	M	51	1550	4
D	M	58	Married	Stroke	10	M	53	1300	7
E	F	46	Single Divorced	Sequels; brain abscess	18	F	53	1300	4
F	M	84	Married	Hip fracture	24	M	57	1400	5
G	M	57	Single	Chronic pain, abuse	10	F	49	1500	5
H	F	52	Married	MS	11	M	42	1850	4
I	F	94	Widow	Glaucoma, advanced age	3	F	34	1650	5

CFS = chronic fatigue syndrome; MS = multiple sclerosis; D/P relationship = duration of doctor/patient relationship ;
M = male, F = female

Level 3 aims at understanding these findings through the application of existing theories [23]. Our analysis' point of departure was a comparison of GPs' statements regarding their patients as persons (Figure 1) to those made by the patients themselves, in order to assess the GPs' familiarity with various aspects of each patient's life. The integration of the findings into theoretical frameworks (level 3) is presented in the discussion below.

Results

Characteristics of study participants

From February 2010, through April 2011, 25 eligible patients were admitted to the rehabilitation unit directly from their homes (not from other institutions or hospitals). Sixteen of these patients were excluded from this study due to: administrative lapses (6), incapacity to consent (4), a preference for not participating (3 patients and 3 GPs). The remaining 9 patients and their respective GPs were enrolled, consecutively, in the study.

Selected characteristics of participating patients and GPs are presented in Table 1. The mean patient age was 64 years (44-94 years) and that of GPs was 51 years (34-61 years). The mean duration of the doctor-patient relationships was 15 years (3-25 years). All doctors were experienced GPs working full time at healthcare centers with at least 2 colleagues. Only 2 of the admitted patients shared the same primary diagnosis (multiple sclerosis).

Comparisons of statements

The following is an annotated presentation of our comparison (second analytical level) of the GPs' statements regarding various aspects of their patients as persons, with the patients' corroborations.

The GPs' statements concerning their patients as persons

Aspects of their patients' lives about which the GPs have comprehensive knowledge

Nearly all GPs described the *personal traits* of patients in a way that was later validated by the patients themselves. Most GPs were also quite familiar with each patient's *immediate relationships* and *occupational life* (Figure 2).

Personal characteristics of their patients

In the following excerpt from a dialogue between the interviewer (I) and patient A (PA), the interviewer recounts GP statements concerning some of the patient's characteristics, which are corroborated by PA:

> I: I asked your GP how he would characterize you as a person. He responded in a nice way, stating that: "PA – he's very steady and firm. A steadfast man."
>
> PA: Yes. [smiles]
>
> I [continues to quote]: "I think he must have been a fantastically good Captain - very conscientious, steady

> and firm.” He also stated that he believes you’re “not someone who enjoys talking about things – but rather prefers to keep things to himself.”
>
> PA: Yes, that’s right!
>
> I: And: “He’s someone to be trusted…”
>
> PA: Yes.
>
> I: Can you recognize yourself in this description?
>
> PA: Yes, I can! [sounding a bit astonished]

Relationships with immediate family (spouse, children, partner)

Although patient E’s closest family relationships are quite complex, when asked about this topic the GP easily provides extensive, detailed yet concisely expressed information:

> “She lives alone in her own apartment, has 4 children with her ex-husband and one child with her latest ex-partner, but she’s not capable of caring for these children on a daily basis. The children from her first marriage are old enough to visit her on their own – but she has limited contact with them. Or, more precisely, she doesn’t have custody of her youngest child, who was born in April, 2007. The 4 older children live with their father – her ex-husband. That is, the oldest son lives on his own. So there are 3 children living with the ex-husband – and the youngest son lives with his father.”

In an excerpt from the dialogue between the interviewer (I) and patient E (PE), the patient corroborates this information as follows:

> I: So you live alone - and your GP told me that you are the mother of 5 children?
>
> PE: Yes, I am!
>
> I: And that 4 of these children live with your ex-husband?
>
> PE: Yes – and he’s Norwegian.
>
> I: … and that you also have one child with another man?
>
> PE: Yes – and he’s Finnish!
>
> I: And the youngest child is a 3-year old boy?
>
> PE: 3 ½- years old. His name is “Tom.”
>
> I: But your GP also told me that, after falling ill, you’ve experienced difficulties taking care of the children on your own?
>
> PE: Yes. But they visit me frequently; they’re between 3 and 20 years old.

Occupational life

General practitioner C’s information concerning patient C’s occupation includes a description of the patient as a person and how the disease has affected him:

> “Before he fell ill, he was a likeable person with a lot of empathy and compassion and plenty of resources. He had lots of interests and hobbies; he used to be a long-distance runner and trained to run marathons, but motorcycles were his main hobby. I got the impression that he had a lot of friends and a passion for soccer – both English and Norwegian soccer teams. He used to work as a therapist at a rehabilitation center and took care of people who abused drugs and alcohol. He very much enjoyed his work and his colleagues supported him a lot when he got ill. They put him to work for a while – even working nightshifts though without salary – so they wouldn’t lose contact. For some time, they also had him making contact with clients by phone. Gradually he became incapable of working, went on sick leave and finally on a disability pension. He hasn’t been able to perform any work for the last 3 years.”

In the following interview, patient C both corroborates and corrects this information:

> I: GP C mentioned your occupational life; as far as he could remember – and before you got sick – you used to work at X rehabilitation center?
>
> PC: No – it was X *treatment* center
>
> I: Treatment center? Yes, that’s something different!
>
> PC: Yes – it’s active treatment for substance abusers.
>
> I: Yes. He told me that you used to work there as, “a therapist who took care of people with drug and alcohol abuse.”
>
> PC: Yeah – that’s a way to put it.
>
> I: And he told me that you enjoyed your work?
>
> PC: Hmm – yes - I had a great time working there! I had *a lot* of good friends there as well.
>
> I: And GP C had noticed that your colleagues at work supported you a lot after you became ill?
>
> PC: Yes – that’s right! [Memories apparently come back; his face brightens up]

Aspects of their patients’ lives about which the GPs have limited knowledge

Significant holes in the GPs knowledge regarding earlier *major events* in their patients’ biographies were revealed in several of the paired interviews. Our use of the term “significant” here refers to the fact that the experiences and events in questions have documented medical relevance to health. In addition the GPs tended to have little knowledge regarding the patients’ *interests, hobbies and social network* or of their patients’ *relationships to their parents* *or siblings*. The GPs had least information regarding the patients' *childhood, upbringing and social background* (Figure 2).

Major life events with probable relevance to health

The GPs were asked to relate important events in their patients' lives with probable medical relevance, defined as: major changes or disruptions that could evoke distress (such as divorce or a relationship break-up), serious accidents or the death of a close relative. Most GPs had some knowledge of potentially distressing life events, although they were not necessarily cognizant of the events' inherent relevance to their patient's health. This was the case for GP D who suddenly became aware of a note in patient D's medical record about the long-ago death of a child but was unable to provide any details about this loss. In the successive interview, patient D spoke with the researcher about the death of this son even though this still evoked strong emotions. Without hesitation, he also brought up a related and important, but apparently taboo topic:

> I: GP D found some information in your records – concerning the death of a child. He believed that you had lost a child – but he didn't know how – and believed that this had happened before he became your doctor.
>
> PD: Yes, that happened before. This was something I couldn't talk about at home. The relationship between me and my wife wasn't strong enough for that, because the child was the result of infidelity. The boy died in an accident when he was 5. The boy's mother and her family refused to notify me of his death. I had to go to the police to have it verified. They obviously didn't want me come to his funeral… [his voice cracks]

Interests and current social network

Most GPs had little or no information about their patients' interests, hobbies, friends and acquaintances; some GPs who seemed uncertain about a patient's social life went on to speculate as to what activities, such as watching TV, that the patient might find interesting. When asked by the interviewer, however, most patients, such as patient D, willingly revealed detailed and comprehensive information concerning their interests and social life:

> I: I asked GP D if he knew about any of your interests or hobbies, and he said he didn't have much knowledge about this topic. He believed you probably enjoyed watching TV and listening to the radio, but didn't know if you enjoyed reading.
>
> PD: Well, reading is okay, but when you talk about TV and especially sports channels – I can watch sports for days and nights on end. I'm interested in all kind of sports – as long as it isn't ice hockey or horse show jumping – but especially biathlon. You know, I've been watching a lot more TV since I got sick, sitting in my wheelchair – because there are a lot of things I'm not able to do anymore. I used to enjoy life outdoors and when I was younger, I was into sports.

Relationship to parents and siblings

In contrast to knowledge regarding their patients' children, spouses or partners, most GPs had only limited information about patients' relationship to their parents and siblings. For example, when the interviewer communicated to patient B the information GP B had reported, he both confirmed it and expanded on it:

> I: I asked GP B about your family when you were growing up. He couldn't recall precisely - but he seems to remember that you had an alcoholic father and that your parents got a divorce. When I asked if you had any brothers or sisters, he couldn't remember.
>
> PB: I have a sister – but we don't have much contact. I was 2 years old when she was born and my father moved out at the same time. I lived with my mother my whole childhood. She remarried and my stepfather was the executive director of a large company in X city, so we moved there. They got divorced when I was 12 and we had to move back again. From that moment on, I had to be the man of the house. During my whole childhood and my teens, my father was there only now and then. When he started drinking – later, after I'd grown up – I had to be the one to straighten things out. I almost had to act as if I was *his* father.

Childhood, upbringing and social background

Most of the GPs had limited knowledge, if any, regarding the patients' *childhood, upbringing, and social background*. The patients all had the physical/mental capacity to discuss such topics and were all, to some extent, also willing to do so with the researcher. Some provided detailed information despite being cognitively affected by their disease, as in the case of patient H suffering from severe multiple sclerosis:

> "I grew up on a farm, living with my parents. I had one older sister and one younger sister and we all had a good relationship, but none of us wanted to take over the farm. My mother lived on that farm until this last year, but then she moved closer to the center of town. She's 84 years old but vigorous! My father died 30 years ago of a stroke. At that time, health personnel didn't emphasize the possibilities for rehabilitation after a stroke – as compared to today's practice. But for him – it probably was for the best that they let him die – because it was so serious."

The fact that the GPs lacked knowledge about their patients' childhoods did not necessarily mean that there was "nothing of medical relevance there to be known." For example, patient A's childhood history might conceivably have had an impact on his health:

> "I was an illegitimate child and my mother died when I was 12 years old. I was adopted by another family and I got 2 foster-sisters. One of them was mentally disabled. My foster parents were nice to me but, of course, they

Figure 2 Summarizes the GPs' degree of familiarity with their patients as persons as outlined in this study

	The nine patients A-I								
GPs' knowledge about:	**A**	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**
Personality	+	+	+	+	+	+	+	+	+/-
Family relations – close	+	+	+	+	+	+/-	+/-	+	-
Occupation – working life	+	+	+/-	+	+	+	-	+	-
Major life events	+	+/-	+	+/-	+	+/-	+/-	-	-
Interests – hobbies	-	+/-	+	-	-	+/-	+/-	-	-
Social network - friends	-	+	+	-	-	-	+/-	-	-
Relatives – parents, siblings	-	+/-	+/-	-	+/-	-	+/-	-	-
Background - childhood	+/-	+/-	+/-	-	-	**?**	-	-	-
Duration of doctor-patient relationship (years)	**25**	**23**	**13**	**10**	**18**	**24**	**10**	**11**	**3**

> could never replace my biological parents. I didn't have any contact with my biological father during my adolescence, but I did some research after I'd grown up and actually managed to find him."

Based on the topics addressed in the interview, Figure 2 visualizes the GPs' differing degrees of familiarity with various aspects of their patients as persons. Each patient is designated with a letter from A to I. The overall duration of the doctor-patient relationships (in years) is shown in the bottom horizontal row.

Color code: Dark Grey [+]: the GP reports comprehensive knowledge about the topic; Light Grey [+/-]: the GP has limited/scarce knowledge; White/blank [-]: the GP has no knowledge about the topic. [?] The researcher failed to ask the GP about this specific topic.

Concerning the topic major life events: A "major life event" was defined as a considerable change in the life of the patient or her/his circumstances – for example, a divorce or broken relationship, serious accidents, death of a close relative – that had the potential to evoke stress. Very "usual" life events such as the death of aged relatives (not expected to provoke considerable stress) were not included. Only GPs who reported one or several major life events, which she/he deemed medically relevant, were classified as "dark grey" (comprehensive knowledge). GPs who knew about a major life event but not whether it was medically relevant, were classified as light grey (limited knowledge).

GPs responses to discovering their "knowledge holes"

During the telephone interviews, the GPs evinced a variety of reactions when becoming aware how little knowledge they had regarding certain aspects of their patients' lives. Their voices and/or the words they chose expressed emotions ranging from embarrassment – sometimes even shame – to surprise, as exemplified by the following exchange:

> GP A sounded surprised when realizing that, despite having been patient A's GP for more than 25 years, he could only surmise what the man's interests might be. He had little information to recount. He presumed, based on the patient's having been a sea captain, that the man had been interested in maritime topics. The patient interview, on the other hand, revealed that patient A was, in fact, interested in hunting and in raising dogs. He had spent most of his spare time the past several years at his cabin, hunting and fishing.

The doctor-patient relationship between GP D and patient D had been ongoing for 10 years. GP D seemed to be aware that his knowledge about patient D as a person was somewhat shallow and, during the interview, seemed to feel the need to justify and excuse his lack of knowledge. GP D explained that, even after the patient had a major stroke, few consultations had taken place:

> "Over the years I've known him, there have only been a few occasions when we actually met. Most of the time, he only needed my help to adjust his medications, apply for rehabilitation, renew prescriptions and so on. He hasn't often consulted me at my office and I've only made a few home visits. We've managed to solve problems in alternative ways. His wife has been his spokesperson and the one providing information and exchanging messages, communicating with the personnel at the health center – or with me, if necessary"

The doctor-patient relationship of the shortest duration, only 3 years, was between patient I and her GP. The telephone interview with GP I lasted only 4 minutes because her knowledge regarding the patient was so limited. After repeatedly replying, "I don't know," GP I, obviously embarrassed, burst out:

> "You could have picked somebody else - one of the patients I know better!"

GP G seemed almost shameful when she was asked about patient G's occupational history and discovered that she knew nothing about it:

> "I should, of course, have recorded something about this. I know that patient G always has been fond of writing and I wonder if he was once a writer. It's terrible to admit, but I actually don't know!"

Some of the GPs gave the impression that, in those cases where they had neither recorded nor could recall anything extraordinary, they had assumed everything was "normal." When uncertain about a given topic, some expressed the assumption that there had probably been nothing of interest to be known about that area:

> Though GP F had known patient F for 24 years, he had no knowledge to recount when asked about the patient's "friends and relatives." He said that he had had the impression that everything was "normal" and that the patient had an "ordinary" social network and was not, at any rate, "an odd character."

Discussion

The first author's professional experience, accumulated while alternating between the roles of GP and consultant, inspired this inquiry. She became aware of what might be called "the presence of a medically relevant absence," that is, the person-related information that, despite the health institution's implicit mandate to care for the whole person, is not emphasized when vulnerable patients are moved from their home to a rehabilitation unit at a nursing home. Analysis of the project material revealed what we have come to see as 4 interwoven patterns.

The first pattern concerns those categories of conditions or details of a patient's biography and life-world that the 9 interviewed doctors were actually familiar with. There emerged, despite the variety of patient ages and cause(s) for admission, a fairly homogeneous overall *pattern of familiarity*, as we label it. We attribute this trend towards homogeneity to physicians' common professional socialization, reflecting both what types of information they are trained to inquire about, attend to and record for medical purposes within a doctor-patient-relationship, as well as what they learn to treat as being of minor or negligible relevance. The rules governing which topics are deemed relevant and appropriate in the context of a clinical encounter have been extensively delineated and discussed by a large number of scholars, among whom we choose to cite Stephen Toulmin [28] and Elliot G. Mishler [29].

The second analytical pattern concerns the under-communicated or missing topics within the GPs' knowledge of their patients, those which are routinely omitted in conversations between doctors and patients and therefore remain unrecorded. These are primarily issues which are traditionally defined as "private," "intimate" or "sensitive" and thus considered either inappropriate to broach and/or irrelevant to the medical problem at hand. This *pattern of omission* reflects the fact that doctors are dually socialized: they are both medically trained professionals and socio-culturally shaped fellow human beings. These 2 value systems manifest in doctors' encounters with patients as behavioral habits, as has been addressed by scholars within the fields of ethics, philosophy and the social sciences [30,31]. Interestingly, a growing body of consistent evidence indicates that much of what continues to be defined as both "private" and "intimate" and therefore "untouchable" in routine clinical practice does indeed hold medical relevance and ought, therefore, to be discussed [6-8]. We recognize, however, that neither such evidence nor professional ways to interpret and implement it has as yet been integrated into mainstream medical practice.

Furthermore, this identified "pattern of omission" reflects not only a 2-layered socialization of the doctors but also of their patients. Patients have in common a socially and culturally informed awareness of what is appropriate to share with a GP – "to 'burden' a GP with," so to speak – unless explicitly encouraged to do so. The way contemporary patients in Western societies have been taught to regard the human body in physical and biomolecular terms might well be considered the layman's version of the formal, biomedical education and training doctors receive. Having this view reduces the likelihood that patients would feel free to address the impact that painful life experiences might have had on their subsequent mental and physical ailments, even if, deep down, they may sense that such a connection exists. Thus, the identified "pattern of omission," arising from authoritative biomedical theory, shared conditioning and social convention, can be seen as contributing to the reluctance both of doctors and of patients to address certain topics.

The third analytical pattern traces the impact that biomedically engendered and enacted *patterns of presuppositions* have such that narratives of salient lifetime experiences are prevented from entering clinical encounters; this concerns both the information doctors hesitate to elicit from their patients and the information patients hesitate to relate to their doctors. This phenomenon has been explored extensively by, among other scholars, Eric Cassell, who has emphasized the importance and impact of attending to and being responsive to reports from the patient's life-world [26].

In face-to-face interviews conducted by a previously unknown physician-researcher on the basis of only a condensed version of information offered by their GPs, the patients in this study did not hesitate to reveal salient details of a private, intimate and at times highly emotional nature. The patients shared, for example: deep, unresolved grief resulting from the loss of an illegitimate child while involved in other very strained relationships; the fear of spousal infidelity, of being abandoned when old and sick; the anxiety linked to the risk of dying from a disease which runs in the family; the shame connected to being an illegitimate child who had been given up for adoption; the social stigma of having an alcoholic father; the secret burden of having been economically exploited by both mother and sister. (To preserve anonymity, specific references to the patients listed in Table 1 have been omitted here.)

Explanations of why such socially silenced and even taboo topics could emerge during a one-hour interview with a stranger while not having been shared with a GP during a clinical relationship that had lasted for years are bound to be complex. The most obvious and likely reason is that, as discussed above, the GPs had never explicitly invited the patients to share significant and potentially sensitive aspects of their biographies. One might argue that another explanation lies in the nature of the research setting, that it is defined as a confidential encounter, without future implications for the relationship between the informant and the researcher and without the risk that information revealed would become part of medical records to which third parties might gain access. We have not, however, encountered research evidence pointing in this direction. What does seem to be documented by studies regarding topics identified as "sensitive" is that face-to-face, open-ended research interview settings provide a better frame and result in more disclosure and more detailed reports, than do standardized questionnaires. Also, considerably more disclosure occurs in clinical settings when patients are routinely asked to disclose as compared to when they are not asked [32]. Thus, the obstacles to disclosure of lifetime adversity seem to reside less on the side of the patients. Researchers and clinicians [33-36] have been shown to demonstrate reluctance both to addressing such topics and to encouraging patients to elaborate on how unresolved and painful experiences have affected their life and health. Researchers and clinicians in particular, often seem to explain such reluctance by referring to time constraints and to the patients' vulnerability, thus framing the avoidance of certain topics as professionally and ethically justifiable [33]. However, the emerging scientific evidence appears to support the conclusion that it is a question not of *whether* to ask but of *how* to ask [37]. As recently shown by Feder and co-workers [38] clinicians who have been properly and systematically trained can adequately and supportively approach even such sensitive topics as domestic violence without doing harm.

The fourth pattern in our analysis, the *pattern of personal relationship*, concerns the GPs' own reactions when, during the course of the interview, they become aware of an inability to provide what they themselves would deem to be "a satisfying answer" to the researcher's questions. As previously described, their reactions included: a straightforward, unelaborated and flat statement, "No knowledge", a neutral excuse, an expression of frustration as seen above in the stated wish to have been asked about some other patient instead or an explicit expression of shock and embarrassment. The interviewer interpreted the paraverbal phenomena registered in the audio recordings of the telephone interviews as expressing astonishment, surprise, a sense of being bothered, perplexed, hesitant or embarrassed, often accompanied by short and timid laughter. Most GPs used tentative formulations, such as assumptions, suppositions and generalizations, when encountering their lack of facts or uncertainty about them. They frequently urged the interviewer to offer them comfort through confirming that such a lack of knowledge was not uncommon.

Contrary to expectations, the degree of the GP's familiarity with the patient's life-world or biography was *not* proportional to the duration of the patient-doctor relationships, which ranged, with one exception, from 10 to 25 years (Table1). Sympathy seemed to increase with greater familiarity with patient facts while emotional distance or even outright strain seemed to accompany a relationship with many factual "holes." Thus, the GP's explicit engagement in the patient's general state of being emerged as pivotal. For example, one GP's detailed and comprehensive presentation of the patient in the interview, even including the highly sensitive information that the patient had recently been both sexually and economically exploited and cheated, was mirrored in the patient's trustful and assertive interview comments. On the other hand, a GP's characterizing of a patient as "a very difficult person to help…very demanding…never satisfied," is reflected in the patient's comment during the interview that, "We've never had a dialogue. You and I, in the time we've been sitting here, have talked more together than my GP and I have during almost 10 years."

A pattern that connects

At this point in our theoretical reflections on our empirical findings we enter an ongoing *debate of models of doctor-patient interactions*, one which transcends traditional – and inadequate – dichotomies and demarcations. The discussion touches upon topics such as: *patient-centered* versus *person-focused* care [22]; how to understand "what it might mean to be a good healthcare practitioner" [39]; how to delineate "the physicians' role in patients' nursing home care" [20]; what to think about "the person in medicine" [27] and, most explicitly, the current and ongoing debate concerning "person-centered medicine as an emerging model for modern clinical practice" [13]. We note at the core of this discussion a rising concern about the expansion and the galloping financial costs, of a technology-driven healthcare system; this system appears to become increasingly de-humanizing and de-personalizing as only those approaches to human disease and suffering which are presumed to be 'value-neutral' and 'objective' are considered appropriate sources for the production and implementation of biomedical knowledge.

As our analysis has highlighted, salient information about patients' life-world remains unknown to the GP while being easily accessible to an attentive researcher. This provides a link to another ongoing discourse. There is a rapidly expanding body of knowledge regarding the impact on health of encountering adverse life experiences. It traces the general medical relevance of highly distressing experiences, in particular, those which are socially silenced, which engender secrecy and evoke shame [7,40-48].

It is now indisputable that a heavy burden of adverse experiences has a detrimental impact on a person's physiology, on her/his embodied life. It follows, then, that GPs who care for people over time ought to express explicit interest in knowledge of such experiences. Our empirical material provides illuminating examples of adverse experiences of which GPs were unaware. Research has shown correlations between various types of adverse life experiences and constantly activated stress responses, compromised immune activity and systemic inflammation [7], accelerated biological aging [45,46], disturbed brain development and dementia [49,50], complex, chronic disease patterns [7,40,41,43,44] and as an acknowledged factor contributing to intermittent admissions to nursing homes [18]. It is highly probable that precisely those life experiences that are traditionally defined as irrelevant to an understanding of human biology and healthcare, may contribute to the sudden health deterioration of someone whose condition is already compromised, such as those we encountered in our study. Consequently, it may be of particular importance for GPs' to elicit and transmit knowledge about patients' life-world, about their patients as persons, when those patients are in transition to other caretakers.

Reflections on validity

A strength of our study is that both the analytical framework and method used enabled us to explore what salient biographical knowledge GPs actually have about their patients as persons. Face-to-face, *personal interviews* with patients facilitated an exploration through "meaningful dialogic talk." This yielded texts that could then be both *validated* and *elaborated*, with *phenomenology-hermeneutics* serving as a framework for interpreting the human life-world thus revealed. The *validation* involved comparing the doctors' accounts to those of the patients while the *elaboration* involved examining the patients' accounts of previously unknown yet potentially medically relevant biographical data. The issue of what sorts of "realities" can emerge during interviews has been discussed by scholars and researchers working in a broad range of disciplines [51]. We agree with Miller and Glassner who emphasize that it is "only in the context of non-positivistic interviews, which recognize and build on their interactive components (…) that 'intersubjective depth and deep mutual understanding' can be achieved." We were cognizant while conducting this kind of interactionist research, aimed at gaining access to and insight into both patients' and doctors' meaningful worlds, that differing social contexts were at play in the 2 groups. Still, the fact that an interview might itself be seen as a symbolic interaction "does not discount the possibility that knowledge of the social world beyond the interaction can be obtained" [51].

The GPs who participated in the focus groups during the first phase of this project claimed to be knowledgeable about their patients as persons [15]. Although a different group of doctors participated in the present study, the findings indicate that physicians' knowledge is, in fact, limited and that the patterns of those limitations are shaped both by professional and social phenomena. Our findings may also be seen to illustrate the well-documented discrepancy between doctors' ways of thinking (attitude, point of view) and doing (actual practice) [52].

One might argue that each participating GP was interviewed about one relatively incidental patient only and we do not claim the findings in this study to be representative for all GPs and all GP-patient relations. The emerging patterns of "present" and "absent" knowledge however evoked recognition among the researchers in our group, where all authors have long clinical experience from primary care in addition to their academic training. In accordance with the traditions of phenomenological-hermeneutical research, we have made our position explicit and aimed for methodological transparency. We have integrated the findings using relevant theoretical frameworks to unfold their implicit features, well-aware that our conclusions are tentative and represent only one of a variety of possible interpretations.

Conclusions and Implications

The present study contributes to a growing and increasingly coherent body of theoretical knowledge and empirical evidence indicating a recent, strong and perhaps paradigmatic increase in interest within medical thought and practice regarding the patient as a person. We are convinced that the current crisis in medicine, with its costly and limitlessly expanding focus on technology, is essentially a crisis of knowledge, a crisis of care, compassion and trust. This is not a question of quantity, as in, "not enough knowledge." Rather, it is a 2-fold form of *inadequate knowledge: inadequate knowledge production* – resulting from a hesitance to grasp the shortcomings of medicine's traditional perspectives on what constitutes knowledge about the human body; and *inadequate knowledge implementation* – resulting from a hesitance to apply the wealth of already existing knowledge regarding the interrelatedness of biology and biography [8]. The challenge which the medical profession faces is the need for a kind of knowledge that reflects the fact that human beings are lived bodies, or, as phenomenological philosopher Maurice Merleau-Ponty has put it: a body we have (object) – yet different from all other objects – and a body we are (subject) [14]. The ambiguity inherent in this dual status of the human body is an inevitable feature of the human condition.

Based as it is on evidence – impersonal, fragmented and de-contextualized in its nature – the current gold standard of clinical practice is too limited to serve as the foundation of an appropriate approach. It must be expanded to include models that facilitate an explicitly personalized and contextualized clinical practice. The most central source of this *different* approach lies precisely in knowledge traditionally regarded as private or personal and thus neglected: the first-person accounts of the subjects themselves, those who suffer and are in need of help. This is something GPs actually need to know and learn to address. However, we are talking about sensitive issues that need to be handled with competence and care. Further research, reflection and professional maturation in the GP community is needed before systematic attempts to change current practice are advisable.

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Paper III

Int J Qualitative Stud Health Well-being

COACTION PUBLISHING

EMPIRICAL STUDY

Standardization meets stories: Contrasting perspectives on the needs of frail individuals at a rehabilitation unit

BENTE PRYTZ MJØLSTAD, MD, PhD Student[1],
ANNA LUISE KIRKENGEN, MD, DrMed[1,2,3],
LINN GETZ, MD, PhD[1], & IRENE HETLEVIK, MD, DrMed[1]

[1]*General Practice Research Unit, Department of Public Health and General Practice, Norwegian University of Science and Technology (NTNU), Trondheim, Norway,* [2]*Institute of Community Medicine, University of Tromsø, Tromsø, Norway, and* [3]*Centre for Health Promotion, Akershus University Hospital, Nordbyhagen, Norway*

Abstract

Background: Repeated encounters over time enable general practitioners (GPs) to accumulate biomedical and biographical knowledge about their patients. A growing body of evidence documenting the medical relevance of lifetime experiences indicates that health personnel ought to appraise this type of knowledge and consider how to incorporate it into their treatment of patients. In order to explore the interdisciplinary communication of such knowledge within Norwegian health care, we conducted a research project at the interface between general practice and a nursing home.

Methods: In the present study, nine Norwegian GPs were each interviewed about one of their patients who had recently been admitted to a nursing home for short-term rehabilitation. A successive interview conducted with each of these patients aimed at both validating the GP's information and exploring the patient's life story. The GP's treatment opinions and the patient's biographical information and treatment preferences were condensed into a biographical record presented to the nursing home staff. The transcripts of the interviews and the institutional treatment measures were compared and analysed, applying a phenomenological–hermeneutical framework. In the present article, we compare and discuss: (1) the GPs' specific recommendations for their patients; (2) the patients' own wishes and perceived needs; and (3) if and how this information was integrated into the institution's interventions and priorities.

Results: Each GP made rehabilitation recommendations, which included statements regarding both the patient's personality and life circumstances. The nursing home staff individualized their selection of therapeutic interventions based on defined standardized treatment approaches, without personalizing them.

Conclusion: We found that the institutional voice of medicine consistently tends to override the voice of the patient's lifeworld. Thus, despite the institution's best intentions, their efforts to provide appropriate rehabilitation seem to have been jeopardized to some extent.

Key words: *Biographical knowledge, lifetime experience, phenomenology, general practice, rehabilitation, standard treatment, person-centered medicine, narrative medicine*

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Modern medicine is grounded in the natural sciences' understanding of human beings, from Newton and Descartes, through the 17th century Scientific Revolution, the Age of Enlightenment, 19th century physics and into 20th century molecular biology (Lock & Gordon, 1988). Within this perspective, body and mind are regarded as separate, and the person's life history and subjective experience are granted at most a "supplementary" status. To assure quality and cost control, diagnosis and treatment are increasingly determined and evaluated using a set of standards rooted in statistical knowledge about groups, rather than in explorations of the needs of individual patients. This "depersonalized" approach has indisputably contributed to breakthroughs and a well-proven practical efficacy in the treatment of many well-defined medical problems. As an approach to human health and

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Correspondence: B. P. Mjølstad, General Practice Research Unit, Department of Public Health and General Practice, Norwegian University of Science and Technology(NTNU), P.O. Box 8905, 7491 Trondheim, Norway. Tel: +47 91 61 41 82. E-mail: bente.mjolstad@ntnu.no

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disease generally, however, it may not be adequately comprehensive and may lack validity (Cassell, 2004; Kirkengen & Thornquist, 2012; Zaner, 2003a). This depersonalized and group-based knowledge shows, in fact, its crucial limitations as we are currently witnessing the rapid growth of scientific evidence documenting both that, and how, an individual's lifetime experiences and existential circumstances have a significant impact on health (Felitti & Anda, 2010; Glaser & Kiecolt-Glaser, 2005; Gruenewald et al., 2012; McEwen & Getz, 2013; Miller, Chen, & Parker, 2011; Norman et al., 2012; Seeman, Epel, Gruenewald, Karlamangla, & McEwen, 2010; Shonkoff, Boyce, & McEwen, 2009; Steptoe & Marmot, 2002; Surtees et al., 2011). Knowledge about the fundamental and reciprocal interrelatedness of human biology and biography (Getz, Kirkengen, & Ulvestad, 2011) may be of particular relevance to the treatment of patients suffering from ill-defined and/or complex health problems (Eriksen, Kirkengen, & Vetlesen, 2013; Kirkengen, 2001). It may also have implications, which are crucial to the care of frail human beings who have decompensated (in terms of functional impairment) to such an extent that rehabilitative institutional care is required. The present study focuses on such a situation.

The field of general practice/family medicine, wherein continuity of care is built upon repeated personal encounters, may well be where the incongruity between the dominant biomedical paradigm (as described above), and the real-life challenges of everyday medical practice becomes most overt. Encountering patients over the course of years, general practitioners (GPs) are likely to gain biographical knowledge with major relevance for the patient's life and health, whether learned coincidentally and perhaps not even recognized as important, or elicited intentionally based on a genuine insight into its potential relevance (Kirkengen, 2008). Over decades, several pioneers in general practice/family medicine have argued for more comprehensive medical models and approaches which could integrate knowledge regarding the patients' context and lifeworld. The most well-known of these are the "bio-psycho-social model" (Engel, 1977) and "patient-centered medicine" (Levenstein, McCracken, McWhinney, Stewart, & Brown, 1986). More recently, the emphasis has begun to shift from the *patient* to the *person*, as reflected in the new terms "person-centered" (Miles & Mezzich, 2011) and "person-focused" medicine (Starfield, 2011). It has been postulated that this emerging interest in the needs of the particular individual, as opposed to an "average" patient, has come in reaction to an ongoing dehumanization of medicine as an increasingly predominating focus on standardized technological *cure* may be in danger of taking precedence over attention to individualized human *care* (Kirkengen, Mjølstad, Getz, Ulvestad, & Hetlevik, 2013; Miles & Mezzich, 2011).

Medical rehabilitation of frail individuals—cure or care?

The difference between a standardized "cure" and a person-centered "care" approach might be explored fruitfully in the context of institutional health care settings, focusing on individuals who are experiencing deterioration in health and function. This group includes individuals who have become frail prematurely due to chronic debilitating conditions, typically more than one (Barnett et al., 2012). The frailty of others in this group may be due to their advanced age or the combination of age and multimorbidity (Martin et al., 2012; Sturmberg, 2012). Today's elderly are generally in better health and function at a higher level for longer than did previous generations. Nevertheless, as the aging population increases, more elderly and frail people are likely to find themselves "in transit" between home and institutions. These patients both want and need to be met by professionals who can coordinate an individualized care plan which takes the specific patient's needs into account (Bayliss, Edwards, Steiner, & Main, 2008). Consequently, an exploration of what kind of knowledge is considered relevant for the patient's GP to transmit to the caretaking institution, when a fragile individual is admitted, is both timely and useful, from a scientific as well as a practical point of view.

Context for the present study

In Norway, where this study was conducted, strong emphasis is currently placed on providing home-based care to elderly and frail people. Within a formal health care perspective, and with governmental support, rehabilitation is conceptualized as: planned, time-limited processes in which several agents provide essential assistance, applying well-defined means to reach clearly delineated goals, supplementing the user's own efforts toward attaining the highest possible level of functioning and coping in terms of autonomy and of participation in a social life and in society (our translation) (Garåsen, 2008). Most frail or elderly people in Norway remain at home until they reach a critically low level of cognitive and/or physiological functioning, at which point the likelihood of being admitted to an institution increases substantially. This is largely congruent with the findings of Gaugler and colleagues (2007) suggesting a threshold model that may predict nursing home admission.

The most appropriate institutions to receive frail patients at such junctures are the so-called nursing homes, some of which have specialized "rehabilitation units." In both settings, time-limited care is provided by an interdisciplinary staff. There exist no national guidelines for rehabilitation in nursing homes. However, in accordance with the definition and the understanding of the concept "rehabilitation," the stated intention of these institutions is to offer individualized care based on comprehensive assessments resulting in a structured, individualized plan which includes therapeutic treatment designed to facilitate recovery. Usually, desirable outcomes (clear goals) are formulated and included in such plans. Specialized rehabilitation units evaluate each patient's condition systematically. Interdisciplinary collaboration, occupational therapists, physiotherapists and consulting physicians focus primarily on monitoring and improving the patients' capacity to manage daily life activities (ADL). Most Norwegians are assigned to a specific GP (list system), a system which, ideally, assures continuity of care. When the patient is transferred from her/his home to a nursing home/rehabilitation unit, the institution formally requests the assigned GP to provide essential medical information including diagnoses, current medication, etc. Currently, no formalized standards regulate what type of biographical and contextual information should ideally follow patients to (or from) health care institutions. After admission to the nursing home/rehabilitation unit, the patient's treatment is turned over to the consulting physician (a GP or, rather infrequently, a specialist in rehabilitation medicine or geriatrics), who is connected to the institution.

Aim of the present study

As the third step in a three-phased project (Mjølstad, Kirkengen, Getz, & Hetlevik, 2013a, b), the present study aims to explore the medical relevance of person-related knowledge both in general practice and at the interface between primary care and institutional care. In the initial phase, two groups of GPs were invited to reflect upon and discuss the potential significance of knowing their patients as persons. The GPs expressed confidence that they did possess medically relevant knowledge about their patients' lifeworld, and that this knowledge might well have relevance for the health of patients admitted for rehabilitation (Mjølstad et al., 2013a). In the second phase, we explored what knowledge GPs *actually* had, by comparing the information provided by GPs to the narratives offered by the patients themselves (Mjølstad, Kirkengen, Getz, & Hetlevik, 2013b). In the present study, we compare and discuss three perspectives on the patients' needs and aims when admitted to a rehabilitation unit, as described above: (1) what GPs recommended on behalf of some particular patient; (2) what those patients themselves considered central to their own functional improvement; and (3) how the institution responded to these individualized priorities.

Theoretical framework

Researchers aiming at exploring and reflecting upon human experience in the context of medicine and medical practice would be well-advised to choose phenomenology as their theoretical framework (Kvale, 1983; Mishler, 1986). As a methodology, phenomenology allows for insight into the interviewee's world of personal experiences while at the same time maintaining and attending to the context. Experiences are always, a priori, experiences of something for somebody situated in a particular context. Consequently, the issue of personhood must be a central component in any research on human experience. While "patient" is a (reductive) role imposed on a person by disease and conceptualized in accordance with pathology-oriented biomedical theory, "personhood" as a status is constituted by other phenomena and rules. In our differentiation between "patient" and "person," we apply Eric Cassell's (2010) view of a person as an "embodied, purposeful, thinking, feeling, emotional, reflective, relational, human individual always in action, responsive to meaning and whose life in all spheres points both outward and inward," so that a person's behavior, whether "volitional, habitual, instinctual or automatic," has its genesis from and in *meaning*. Since "meaning" and "personhood" are mutually constituting, statements about persons are statements about values and social phenomena. Any investigation of experience as communicated through first-person accounts involves encountering and exploring systems of values and of symbols as they are conceptualized and expressed in language, spoken, and written. Consequently, they demand a competence in hermeneutics (interpretations) (Kvale, 1983; Mishler, 1986, 1999).

Experience relates as much to the body as it is bound to the person; bodily being is the basic premise for experience, which is first perceived bodily and then interpreted personally. French philosopher and phenomenologist Maurice Merleau-Ponty (1989) regards the body, including when it is diseased and incapacitated, as embodied life—a lived body. This contrasts to the biomedical body, which is conceptualized as devoid of history and experience (Cassell, 1992). From a phenomenological perspective, rehabilitation might thus be understood as a personal, relational as well as bodily process, as the person's embodied, lived experiences. When searching for appropriate measures relating to a specific person, that person's lifeworld of subjective phenomena and inter-subjectively constituted values and symbols must inevitably be included among the premises (Zaner, 2003a). In the true sense of the word, "rehabilitation" signifies the means for "restoring a patient to the status of person" and "reinstating that person within the realm of dignity" (our translation) (Helse og Omsorgsdepartementet, 1997).

This project is distinctive not only by involving the interface between differing aspects of the health care system. It also takes place at the intersection between *cure* and *care*. The basic definition of rehabilitation alludes more to providing active medical treatment/therapy than to accommodating to people, or nursing them. *Curing*, in the sense of "treatment," is the hegemonic realm of physicians while *caring* is the traditional province of nurses and other caretakers. This implies that the models and principles of biomedical knowledge production are the frame of reference for all interventions and treatment measures despite an apparent integration of cure and care in modern medicine. Still, between these domains, that of *cure* and that of *care*, there exists a demarcation line and an asymmetry of rank and authority.

Methods and material

Research site

This study was conducted in a rehabilitation unit at an urban nursing home in Mid-Norway with 32 single rooms for patients undergoing short-term rehabilitation (2–3 weeks). The staff included consulting physicians, nurses, physiotherapists, occupational therapists and nurses' aides. The service provided was based on an interdisciplinary approach involving multiprofessional cooperation, with shared protocols but separated record keeping. In principle, records were data-based, but the various professional groups used different software systems as well as paper records. Information about the patient considered essential for the rehabilitation purpose was made accessible for all the professional groups. The patient her/himself (or family members) had to apply to be admitted (self-referral) with the Health and Welfare Agency in the city being responsible for granting permission. Accessible health information from the patient's GP and the community home care services was obtained and evaluated. If a patient had been hospitalized recently, the discharge letter was obtained.

An entry procedure was carried out, typically a dialogue with a nurse, aimed at identifying the patient's needs. The "mapping tool" included a checklist for the "patient care plan" as well as a questionnaire. The checklist contained a schedule, indicating the sequence of treatment measures and the distribution of tasks among staff members. The questionnaire addressed the following topics: actual health problems, mobility, ADL, family relations, social behavior/functioning, housing conditions, and the patient's own expectations and goals for rehabilitation. The nurse was mandated to delineate appropriate aims for the stay, resulting in a description of a primary goal. The primary goal was then broken down into several secondary goals. Finally, an individual rehabilitation plan, designed to take into account all of the collected information, was drawn up.

Research design, data collection, and ethical approval

Only patients who were living at home when admitted for a rehabilitation stay were considered for inclusion. If the staff deemed a patient capable of giving informed consent, she/he was invited by the staff based on a preformulated invitation. Once the patient's consent was received, the researcher introduced herself to the patient, asked for permission to contact her or his regular GP for further information, and, provided permission, phoned the doctor for consent to discuss her/his knowledge regarding that patient as a person. Further information about the study was telefaxed to each GP's office along with a copy of the patient's signed consent form. After consent was provided, a 10–15-min telephone interview with the GP was scheduled within 3 days. This interview, based on two main questions, explored the GPs' reflections concerning the most salient needs of this particular patient with regard to her/his rehabilitation (Mjølstad et al., 2013b). Each patient interview, performed face-to-face, took place shortly after the respective GP interview and lasted for approximately 1 hour. The departure point for each of these interviews was a condensed version of the information, which the GP had agreed the first author could share with the patient. The patient was encouraged to correct and/or deepen this information. In addition, the GP's proposal as to the central aim of the rehabilitation process was discussed with the patient. Based on these two integrated sources, the first author wrote a paper-based, biographical patient record, including a description of the patient as a person, the advice of the GP, and the explicit wishes of the patient regarding her/his rehabilitation. This record was then handed over to the staff member(s) responsible for the care of this patient, typically one of the

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consulting physicians and/or a nurse. The staff members were encouraged to consider this information in terms of appraising the biographical records when establishing the patient's rehabilitation plan. The patients and the health personnel had granted the first author access to the complete medical records of the participants.

The first author recorded detailed and comprehensive notes regarding each of the included patients from the moment these had consented to participate and through her frequent visits during the entire period of data collection. The notes included reports after having talked with staff members and participated in unit staff-meetings concerning these patients. The notes also comprised observations, comments and reflections linked to the interview settings and to interactions with staff members. Finally, they were completed with excerpts from the patients' electronic and paper-based records (including staff members' notes). The first author was not given access to information about other patients than those included, or about other aspects of the unit, nor was she a regular observer of everyday routines or procedures. Her interest was not directed towards observing organizational or structural aspects or interaction among staff. An audio-taped and transcribed second interview with every patient regarding her/his final appraisal of the rehabilitation period completed the datasets for each of the nine persons included in the study. Thus, the complete materials consisted of: GP interviews, patient interviews (1 and 2), biographical records, excerpts from the medical records, and field notes (Figure 1).

The Regional Committee for Medical Research Ethics for Central Norway approved of the study, the collection of patient information, and the consent form structures (approval date 07.05.09). Prior to inclusion, each participating patient, GP, and staff member at the nursing home signed an informed consent form.

Descriptions of study participants

From February 2010 through April 2011, nine patients and their respective GPs were included, consecutively, in the study. The mean age of the patients was 64 years (44–94 years), and that of the doctors was 51 years (34–61 years). The mean duration of the doctor–patient relationships was 15 years (3–25 years). The patients admitted had differing primary diagnoses, except for two, whose main diagnosis was multiple sclerosis (Table I). For all patients, the central aim of their stay was rehabilitation.

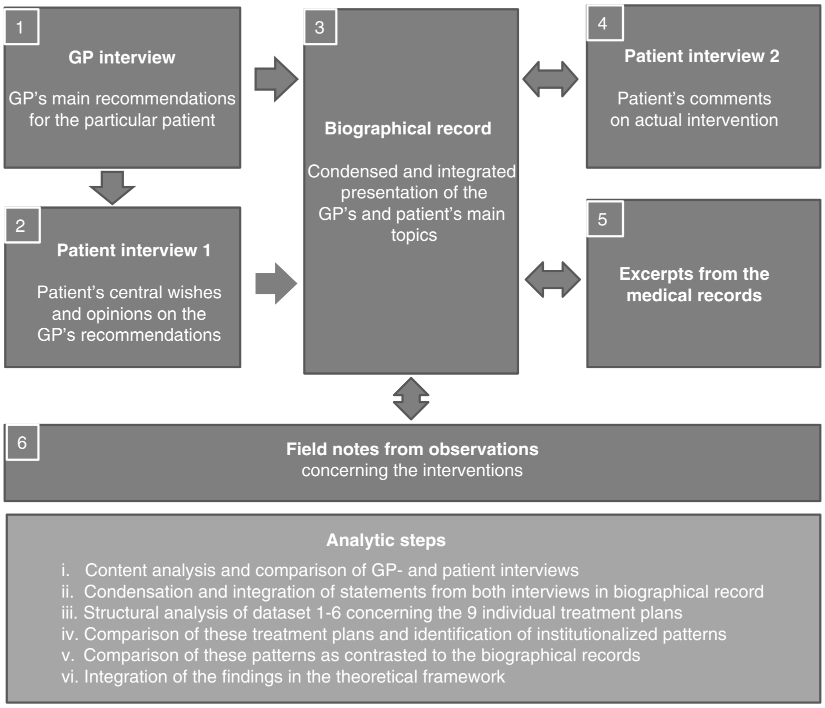

Figure 1. The components of data material (1–6) and description of the analytic steps (i–vi).

Table I. Characteristics of the participants.

Participants	Patients				D/P relationship (years)	General practitioners			
	Gender	*Age (years)*	*Civil status*	*Medical diagnoses*		*Gender*	*Age (years)*	*Listed patients*	*Doctors at the office*
A	M	83	Married	Parkinsons disease	25	M	58	1850	3
B	M	44	Married	CFS	23	M	61	1100	5
C	M	58	Single divorced	MS	13	M	51	1550	4
D	M	58	Married	Stroke	10	M	53	1300	7
E	F	46	Single divorced	Sequels; brain abscess	18	F	53	1300	4
F	M	84	Married	Hip fracture	24	M	57	1400	5
G	M	57	Single	Chronic pain, abuse	10	F	49	1500	5
H	F	52	Married	MS	11	M	42	1850	4
I	F	94	Widow	Glaucoma, advanced age	3	F	34	1650	5

CFS = chronic fatigue syndrome, MS = multiple sclerosis, D/P-relationship = duration of doctor-patient relationship, M = male, F = female.

For patient B, D, and H, the aim was also to provide needed relief to their usual caretakers.

Analysis

The analysis was performed by the first and second author who included the other authors in consecutive discussions for clarifying and refining the issues in question. All the authors have extensive clinical experiences as GPs and doctors in primary care, and three of them are also experienced researchers and academic teachers. The first author has worked in the double position as a regular GP and a part-time consultant physician in a nursing home for longer periods. Her repeated observation of a certain informational "gap" between primary care and institutional care had engendered the current project (Mjølstad et al., 2013a).

The first steps of our analysis of the GP and patient interviews, inspired by a hermeneutical canon developed by Kvale (1983, 1996), have been presented in a previous paper dealing with the difference between GPs' believed and actual knowledge about their patients (Mjølstad et al., 2013b). The first analytical level dealt with the participants' self-understanding while the second level was based on critical common sense understanding (i.e., critical understanding of what is being said by using general knowledge/common sense). This approach was double-layered, guided by the questions "what does the person state about the matter at hand?" (objective approach) and "what does this statement say about the person?" (subjective approach). Finally, in the third analytical level, we aimed at understanding these findings through the application of existing theories.

In the current paper, based on the previous analyses of two texts (telephone interview of the doctors and first interview of the patients), and supplied with three other texts (excerpts from the medical records, the biographical records and second interview of the patients), we performed a comparison of what we, according to Mishler (1986), refer to as three different "voices." For this purpose, the interviews were compared topic by topic with regard to concurrence or divergence between the GP and the patient as to the most essential elements of the rehabilitation (for description of the analysis step by step—see Figure 1. Further details have been elaborated in Appendix). Any lack of salient information and/or attention to specific, significant details which the GP exhibited was also identified. Both the GPs' and patients' concurring and diverging statements were compared to the institution's interpretations of the information provided, as reflected in the institutional rehabilitation plans. These plans included certain explicitly stated, standard forms of intervention. Other treatments and interventions that were less explicitly offered, was deduced from the first author's field notes and from the patients' medical records. This part of the analysis involved de-contextualizing and re-contextualizing both the observed and the recorded elements, examining both the structural and the habitual aims as they manifested in the routines. Finally, we integrated these findings into theoretical frameworks, exploring the balance between the three voices. Here, we applied the distinction Elliot G. Mishler (1984, 1986) introduces regarding the patient's voice as the voice of the lifeworld, a first-person account, with the institution's voice as the voice of medicine, a third-person account. The GP acquires an "in-between" position: partly third-person—the professional voice of medicine—and partly first-person—the personal voice of someone acquainted with the patient's lifeworld.

Results

We now present and compare, in condensed form, the three different elicited perspectives on the participating patients' needs and aims upon their admission to the rehabilitation unit: *the GPs' recommendation*s, *the patients' own wishes and the institution's priorities, and the therapies actually chosen for and implemented in the rehabilitation plans*. Subsequently, we focus on certain specific patient wishes documented in the biographical record and presented to the staff by the researcher. We examine these in terms of the relevance such wishes hold for the overall aims of the rehabilitation process, and the degree to which they are consistent with what a typical, contemporary, rehabilitation institution might be expected to offer, in terms of capacity and mandate.

The GPs' recommendations

The GPs formulated an "optimal rehabilitation plan" for specific patients based on their personal knowledge, detailing their specific needs while also taking into account the patients' personality and life circumstances. However, as revealed in a comparative analysis of the GPs' recommendations versus the patients' wishes, the degree to which the GPs were capable of recommending measures that coincided or harmonized with their patients' own wishes differed markedly. Those GPs who had developed a personal, long-term doctor–patient relationship were able to formulate recommendations that harmonized better with the patients' own preferences than did those of GPs who were less familiar with their patients' lives. In those cases in which the clinical relationship was less developed (although it could have been long-lasting), the GPs tended to recommend non-specific measures, seemingly based on professional assumptions regarding the types of services a rehabilitation unit might be expected to offer routinely. Further details concerning the participating GPs' actual knowledge of their patients as persons have been published elsewhere (Mjølstad et al., 2013b).

The patients' expressed wishes

Given sufficient time and opportunity to elaborate on their reflections, and despite certain physical and/ or mental impairments, all of the patients proved able to express detailed, comprehensive and coherent descriptions of their specific needs for the rehabilitation stay. Subsequently, they were willing to have this information passed on to the staff in the form of biographical records. Certain of the patients' wishes could be incorporated easily into the standard institutional program by making relatively minor adjustments. For example, one patient requested receiving physiotherapy later in the day to avoid getting up early in the morning. Other patients requested that the staff familiarize themselves with details regarding their daily routines. A wide variety of issues proved to lie at the core of the patients' actual needs; the specificity of these could be seen as mirroring fundamental, preexisting realities within their lifeworld. Some of these will be elaborated below.

Interventions actually implemented by the institution

In accordance with the rehabilitation unit's daily routines, the nurses encouraged all patients to participate in common meals and social activities, as well as to be physically active generally. In addition, they systematically observed and recorded in detail how much time the patients spent in their rooms, the group activities they attended, whether they ate and drank sufficiently, and the extent to which they communicated with fellow patients and received visitors. When determining the individual patients' rehabilitation plans, the staff drew from a limited number of standard interventions (Figure 2). Upon admittance, all patients underwent a thorough *medical examination*, performed by the unit's consulting physician. The staff all agreed as to the relevance for all patients of *structured physiotherapy*, and all patients received input from the unit's physiotherapists at some point during their stay. Most patients, particularly those considered to be at risk of suffering from "loneliness," were explicitly encouraged to participate in *social activities* (common meals, group gymnastics to music, entertainment, etc.).

Patient Intervention	A	B*	C	D*	E	F	G	H*	I
1. Medical examination	+	+	+	+	+	+	+	+	+
2. Structured physiotherapy	+	+	+	+	+	+	+	+	+
3. Social activities	+	+		+	+		+		+
4. Enhanced nutrition		+	+	+			+	+	
5. Training of ADL	+	+				+			
6. Adjustment of daily habits		+			+				

Figure 2. An overview showing what kind of interventions (1–6) the patients (A–I) received at the nursing home during their stay. Grey [+], intervention determined; white [], intervention not established; [*], the rehabilitation admissions of patients B, D, and H were motivated in part by the needs of their primary, daily caretakers for relief.

Certain patients were singled out to receive special care: (1) *enhanced nutrition*—increasing their food consumption, and/or supplementing their diets with nutrient-rich food or drinks, and/or modifying their diets, for example, in cases of diabetes; (2) *training of ADL*—including dressing, eating, and personal hygiene; and/or (3) *adjusting daily habits*, such as receiving help to rise earlier and/or observe more regular sleep habits.

Standardization and stories

The in-depth interviews with the patients, the first-person accounts, proved at times to be the only source of knowledge about very specific personal needs, information that was not mentioned by their GPs, and neither identified nor addressed by the institution. These related equally to two types of patient requests: those within the scope of what the standardized institutional treatment repertoire was equipped to identify and respond to, and, those raising issues which warranted a frame of understanding and a repertoire of responses which might be seen to extend beyond the purview of this type of institution.

Patient wishes falling within the scope of the institution's customary repertoire

When examining how a standardized repertoire of interventions was implemented at the individual level, we looked at three categories—physiotherapy, social activities, and nutrition—and found what we have termed an implicitly double-layered standardized repertoire. That is, not only was the division of intervention categories as such standardized, but the approaches within each category were also standardized, despite the obvious feasibility of individualized adjustments being made. This can be seen in the following examples reflecting the institution's responses to the wishes patients had expressed in their first-person accounts.

Personal aims regarding physiotherapy. The staff's emphasis on structured physical training supervised by a physiotherapist seemed to suit the initial wishes of most patients. However, it soon became clear that they also had preferences as to how they were to be trained and assisted by the physiotherapist. All patients had articulated various aims for their physical rehabilitation, described in the biographical records. Despite the staff being explicitly trained and educated to formulate plans adapted to individual patient's needs, and despite procedural documents encouraging them to do so, the patients' expressed preferences were almost never acted upon by the staff.

> Patient F was a recently operated, 84-year-old man who, when interviewed, elaborated detailed preferences for his rehabilitation stay to include solutions that had been worked out for him at home. There, a special walking aid made it possible for him to go out into his yard and around his house by himself, allowing him to enjoy the garden and a terrace which his son had recently constructed for him. This practical and relationally meaningful physical aid was not integrated into his individualized treatment plan, despite having been documented in his biographical record.

> Patient H was a 52-year-old woman suffering from severe MS who was eager to exercise using a stationary bicycle. Her explicit goal of counteracting her restricted mobility was jeopardized by a technical mismatch between her wheelchair and the exercise bicycle's pedals. The physiotherapist did not prioritize solving this problem but rather focused on the patient's spastic paralysis, which was deemed more urgent to treat. Consequently, patient H was the passive recipient of stretching (massage) yet was hindered in taking the initiative to exercise actively by herself—despite the importance the unit claimed to ascribe to such independent activities.

Patient wishes in relation to social activity. The unit staff actively encouraged the patients to take part in common meals and social activities as well as to communicate with one another. Although clearly focused on observing and documenting the social behavior of each patient, the staff did not seem to consider what each individual patient might deem to be meaningful activities. Nor did they take into account variations in the patients' ages, personality, or interests, which, in all cases, had been detailed in the biographical records.

> Though patient D, a 58 year-old man, described himself as a social person, he was very determined to decide for himself with whom to interact. He refused to allow the staff to couple him randomly with patients he didn't know, stating that he was fully capable of establishing contact on his own, but only if and when he were to encounter someone he considered interesting to talk to.

> Patient E was a 46-year-old woman who, during the first interview, had shared her fears that her increasing incapacitation would cause her to become ever more isolated. She very much wished for help to go to a cinema and to find other ways to socialize with people her own age. That her innately social nature and need for physical training were so compatible with the unit's standardized programs, might have contributed to her specific personal ambitions and wishes not being taken into consideration.

Personal needs regarding nutrition and diet. Nutrition was another central topic for the rehabilitation unit, as patients might arrive either underweight or obese, though for very different (underlying) reasons. Consequently, any potential improvement would require nutritional approaches that were customized and contextually meaningful.

> Patient G was a 57-year-old man who suffered from intractable chronic pain. He was also seriously underweight, which presented an obstacle to his undergoing a surgical intervention which could potentially reduce his pain. He usually gained weight during his stays at an institution because, he said, his appetite and well-being improved greatly when he was feeling less lonely than he did at home. Nonetheless, the unit did not—or could not, due to standardized restrictions in the length of admissions—offer to extend his stay in order to help achieve a sustainable improvement in his general state of health.

> Patient D had had a stroke seven years earlier, forcing him to use a wheelchair. Since then, his weight had increased and he very much wanted to be put on a diet. He feared that he would literary "grow out of" his wheelchair; using a larger one would require him to widen all the doorways in his house. This was an expensive procedure, and one which he had already had to go through after the stroke. Despite this explicit wish, no tailor-made, long-term weight reduction plan was established for him during his stay.

Patient wishes extending beyond the scope of the institution's customary repertoire

Some of the patients' wishes and requests might be seen as extending beyond the scope of the standardize repertoire of this type of rehabilitation institution. Such needs involved highly specific concerns and existential issues (complexes of values and meanings), the subtlety of which only became apparent when the researcher had access to relatively detailed information regarding the patients' particular lifeworlds. Some information of this sort was provided to the researcher by the patients themselves during the interviews. Some of it emerged during the short telephone interviews with the patients' GPs, in cases where a well-established doctor–patient relationship existed. The GPs in cases A, B, C, for example, had all known their patients for a long time, and there was clear doctor–patient agreement as to what was at stake. Though some of the patients' wishes were far from concrete, they could nevertheless have been attended to, given a flexible mind-set and time to discuss them with the patients. The following stories illustrate such complex constellations.

Fear of being abandoned. Patient A, an 83-year-old man suffering from Parkinson's disease, was in need of rehabilitation. He usually lived at home with his wife, his main caretaker. The patient's need for comprehensive and reliable care was considerable. GP A perceived that the high level of strain in his marital relationship was a topic which would be crucial for the health personnel at the rehabilitation unit to bring up and respond to since it posed a threat, potentially jeopardizing not only the man's confidence but also his actual safety. When asked by the researcher about his situation at home, patient A quite frankly confirmed the GP's concerns and his own fear of being abandoned as follows: *To be honest, I'm afraid our relationship is over—there'll be a break-up. I feel desperate!* Referring to fruitless attempts to enter into a dialogue with his wife on this matter, he stated: *My wife is quite an introvert. I don't manage to get close enough to her to talk about this*. In addition to his fear of being abandoned by his wife, he also expressed a worry that death from Parkinson's, his main diagnosis, was imminent. Although these existential matters were clearly documented in the biographical record, and brought up explicitly by the researcher during meetings as being important human concerns, the topics were never addressed by the consulting physician during the patient's stay. One reason the doctor gave was that it would have been too time-consuming. Also, such issues might be regarded as falling within the purview of the patient's GP; consequently, the biographical record was included in the discharge report the institution provided to GP A.

The importance of being trusted and believed. Patient B, a 44-year-old man, lived at home with his wife and two children. Chronic fatigue had dramatically impaired his capacity to function, forcing him to stay in bed most of the time and causing him to have to struggle to coordinate his daily rhythm with his family's everyday activities. The fact that examinations at several hospitals had failed to yield any unambiguous diagnostic results provoked scepticism among medical staff regarding the nature of the patient's problems. GP B stated: *Patient B is very concerned about being believed because he has previously experienced the opposite*. GP B was concerned that the patient would equate his sense of being judged for not "really" having a disease with not being taken seriously as a human being. Consequently, GP B considered it crucial to any successful rehabilitation that the patient be perceived and treated by the staff as reliable and trustworthy. The importance of being believed was explicitly confirmed by patient B in the interview: *The last time I was here, one doctor actually came to my room and told me that some of the staff doubted that there was any valid medical explanation for my symptoms or disease*. In addition to the patient's fundamental need to be met as "a person with credibility" being documented in the biographical record, existential worries about the future were also revealed. Much to the patient's surprise, these worries were interpreted by the consulting physician, with no further exploration of the patient's life-world, as being "depressive thoughts." A personal, *meaning-laden*, existential worry was thus translated into a generalized and depersonalized medical category: depression. Had the staff invested more time in talking to him, they might more likely have interpreted his concerns as existential rather than as indicating a depression. During his stay, patient B's wish not to be confronted with doubts surrounding his disabling condition was never addressed explicitly. The institution may have responded implicitly, however, given that he reported no incidences of remarks or offending discussions as having taken place during the present stay.

A wish to be "pushed" but in a tailor-made and respectful way. Patient C, a divorced 58-year-old man with MS, usually capable of taking care of himself, was now in the need for rehabilitation. Patient C had known his GP for 13 years, and had shared very personal problems with his doctor. GP C emphasized that the disease had "transformed" the patient from being strong, sociable and independent into being weak, dependent, and self-pitying. GP C stated: *I've tried to focus on his strengths and be supportive. And I've told him to stop feeling sorry for himself!* When his GP's reflections were shared with patient C, he confirmed and also commented on the GP's strategies to motivate him: *GP C was right of course—to tell me to stop feeling sorry for myself. And he got me going again. But he couldn't have said that if he hadn't known me so well*. GP C deemed it important for patient C to be supported in interests and activities that he found pleasurable. Although the patient basically agreed, he stated explicitly that such a resource-oriented approach would only work if he were "pushed" into tailor-made activities—in a non-patronizing and trusting manner, which could, however, be both frank and firm. Under those circumstances, he believed, he would be able to avoid succumbing to depressive moods, passivity, or hopelessness. The institution did not seem to have much to offer in response to this wish. The patient complained of being "bored stiff" during his stay and was so dissatisfied that, at one point, he wanted to leave the unit. The solution found was to grant him several "leaves of absence" to go home, watch the soccer matches he was interested in, be with his friends. The result was that he was more often absent than present, which interfered with the routines at the unit and frustrated the staff.

Observable mismatches between stories and routines

To sum up the results, a series of minor and major mismatches could be observed between the GPs' recommendations and patients' wishes on the one hand, and the institution's actual rehabilitation treatment schema on the other. Although the rehabilitation unit's procedural documents formally commit the institution to delivering *individualized* care, it was evident that those treatment interventions which were actually implemented were, in reality, individualized to only a very limited degree. This was so even in situations where the expressed wishes of the patients regarded one of the core institutional activities, such as physiotherapy, nutrition, and social engagement. The detailed content included within each of the standardized categories of intervention remained relatively fixed as well, despite the obvious feasibility of individual adjustments being made. The researcher was typically told that the biographical document was valuable and relevant; this was said also in situations where it had highlighted patient wishes and needs of a more personal, even existential, nature, which would thus have demanded an even more highly individualized flexibility and engagement on the part of the staff. Nonetheless, the institutional responsiveness was limited, as can be deduced both from the records and from the patients' final reports during the second interviews.

Discussion

Our study indicates that the premises for rehabilitation, "a process of enabling someone to live well with an impairment in the context of his or her environment and, as such, requires a complex, individually tailored approach" (Hammell, 2006) might not be adequately met, even when individualized care is a stated goal. This ambition proved to be more of a professional vision than an actual clinical reality. Our findings raise a variety of questions. We have chosen to reflect on three: (1) What lies at the core of the institution's reluctance or inability to implement genuinely individualized care? (2) Are there arguments to support relational and existential issues being addressed in a rehabilitation institution? and (3) If this were to be recommended, might it also be wise, structurally, to train the patients' regular GPs to serve as consultants to the process of eliciting details (with patient consent) of the individual patient's needs and resources? We'll use an excerpt from the material regarding one of the nine cases to open our exploration of these three questions (see Box 1).

Box 1. **An illustrative scene**

Patient A's biographical record, describing his strained marital relationship and his existential fear that death from Parkinson's disease was imminent, was presented to the staff in a meeting. Even though these issues were overtly acknowledged as being of significant human concern, they were never addressed during the patient's stay. This is confirmed in the following dialogue between the researcher (I) and patient A (PA):

I: Did the consulting physician talk to you about these matters?
PA: Well – hello! [Ironic, meaning "No way!"]
I: So the doctor didn't talk to you?
PA: The doctor came by my room the other day and asked; "How are you doing?" What else could I answer but: "Fine - under the circumstances."
I: So you did have a conversation with the doctor?
PA: I wouldn't call it a conversation. The doctor just popped in and then left.

Why was genuinely individualized care not implemented?

A staff perception that the treatment was, in fact, individualized. In dialogues with the researcher, the staff typically emphasized lack of *time* as the main obstacle. We presume, however, that more complex barriers might be involved. To begin with, the staff might have perceived the institution's treatment plans to be relatively customized since all patients had routinely been given a questionnaire about their personal aims for their stay. Furthermore, the staff might have interpreted the fact of the patients receiving differing sets of activities from the institution's standardized repertoire as indicating that their treatment had been individualized.

A disease-oriented, biomedical focus on cure. We suggest that, at its core, the lack of concrete responses to patients' expressed wishes and needs might reflect the dominant, disease-oriented mindset associated with scientific biomedicine as it relates to the concept of *cure* (Barbour, 1995; Baron, 1992; Cassell, 2004; Montgomery, 2006; Toombs, 2001; Zaner, 2003b). Several scholars have conceptualized biomedical and humanistic therapeutic approaches, associated with *cure* and *care* respectively, as being complementary within Western health care systems (Miles & Mezzich, 2011; Silva, Charon, & Wyer, 2011). The therapeutic, that it is, cure, concept has the objectified, material, physical body as its scientific basis (Leder, 1992); evidence-based interventions, from so-called evidence-based medicine (EBM), have become the gold standard within this realm. The concept of care, on the other hand, is based on methods for appraising subjectivity, including relational and social phenomena (Montgomery, 2006). To reconcile these differing views, a patient-centered model (Levenstein et al., 1986) has been conceptualized, suggesting that two parallel "agendas" (the doctor's and the patient's) should be allowed to evolve and eventually fuse during the medical encounter (Miles & Mezzich, 2011). "Patient preferences and values" are also emphasized in models of evidence-based practice ("The EBM flower") (Haynes, Devereaux, & Guyatt, 2002). However, the fundamental clinical validity of the hegemonic epistemology of biomedicine as such (the basis for EBM) has rarely been challenged (Kirkengen et al., 2013). Consequently, the discourse on "patient preferences and values," and the associated training in patient-centered communications, typically aims at eliciting patients' views and preferences with reference to biomedically defined problems and options. Very little emphasis has hitherto been put on teaching and training doctors to recognize and address more fundamental existential issues as they pertain to a patient's subjective life-world. The medical relevance of such issues is, however, becoming consistently more evident, as we will later explain. In the Norwegian context, health care researcher Marte Feiring (2012) has asked if it is possible to increase governmental control and oversight while simultaneously enhancing user involvement and empowerment. It is certainly difficult to be guided both by group-based, scientific evidence and by the subjective opinions of the individual user. If these principles, which are cornerstones of rehabilitation in Norway, appear contradictory or even incompatible, which of them should be given precedence? Or, from a different perspective, what is needed to unite seemingly incompatible principles in order to prevent the fundamental aims of the overall effort from being jeopardized?

Epistemological obstacles to actual patient involvement and "empowerment". The term "to empower" is ambiguous, implying both that power is at stake and that someone "in power" may be willing to renounce it (or some of it) on behalf of someone less powerful or even powerless. Implicit in the notion of "empowering patients" is the fact that medicine does hold power, a reality that has been broadly discussed within sociology, anthropology, and philosophy (Zaner, 2003a). The main source of this power has been identified as being the type of knowledge about the human body which medicine is mandated to administrate, and the type of knowledge production, grounded in scientific methodology, which it applies (Foucault, 1975). Medical professionals certainly recognize an asymmetry in the amount of knowledge doctors and patients have. However, the fact that their professional knowledge, grounded in the sciences, is presumed to be value neutral seems to help them remain unaware of the power inherent in the objectifying biomedical episteme as such (Foucault, 1975; Faubion, 2000). Other scholars have explored the impact of the biomedically framed and asymmetrical doctor–patient relationship with regard to certain non-objectifiable phenomena in human illness (Frank, A.W., 1991, 2007; Kleinman, 1988; Toombs, 1992). Correspondingly, philosopher Pierre Bourdieu has explored what he calls "habitus," in the sense of particular habits resulting from professional training and socialization; these manifest as incorporated "ways of doing" that are no longer reflected upon but simply presumed to be correct and adequate (Bourdieu, 1990). Such "habits" might be expressions both of explicitly assigned power (the right to decide) and of implicit power, that is, the authority to define the nature of a problem and determine what should count as relevant. Such convoluted power is elucidated by Norwegian physician and philosopher Kari Agledahl, who, based on observations of doctor–patient consultations, demonstrated a habitus of *polite avoidance* when it came to engaging in patients' existential concerns (Agledahl, Gulbrandsen, Forde, & Wifstad, 2011).

Are there arguments to support relational and existential issues being addressed in a rehabilitation institution?

Support from science. Until fairly recently, there was only a small body of medically authoritative, biologically based evidence to support the claim that lifeworld phenomena matter to overall, clinical outcome, including in a literal, biological sense. During the last decades, however, empirical knowledge has been accumulating, showing that—and in increasing detail also how—a person's lifeworld experiences have direct impact on that individual's body, down to the sub-cellular level (Getz, Kirkengen, & Ulvestad, 2011; Tomasdottir et al., 2013). It has now been demonstrated beyond doubt that

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relational and social matters are of general medical relevance (Blackburn & Epel, 2012; Danese et al., 2009; Friedman, Karlamangla, Almeida, & Seeman, 2012; Gruenewald et al., 2012; Kiecolt-Glaser, Gouin, & Hantsoo, 2010; Surtees et al., 2011). This long-avoided topic within medical knowledge production is fast becoming obligatory, seen now as an essential component of adequate medical comprehension. Such knowledge may also be of particular relevance to the care of frail and decompensated persons (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013; Gruenewald, Seeman, Karlamangla, & Sarkisian, 2009; Kuchel, 2009; Szanton, Allen, Seplaki, Bandeen-Roche, & Fried, 2009). Given the mounting evidence of close links between existential strain and ill health, we assert that all medical institutions should be prepared to consider the health implications that hardships and other life experiences have on the persons in their care. This is particularly relevant for institutions specially "designed" to rehabilitate frail and decompensated people, to assist them to recover and maintain the spectrum of capacities and functions required for them to return to their homes and enjoy their privacy and independence as long as possible. It is our contention, consequently, in response to the second question engendered by our study, that research does support that such issues should be addressed. The question is how and, perhaps, by whom. Implicit here is the contention that standardized programs for such patient groups are highly inappropriate. Person-specific and context-specific measures must be applied if the medical intervention of "rehabilitation" is to be successful and sustainable. Western societies, despite limited resources, have to care for a growing patient group characterized by advancing age, complex morbidity and the desire to enjoy living independently as long as possible. To face these challenges, new modes of collaboration within health care systems are now being developed. Standardized interventions and routines may seem to be a feasible, cost-effective and reasonable way to meet the demands of care and transition. However, adherence to such standardized interventions and routines might prove inadequate to meet the diversity of specific needs that characterize that patient group (Rosstad, Garasen, Steinsbekk, Sletvold, & Grimsmo, 2013). According to the late Norwegian scholar Harald Grimen (2009): *Routines are double-edged swords. They facilitate work but restrict the field of vision. Routines can bring both mental comfort and medical (and juridical) disaster. This is the paradox of routinization: What makes routines helpful also makes them dangerous.*

Support from human rights. Another argument for professionals to prepare to address existential issues in settings such as a rehabilitation unit, and in care for the elderly in general, is found in recent Norwegian legislation. Here, the explicit political emphasis that is placed on the relationship between dignity and existential questions coincides with the increasing focus within medicine on the relationship between health and experiences. A governmental document entitled "Verdighetsgarantien" ("The Right to Dignity") (Helse og Omsorgsdepartementet, 2010) acknowledges elderly people's rights to privacy and autonomy, to participate actively in individualized service or care, and to receive qualitatively appropriate assistance. The explicitly stated intention is to "safeguard security and ensure the possibility for each individual to lead a meaningful life." An explicit institutional obligation *to facilitate and participate in dialogues regarding existential matters* (§ 3) is also affirmed.

A future role for GPs as "negotiators of personal knowledge" during transit situations?

In one of this project's previous sub-studies, a group of seasoned, urban GPs expressed a high level of engagement with and interest in their frail and/or elderly patients. They stated that they would be more than willing to make "strategic" consulting visits whenever their most vulnerable patients were admitted to a rehabilitation institution or nursing home (Mjølstad et al., 2013a). The GPs perceived this to be a more cost-effective use of their professional time than participating in the many compulsory "co-operation meeting activities" currently mandated by the Norwegian health and social care system. The present study adds depth to that perception. We were able to show that, even in the absence of specialized, formal training, and even in the context of only a brief telephone interview, experienced GPs were able to contribute important information about their patients as persons, knowledge which clearly extended beyond information that is customarily considered "medically relevant" for transmittal between actors in the health care system. Any new, professional routine wherein GPs would be expected to contribute "personal" information about their patients would obviously require patient consent. It would also presume that the doctor had received adequate education and training. In our opinion, the present study gives reason to believe that GPs might thus become valuable advisors in the process of discerning which issues in human biographies are most salient with respect to health. Such issues might be particularly useful to shed light on situations in which a person's health has decompensated for reasons that are difficult to identify when viewed from a traditional biomedical perspective.

In the debate (Miles & Mezzich, 2011) that has been going on since George L. Engel proposed "the bio-psycho-social model" as an appropriate framework for medical encounters (Engel, 1977), various scholars have pointed to limitations in the model as such, in particular, its "lacking dimensions" regarding the existential and spiritual realms of human life. One predictable consequence of these debates has been the "appending" of the word "spiritual" to the model's "bio-psycho-socio" title (McCullough, Hoyt, Larson, Koenig, & Thoresen, 2000; Powell, Shahabi, & Thoresen, 2003; Sulmasy, 2002). The unresolved epistemological shortcomings of the original concept, however, have hardly been addressed. To simply add a human dimension that is conceptualized, philosophically, as separate, does not address or account for the experiential unity of being-in-the-world as "Me," which endows every human being with a unique "core sense of mineness," as ethicist Richard Zaner (2003b) has termed it. It is precisely this corporeal being, this "mineness" of the human body that has been shown to be of central medical relevance.

Recent efforts to improve the way medicine meets the challenge of the suffering human being are giving rise to various "movements" which might ultimately contribute to radical changes in the medical encounter as well as profound enrichment of the therapeutic repertoire. One of these movements, "person-centered medicine," aims at making doctors more aware that implicit in each medical encounter is the presence of two *persons*: the patient and, on an equal level, the physician. Another movement, "narrative medicine," aims at giving the diseased person, the suffering subject, the possibility to make sense of her/his situation, to tell and to be heard (Frank, A.W., 1998). In addition to acknowledging the subject's right to voice her/his own experience, the listening professionals must also deepen and refine their empathic abilities if they are to understand what they hear. Narrative competence, that is, the empathic ability to recognize relevant patterns in other human beings' life stories, can both be learned and taught (Charon, 2012). At the same time, it is of paramount importance neither to reduce empathy to merely another instrumental skill (Macnaughton, 2009), nor to confuse it with sympathy or identification. Empathy, as understood within the phenomenological tradition, particularly as elaborated by scholar Edith Stein, means to appraise another person's "otherness" (Frank, G., 1985). This crucial "open-mindedness" on the part of the medical professional is echoed in Richard Baron's (1985) seminal paper entitled, "I can't hear you while I'm listening". French philosopher and psychiatrist Pierre Janet (van der Kolk & van der Hart, 1989) has traced the detrimental impact it has on health for people to be prevented from telling and being listened to as they attempt to come to grips their own experiences, especially those which engender existential upheaval. The work of psychologist James Pennebaker (2000), among others, has demonstrated the health benefits of *formulating a narrative*, including its impact on reducing stress and physiological overtaxing.

We may now conclude that, in order to provide effective and sustainable health care, current general practice as well as institutional norms should be expanded to encompass "personal" topics, in the sense of their being relational and existential. The question will arise, of course, as to how to identify those patients who are most likely to benefit from this kind of attention and help. Our study has shown that a simple "screening" approach is unlikely to yield that desired clarity; we observed the lack of effectiveness both of routinely questioning patients about their own "aims" for their stay at the institution and of the consulting physician's informally visiting the patient's room as part of a busy schedule (Box 1 at start of Discussion). Both the patient's capacity to conceptualize and express those existential phenomena which have clinical significance, and the health care worker's capacity to identify them, are likely to be enhanced considerably through the investment of time, and with increased interpersonal experience and trust. Here is where we envisage a potential future role for GPs, when their primary focus on diseases themselves shifts to emphasize knowledge of the individual *persons* who suffer from these diseases (Starfield, 2011).

Methodological considerations

The strength of our study lies in the way its design, method, and analytical framework enabled us to capture differing perspectives on the needs of frail individuals at a rehabilitation institution. Even though the participants were consecutively included in the study (as opposed to strategically), we obtained a varied sample of informants, representing a diversity of experiential backgrounds; this also helped counterbalance the low number of participants. The study yielded insight into how the wishes and needs of the patients were informed by the specifics of their lifetime experience and their everyday lifeworld, and provided nuanced knowledge about the complexity of the rehabilitation process. As to the transferability of these results to other similar groups, the individual situations of study participants and the routines at institutions will, obviously, differ. Based on our clinical experience, however, neither the range of patients nor the nature of the institution stands out as being unusual. The limited time available for telephone interviews with the GPs (10–15 min) might have impacted their capacity to articulate recommendations for their patients. On the other hand, this might bode well for the prospects for transferability of the results since such stringent time constraints exist in real life practice. It is also possible that even better results might be seen in the future using this same time frame if routines were formally established and acknowledged so that the GPs expected, and therefore were mentally prepared, to take a role as "consultant" for patients in transit, as described in this paper. The detailed and comprehensive field notes contributed valuable insights into the institution's routines and the medical records. More consistent observation of the interactions among staff members, and/or additional interviews with them, might, however, have yielded deeper or more differentiated insights into the rationale informing their actions. In accordance with the traditions of phenomenological–hermeneutical research, we have made our position explicit and have aimed for methodological transparency. We have integrated our findings using relevant theoretical frameworks to unfold their implicit features, well aware that our conclusions are tentative and represent only a selection of a wider range of possible interpretations.

Conclusion and implications

In the present study from a rehabilitation unit, we found that the institutional voice of medicine consistently tends to override the voice of the lifeworld; that is, patients' stories became subordinate to the institution's routines. Consequently, despite the best of intentions and the application of the best knowledge according to current standards, the overall aim of health care seeking to provide appropriate rehabilitation to frail and decompensated patients in order to help them return to their everyday life at home might have become jeopardized to some extent. We suggest, therefore, that a "closer look *and* a wider view" might be well worth trying in the future. By this we mean: (1) a closer collaboration between the GP and the institution to elicit and explore information as to the specific context of each individual patient, and (2) a more flexible and openly *person*-oriented (in addition to the more limited and standardized *patient*-oriented) conceptualization and application of patient treatment care plans so that they are more genuinely tailor-made to better represent the "best possible effort/approach to suit this specific person's lifeworld." When health personnel do not know about their patients' life circumstances, mere chance will determine whether the treatment measures selected are the optimal ones. Or rather, the probability of knowingly selecting optimal, or even adequate, treatment measures will be low.

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Appendix:

Example of stepwise analysis patient A.

GP A's recommendations:

-Important to focus on the stressful home situation involving marital strain.

-Important to provide relief for caretaker (wife).

Patient A's expressed concerns and wishes:

-Worried about the difficult situation at home due to marital strain.

-Existential worries regarding sickness and death due to Parkinson's disease.

-Desire to receive physical training to improve his ability to walk.

Patient A's biographical record:

"Patient A is worried about his strained marriage and very difficult home situation. He wants to receive physical training to help improve his ability to walk. He has many questions about his chronic disease; he knows two people who died from Parkinson's and is anxious regarding whether he too will die of the disease. His GP emphasizes that the most import issue to address during the patient's stay is how to safeguard his care in the future, which seems endangered by marital strain."

Actual interventions as identified in patient's medical records:

-Medical examination (report from consulting physician)

-Structured physiotherapy (report from physiotherapist)

-Social activity, training of activities of daily living (ADL) (reports from nurses)

Observation concerning the actual interventions as recorded in the field notes:

"The consulting physician has not talked to the patient about his stated concerns and neither has anyone else (nurses)."

Patient A's comment on actual interventions (from vignette in Box 1):

I: Did the consulting physician talk to you about these matters?
PA: Well – hello! [Ironic, meaning "No way!"]
I: So the doctor didn't talk to you?
PA: The doctor came by my room the other day and asked; "How are you doing?" What else could I answer but: "Fine – under the circumstances."
I: So you did have a conversation with the doctor?
PA: I wouldn't call it a conversation. The doctor just popped in and then left.