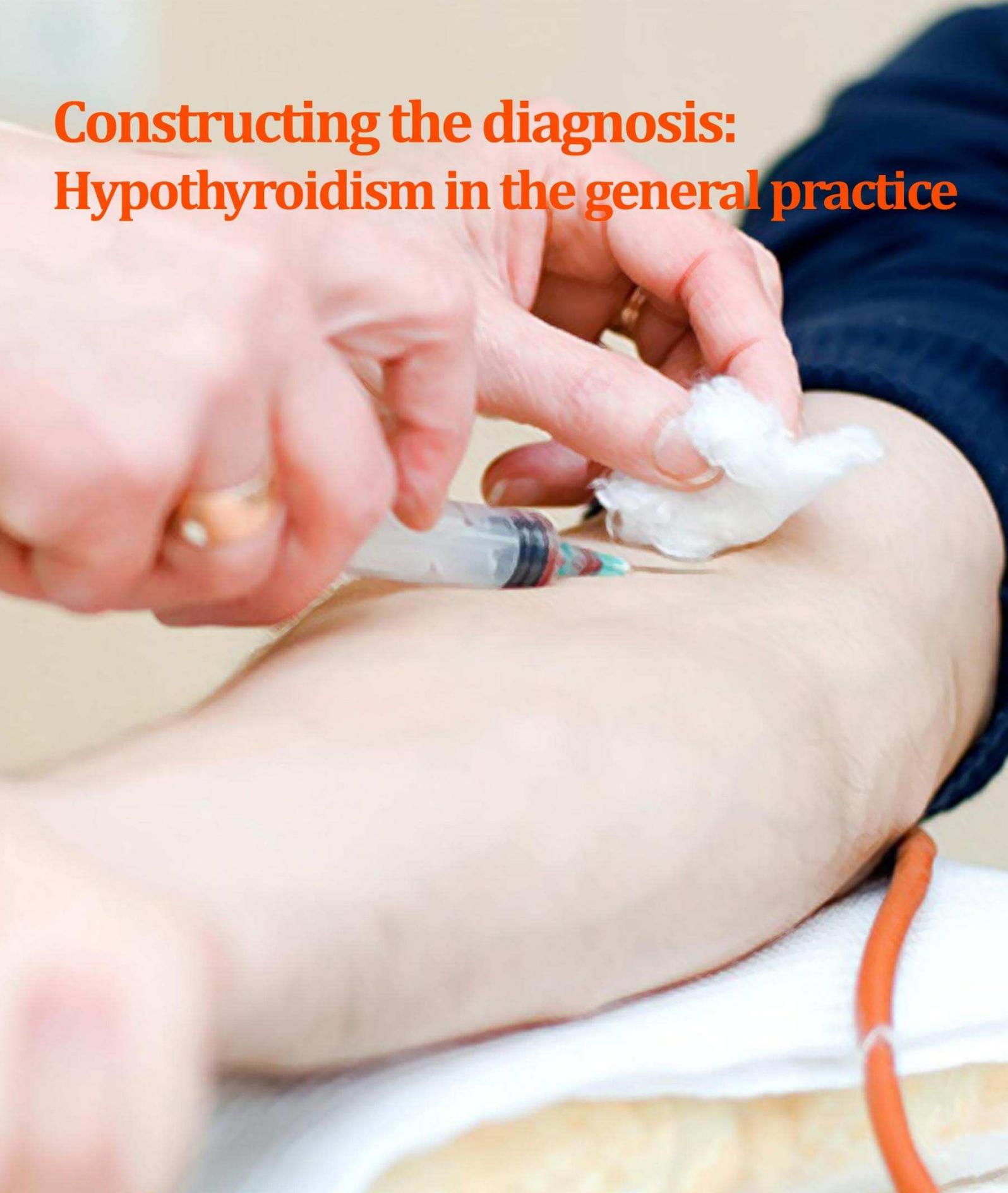


Constructing the diagnosis: Hypothyroidism in the general practice



Elise Doeschot
ESST Master Thesis



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Hypothyroidism in the general practice

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Introduction

It seems rather straight forward: a general practitioner sees his/her patients, finds out about their symptoms and complaints, combines this information with the accurate medical knowledge, his/her logical judgment and experience, and a diagnosis is constructed. Or not? With the border-crossing possibilities of internet, new technologies and an uninterrupted stream of new scientific insights, what information is of use for the GP when constructing a diagnosis? And patients, do they have something to bring to the doctor's table? It seems as if the idea of a passive patient, mere a subject of study to the GP, is outdated. The latter raising another question deserving a closer look: what is the role of the patient in the diagnostic process? In addition to the unbalanced information supply, physicians working in different settings account for different practices and, not unimportantly, different interpretations of what certain symptoms mean and which disease(s) these symptoms can refer to. Even the definition of certain diseases is not universally distributed (Berg & Mol, 1998; Mol, 2002).

Although the diagnosis is of the utmost importance for patient and doctor - after all, it is with the aid of a diagnosis that often a treatment regimen and prognosis of disease is determined - it is not yet fully understood (Ridderikhoff, 1993, 3430). A diagnosis, in STS terms, is not out there to be discovered in nature, even though you can make CT scans and do MRI's and blood tests, nature does not tell us what is medically wrong with someone. It is us humans who decide what is considered normal and abnormal, and therefore what can be classified as a disease or not (Grundmeijer, Reenders & Rutten 2002, p.16; Mol, 2008; Dehue, 2008, p. 64-65). Diagnoses thus serve as labels: a patient comes into the consulting room with 'something wrong', and may come out of the consulting room with a 'disease', thus a diagnosis (Helman, 1981, p. 548). It is the interpretation of the physician, and/or even the physician's interpretation of the CT scan, blood test or MRI, which is kneaded together into a diagnosis. However, the latter does not imply a diagnosis is just an opinion of an educated person. A diagnosis does say something, and people do act upon a diagnosis; a diagnosis made by a professional (educated and licensed as such) has authoritative explanatory power. (Dehue, 2008, p.62).

Research Question

Jacobus Ridderikhoff (1993) studied problem solving strategies in the general practice. He makes a convincing argument that most theories which were developed to acquire a better understanding of what happens in the heads of physicians in the decision making process,

assume a rationality which does not seem to be consistent with the reality of practice (pp. 343-344). As Ridderikhoff points out: “Cognitive biases, uncertainty and unreliable clinical data, suboptimal and prejudiced data acquisition, early reduction of possible states of affairs and the communication and interaction of problems between patients and doctors make the thought of a strict and rational process of information-handling rather unrealistic” (1993, p. 344). His quote is the point of departure for this thesis: a diagnosis in the General Practice looks like a messy, although formally structured, inconsistent process, in which patients behave in unexpected ways and therefore the GP can never act routinely.

Particularly important is the notion of suboptimal data acquisition. GPs rely on information and technologies which are not always up to date or which may be part of a controversy, such as the prescription of anti-depressants is nowadays (Dehue, 2008). GPs base their decision on information which is readily available. It is as if the GP is a referee in a soccer game observing a foul. Only in retrospect, when (s)he sees the playback video of the foul, s/he knows whether s/he was right concerning the verdict.

I think these issues regarding the diagnostic process are far from having been treated exhaustively. Therefore, my aim is to find out what elements play a role in the decisions of the GP when producing a diagnosis. What happens in the room when the doctor is seeing a patient? What are his or her contemplations and reflections in the process? And: what kind of behaviour does the patient show? How does the patient present his/her symptoms? And how does the doctor mould this into a medical decision? These questions mount to the central question in this paper: “How is a diagnosis constructed in the General Practice?”

Doctors

At medical school, physicians are taught what to look for when diagnosing patients. Different methods are described for different contexts including which test methods are applicable. Theoretically, the doctor has a plan, a structure to go by. However, in practice, the structure is less applicable than one might think. Physicians have to find their own way in a myriad of instructions and pieces of information. The way knowledge is used, differs among physicians. (Ridderikhoff, 1993, p. 343). In addition to that, the question is: ‘which knowledge do they regard as important?’ Doctors are not robots: they have their own interests and their own ideas about certain diseases, the concepts which accompany them, test methods and so forth. (Berg & Mol, 1998; Grundmeijer, Reenders& Rutten, 2004).

A general practitioner in Dutch society specifically functions as a professional who is able to direct and refer people to accurate help and care. According to the Landelijke

Huisartsen Vereniging [LHV, National General Practitioners Association] it is a function which is necessary and important for the patient in order to be able to make choices in the continuously growing supply of health care options. They explain: “When you are ill you often do not have the time or energy to consider different possibilities. First and foremost, patients therefore, choose to consult their GP in case of illness or when they need care. (...) GPs are the first contact in the care for all patients” (2010, ‘Thema en Achtergrond’ & ‘Belang voor huisarts, patient en overheid’). GPs are the ‘gatekeeper’ in the Dutch health care system, as is laid down in legislation. In most cases patients have to consult the GP before being allowed to go to a specialist. (‘Belang voor huisarts, patiënt en overheid’). Because the GP has such a crucial task, it is particularly important to understand how the GP arrives at a diagnosis.

As the job of the GP is very different from that of the specialists, constructing a diagnosis in the general practice will be unlike that in the hospital. According to Ridderikhof, significant differences between the hospital and general practice are: “(1) a wide range of problems; (2) problems are presented in an undifferentiated fashion; (3) a much more personal and continuing relationship with the patient; (4) contacts are shorter and more frequent” (1993, p.345). The greatest challenge for the GP is to make sense of the problems the patient takes with him/her to the practice, whereas the specialist can build on the information provided by the GP.

Patients

In practice patients do not present their symptoms in an orderly fashion. For reasons such as shame, believing it is not relevant for the GP, or being afraid to be seen as excessive complainers (‘zeuren’ in Dutch), patients forget to inform the GP about all the symptoms they experience, or simply present them in a different way than expected. Also, patients may have tried to find out for themselves what their symptoms might be a sign of. Can these presentations steer the doctor in a certain direction – a path which he/she normally would not have taken- irrespective of the patient’s correctness or incorrectness of his/her self-diagnosis?

How the patient and the doctor interact is another factor that might influence the diagnostic process. The relationship between a patient and GP is dynamic, and may account for a completely different outcome of the diagnostic process. Is the GP only a producer of a diagnosis and the patient a more or less passive consumer of that diagnosis, or is there something else going on? One could argue that the patient is not a passive actor in the diagnostic process. In the comprehensive study ‘Diseases and Procedures in General Practice’

(Van den Brink-Muinen, van Dulmen, Schellevis, Bensing, 2004) the way patients and GPs communicate was studied by watching video recordings of consults. The researchers tried to find out whether generally held ideas about societal developments such as “the epidemiologic swing from acute to chronic disease, the change from disease-focused to patient-focused communication, the increased access to information and a more balanced GP-patient relationship” could be observed in changes in the communication between GPs and patients (p. 11). One of their conclusions from studying the communication between hypertension patients and their GPs is that (in 2001) the relationship between patients and GPs is not more balanced: patients are more involved in decisions concerning possible treatments, but do not participate very actively in the rest of the consultation. (p.12). Is that also the case when it comes to the route to the diagnosis?

Disease

A disease affecting the thyroid gland, called Hypothyroidism, is a suitable case to study regarding the construction of a diagnosis, as it incorporates many diagnostic difficulties. Hypothyroidism is defined, roughly, as a condition in which the thyroid gland does not produce enough hormones. The thyroid is central to regulating the metabolism in the body; when the thyroid is scarcely producing hormones, the metabolism slows down. (Wessels, van Rijswijk, Boer & van Lieshout, 2006, ‘Fysiologie’).

The type of hypothyroidism I take as an exemplary case for the diagnostic process is different from congenital hypothyroidism. Congenital hypothyroidism is hypothyroidism which already manifests itself at birth, as the term implies. In the Netherlands newborns are routinely tested in order to find out whether they are suffering from hypothyroidism, whether it is on the basis of not having a thyroid at all or a non-functioning or inadequate functioning thyroid, by means of drawing blood of the newborn’s heel (heel-stick screening). (Romijn, Smit & Papapoulos, 2005, 684; Rijksinstituut voor Gezondheid en Milieu, n.d., ‘Hielprik’).

In most cases, 80 percent, hypothyroidism is caused by an auto-immune condition called Hashimoto’s disease. (Wessels et al., ‘Oorzaken van hypothyreoïdie’). Hypothyroidism may also be caused by an iodine deficiency or may appear later, after a postpartum thyroiditis (an inflammation of the thyroid gland). There is also the opposite condition, in which the thyroid works too fast, called hyperthyroidism (hypo versus hyper). Hyperthyroidism may be treated by radio-active iodine, among other treatments, and this may result in an underactive thyroid after treatment. In this case the cause and the chances are known, so these patients are not diagnosed in the way that patients suffering from other forms of hypothyroidism are.

The main reason for choosing the diagnosis of hypothyroidism is the fact that it is a condition which is difficult to detect and is characterised by ambiguous symptoms and a vast overlap of symptoms with those of other diseases. The difficulty of detecting hypothyroidism is strengthened by the gradual development of the symptoms. Symptoms remain unnoticed for a long time: for the patient, environment and the doctor.

Secondly, diagnostic instruments are inconclusive and subject to many and various interpretations. In other words, there is no gold standard test in the General practice which can perfectly determine whether someone is suffering from it or not. (Smit, 2008).

Then there is the problem of which symptoms count as symptoms of hypothyroidism. The five symptoms mentioned the most by patients are fatigue (98% of the patients), cold intolerance (95 %), dry/rough skin (79%), weight gain (76%), and shortness of breath (72%). (Romijn, Smit & Papapoulos, 2008, p. 692). But these five symptoms are just the tip of the iceberg. Many more symptoms, though with a lower prevalence, have been reported, such as: dementia, depression, paraesthesia, constipation, hair loss, anorexia, muscle pain, menorrhagia, joint pain, pre-cordial pain. Also symptoms are mentioned which can more or less be visible to the GP, such as face-oedema, eyelid-oedema, cold and/or dry skin, delayed phase of relaxation (APR), brittle hair, hoarse/low voice, slow speech, muscle weakness, tongue swelling, brittle nails, deafness. Most sources have a number of symptoms in common, but it is hard to find two identical lists of symptoms. This may be due to the vagueness and broadness of the symptoms associated with hypothyroidism.

The many vague symptoms also overlap with symptoms of other psychiatric and physical diseases. Hypothyroidism may, among others, resemble Lyme's disease, depression, burnout, dementia, ADHD, CFS (Chronic Fatigue Syndrome), menopause and in some cases even the opposite condition, hyperthyroidism (van de Pol, 2011, 'Verminderde Schilddklierwerking'; Haak & Kootte, 1985, 1809; Raven, 2011). The symptoms of hypothyroidism associated with psychological conditions have been discussed extensively by the Dutch patient association for thyroid related disorders, 'de Schilddklierstichting' (the Thyroid Foundation). They mention (freely translated): forgetfulness, 'brain fog', lack of initiative, apathy (flattening of feelings, insensitivity to psychological stimulants), low self-esteem, inertia, pseudo-dementia; and sometimes irritability, agitation and aggression (Van Rijen, 2011).

I further want to point out that in the English (academic) language; disease and illness are not one and the same concept: they have come to mean different things. Disease is that which is used by the doctor when diagnosing a patient, illness is that what the patient experiences and takes to the doctor (Casell, 1976). Since I am not looking at hypothyroidism as a disease

in itself, but at the diagnostic process, I do not make a distinction between the two concepts.

Diagnosis

‘Diagnosis’ is derived through Latin from the Greek word ‘διαγιγνώσκειν’, meaning to discern or to distinguish. The word Diagnosis is mostly used to refer to the way physicians try to make out what a patient is suffering from: they discern or distinguish a condition or disease in the patient. (Oxford English Dictionary, 2012, ‘Diagnosis’). When thinking about diagnosis, we automatically assume it is made by an expert, not a layperson. Laypersons are allowed to diagnose: it is not forbidden. However, only a person who is qualified according to Dutch law can derive rights from their diagnosis (Van den Boomen & Vlaskamp, 1996, pp. 9-11).

A doctor, by virtue of her/his profession, is obliged to take responsibility for the diagnosis. S/he also has authority which gives credibility to the diagnosis which is often lacking when a layperson arrives at the same diagnosis. Through the diagnosis, the physician is able to say something about the prognosis and treatment. Not being able to diagnose a patient makes it difficult to help or cure the patient. A diagnosis does not mean that it is the truth, that it says something about what the patient feels or what is actually wrong with him/her.

In the text book ‘Het Geneeskundig Proces, van klacht naar therapie’ (‘The medical process, from complaint to therapy’) the authors ask themselves: “How certain do you have to be as a GP before a therapeutic program is allowed to be initiated and who determines what criteria have to be met in order to be able to diagnose? (Van Duijn, van Weert & Lackamp, 2004 p. 129). A diagnosis can be ‘wrong’ as we may have picked up from the various (sensational) stories in newspapers and on television and from websites where duped patients tell their story or file a complaint about their practitioner (Nu.nl, 2011, ‘Zelfmoord na verkeerde diagnose’).

At any rate, diagnosing is challenging: there is a GP interpreting things, patients presenting their complaints in numerous ways, the doctor-patient relationship, medical knowledge continuously under revision, and diagnostic instruments which are never fully conclusive. Hypothyroidism seems to be a case in which many difficult aspects of the diagnostic process come together.

Chapter 2 - Methodology

What is going on in the kitchen of the GP? Or better still, what are the GP's contemplations and considerations in the diagnostic process? These questions I have set out to answer and in order to do so I have conducted a qualitative study. I started with a literature study to gather what is theoretically known on the diagnostic process, hypothyroidism, and the different controversies surrounding the blood tests. I found presentations, testimonies and even video-material on the internet. I followed the messages posted on the 'Facebook' and 'Twitter' of the Dutch Thyroid Foundation. I read the guidelines which GPs consult, the way guidelines are implemented and whether they are followed by physicians. I studied text books used by students in Dutch medical schools.

For the empirical part of the thesis, I conducted in-depth interviews with the GPs, in which the central questions were how they would diagnose hypothyroidism and what they experience when trying to diagnose a disease, such as hypothyroidism. I cycled around the city, to hand out letters addressed to the GPs to their assistant, so that they could inform and ask the GP whether he/she wanted to participate in my study.¹ These GPs were all located in a city in the West of the Netherlands. I managed to recruit five GPs to participate in the interview. Two GPs participated because they wanted to contribute to the education of students. Three GPs were willing to help me, because they thought the topic was interesting. The conversations with the GPs took place in their offices.

I have conducted in-depth interviews with hypothyroid patients: I wanted to hear their stories of their route which lead to their diagnosis, how they experienced the diagnostic process. In order to find hypothyroid patients to participate in my study, I have put an announcement on the internet forum of the foundation for hypothyroid patients: 'Hypo maar niet happy' (<http://www.hypomaarniethappy.nl>), in order to invite all who had received a diagnosis hypothyroidism, underactive thyroid or Hashimoto's disease. Initially around 35 people responded, ranging from 27 to 55 in age, from which I finally selected 26 people to participate in my study. From most patients I received stories by email. Two patients preferred an online interview, the one because she was suffering from severe muscle pains

¹ Getting an interview with a GP depended a lot on the willingness of the assistant to put some effort into it. Sometimes the GP did not want to participate. One assistant told me it was due to a busy schedule, another told me the GP was not interested. The assistant uses 'triage' when a patient calls or comes in, and the same was applied to me, although I was not a patient. With triage, the assistant tries to determine what kind of priority the patient has by evaluating their complaints or condition verbally. See <http://www.hethuisartsteam.nl/werkassistente.html> for more information on triage (Dutch).

and therefore was not able to write long pieces of text and the other because of intense fatigue. I also interviewed two patients in a face-to-face meeting.

All interviews and conversations with the GPs and patients were conducted with a topic list at hand in order to make sure that I would not miss any information. I encouraged them to share as much considerations and reflections as possible.² I want to point out that the patients, who have shared their story with me, may differ from patients I did not interview. Numerous reasons may account for that: physical state, no access to internet, busy, not knowing how to express themselves or simply not interested. Patients, who did participate, are exclusively people who were willing, or even eager, to share their story. They responded to my call maybe because they are just very interested in helping students or because they have experienced difficulties with getting a proper diagnosis. The latter may have resulted in a bit more negative picture of the diagnostic process than what is actually the case.

The same applies to the GPs I have interviewed. The ones, who participated in my study, are different from the GPs who did not. Perhaps they were more interested in the subject, were more open to helping a student or were less busy than the GPs who did not respond. In any case, there is no reason to assume that the GPs who participated were worse than other GPs in diagnosing hypothyroidism. Maybe even the opposite. This means that the findings may portray a slightly better picture of the diagnostic abilities of GPs than what one would find if all GPs had participated.

The names used in the interviews are invented and no association with real persons or practices are intended or should be inferred. I have retrieved the names of a database of the Meertens Institute which listed the top hundred most common Dutch surnames in 2007.³

The diagnosis ‘hypothyroidism’ or Hashimoto’s disease is a label which is given by the GP or the specialist at the end of a process. The patient’s stories are about problems and complaints which they relate to hypothyroidism. I am not making the judgment whether this is correct; I merely gathered what happened with this person in the context of a diagnosis which led to the label ‘hypothyroidism’.

Different doctors, different bodies

Annemarie Mol has done major work on a condition called ‘Atherosclerosis’ in her book ‘The Body Multiple’ (2002). With an ethnographic gaze she investigates the practice around the treatment, diagnosis and daily life of patients with atherosclerosis, a condition which is not an

² I have recorded the conversations on the Telephone/VOIP and in face-to-face settings.

³ Meertens Instituut, database van populaire namen: <http://www.meertens.knaw.nl/nfb/documenten/top100.pdf>

absolute entity: meaning different things in different settings, times and for different actors, patients and professionals alike. Elements of stories of patients, nurses, surgeons, family and other caretakers are included, as well as the practice around atherosclerosis itself: the instruments, the surroundings, the activities and performances and the ways patients and care givers interact. I adopted a similar approach in this study; however, I was limited to interviewing patients and GPs. I have not been able to see a diagnosis being constructed on the spot; nevertheless, by interviewing both patients and doctors, I got an interesting peek into the diagnostic process. By comparing what the patient and the GP say, I found that sometimes they contradict each other, but also that they say similar things. The perspective of the patient differs from that of the GP. Each is valuable in its own right and may supplement each other. Sometimes the perspective of the GPs cannot be properly understood or does not even make sense without the input of the patient, and the other way around.

Boundary Work

The techno-scientific knowledge collected from (epidemiological) research and clinical trials are the main sources of knowledge for the GP. This knowledge has to be translated into practice, however, that is not always easy as GPs will stumble upon many situations which do not exactly correspond comfortably with the knowledge provided by scientific research. GPs are required to use the knowledge and technological devices in their own way: the information stemming from clinical trials and the technologies used in those trials are not always appropriate for the daily practice of a GP. Some technologies are very practical in hospitals, but too laborious and costly for the General Practice. At the same time, there are many new and older scientific insights, which do not even make their way into practice. It sometimes seems as if there is no consistency whatsoever in what knowledge sources GPs use and do not use, and therefore what it is worth knowing. In addition, GPs are confronted with patients who bring along corresponding - but also different - sources of knowledge, so that they are always busy with tinkering with and/or defending their field of expertise.

The latter phenomenon has been described and theorized by Thomas Gieryn(1995), calling the way boundaries are constructed and maintained, whether it is for a discipline or profession, ‘boundary work.’ Boundary work is present in all the cases in which boundaries, borders or other separations between areas of knowledge are constructed, established, advocated, reinforced or attacked. With the concept of boundary work, Gieryn sought to find answer to the question: ‘What is science?’ Science, for Gieryn, is not sharply, solidly demarcated field, insensitive to change. On the contrary, it is a fluid realm, flexible and ever-

changing, throughout context, circumstances and time. In the case of medicine, GPs are continuously defining what belongs and what does not belong to their discipline. They do that by the technologies they use, how they talk with their patients and with each other, which sources they accept and which not, and so forth.

Expert of bodies or expert of your own body?

Medical knowledge is not only confined to the realm of GPs: citizens, increasingly by their investigations on the internet, are able to employ similar knowledge the GP has to his/her disposal. According to Collins & Pinch (2005) “Citizens can try to develop their own expertise and, as in the early days of medicine, enter into a more even handed dialogue with the doctor.” They add: “Sometimes the patient’s expertise can be at quite a high level” (p. 13). They call this ‘interactional expertise’.

Interactional expertise is different from other kind of knowledge such as Beer-mat knowledge. According to Collins and Evans (2007, pp.18-19) beer-mat knowledge is the knowledge about a certain subject or object, which does not pertain to how to apply the knowledge, but which is more or less something which can be used to answer questions in games, such as trivial pursuit. Then there is what Collins & Evans call ‘popular understanding’: “Popular understanding of science does involve a deeper understanding of the meaning of the information than does beer-mat knowledge.” However “Popular understanding hides detail, has no access to the tacit, and washes over scientists’ doubts” (p. 20). Because of the latter, the knowledge obtained by patients about the disease they suspect they are affected by, and the articulation of this knowledge to the doctor, reveals a more tacit understanding. The patient is in this case able to ‘challenge’ the doctor with the things s/he knows.

“The transition to interactional expertise is accomplished, crucially, by engaging in conversation with the experts” (Collins & Evans, 2007, p.32). A patient would reach this stadium in this line of thought, by being involved in his/her own diagnostic process, and talking about these things in a more ‘medicalised’ way, learning and communicating specific things about the suspected condition. It does not mean that the patient is suddenly an expert as the doctor is an expert; in that case there would be no use in having medical training or apprenticeship. However, it should be taken seriously, since the patient’s knowledge can be of such a high level that it can improve the diagnostic process (Collins & Pinch, 2005, p. 13). The account of Collins and Pinch makes it feasible that indeed patients can and may play a role in their own diagnosis. Thus, if we accept that a patient’s knowledge plays a role in the

diagnosis, the question that rises subsequently is to what extent the patient is able to influence the outcome of this diagnostic process?

Looking at patients and their symptoms

To make sense of how the GPs look at certain situations, patients or diseases, I have looked into the concept of 'framing'. The way people use mental filters to make certain judgments or understand the world, or the way in which they define or construct an issue, is called 'Framing', a term used ubiquitously in the social studies. Framing as a theory has been initially assigned to Erving Goffman, who coined the concept in his book 'Frame Analysis' of 1974. One can 'frame' an individual, a situation, a discourse. The concept of framing has been used by many STS-scholars, such as Brian Wynne (2007) and also Nicolas Dodier (1998) in the book 'Differences in medicine', edited by Berg & Mol (pp. 53-85). In the words of Dodier: "(...) once people seek to establish some sort of connection with others within a certain relationship, they are automatically involved in the web of associations already woven by past events. They are faced not only with the stethoscope, the actual technical object, or the word, but with medical practice, a socio-technical network or a language game" (p. 53).

Dodier demonstrates in his account that the way in which the occupational physicians use the rules and protocols relies on their 'frames' of the situation they are dealing with. The frames Dodier has defined are applicable to my case since GPs are confronted in similar ways with protocols and statistical data, and deal with them in a specific manner. Dodier discerns two frames which dominate the approach of occupational physicians toward regulations: the administrative (bureaucratic) frame and the clinical frame. He discusses the connection between "the administrative frame, in which all the people of the same category are treated in the same way, and the clinical frame, in which the doctor follows a course that leaves room for the individual's unpredictable particularities" (p.55).

The administrative frame makes it possible for the doctor to diminish the duration of an interview with an individual "by identifying a person as belonging to a population at risk" (p. 59). This frame is an attempt to standardize practices (p.62). It will determine whether additional information is needed, or whether the category itself covers all aspects. In the clinical frame, the whole set of symptoms, referring to a personal situation, is considered. Dodier describes it as: "The individual's points of reference are no longer connected to general categories, but to personal norms" (p.63). In the clinical frame, as opposed to the administrative, the diagnostic process is more or less an exploration of possibilities. Although, according to Dodier, both frames should be understood as opposing each other, the frames do

not exclude each other. They are able to co-exist. Three forms are possible: “temporal succession” (p. 73), “appearance of controversies” (p. 73-77) and “a combination of forms of action, inscribed in the tools themselves” (p. 77-78).

Temporal succession means that the doctor is continuously switching between the administrative frame and the clinical when working. In the second scheme, the appearance of controversies, there are confrontations between the two frames. For example, a doctor may not adhere to the general rule which considers “all epileptic employees unfit to drive cranes or heavy loads for safety reasons” (p. 74). He might deviate from the prescriptions of protocol and make an exception for the worker, seeing possibilities for the employee despite his/her suffering from epilepsy. This may for example be based on the information the person provides concerning his/her fitness. The last form, using a combination of the frames, signifies following an administrative frame in which in a particular case or moment a clinical frame may be used. When it comes to my findings, the temporal succession scheme seems most applicable, as the GPs seem to switch between doing administrative activities (and therefore adopt this frame) and a more clinical practice, and therefore having a more clinical view. The question rising from this literature is how the frames influence the diagnostic process and outcome?

Chapter 3 – The Diagnostic Gaze

“When students are sitting in on the consult of an experienced physician, in their opinion something magical happens: after asking some questions and after a short exam, the doctor constructs a diagnosis. However, there is nothing magical about that; every experienced physician follows, mainly subconsciously, a complicated process which can be divided into different steps and can be taught piece by piece.” (Grundmeijer, Reenders & Rutten, 2004, p. 57)

In the book ‘Het Geneeskundig Proces’, (Grundmeijer, Reenders & Rutten, eds., 2004), van Leeuwen, Muris and Dinant (pp. 57&58) describe a model of different steps in the GP’s diagnostic process. They point out that a more experienced doctor will not proceed step by step; however, they contend that in some cases it is very useful to do so, in order not to miss any critical information. In order to categorize the empirical results, I will follow these steps as described in this text book, which is used by Dutch and Belgian students in their study of medicine.⁴ It is written by GPs and it is based upon the ‘Raamplan 1994’, which depicts the requirements (‘Eindtermen’) for graduating the medicine study (Schadé & Sminia, 1995, 35). With the revision of this book in 2004, also some adjustments are made in its chapters, since the Raamplan ’94 was revised in 2001. (Grundmeijer, 2004, p.8).

According to the authors, the first step in how the diagnostic process proceeds is “generating a differential diagnosis”. The second step is “bringing a hierarchy in the differential diagnosis” (van Leeuwen et al., 2004, p. 57). The third step is called “the course from the differential diagnosis to the diagnosis”. Although the authors consider setting up the differential diagnosis as the first step in the process of diagnosing (p. 57), I take ‘defining the patient’s problem’ (‘Vraagverheldering’ in Dutch, p. 46) as the starting point in the process. ‘Het geneeskundig proces’ dedicates a whole chapter (chapter 2) on the practice of defining the problem, preceding the chapter in which the steps of the diagnostic process are explained. Of course, the patient’s aim in visiting the GP may be for several reasons, such as seeking information or reassurance, which does not in the strict sense lead to a diagnosis, and therefore might be dubbed as not being a real step in the diagnostic process. However, defining the problem is important because the GP has to understand what exactly the patient wants from him/her. It is not always clear from the onset what kind of ‘help’ the patient is

⁴ The book ‘Het Geneeskundig Proces’ was delivered to me by students of medicine of Maastricht University and Leiden University. Since it is written for educational purposes I assume it is commonly used to educate students in medicine at universities around the Netherlands.

looking for. In some cases patients look for comfort or reassuring instead of a pill or a diagnosis. Since hypothyroidism is a condition which often manifests itself with very vague symptoms, defining the problem is a very important aspect in the diagnostic process. It is crucial to exactly find out what the complaints mean and how the patient experiences them and in addition, what the patient's ideas are about what s/he is suffering from.

After clarifying the problem, a GP can attempt to generate a differential diagnosis. (p. 57). A differential diagnosis is a list of all the possible conditions which could be the cause of the patient's symptoms. Constructing a differential is sometimes referred to as induction: the doctor starts with specific indicators and tries to extract a general conclusion from them. This may also be summed up as reasoning from 'phenomenon to explanation'. (p. 58).

When the differential is set up, a possible hierarchy is introduced. In the first step (p.60) the GP may use epidemiological knowledge in order to rank the possible diagnoses (incidence and/or prevalence of disease). The second step, then, is to adjust the hierarchy based on gender and age (p. 62). The third step is to adjust the hierarchy on the base of pre-existing knowledge and contextual factors (pp. 63-64). Obviously, in practice, these are not steps but components, which can come up in any order.

Now the 'real investigation work' can begin, according to the authors. For this part of the process, GPs have a variety of diagnostic instruments available: they can make up the medical history (De Jongh, 2004, p. 92), can do a physical examination (p.99) and they are able to do additional testing (p. 103). All are directed by some kind of logical sense.

In most cases the GP starts now with the anamnesis, also called 'patient history'. This is called the most important part of the diagnostic process. In connection to the anamnesis, doctors often do a physical exam depending on the nature of the problem. For example when somebody is brought in after a football match and cannot move his leg, it is quite probably fractured. In that case it is important to find out where the bone is broken and how severe the fracture is. A full anamnesis is not relevant in this case. In other cases establishing the patient history is crucial (de Jongh, 2004, p. 89). De Jongh argues that "most doctors make use of a guided interview for the medical history, in which only questions are posed which are related to the main complaint and the differential diagnosis of the doctor. However, in the case of vague symptoms, a more general medical history is obtained, which consists of - in addition to the history of the present and past illness, family history and social circumstances - an evaluation of the organ systems (p.92).

The element often saved for last, is doing additional tests. In this phase the GP can try to exclude or confirm the remaining possible diagnoses by additional testing. This can consist of,

among an extensive range of other possibilities, doing a blood test, measuring the pulse, measuring blood pressure. (p. 58).

A variety of sources discuss the discrepancies between text book and the reality of a physician's diagnostic course, among others Ridderikhoff (1993) and Stolper, Rutten & Dinant (2005). Stolper, Rutten & Dinant try to find explanations for the discrepancies. They state in their article that GP's in first instance have been taught to collect information of their patients systematically, and establish a differential after the physiological analysis of the data. However, in practice it does work out differently: "already in the first quarter of a consult of GPs, three quarters of hypotheses are generated which account for a certain direction in the diagnostic process, especially to confirming questions and the selection of information". (p. 16). Not only the sequence of the steps is a matter of debate: Reidun Førde, in her article 'competing conceptions of diagnostic reasoning' (1998), tries to make the sources of knowledge visible and wants to explore those sources which play a significant role in the diagnostic process. She critically analyses three "simplistic and competing models of diagnostic reasoning."

The steps in the diagnostic process do not have to be followed in the order presented above since they mark different aspects of the relationship between the patient and the doctor as I will show in the following paragraphs.

Step 1 - Defining the problem

When patients decide to go and see a GP, it has been preceded by another decision: the decision that they need professional help. Six out of seven persons choose to go to a GP in that case (Rutten, 2004, p. 35). A consult with the GP starts with defining the patient's problem. The GPs I interviewed considered this as the first and foremost step when seeing a patient. GP Bakker told me that defining the problem is a very important step to take before asking questions about the technicalities of a complaint, or doing a physical exam. She explains:

“(…) why is this gentleman or women now, with this complaint, here? Well, if he has knocked his head (…) it is very clear. And sometimes you do not have a clue. As in, hmm, you are already suffering from it for 6 weeks, why did you decide to come just now? Well the neighbour, she said, that someone she knew also had the same symptoms as I now experience, and he was diagnosed with Leukaemia. Or, patients say, someone I knew felt similar things, and died because of it. (…) If you fail to ask, to investigate that further, you will not find out. Sometimes these are such far-fetching connections people make, you can't think of that yourself.”

The quote above provides a good example of what the GP needs to do in practice fitting the description of ‘finding out what the real problem is’ in the text book. The work of the GP is especially context-bound, and does not or should not follow the standards rigorously, because every situation presented is different. Also some important elements of diagnosing are raised. For example: “Which considerations of the patient were playing a role in the decision of consulting the GP at this moment in time?” and “What is the precise request for which the patient seeks help?” (Grundmeijer, p. 46). It is important that patient and GP understand each other correctly. The GP has a very decisive role, because s/he often is confronted with patients who cannot clearly or precisely articulate their problems, or cannot articulate them yet. GP Bakker offers an example of this: “Not many people say literally ‘I am feeling so depressed’, no, it is more like ‘I am so tired’ or ‘I am out of sorts’. (…) You will explore that further, considering both the psychosocial as the physical side of things.”

Presentation and Selection

Ms. Brouwer explains the difficulty in presenting a clear picture of her symptoms to the GP:

“For a long time I have experienced vague complaints, which I did not find severe enough to consult a GP for. I never thought in terms of a ‘bigger picture’, and I truly did not realize that some complaints were clinical, for example, the tiredness; I always thought that was caused by my busy family life – having four kids and all. I did go to the GP for having muscle problems of half a year; however, he could not find a plausible explanation. (...) Only when my menstruation cycle changed - menstruating very often and a long run-up and aftermath, so menstruating for about half a month - I got referred to a gynaecologist.”(Ms. Brouwer)

The GP is in the first instance not able to explain and find a solution for the muscle pains, and when another symptom, menstrual problems, comes up, it is taken as separate, leading to a referral to a gynaecologist. Ms. Brouwer does not see a connection between her symptoms herself, and does not mention the other ones, which she thinks are unimportant, which leaves the GP with an incomplete picture.

In the case of Ms. de Wit the GP does not get a complete description of the symptoms either, since her own ideas about the cause hinder her to express other symptoms. She elaborates:

“I have never mentioned all these ‘vague’ complaints such as constipation, dry skin and more of those. I thought that I shouldn’t be complaining so much. Unfortunately. Only when my blood was tested due to advice of the ophthalmologist, she [the GP] said: But then you should be also experiencing this...and that... Not surprising that I indeed could recognize all my symptoms in the list. However, I never had defined it as such” (Ms. De Wit).

She interpreted her symptoms as being probably irrelevant to her doctor. In addition to that, she is afraid to be seen as a complainer who will not be taken seriously by the GP.

If we look at Ms. Brouwer’s case again: She only consulted the GP for muscle pains, even though she had a broader range of problems. This may be a problem of the interaction between her and her GP, a personal thing, or the attitude of the GP towards her or her symptoms. It makes clear that patients have certain expectations when they visit the GP. These expectations have an impact on the way patients present themselves and on which

information they share with the GP. Obviously, this influences the direction the GP takes in the diagnostic process. The GP should give the patient ample space for expressing thoughts and feelings as that allows the patient to voice doubts and other things that are bothering him/her (Rutten, 2004, p.48-49). These unmentioned symptoms may shed a whole different light on the possible diagnoses. Ms. Brouwer, just like many other patients, does not realise that some of her 'characteristics' or 'habits' are a symptom. Ms. van Dijk told me for example:

“In 2009 I went to the GP again with the same complaints [always feeling cold, tiredness E.D.]. I now realise that I also had constipation, however, for me it seemed perfectly normal to go to the toilet once every two or three days. Now I know better: since the moment I have started with medication I am able to go to the toilet every day”.

Expertise & the Internet

How the patients present their symptoms and which symptoms they select to discuss at the GP, are not the only components playing a role in 'defining the problem'. Although the problem definition depends obviously on the knowledge and skill of the GP, - for example how and what questions are asked, how deep the GP digs into the problem - my interviews show that the patient's knowledge is relevant as well. Before an appointment patients may have tried to find out what they are suffering from and bring that to the table. For example, Ms. Peters had her own ideas about what the problem was. She recounts:

“In April 2010, I developed problems with my joints, everything itched and I could not breastfeed anymore. I went to the GP because I wanted to know whether I was suffering from Rheumatic Arthritis, because that is how the pain in my joints felt.”

From this quote it becomes clear that 'laymen' also are able to connect certain information and medical labels to their condition. Collins & Pinch call the medical knowledge of patients: 'medical literacy' (2005, p. 78) and in the case the patient diagnoses him/herself, this may have an effect on the 'impartiality' of the diagnostic process (p.79). Also other patients were not blanco when they went to the GP. Mr. Dijkstra also had his own ideas about where his symptoms came from and he was more or less looking for a confirmation by his doctor:

“You know how that is, you see your GP and you hear yourself saying: I am overworked or... You have your own idea, and that is what you tell the doctor. And then he asks, well, do you have reasons for believing that this is it? Well, we had a reorganisation at work and I had an executive position at that time. A lot had happened in that half a year, so it was quite plausible, I would say.”

Also Ms. Meijer recognised the symptoms of hypothyroidism, because she knew her sister was suffering from it. She decided at one point to just ask her GP directly:

“So, at some point, and when I was, I think, between 25 and 30 years old, I pointed out to my GP at the time, when living in Amsterdam, my sister suffered from an Auto-immune thyroid disease and told him I recognised a lot of these symptoms. So I asked: 'is it possible to get me tested?'"

According to the GPs, commonly people who are overweight think they have a thyroid problem. GP van der Berg says about this:

“Very often I have seen patients who thought there was something wrong with their thyroid, very often. Especially people who are overweight. However, I have never experienced that someone who thought he/she had hypothyroidism, in reality was suffering from the disease.”

GP Bakker is willing to explore into depth when people come in to ask her whether their thyroid is not working well:

“And of course there are people who are overweight and want to lose weight, and it is not working so well. Those also always come, they directly pose the question: Is my thyroid okay? Because it is generally known that when it is impossible to lose weight it is perhaps due to your thyroid. It is very rare, but it is possible.”

I asked her where these patients got their information from. She answered: “Beats me, Internet, Libelle, Margriet (women’s magazines)?”

For a long time knowledge about health and medicine was only accessible by people through books and what the doctor would tell them, but nowadays obtaining medical

knowledge has really become easy due to the arrival of the internet. (Messing, 2011, 'Internet emancipeert de patient'). Patients admit they often try to find out what they are suffering from, for example looking up their symptoms in a search engine. Collins & Pinch (2005) say in *Dr. Golem: how to think about medicine* that interactional expertise of the patient "is made possible by the rising levels of education and easy access to information provided by the Internet" (p. 13).

An example of a 'googling' patient is Ms. Bos and she elaborates on why she went on the internet to find some information about her symptoms:

"(...) I was very tired. We were on the brink of going on a holiday, however, I felt slow and listless. And I actually lacked the energy to go on a holiday. Also, I felt easily irritated for some months, for example in traffic. So I started to think I had a depressive disorder or a burn-out. I started to search on the internet, to see in which cases you are dealing with a depression and in which cases it is a burn-out. I arrived at a website about the thyroid. I finally saw the light, because the ENT-doctor [Ears, nose and Throat physician, whom had stated she had a 'big' thyroid a year earlier], also talked about my thyroid. So the next day I went immediately for a consult to the GP. However, there, in the waiting room, I started to doubt about how I would tell the GP about my findings. Just talking about my symptoms and pretending to know nothing or talking about my internet consultation. I decided to tell my doctor, because I really wanted my thyroid to be checked since I recognised those symptoms."

As becomes clear from her account, she is somewhat hesitant to tell her GP that she has been searching information herself and was not sure how to present her findings, or whether she should present them at all. The reason why she did not know how to present her story to the GP, she explains as follows:

"I have always been interested in medicine and health care. I watch programmes about disease, and read about it in newspapers. And I always try to find an explanation for things myself. (...) However, I did read once that GPs experience that patients are more and more assertive. In other words, (in my opinion), they are not so comfortable with the fact that we come up with explanations and solutions ourselves."

Ms. Jacobs had many complaints such as tiredness, recurring sinusitis, dizziness and a general

feeling of being unwell. She consulted her GP numerous times for these complaints. Her HB was tested many times, but all was fine according to her GP. Eventually she was becoming more ill and she thought:

“There has to be something wrong? I went on the internet and I bumped into a website about thyroid disease. I wondered why I never thought about that, my mother is affected by it too! However, she got little information of her doctor, so we weren’t knowledgeable on the subject. (...) I asked my GP for a new blood test. A week later I knew I was suffering from an underactive thyroid. (...) The GP wanted another blood test, to be sure, because she thought it to be extraordinary that I came with the diagnosis myself.”

Her GP could not find out what was causing her problems and Ms. Jacobs took matters in to her own hand, eventually coming up with the right diagnosis. Although the outcome of the blood test requested by Ms. Jacobs pointed towards an underactive thyroid, her GP wanted to repeat the test. It seems that she felt uncomfortable with her patient constructing her own diagnosis and perhaps knowing more about it than she did. Ms. Jacobs adds to this: “I quickly realised that she did not know a great deal about thyroid matters”.

The GPs I interviewed told me they often see patients in their practice who want to discuss their internet findings. Some of the GPs are okay with it: they are open to the potential aid in the diagnostic process. GP Bakker for example shows she is not easily thrown off balance when people consult her and talk with her about internet findings:

“You will ask that as well, as in: have you already ‘googled’ it? Did you already look it up? Yes, sometimes they come to you with an entire book. There are also a lot of people who do not look up things on the internet anymore because when you type a symptom, you get a huge story. Or they say something like: ‘on the internet you read such scary things. So I am not going to do that anymore, I will just come to you instead’.”

Setting the boundaries

GPs can be busy with balancing incorrect outcomes from the internet. The information on the internet may not always correspond with what the GPs have learnt. In many cases, their knowledge of epidemiology is necessary, in order to balance the information. For example,

very dangerous conditions are extensively described on the internet; however, the chance that someone has such a condition is rare. In some cases, the information derived from the internet just does not fit their professional perspective. GP De Jong, for example, experienced that some of the information patients find on the internet puts her in a somewhat uncomfortable position:

“Because they have been searching on the internet, some people come up with T3 [thyroid hormone], that something should be done with it, and that there is a clinic, such and such, where they in that case prescribe this and that. However, this is outside the regular field, so we do not use it, but yes, people will go and look for themselves. (...) At least the things I do here, I am certain of, I support it. I always try to make that clear. But you have to know, that is not easy.”

This quote shows that GP De Jong actively sets the boundaries of what belongs to her ‘science’, and what does not when discussing with her patients, fitting Gieryn’s theory on maintaining and constructing boundaries. All GPs are continuously engaged in defining what belongs to their discipline. However, there are differences in where they draw the line. GP de Vries explains his opinion about the use of internet for medical matters:

“People -and they are completely right in my opinion- often informed themselves broadly on the internet. And I am okay with that. However, the internet can be true, but it can lie as well of course. You are able to put everything on the internet if you want, so, it is a bit dependent on the sources which are used. The only thing which is a bit the limit for me is that, I am still the expert, I am still the doctor. Nothing authoritarian about that, but what I mean is, in the case, that people do not accept me as someone with a specific expertise on the basis of information on the internet, I do not see any point in it anymore.”

All in all, the information patients find on the internet, may influence the GP in numerous ways, depending on whether s/he is convinced by it or not, and that depends strongly on how s/he draws the boundaries. Among the GPs I interviewed, there was not one who was strongly opposed to the use of internet for medical matters. However, as the examples show, they have a critical attitude towards the information derived from internet sources. This largely

corresponds with findings in the literature, such as the paper of Nettleton et al. in which the way patients use internet for looking up health matters is discussed (2005, pp. 973-4).

Knowledge

The information extracted from the internet may be a lot more specific than the information the doctor has. Central to the General Practitioner's task is knowing a little bit of everything. The knowledge of a doctor about the disease, such as being able to recognise certain symptoms and link them to hypothyroidism, can to a high extent influence the outcome of the diagnosis. A broad command of medical (factual) knowledge is not the only requirement in proper diagnostic reasoning. Also the ability to "combine the clinical knowledge correctly" is crucial according to Førde, who looked into the different ways of diagnostic reasoning. (1998, p. 59). In their study, medical students will come across hypothyroidism in their courses on Internal medicine. (Romijn, Smit & Papapoulos, 2008, pp. 673-727). Since the field of medicine changes rapidly, it is important to stay up to date. GPs will do this by reading the relevant information in their field. However, it is hard to see the wood for the trees, given the number of journals being published. Buntinx explains why it is so difficult to stay up to date: "At this moment about 20000 biomedical journals are being published in which annually two million articles appear and I do not know any doctor who reads two million articles every year." (Buntinx, 2000, P. 15).

In addition to the medicine study and journals, there are refresher's courses, which are supposed to be updating the GPs on subjects in which new insights are developed or which are so important that they need annual reflection. Dr. Bakker explained to me how it works with refresher's courses. She told me that, as a GP you have to do 200 hours in 5 years and it is best to spread those hours over 5 years equally. Part of these hours also are spend on small-scale training, for example 'intervisie' (sharing experiences and knowledge between co-professionals) or/and supervision. However, she remarked: "when it comes to the subject, you may choose yourself. If you want to train yourself in ophthalmology 40 hours per year, you can." Thus, as becomes clear from this quote, refresher's courses are not drafted by the government or medical organisations to keep GPs up to date on certain subjects, because they may choose themselves. I asked her whether GPs could develop their own specialty in this way. She answered:

(...). It is their goal eventually that certain expertise is with certain GPs, also in primary care. Of course you are inclined to choose the refresher's courses that are of

interest to you. But, you actually need to train yourself in things you don't know much about, right?"

By her somewhat rhetorical question directed at me, GP Bakker indicates she is slightly worried about the fact that GPs can choose their own refresher's course. I asked her whether she meant that the knowledge of a GP should not be developed in one direction solely. She responded: "No, the idea is that you are reasonably knowledgeable in everything, without going extremely deep into the matter." According to her, this should not be the direction taken when it comes to training a GP. A GP in this view should be able to turn their hand to anything.

So how do matters stand in respect to hypothyroidism as a subject in, for example, refresher's courses? Hypothyroidism seems not to be very high on the agenda when it comes to those courses. GP Jansen is clear in her idea on hypothyroidism as a subject:

"In any case, in the refresher's course it is a subject taking a back seat. Well, yes, nobody is interested in that. Everybody knows how to deal with it. I guess hyperthyroidism now is more of interest in relation to its new developments and the protocols about what to do when you feel a node. There have been all these adjustments of what the possibilities of diagnostics are etcetera. When it comes to hyperthyroidism, I think some of it will end up in the refresher's course, but about hypothyroidism I haven't had a refresher's course for a long time."

The GPs have different opinions on how much attention there is in the training. As GP Jansen says, hypothyroidism is the poor relation in refresher's courses. According to her, hyperthyroidism on the other hand receives more attention, because there are new developments. Maybe there is more attention for hyperthyroidism because the consequences are somewhat riskier. As GP de Jong points out: "What you want to avoid is a thyroid storm". 'Thyroid storm' is also called life-threatening thyrotoxicosis, a rare complication of hyperthyroidism" (Codex Medicus, n.d., 'Thyreoidstorm').

The other GPs, when asked, indicated that they didn't see any point in having a refresher's course about hypothyroidism. Like GP Jansen, they told me it was too easy a subject for the refresher's course. According to them, there have been no (significant) updates and the guidelines (from 2006) say it all. GP Bakker voices the general sentiment:

“There is hardly any news. It is a clear guideline. So if you come to me with a poster saying you are organising a refresher’s course on hypothyroidism, nobody shows up. Everybody will say: I know enough. Yes and it is difficult, making refresher’s courses for GPs. Because if you make it too specific, they will say, oh that specialty is too far-fetched. If you make it too simple, for example with hypothyroidism, right, in primary care, ‘pff I know that already’. In between these two extremes you’ll find the interesting refreshing courses which are frequently attended.”

Patients tell a different story: their experiences contrast the GP’s statements that hypothyroidism is a ‘simple’ subject and that they know everything there is to know. Ms. Meijer describes it clearly:

“My conclusion throughout the years is that there is primarily a lot of incompetence in the area of thyroid disease. You initially consult a GP, and especially at the general practice there is very little knowledge. I even got an apology from my GP this year for all that has gone wrong. For which she now eventually received a refresher’s course on thyroid disease, taught by someone of the Amsterdam Medical Center. And she said: ‘yes, I think I have to admit I have missed quite a few diagnoses because I have learnt so much I did not know about’. Well, that is, I think, exactly what characterizes the diagnostic process in the Netherlands. I have seen in many cases in my family where it was going wrong for a long time, or that for ages it [hypothyroidism] was not detected, while they became more or less a complete wreck”. (Ms. Meijer)

As the GP of Ms. Meijer severely lacked knowledge of hypothyroidism, she was even assigned a refresher’s course. The question is: is this case exemplary or is it an exception to the rule? Does it imply that there should be more attention paid to hypothyroidism in refresher’s courses?

Also Mr. Haverkamp, while at the General Practice, noticed that doctors have little knowledge of the physiological side of the disease. He thinks that is because of the broad spectrum of symptoms and the fact that most GPs do not exactly know how bodily processes work:

“I remember once being at the GP where a GP in training was present, (...) And I asked, once again, how does it [t3 and t4] work again. And this GP in training, I

noticed at that moment, really had to think hard, as in, what does the pituitary gland do, and the hypothalamus and the thyroid, what is their function again? And how are these communication systems connected?(...) She even got herself an image on the computer, in the sense that I thought that, indeed, this is really a niche and they are not confronted with it daily at the GP. So something for what they really need to be sensitive to, also in the refresher's courses: that very broad, strange and big range of symptoms.”

The problem with not having sufficient knowledge of hypothyroidism is that doctors are not aware of the disease and hence fail to recognise its significance. GP de Vries says about this:

“...also our attention is drifting towards what is relevant in society and what people talk about and on which there are refresher's courses. However, I am of the opinion that it would be very sloppy if you as a doctor, as a GP, would forget that piece [hypothyroidism].”

Step 2 - Considering and ranking possible diagnoses

After the GP has clarified the problem of the patient, he comes up with possible hypotheses concerning what the patient may be suffering from. In setting up the list of possible diagnoses, how and what knowledge GPs have learned (in medical school and in the subsequent training specific for becoming a GP) is important, but also a lot of practise is needed. This step is according to the authors in 'het geneeskundig proces' (2004), "the most difficult to learn and requires a lot of experience." (p. 57).

Recognition

According to the authors of the guidelines for thyroid function disorders, which are under authority of the Nederlands Huisartsen Genootschap (NHG, Dutch College of General Practitioners), called NHG-Guidelines ('standaarden'), it is assumed that only a limited part of people with a thyroid function disorder are recognized as such or make their way into the practice. (Wessels, Rijswijk & Boer, 2006, 'Epidemiologie'). Internists learn that "Hypothyroidism often proceeds imperceptibly and it frequently is not being recognized" (Elte & Nieuwenhuijzen Kruseman, 2005, p. 191). So, an unknown number of patients with hypothyroidism is not diagnosed or might be diagnosed with something else.

As hypothyroidism is characterized by many vague complaints, which tend to overlap with other diseases and do not seem to be connected, GPs have trouble recognising it. So, when the GP attempts to create different hypotheses of which condition the patient may be suffering from, arriving at the accurate diagnostic associations with a certain complaint is very difficult. GP de Vries says about his challenge with recognising hypothyroidism:

"Well, hypothyroidism is a diagnosis hard to verify. Because the clinical picture is something that very gradually develops. And very often without the patient being aware that something is wrong with him or her. (...) You have to keep it in mind. When someone comes into the office, of course you have to be open to their complaints. However, it is often the case -that is the trouble with hypothyroidism- that you are mainly focused on changes. Changes always indicate that you have to be alert. And these changes with hypothyroidism often develop very, very slowly. In that case, they are not so much visible, not for the patient, not for the environment, and not for me. (...) That's the hard thing about hypothyroidism."

The other GPs said more or less the same thing, as the disease presents itself in many shapes and often in such a slow-proceeding, sneaky way. As GP de Vries points out, often patients do not notice either that they are suffering from hypothyroidism. Patients also mention they did not notice they had changed. Ms. Hendriks is one of these patients. She remembers:

“Without being aware of it, I had turned into a completely different person. Such as being puffy, slow and cold, and having the pace of a snail. It is like becoming a zombie, without knowing it.”

Despite its gradual development and vague, overlapping symptoms, hypothyroidism does have some specific characteristics which do not always show but when they show, they are recognised straight away by the GPs. They indicated that they are triggered by certain symptoms to think in the direction of hypothyroidism. Unfortunately, these stereotypical symptoms are often not present. GP van der Berg says:

“I think of hypothyroidism, when people are starting to function less well, getting gloomy, (...) constipated, cold, have a bad appetite. Those are for me the most important issues which trigger me to think of it. (...) With hypothyroidism the symptoms are often very broad, and the picture is often not perfectly complete. It is not the case that there is this puffy podge is sitting in front of you, who is obstipated, sluggish and has a hoarse voice. You rarely or almost never see the classical symptoms. I see hypothyroidism quite often, however, that classical image which develops so well, rarely or never.”

GP van der Berg shows here that the classical clinical picture of Hypothyroidism is easiest to recognise, but rarely seen. In addition he said: “In respect to hypothyroidism, thinking of it is the most important part of the diagnostic process.”

Since the classical text-book hypothyroidism is rarely seen, it is a challenge to detect or think of hypothyroidism when less typical symptoms presents themselves, as GP van der Berg’s case shows:

“Honestly, I have to admit that I have been looking at someone with hypothyroidism for quite a while without recognizing it. (...). I can remember because it was quite unpleasant. That patient had some problems in his relationship. He did not really have

physical complaints, but more problems with his mood. And I thought this was due to his relational problems. He did not have a clue of what he could be suffering from.”

The fact that the patient only presented ‘relational problems’ and was complaining about feeling depressed, prompted GP van der Berg to think in other directions than a possibly slow-functioning thyroid. He subsequently pursues the ‘psychosocial path’. In the guidelines for depression, it says that when there are signs of depression and/or a depressed mood, the thyroid might be playing a role (Van Marwijk, Grundmeijer & Bijl, 2003, NHG-standaard *Depressieve Stoornis*). However this information is of little significance if the GP is not thinking in that direction. GP van der Berg demonstrates how the direction of the diagnostic thinking is influenced by the symptoms presented: in this case the psychosocial direction seems to overrule the physical.

Also GP de Jong has the same kind of remark: “Very often when we think it is [hypothyroidism], it is not, I always say. And the moment we forget about it, someone is suffering from hypothyroidism.” Ms. Meijer realises how hard it is for the GP to recognise the disease, especially if one does not fit the description in the text books:

“... I remember that the doctors did not ever think of a thyroid disease in my case, because I was not the stereotypical hypothyroid patient. I was skinny, and normally people gain weight, they get bigger. Well I never experienced that, I still do not. And they could not clearly see an enlarged thyroid. And well, they thought I was still very active, not speaking more slowly and well, thinking more slowly”.

So when the GP weighs possible diagnoses, it is evident that knowing about the symptoms of hypothyroidism and being able to recognise them, plays a huge role. Setting up a broad differential would obviously not be a frivolous luxury when it comes to vague symptoms. However, broad knowledge of hypothyroidism is not the only aspect playing a role. The way the GPs look at the symptoms, reveals a dominance of an ‘administrative frame’. GPs who think that way assign patients to a particular group. For example, Ms. Meijer does not fit the category, and therefore will not be treated as belonging to the group. As Dodier explains:

“The reasoning involved is as follows: As soon as an individual belongs to a given population, the doctor assumes that s/he knows enough about the patient’s situation. (...) Regardless of other particularities, s/he will be treated just like all the other

members of that population. Association with a population is considered sufficient to justify action. It allows the doctor to come to a firm decision” (1998, p. 61).

Since Ms Meijer is not perceived as ‘belonging’ to the category of patients with hypothyroidism, the question then arises which group she is assigned to. When Ms. Meijer went to the GP summing up her symptoms, she emphasised her insomnia, since that was the most problematic for her:

“But well, a GP says in the first instance something like, go to the psychologist. ‘You are probably worrying, you are most likely distressed’. (...) I refused that, there was absolutely nothing wrong with me [mentally]. I intuitively felt that it did not have anything to do with that”.

The result was that she was assigned to the ‘psychosomatic’ group. This was the first hypothesis of the GP and he did not come forward with alternative explanations for her problem. It seems like a limited differential. ‘Insomnia’ in the NHG-guidelines is listed under the heading: ‘Psychological problems’, which does not make it unusual that a GP thinks in the direction of mental issues when s/he hears from a patient about suffering from insomnia. However, does that make it right that her GP does not investigate any further?

Epidemiology

When a differential is set up, the possible diagnoses are supposed to be ordered from most probable to least probable and possible risky diagnoses are taken into account. A strategy which is very important for GPs to use when trying to introduce a hierarchy in the list of possible diagnoses draws on the field of epidemiology. Epidemiology has to do with the prevalence and incidence of a disease in the population. (van Leeuwen et al., 2004, pp. 60-61). This means that a GP by knowing what kind of numbers of the population are suffering from a certain disease, can work out what chances are that the patient in front of them are actually suffering from it. GP van der Berg remembers a nice example of his professor:

“One of our most important tools is of course the epidemiology. As our professor of general medicine in Leiden says: if you hear the clatter of hoofs, you know it might be a zebra horse; however, a normal horse is a bit more probable. You should not, of course, only work on the basis of assumptions, but... (...)”.

As Stolper, Rutten & Dinant state in their article (2005), in the general practice statistical probabilities are translated in terms of a greater or smaller chance a patient is suffering from a certain disease. Doctors do not work with pure figures. Of course, GPs will not be able remember such probabilities exactly, but after some years of experience GPs will be able to intuitively know the chance a certain disease occurs (Van Leeuwen et al., 2004, p. 63).

Age and gender are also a way to rank the diagnoses. A very important point for a GP to remember about Hypothyroidism is that it does not affect women and men equally. It is more common in women: they are 4 to 8 times more often affected than men (Van Boven & van der Bosch, 2008, p.8; Schildklierstichting Nederland, 2011). Also, according to the GPs, they see it more often with middle-aged people than those in their twenties.

Last but not least, the GP can class the possible diagnoses on the basis of foreknowledge (for example knowing the patient since he/she was a baby) and contextual factors. In the general practice, the context of the patient is very important. According to GPs, the patient in their practice often differs from the general population in more way than one (van Leeuwen & Baggen, 2002, p. 67). When it comes to the context, the GP has a significant diagnostic tool available: gut-feeling. The better the GP knows the patient - personal traits, social circumstances and other background aspects - the more s/he can rely on his/her gut feeling. (Stolper, van de Wiel, van Royen et al., 2010). By merely judging the way patients enter the consultation room, whether they have someone with them for support, already says a lot about this person and the circumstances.

Context and Foreknowledge

The GP in the following case knows Mr. Haverkamp already twenty odd years:

“My complaints were something like, I was listless and I was very tired. And I was not very interested in things. I was rowing and it didn’t go well. So I went to the GP, I think he did some tests, like HB and Sed. rate, and he thought it was something psychosomatic. I think it was around November or December and then he examined some things of which he then thought it was psychological, because he told me, well if you come to me, it is always something psychological. Physically, nothing was ever wrong with me, you have to understand. I never had physical symptoms. I mean...”

Mr. Haverkamp illustrates that his GP most immediately thinks of problems in the ‘psychological’ department. In the eyes of Mr. Haverkamp’s GP, Mr. Haverkamp’s symptoms

are an expression of something for which he consulted his GP earlier. His GP had diagnosed him 20 years earlier with depression, “so he was on the track of a psychological disease”, Mr. Haverkamp said. The attitude of the doctor seems to portray the idea of: ‘the last time it was something psychological, most likely it is that again’. There is a great chance that something like depression recurs, as research of Elgersma, Bockting & Kok shows (2011, p.65). The psychological symptoms guide the GP’s direction of thinking.

On the one hand, knowing your patient well can be an advantage in the diagnostic process; on the other hand it can be an obstacle. The advantage can be that the patient feels more at ease and does not have to tell his story over again. On the other hand, the doctor who knows the patient well, may not always be open to symptoms and behaviour out of character, and may not always look further, because the doctor thinks s/he is completely informed. The attitude towards the patient may be different depending on how well the GP thinks s/he knows or knows the patient. In the following case it is, according to Ms. de Groot, beneficial that the GP knows her because in her view, the symptoms were so vague. Since he knows her as someone who does not consult him for every trivial thing, she felt that he would take the complaints seriously:

“On the 25th of March 2011 I went to the GP with a whole list of complaints. They were all kind of things which at first sight did not seem to be connected in any way, but with which I was struggling nevertheless. For some time I felt uncomfortable in my own body and I could not take it anymore. My GP could make little of it, because, how are irregular menstruations, bruises which do not go away, muscle pain after exercising which does not disappear, being lethargic, forgetful and gaining weight without a reason and spots which do not go away, related? Fortunately, my GP knows me for quite a while: he has been my GP for eleven years and he knows I’m not consulting him for every little thing. (...) From the tests it became clear that my TSH-level was not that what it was supposed to be.”

What is striking about this quote is that knowledge or recognising certain symptoms of a disease is connected by Ms. de Groot with how well her GP knows her and might think of her. She contemplates the possibility that her GP might not take her seriously, however, she adds that he knows her well so that it is not a problem. A GP should be very aware of this, since it can hugely influence the direction of the diagnostic process. If a patient is playing down

his/her complaints, it becomes harder for the GP to assess the problems and to arrive at the right diagnosis.

A 'good' doctor does not assume too easily that patients exaggerate their complaints, because the risk that s/he misses something important is not one s/he would like to take.

GP de Vries is very clear about this:

“It is a pitfall of our profession. I will give you an example: you are afraid that you suffer from breast cancer and consult me every half a year for breast cancer. You never suffer from breast cancer. What will I do the eleventh time you are here? You think I will say: ‘Miss, I have already checked you 10 times and you are not suffering from breast cancer?’ No, again I will check your breasts. Why? Because you need it to put yourself at ease, and also because it can be true. (...). So this is an example of how you should cope with that as a GP. Do not step into that pitfall of the complainer or the whiner.(...) I always say: there are no ‘complainers’, there are a lot of people which put a disproportional demand on you time-wise, attention-wise, however there is a need /request behind that: fear. Only a few are real whiners. And if you think a person is really a whiner, you have to look in the mirror yourself, ask yourself why you have this opinion. It is your problem.”

GP de Vries indicates that the chances of this hypothetical person being affected by breast cancer, is probably very small. Still it is important to take this patient seriously. As a patient you should be able to tell your story without having to worry about how it comes across. But this is easier said than done. In addition to that, patients are also afraid that the GP will tell them it is all in their head or stress due to home situation or work. Ms. De Graaf is a good example. She experienced her whole life severe pains and problems, due to her thyroid. It got detected very late, and was not taken seriously by her GP. Her GP stopped working and she now has another one but she says:

“Unfortunately when I come in they will in first instance say it [the symptoms, E.D.] is due to tension, unless I take someone with me.”

As in the case of Ms. De Groot, with Ms. Peters the fact that the GP knows her and her family seems to have been an advantage. When Ms. Peters checked with her doctor because she felt ‘rheumatic pains’, her GP: “immediately told me that my thyroid should be tested because

they found out recently, after years of problems, that my mother suffered from an underactive thyroid.”

However, it is not always beneficial to have a GP who knows you well. Ms. De Wit for example has a GP who knows her family well and therefore she thinks she knows what the problem is:

“In January I consulted the GP for the first time with problems such as being cold, tired, not thinking clear. She blamed it on the fact that all mothers with little children are tired and that I was just unfortunate with a husband who had a ‘burnout’ and a father in law who recently passed away. But I would probably be fine in no time. To be sure she tested my blood for HB, but it was okay, so I carried on. In April I went back, and I got the same advice again. Now also my glucose level was tested, but it was fine. The advice that followed was: make sure you rest enough. (...) She quickly connects those things with stress or work pressure. She had been our GP for 6 years by then and knew our family very well.”

Because this GP is very familiar with the family, she interprets the complaints on the basis of her knowledge of the family situation. This narrows her scope in the sense that psycho-social circumstances seem way out in the front for her. She is not able to see an alternative explanation. Also here, the administrative frame has a firm grip on the way particular circumstances are assessed. The particular circumstances fit in a broader picture. The complaints serve, in fact, as a confirmation of a broader picture. Or, as Dodier elaborates, the doctors adhering to the administrative frame mostly, “in fact do [take into account the particularities of the individual] by relying on properties that allow one to group the individual in certain categories” (Dodier, 1998, p. 61). And that category in this case is psycho-social.

There are some examples in my interviews in which the diagnosis was not made by patients’ original GPs, but by substitutes or specialists, such as the ENT-physician, the neurologist and even an ophthalmologist. This shows that it is not always helpful for a GP to know his patient well. Ms. Van der Meer went a few times to the GP and was referred to a gynaecologist, and later to a rheumatologist whom she asked for advice. She suspected a thyroid problem. How come the GP did not spot it? She says about her GP: “I have been referred many times by my former GP; however, he never felt my thyroid and the blood tests were fine.” Although a physical exam can be very much in place when it comes to thyroid

problems, again the GP did not use that diagnostic tool, because he was simply not thinking in the direction of the thyroid.

The case of Ms van Dijk shows that she was lucky to see a new GP, instead of the one she always consulted. After her trip to Australia in the beginning of 1997, her complaints started. This is her remarkable account:

“I have continuously complained that I was cold, always cold and very tired. I also took a shower at a minimum of 2 times a day to get at least a bit warmer. (...). The tiredness was attributed to my fulltime job. I started in 2002 with the police academy and irregular working hours. This gave me extra tension and stress, and my GP was convinced that it was precisely that which was making me feel exhausted. (...) I have consulted the GP multiple times with complaints of tiredness and coldness. Blood was drawn but for what precisely, nobody told me. I was only informed about the fact that my blood results were fine, so nothing was wrong. (...).

In 2009 I again consulted the GP with the same symptoms and I got a referral to the psychologist. I did not feel like I needed it, but after so many years I could not think of anything better either. People around me also talked about me possibly having psychological problems, being depressed, even though I was sure that was not the case. (...) I went some 20 times, however, there was no news for me, and did not benefit from it.(...) Increasingly infections on my shins and my face appeared, so I went to the dermatologist. Enough cures for an elderly home, but again, no connection was made. I was so tired in 2010, I had so much pain in my legs, muscle pains, and I could not do any sports anymore and was covered in bruises. I consulted my GP; however she was on a holiday so I got a substitute GP. This GP thought I was being abused severely. Subsequently, she sent me for a blood test, and the thyroid, that was what the problem was.”

Apparently the substitute looked in a different direction which resulted in this diagnosis. Knowing the patient well may seem an advantage, but, as these cases demonstrate, it can be the opposite. Is it the fresh look of a substitute? Or is it perhaps a different command of knowledge? Perhaps it has something to do with the fact that a substitute is more uncertain and about what to do and want to know every detail to avoid making a mistake.

Step 3 - From possible hypotheses to the construction of a diagnosis

In this step, a medical history (anamnesis) of the patient can be obtained, a physical examination can be carried out and when necessary, additional tests, such as a blood test or a scan can be requested. This is a very relevant step for patients displaying the broad and vague symptoms of hypothyroidism. There are many strategies which can be used to come to a diagnosis, to confirm or exclude the possible diagnoses set up in the differential. De Jongh (2004) says that the strategies used depend on the context. (p. 71).

Strategies

First of all, (often) experienced doctors, can recognize certain patterns. This strategy, therefore, is called ‘pattern recognition’ or ‘disease script’. When the GP is certain about a disease right from the start, often the following steps, the anamnesis, physical exam and additional testing, are not necessary anymore. (Stolper, Rutten & Dinant, 2005, pp. 16-17). It seems that GPs are not able to recognize patterns when it comes to hypothyroidism, as it is barely recognised. However, in the case of Ms. Bos, her GP recognised the goitre and made the right association with the thyroid. Ms. Bos went to the GP because she already thought she was perhaps suffering from a thyroid disease. The GP told her to come back a week later for the results of a blood test:

“My TSH was 10 and my FreeT4 was 11, so not well. And my GP told me that I needed to see an internist, in order to let my goitre be examined. The goitre could have been caused by a iodine-deficiency. She thought I was depressed and would benefit more from anti-depressants. Fortunately I never started with that. (...). Meanwhile, I am taking 175 Mg. of Thyrox [thyroid-hormone medication] and a great deal of my complaints has disappeared. I have become a different person.”

This case shows that even although the GP recognises the goitre, the symptoms of depression are not connected to the thyroid, even though it is or should be common knowledge that depression can occur with hypothyroidism. (van Marwijk, Grundmeijer & Bijl, 2003, ‘Anamnesis’). Perhaps if she would take it up and study the matter, she would not have advised to take anti-depressants. It is not clear whether it is pure ‘not knowing’ or ignorance on her side, the latter having to do more with her attitude.

Physicians can furthermore use an “algorithm, (decision tree) which is a generally applicable, consistent action scheme meant for a defined problem.” (p. 68). The NHG has established guidelines for thyroid function disorders, and included is a guideline for diagnosing and treating hypothyroidism. (Wessels, et al., 2006, ‘Richtlijnen beleid bij Hypothyreoïdie’). Thus, Hypothyroidism is a ‘defined problem’, described in the NHG-guidelines. However, GPs will rarely end up using this algorithm, because they need to think of hypothyroidism first, and that is precisely where the problem lies: they often do not recognise its symptoms. Depression and tiredness, both vague symptoms which could be connected to hypothyroidism, have their own algorithms and these are used instead of the guidelines for hypothyroidism

The third strategy used by a GP is called “the exclusion or confirmation of one diagnosis” (De Jongh, 2004, p.69). It is used when in the differential a potential diagnosis prescribes immediate action or has severe consequences when it is confirmed. Obviously, it is important to initially exclude that diagnosis before switching to the less ‘urgent’ diagnoses. To be able to confirm or exclude a diagnosis, a thorough medical history of the patient, a physical exam and additional tests are helpful.(p.69)

Strategy four is called the sequential hypothesis testing method. It means that the GP starts with the most probable diagnoses and test them separately until he/she found the right diagnosis. “From the list of possible conditions, the one or two most probable are selected: the hypotheses.” (p. 70). These will be tested by means of a medical history and a closer examination.

Then there is a fifth strategy, which is the most appropriate strategy when a patient has indistinct symptoms and complaints, as in the case of hypothyroidism. When setting up a differential diagnosis is hardly possible or when the list of possible diagnoses is too extensive without a clear hierarchy, the method of ‘unfocused data trawling’ is suggested (De Jongh, 2004): a medical history is obtained of all the organ systems and a wide-ranging physical examination and additional testing is conducted, in the hope that the diagnosis will be ‘caught in the net’” (p. 71). A disadvantage with this strategy is, according to De Jongh, that it is time consuming, costly and puts a strain on the patient. Considering the short time available for the GP to see the patient in his/her office, one would think it would take too much time to use this strategy: gathering as much information as possible from the patient, from guidelines and other sources of information, and feeding this back to the patient. I asked the GPs whether time was an issue in respect to establishing a diagnosis. The GPs denied. One responded: “In that case I will take my time”, another said, “I can always make a new appointment with that

patient, to find out more”. GP de Vries explained that this is precisely the difference between the GP and the specialist. In the general practice the visits are short and frequent; the appointments with the specialist take up more time, but are usually limited to one or two sessions. Additionally, the patients did not mention time as a limiting factor. So the lack of time does not seem to be a major issue in the diagnostic process.

Although this fifth strategy is best for patients with a-specific complaints, none of the GPs I interviewed tried to obtain a broad medical history. They failed to ask the patient questions about every ‘tract’ (body/organ structures) , about the patient history, the family history and social circumstances.

So, despite the fact that this strategy seems to be the most appropriate in diagnosing hypothyroidism, it is not used.

Treating the symptoms separately

The GPs of the patients in my cases did not even try to find out what could be wrong, but reacted to the problem by providing a quick fix:

“I can remember well that it began for me especially with the fact that all of a sudden I could not sleep anymore. I lost, as I would call it, my ability to sleep completely. (...). Eventually I felt that life was being sucked out of me. If you do not sleep for months, it is really not going well. And with these complaints I went to the GP, with sleeplessness. And when I told the GP how severe it had become, and that I did have some objections against using sleep medication (...). The GP eventually said: well, I it choosing between two evils; you can start with sleep medication and yes you can get addicted to that, however, not sleeping for this amount of time is not healthy for your body either. So maybe you have to do that to breach the vicious circle.”

At first glance coming up with a quick fix for the problem appears to be a good idea. The fact that her GP offers sleep medication seems normal; he is solving the problem straight away. The problem is that instead of exploring the root of the problem, the GP chooses a more short term solution. He did this in spite of the fact that Ms. Meijer pointed out that she did not want to take sleep medication because: “My mother had the same problem and was addicted to sleep medication.” He did not do a physical exam nor blood test, and he eventually referred her to a psychologist. This would have been fine if he at least had tried to exclude other

causes/possible diagnoses. Ms. Meijer felt that this way of looking at things by the GP ignored the bigger picture. She was convinced that these symptoms had some kind of relation.

Ms. Meijer is not the only one who is frustrated by the ‘complaint by complaint’ treatment of GPs. A majority of the patients I interviewed either commented on it or demonstrated how the solution-oriented approach delayed a correct diagnosis. The story of Ms. Van Dijk illustrates that the length of the period between visits perhaps contributes to the fact that the GP thinks the symptoms are unrelated:

“I consulted my GP every time with a different complaint and have never connected the dots. Also, I am not a person who runs to the GP, so every time there were 1,5 or 2 years in between my visits. It is crucial that your GP makes those connections because I knew until that moment that I was supposed to have a thyroid but where it was located or what purpose it had was beyond my knowledge.”

So knowing the history of a patient is not enough; it is equally important connecting information obtained in those visits. In clinical practise one would expect the GP to “connect the dots”. Dodier considers this to be part and parcel of the clinical frame: “...it is not enough to apply a rule to be able to deduce something. One must have additional indices for the individual” (p.63). Ms. van Dijk’s symptoms were not connected by the GP, and were seen as ‘isolated factors’.

GPs are not specialists and are supposed to turn their hand to everything. They simply cannot know everything. Often they have to look up more specific information or refer their patients to a specialist. Obviously, they do have to think in a certain direction to be able to refer, so they need to make certain steps in the diagnostic process using a strategy to find out to which department the symptom(s) may belong. Ms. Meijer was happy that at some point in her struggle with her symptoms, she was referred to an internist. This happened after she had moved and had to find a new GP:

And well, I also told the story [about the thyroid], that many family members suffered from it and that I had so many complaints. She said, yes, your complaints kind of fit with the thyroid. Well, let us test it again. She also thought that a TSH of about 7 was not alarming. But she said, maybe a bit on the elevated side, maybe you will improve with a little thyroid hormone. Shall I then indeed send you to an internist? Well I was really happy with that, because then you can circumvent the GP which did not bring

you anything good.”

Obviously, this GP does not feel at ease with treating Ms. Meijer with thyroid hormone herself, and needs the opinion of the internist to confirm whether the treatment or test trial can be initiated. Being referred also has its down sides, especially when it happens often. Mr. Smit was not treated, but referred to a specialist on a ‘complaint by complaint’ basis:

“In May 2009 I was to stay at home because of a burnout. I had been very tired for years, I had little interest and energy with mild depressive symptoms. For these reasons I got psychotherapy. (...) My CTS (carpal tunnel syndrome) did not go away, so I decided to go to my GP. She referred me to a neuro-physiologist. (...) About two weeks later I consulted the GP again, because my girlfriend had noticed that when I slept I stopped breathing for a couple of seconds. In addition to that, I started to snore more intensely. Most probably it was sleep apnoea and my GP referred me to the sleeping centre for further examination.(...) I did not get the idea that my GP really wanted to find out what the cause for all these problems was. In my opinion, she was too solution-oriented. (...) The complaints of which they were informed were weight gain, sleep apnoea and burnout/mood problems. (...) She did not look for the underlying cause, but dealt with it complaint by complaint”. (Mr. Smit).

Eventually, Mr. Smit diagnosed himself by looking up his symptoms on the internet. A substitute GP confirmed hypothyroidism after Mr. Smit’s TSH (thyroid stimulating hormone) was determined.

Obviously Mr. Smit is not very happy with the way his symptoms were addressed: for every complaint there was a readymade solution or referral, and the symptoms were not linked together, so that the final diagnosis of hypothyroidism took longer than necessary. The GP may have felt that she offered a solution to the problem, but in reality it was typically a quick fix.

Complementary Tests

As some of the quotes show, a blood test is often used by GPs to confirm their assumptions, or more often, to make sure they are not missing anything. A blood test is part of the additional tests a GP can do in order to confirm or dismiss earlier assumptions about what

could be wrong. In case of hypothyroidism in addition to the blood test, a GP can request a TPO-antigen test, in order to establish whether there are TPO-antigens in the blood. An echo of the thyroid may also shed some light; however, it can only be requested by a specialist.

Some more exotic, such as a temperature-test, we will not discuss.. In practice, only the blood test in which they determine TSH and T4 levels are used by GPs. The TPO-antigen test is not very common for a GP to ask. The amount of Thyroid-Peroxidase antigens (TPO-antigens) in the blood can point to hypothyroidism caused by Hashimoto, in which an auto-immune response breaks down thyroid cells. (Romijn, Smit & Papoulos, 2008, 687; Wessels et al. 2006, 'Oorzaken van hypothyreoïdie'). GP Bakker told me the test for TPO-antigens is sometimes done in the hospital but not in the general practice: "it is not something we test for". GP De Vries illustrates why he would not do a test for TPO-antigens:

"The more or less acute phase has then passed, before you have noticed somebody is suffering from hypothyroidism. There is not so much point then to find out what the cause is, right? It has so few consequences for your therapeutic decisions. You either supplement or you don't. I do not use it as proof. (...) For me, the question is, does it have any therapeutic use when you treat the patient?"

So GP De Vries believes that when a test does not have any merit for the therapeutic course, there is no point in using it. It seems to express the feeling that it is a waste of time and energy to do such a test, although patients might want to find out what exactly the problem is.

The conclusion must be that GPs usually only determine the TSH-blood levels, which reveals the demand for thyroid hormone in the body. In addition to that, they may determine the level of Ft4 ('indirect' thyroid hormones) in the blood. Determining the Ft4 happens automatically when the TSH is deviant.

A reference range, determined by the laboratory, defines whether a person's levels are still in the 'normal' zone and when they are below or, in case of hypothyroidism or subclinical hypothyroidism, above it. The exact reference range of TSH may differ depending on the laboratory, but as a general rule the lower limit is: 0.4 mU/l and the upper limit is 4.0 (Balen et al., 2006, p. 84-85). Ms. Meijer tells the story that her GP was not completely aware of how to interpret the blood levels which shows a lack of knowledge of the disease. She relates the following remarkable story:

“And I remember that one was elevated and the other was low. So I think that the TSH-level was elevated, of which it was generally thought to be inside the limits. Nowadays people think completely different about that, because the TSH was 7. Until recently, that was the upper limit of ‘normal’. And I guess in that case the Free T4 was on the low side. And I can remember her remark: ‘Consider yourself lucky with that, because those two may balance each other. One is elevated, the other low, well, they keep each other nicely in check’.”

According to the NHG-guidelines, when the TSH is elevated it could be a sign of an underactive thyroid. When in addition to that, the Free t4 (the actual availability of thyroid hormones in the blood) is low, it is almost certain the patient is suffering from hypothyroidism. This GP is confused about what the different levels mean and is convinced the levels are not yet in the red zone. So she does not take any action.

In other cases, the limits were interpreted correctly, according to the guidelines (Wessels et al., 2006). However, they are not absolute, as GP de Vries explains:

“Of course, these figures are always cut-off values. What is normal for you is not necessarily normal for ‘Peter your neighbour’. And it is a very broad range, especially the Ft4: from 7-21 globally taken is the cut-off value. (...). In addition to that you also know that there are people which are below these values and above it, by nature. That is also the case. And it is by definition of course the case with cut-off values: it is a Gaussian Curve; there is always 2 percent below and 2 percent above. That’s why you have to be careful: it is so important that the clinical picture plays such a significant role in your therapeutic decisions.”

As GP De Vries points out, the blood test is not the be all and end all in deciding whether someone is suffering from a disease or not. It is an ‘addition’.

Although the term reference range include the word ‘reference’, implying that there is no fixed value which cannot be contested, most clinicians interpret this reference range very strictly: when a patient’s value is within the ‘normal’ range, it is assumed that the patient does not have thyroid problems.

GP de Jong perceives the blood test as decisive when diagnosing hypothyroidism:

“In most cases I explain: it is very easy to check. That is the easy thing about an underactive or overactive thyroid. It is a matter of doing a blood test and you know. (...) Normal values, different for each laboratory, that’s always the case. So, you always have to look closely at your own [General practice] normal values. But, the normal values are in the end, as I call it, proof.”

GPs have difficulties with interpreting the blood values. Still, they think the tests are: “easy to do”, “reliable” and “trustworthy”, by respectively GP Jansen, Bakker and de Jong.

As GP de Vries already indicated, it is not so easy to see TSH/fT4 as proof. He adds to his explanation of the ‘Gauss curve’:

The story of the patient and the laboratory, they go hand in hand. One does not replace the other. Neither is a panacea. I always think that medicine is the story of the patient, to ask into depth and translate, what is wrong exactly? What kind of problems are there? Then you will get a clinical picture, complemented with additional tests. And, yes, I do not think that laboratory research is the number one choice, even not in your therapeutic conduct. Of course, it needs to be integrated. It is an addition to what you have discovered on the basis of the anamnesis and physical exam, and this is being complemented with the lab results, which can confirm or deny. And based on this combination of factors, you determine whether or not you treat someone, never merely based on one.”

Contrary to what GP De Vries says, patients feel that a technology such as a blood test, seems to overrule their (personal) account, as Mr. Haverkamp puts it:

“...what I really find frustrating is you are not a blood value. You have complaints and you feel okay or less okay. Values may say something, of course, but...”

Understandably, patients do not want to be just a number, but someone special. They want to be judged on their own individual characteristics and circumstances. However, that is the trouble with an administrative viewpoint: “The interpretation is statistical, because it is not interested in taking people one by one but in populations” (Dodier, 1998, p.76).

Many patients give the impression that their diagnosis is missed due to the results of blood tests. In these blood tests the TSH or/and the Ft4 were determined, however, according

to their GPs these results were still within ‘normal’ range. Ms. Vos, after many years of complaints, having consulted two GPs, having been diagnosed for depression and having been referred to a sexologist, eventually got diagnosed in Poland:

“In the summer of 2011, in Poland, where I now live, I just requested a complete blood test (commercial), included in it also the TSH. (...). Conclusion: subclinical hypothyroidism. The GP in the Netherlands agrees, however, it would not yet be treated in the Netherlands. With a TSH of 7,5 and a Ft4 still within the range. Moreover, after I visited my GP in the Netherlands, he requested a blood test again, obviously resulting in the same levels as those measured in Poland (throwing away money)”.

Whether hypothyroidism is diagnosed, is, in addition to the recognition, very much dependent on the way the laboratory results are interpreted. Ms. Meijer had many complaints, and tried to get a diagnosis for 20 years, in which her problems got so severe that she barely could work and lived with pain every day. When she was 35, she finally got diagnosed by an internist. Her GP always thought the results of the tests were fine:

“But as long as I had that GP, and I lived there about, well, 6/7 years, - a very sweet person - I was not progressing. She kept saying: ‘well, okay, I will test you again, let us draw some blood again.’ And she said ‘well, the test does not show anything wrong. The levels are precisely in between the normal reference limits, it cannot be the thyroid.’ And she has never requested a TPO-antigen test. That is the reason why it has been overlooked for so long.”

Although the blood test may be very useful, this GP seems to rely excessively on the test and does not question it. The present range is contested by some clinicians (Andersen, Pedersen, Bruun & Laurberg, 2002; Baisier, Herthoghe & Eeckhaut, 2000; Bolhuis, 2011; van’t Riet, 2010; Skinner et al., 1997. The debates are primarily about the upper limit of the range, which is important to answer the question whether a patient is suffering from hypothyroidism. Van ‘t Riet (2010) states that the guidelines of the NIV/NHG are 2,5 years old, “based primarily on literature before 2006”. She says it is important to be aware of insights after 2006, which can shed new light on the ‘normal’ TSH-range. She argues that the current reference range for TSH-serum dates back a couple of decades and should be updated:

“recent insights such as the predictive value of TPO-antigens or the individual set point of the thyroid metabolism are not taken into account.” And:

“Studies looking at the TSH-range in healthy test persons, without thyroid conditions, auto-immunity or heredity, shows a TSH-range which’ upper limit is (much) lower than the regular 4,0 mIU/l.” In addition to that, there is much variation in the individual set points: “A TSH-level of 4 mIU/l for example, can for one person mean euthyroidism (the thyroid functions normally), whereas an individual who normally has a TSH of 1,0 it can be the start of hypothyroidism”(p.68).

Also, one uniform TSH- normal value neglects the variation which can occur during life time: determining the upper limit is dependent on age and pregnancy, for example. Her conclusion is: “A TSH-value within the so-called normal range is no guarantee for a healthy thyroid.” (p. 69). In a letter discussing the proposed UK guidelines for the use of thyroid function tests, the physicians Skinner et al. (1997) objected:

“There is no evidence to hand that teaches that free thyroxine [Ft4] or thyroid-stimulating hormone [TSH] levels within 95% reference intervals exclude a diagnosis of hypothyroidism.” (p. 1764).

It seems evident from the debates that it is unwise for a GP to blindly trust the reference range set by the laboratory. Some do, however. Differences between GPs can be described in terms of the administrative and the clinical frame. The administrative frame “examines the individual’s place with regard to reference points in the wider population” and the clinical frame “waits to be able to compare several individual reference points”. Dodier says that “In both the administrative and clinical frame, the point of departure is identical”. That is to say, in both the GP employs statistical data to exclude or confirm disease. However, the approaches are different: “In the administrative frame, the doctor uses the value as a parameter” and:

“In the clinical activity, the doctor proceeds differently: before coming to closure, s/he will wait to have several values of one parameter for the same individual. In this way, the doctor aims to delineate the individual’s personal point of equilibrium, while

remaining open to conceding discrepancies with the ranges outlined in the texts” (1998, p.67).

There is another way to test whether someone is suffering from hypothyroidism. This special way of diagnosing can be referred to as diagnosing ‘ex-iuvantibus’. It means that a GP can make an inference about the diagnosis by analysing what the effect of a therapy is. It can prevent a great deal of expenses and burdening examination (Muris, van Leeuwen & Dinant, 2004, p. 83). In the case of hypothyroidism, it is possible to try and treat someone with a little bit of thyroid hormone while monitoring his/her symptoms and TSH-levels. GP de Vries says he has no qualms doing a test trial with thyroid hormone, even when patients seem chemically euthyroid (normal thyroid condition). He says that a test trial is a very real option. However, he adds, “you should always discuss it thoroughly with the patient and increase the dosage gradually and carefully”. Two other GPs expressed a very different opinion. For example GP de Jong thinks it is harmful to ‘try’ thyroid medication:

“Thyroid hormone is not innocent stuff. It is not something you just do test trials with. Thyroid hormone puts everything to work, so to speak, it adjusts the thermostat. So it influences all kinds of processes. And you really need to be careful with that. You sometimes hear about diet pills with which people lose weight instantly, but in the end you discover they are partly made with thyroid hormones.”

She is uncertain about the consequences. GP de Vries feels that if he monitors and makes sure he increases the dosage slowly, no harm can be done. GP Jansen is convinced she is not a good doctor when she would subscribe a little bit of thyroid hormone to see whether it has positive effects:

“I will not do a test trial. I do not think that I am correctly treating the patient if I do so. In that case I am treating something other than what he is suffering from. If he has complaints of tiredness or other complaints and it cannot be accounted for by the thyroid on the basis of the levels of thyroid hormone in the blood, then the complaints must be caused by something else. In that case I do not think that I treat the patient well with thyroid hormone, rather, I should look somewhere else.”

It is not a common way of diagnosing, and none of the patients mentioned that they were able to try thyroid hormone to look whether they benefited from it. GP de Jong is just very afraid of harmful consequences; GP Jansen feels that she has to be more certain before doing a test trial. In both cases they feel uncomfortable with trying such an 'experiment'. It seems to correspond to the way the GPs view the results from the blood tests: absolute.

Conclusion

As I showed in this thesis, hypothyroidism, with its indistinct and atypical symptoms, overlapping with symptoms of other conditions, is hard to recognise. Nonetheless, the complexity of recognising this disease does not by itself account for the diagnoses that are missed.

Patients can experience problems in articulating themselves when consulting the GP and due to various reasons, do not mention all of the symptoms they are experiencing. On the other hand, patients can be very articulate, to the extent even that they gain a certain specific expertise, an expertise not possible for the GP to attain. As I derived in my study, this ‘interactional expertise’ may not always be valued by the GPs, as they might feel threatened by it and/or make them feel uncomfortable. But in most cases, as I have demonstrated, the knowledge patients derive from books and the internet may clash with the point of view of the GP. GPs feel that they have to explain what belongs or does not belong to ‘their medicine’, and are hereby constructing boundaries. Patients may unwittingly influence the direction of the diagnostic process by the way they present their symptoms. However, in most cases, this influence is minimal, because it is necessary that the ideas of the patients fit the ideas the GP has about the possible causes of the symptoms. This way of interacting is conservative and does not correspond to the current popularity of the idea ‘treating the patient as partner’. It would perhaps be a better idea to integrate the knowledge of the patient or his/her self-diagnosis in the diagnostic reasoning.

As my interviews showed, there is not much attention for hypothyroidism. Since the interviewed GPs think that hypothyroidism is too simple for refresher’s courses – they think they know enough about the subject- their overwhelming attitude seems to express they are not very interested in it. The extent of knowledge, and to which extent the GP wants to learn new things, is a matter of framing. The reason for the lack of knowledge of hypothyroidism may be found in the fact that most GPs in my study are leaning towards the administrative frame. This administrative frame is translated into following guidelines quite rigidly, in which the information is foremost based on the average figures from a limited part of the population, in a dependence on medical text books, which’ information may be as old as three decades, and relying exclusively on the blood test results which fail to incorporate individual levels.

As a result, the GPs in this study construct a limited differential instead of a broad one. They have a weak foundation for considering potential diagnoses. Therefore, they try to find answers in psycho-social and psychological explanations. These psycho-social explanations

are not completely off-track, since the GP often knows the patient and his/her social circumstances well. However, knowing the patient well is not always beneficial, as some of the cases I have described showed. A fresh look, whether it is from a substitute GP or another health care provider, may account for better outcomes. Perhaps the use of the clinical frame in new situations instead of the administrative frame, plays a role here.

If the GP decides to do complementary tests, often his/her diagnostic skills seem to be left to technological inventions such as a blood test to determine TSH and T4 levels. Probably without the technology, the diagnosis would have been missed much more often. However, judging from the interviews, it seems that the GP relies on this blood test excessively: it acquires the status of a technology that proves whether a patient is suffering from hypothyroidism or not, instead of something that may or may not confirm former assumptions of the GP. And the latter is exactly where the difficulty lies: there are no former assumptions made by the GP. When the GP thinks of testing for it, and the results are in between the laboratory determined reference range, s/he will accept the outcome without questioning it. It is not the case that the GP requested the blood test because s/he thought that one of the potential diagnoses could be hypothyroidism, but the GP requested it to be sure s/he would not miss it. GPs do not recognise (the symptoms of) hypothyroidism beforehand. The latter also explains the 'treating symptom by symptom' of patients: their symptoms are not considered together as part of a condition, but each symptom separately is representative of a condition.

With the administrative frame of mind, GPs strive to fit a first impression of a patient in an established category, thereby scarcely considering complementary data. As becomes clear from this study, the clinical frame is neglected on crucial moments in the diagnostic process.

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