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## Chapter 4

# *‘Why Me?’* Phases of understanding in chronic illness: learning from a narrative account

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## Abstract

Research demonstrates the importance patients ascribe to understanding the meaning of their disease in the context of their lives. Simultaneously, patients express a need to be understood by persons surrounding them, including healthcare professionals. This article aims to gain insight in the process of understanding of chronic disease and the phases experienced by a woman with a chronic disease. The process of understanding that she experiences, consists of three phases. The first phase occurs when she relates to the 'strangeness' that has entered her life. An illness is a strange, disorienting experience that draws a person – who suddenly becomes a patient – out of the familiar world. The article shows that the existential tension that is experienced, can enhance understanding. The second phase starts when she searches for knowledge about her illness, either by conversations with experts or written information to be found on the internet and other sources. The third phase is dialogical: the patient is being acknowledged in her authority by someone else, a health practitioner. This article explores the three phases of understanding by reflecting upon one narrative account. From there, 'petite generalizations' may be possible. Relevance for theory on processes of understanding is discussed.

**Keywords:** understanding, hermeneutic philosophy, chronically ill, patient-practitioner relationship, narratives, moral competence.

## Introduction

Health can be regarded as 'homelike being in the world' (Ahlzen, 2011), a situation that one has become used to. One's routines are clear, coherent and feel familiar. When a person is confronted with a severe chronic disease, the familiar lifeworld with its routines, rhythms and meanings are challenged. A sudden interruption or slowly emerging situation introduces a 'strangeness'. Initially, this can cause feelings of confusion and fear. After a while, in general, people actively try to understand the strangeness that has entered their lives. They interpret and respond to an experience that has interrupted their lives. This has consequences for how they perceive themselves, their lives and the world around them. People who experienced critical events often report that the event made them see themselves in a new way (Tedeschi & Calhoun, 1995; Stull, 1999). This kind of understanding, as a process of 'meaning-making', is of great value for patients in the process of recovery (Frank 2002, 2010). Studies report on the importance of another kind of understanding as well: the process the attainment of knowledge about one's disease by acquiring information (Harding et al, 2008). A third kind of understanding concerns finding ways of dealing with the disease in interaction with the physician. This requires a dialogue, in which the perspectives of the physician, who brings in expert knowledge, and that of the patient, who presents experiential knowledge, come together (Oeseburg & Abma, 2006; Caron-Flinterman, 2005). This dialogical understanding has been elaborated in hermeneutic philosophy (Widdershoven, 1999). This article aims to explore how a chronic patients' understanding develops. We will investigate how a patient with a chronic illness experiences the various kinds of understanding mentioned above, and show that her process of understanding can be characterized as three phases. We start by describing a hermeneutic philosophical perspective on understanding and relate it to the context of health and illness. Then the method of the article is presented. Subsequently, we will explore the phases of understanding of one clinical narrative of a woman who had several cardiac incidents in depth.

The paper does not aim to develop a procedure or 'method' for understanding in order to generalize it to people with a chronic disease. Instead, we aim to clarify the process of understanding that one single patient goes through as a single case study (Abma & Stake, forthcoming). From there, 'petite generalizations' may be possible (Stake, 1995). This means the reader may recognize features that can be meaningful to his or her context and benefit from them. In addition we aim to enrich theory with the insights this case provides. Hence, the article follows an empirical ethics approach, in that it implies a process of practical and situational learning (Widdershoven et al, 2009).

## Hermeneutic philosophy

Theoretically, the paper is grounded in hermeneutic philosophy. The primary concern of hermeneutics is the philosophy of understanding. From a hermeneutic perspective, understanding is a process of meaning-making. To understand is to grasp, to hear, get, catch, or comprehend the mean-

ing of something' (Schwandt 1999, p.452). Understanding is not the result of a methodology. Instead, it can be seen as a way of 'being in the world' (Schwandt 1999).

According to Gadamer, understanding starts when we experience a break-down (Gadamer, 1975, p.160; Gadamer, 2004, p.182). The need for understanding arises when we experience something which 'interrupts the ordinary, taken for granted aspects of existence' (McManus Holroyd 2007, p.2). When something happens which we do not expect, or someone gives an answer which is not in line with our preconceived ideas, our view of the world is challenged, and the question of meaning comes to the fore. How can we make sense of the strange event or response? As long as the situation is familiar, events are experienced within a natural frame of meaning. When someone is confronted with something unfamiliar, like an illness, one experiences a tension between the unfamiliar and the familiar. Illness is an example of an experience that may cause a tension between oneself and one's world. The hermeneutic task is not covering up this tension by attempting an assimilation, but, Gadamer argues, 'consciously bringing it out' (1975, p.273). Dissolving the tension between what is strange and familiar is one of the characteristics of the process of understanding.

When we are confronted with new and unexpected experiences, we try to find an explanation, which may help us to make sense of the strange situation. In order to explain the situation, we may turn to texts and narratives, which enable us to place the strange event in a natural or moral order. Thus, an illness can be explained as a consequence of disturbance of natural processes (either in the classical sense of a disturbance of body fluids, or more modern, as a disturbance in organ functioning), or as a consequence of improper behavior (either in the classical sense of a sin against God's commands, or in the modern sense of unhealthy behavior, such as smoking). Texts and narratives offer us a new perspective on the situation, and thus enable us to make sense of it.

The process of changing one's perspective is also at work when we are confronted with an unexpected reaction of another person. When another person responds in an unexpected way, we are urged to come and see her point of view, see the world through her eyes. According to Gadamer, the process of widening one's own point of view is dialogical. Through dialogue, people articulate, explore, interpret, 'test' and transform their experiences. This does not happen intentionally, but occurs in and through conversation. This means we cannot control or influence understanding deliberately. We can however, be open to understanding, by listening to the other and being prepared to move into a shared dimension of meaning. The process of dialogical understanding is based upon the tradition of the interpreter (the one who understands). Given our tradition and history, we have certain prejudices and bring them into dialogue. '(...)The prejudices of the individual, far more than his judgments, constitute the historical reality of his being' (Gadamer, 1975, pp. 245). Prejudices can be seen as pre-understandings of the world, structures of meaning that we always carry with us (Freeman, 2011). Understanding involves sorting out prejudices that we become aware of when we are confronted with something that is unfamiliar to us. In every polarity of something familiar and something strange, a potential for understanding is present. From this in-between position, understanding can grow.

This does not imply that 'old' assumptions will simply be replaced by new ones. The old horizon is not changed for a new one. Instead, in the process of understanding, 'a fusion of horizons' takes place (Gadamer, 1975).

We may conclude that philosophical hermeneutics distinguishes various kinds of understanding, which are mutually related. Understanding starts with a breakdown of expectations, shaking one's presuppositions, and challenging one's point of view. The experience of something strange and unfamiliar invokes attempts to make sense of the situation by referring to texts and narratives which may explain what has happened. Texts and stories may offer new points of view, and may help to widen one's perspective. This dialogical process is experienced prominently in interactions with other people. According to Gadamer, dialogical understanding leads to a new and common way of viewing the world, a merger of perspectives.

## Case

In order to get more insight in the process of understanding, we will explore the experiences of a patient and elaborate how her particular experiences can be interpreted. We will present and analyse a case, selected from a descriptive qualitative study which examined perspectives of patients with a cardiovascular disease on psychosocial care. The qualitative study consisted of 24 in-depth interviews with cardiovascular patients. The particular case was chosen because of the importance the respondent ascribed to 'understanding' and 'being understood', and its learning potential (Stake, 2004; Abma & Stake, forthcoming). The case concerns an in-depth interview with a female respondent in her early forties.

In the following we present a narrative account of the case, based on the interview. The interview was conducted by the first author at the respondent's home and lasted for 2,5 hours. After the interview, a transcript was made. The researchers' first interpretation of the transcript was primarily focused on themes concerning the improvement of psychosocial care. This first interpretation has been sent to the respondent with the question whether she had any remarks. This appeared not to be the case. The respondent agreed with the interpretation.

For this article, the first and second author again analysed the transcript of the interview time, following an interpretative narrative analysis approach (Riessman, 2008). Interpretative *narrative* analysis can be described as a technique that seeks to interpret the ways in which people perceive reality, make sense of their worlds, and perform social actions (ibid). The purpose is to see how respondents make sense of the flow of experience. The analysis consisted of four steps. First, the transcript was read several times until a pattern emerged that informed us about main themes and events of the narrator. Subsequently, the transcript was coded. Through open coding, the researchers searched in more depth for themes and events that relate to the main question. We were sensitive for frequently used words, phrases related to key terms of the research question and expressions about the identity of the respondent and her relationships to other persons, for instance her children and cardiologist. During this step, the researchers were attentive for what is unsaid (silences) and moments of uncertainty. Next, a

draft of the interpretation of the respondent's narrative was written by the first and second author. The authors discussed how to include narrative elements (time, space, beginning, middle, end) and the balance between themes in the original data (transcript) and the draft.

The interpretation was member checked with the respondent by asking her: does what we have written make sense to you? Does this account justice to your experience? Were aspects of your experience omitted? A conversation between the first author and the respondent followed. The respondent agreed with the text and the narrative presented below.

### *Marga's narrative*

Marga<sup>22</sup> is relatively young when she suffers several heart attacks. She is in her early forties and lives with her second husband and two sons and a daughter, aged 6, 9 and 11 in a big city in the Netherlands. She works part-time as an administrative assistant in an office.

Marga tells the first cardiac insult happens in 2005 when she is home, sitting at her computer. Her hand suddenly doesn't move. She thinks it is just a muscle, but soon her chest starts to hurt and she can't breathe. Everything then goes fast: *'[t]his is no good, it's not hyperventilation, it's a heart attack.'* She tells one of her sons: *'[w]ill you get daddy please, because this is going wrong'*. Shortly after that, the police and ambulance arrive. The ambulance crew says they have never seen anything like it, and bring her to the university medical center. In the meantime, the police stays at home, with Marga's children. Whilst Marga's son's are relatively calm about the situation, the police has to comfort Marga's daughter who is terribly upset by what happened to her mother.

The medical staff in the hospital where Marga arrives, tell they can't find anything wrong so she is transferred to a regional hospital immediately. The next day, while Marga is still in the hospital, she has another heart attack. Marga is very calm after this second incident: *'panicking won't help'* she explains. Nevertheless, later on she admits to having been scared, not for herself but for her children's sake – not to be able to help them grow up. As tubes and machines around Marga scare her children, her doctor proposes to have a talk with them about all that is happening; *'[h]e explained it to them in a good child-like way.'*

It was only after her cardiologist had been in touch with colleagues abroad, that he realizes they are looking at coronary vasospasm. *'I'm supposed to have a serious condition.'* However, what makes the most impression on Marga is that *'...they said I'd never be able to work again, and that it was a disease I'd never get rid of.'*

At the time, Marga works as an administrative assistant in a local office. She loves her work and especially the social contacts with her colleagues. She wants to do anything to go back to work, it means *'the world'* to her. At home, things are quite different. She is married to a man with an alcohol problem. Marga's days are long and filled with activities: she takes care of the house, the children, her work and she leads an active social life with regular visits to a sport school. After her first cardiac insults, when she is back at home, her husband tells her he *'suffered so much because he had to*

*take care of the children all the time'*. He feels sorry for himself, being unemployed and Marga tells he *'used my health situation as an excuse not to find work'*. Marga's mother and her befriended colleagues help her with doing groceries, cleaning the house and taking care of the children. Marga's children respond differently to her health situation. Especially Marga's daughter has difficulty with the situation and this concerns Marga a lot. *'As long as I am okay, my daughter is okay'*.

Some weeks after her discharge from the hospital, strong feelings surface. Marga can barely do anything and feels she has been transformed from an active, sporty person into a tired 'wreck'. Before her heart attack, her days were hectic. Marga would get up early in the morning and do all the things that had to be done, ironing, grocery shopping, cleaning, bringing the children to school, working, picking up the children, cooking, sport and continuing if necessary, ignoring her body and she went to bed very late. Her life has changed radically. Now, she is only able to walk from the living room to the bathroom: *'on the toilet I cried from exhaustion and didn't know how I would be able to get back to the couch again where I spend my days'*. She receives some help from a nurse at home. Marga's mother brings a strolling device and Marga uses it to walk around a bit. Feeling disappointed and aggressive, she wonders: *'[w]hy [me], and not someone else?'* Marga quickly learns that nobody can answer the question why she got her disease. *'Nobody can tell why some people get it, and others don't, not even my cardiologist'*. Only in hindsight and after several years, she knows excessive stress and her strong will have probably been an important factors, but at the time she wasn't aware of it.

In the seven months after the first insults, Marga is admitted to the hospital five times because of recurrent symptoms. She attends a cardiovascular rehabilitation program that primarily consists of physical exercises under guidance of specially trained physical therapists. Her colleagues bring her to rehabilitation twice a week: *'[r]eally great. Then I said 'I truly will try to come back [to work].''* During her rehabilitation, Marga goes through an uncertain phase of experimenting with different kinds and amounts of medicine. This is challenging because of the lack of standard treatment for people with coronary vasospasm.

In 2006, a year after her cardiac incidents, Marga divorces her husband. This decision brings her and her children peace and rest. Marga wants to stay in the house, whilst her ex-husband moves into an apartment in the neighborhood. The children visit him every week. Although not ideal, Marga's situation is relatively stable, there are no new cardiac incidents as long as she rests and takes her medication. Marga also adjusts her lifestyle, for example her diet. She still is unable to work, something she regrets very much. It feels that she is not living a *'normal'* life.

In 2007, a year after she divorced her ex-husband, Marga meets a man whom she eventually marries. They date for two years and in the spring of 2008 Marga decides to move in with him. Marga and her children sell the house they have been living in for more than seven years. Although Marga is certain of her future with her fiancée and the decision to move, the impact of the move is huge. To her, it feel as if she *'left everything that belonged to her and her children'* to start a new life. Instead, she gains *'something beautiful, but it felt like I had to rebuild my whole life again. I left my history'*.

In Marga's eyes this results in a relapse in the spring of 2008. This leads to new admissions because of recurrent signs of a cardiac incident. Fortunately no new cardiac incidents occur, but the fear for a new incident is constantly present.

This setback evokes feelings and questions similar to those during her first cardiac incidents: *'why am I always tired and what are the side effects of my medicine?'* Her relapse brings about a strong desire to investigate the workings of medicine and the nature of her disease. Marga does not rest before knowing the working of every medicine prescribed to her. *'[O]nly then can I accept it. (...) This was very important [to me]. (...) I wanted to know everything, I really digged deep and that provided me with a sense of security. (...) All I wanted was to lead a life as normal as possible.'* In this process of trial and error, Marga discovers her need for regularity and a daily routine. To help her maintain a balance, she sets fixed times for getting up, taking her medication and resting. At this time, the internet becomes an important source of information. It becomes indispensable in her search for information, testing and evaluation of her experiences and knowledge on her disease and way of life.

Marga feels understood by her cardiologist: *'My cardiologist always smiles at me when I come in, he always asks 'and, did you find something new?' I appreciate it a lot that he understands what I bring in, also because he is not so familiar with this disease as I am'*. Her cardiologist learns from and uses her information and shares it with other cardiologists. He respects her experiences, thoughts, concerns and decisions concerning her health. At some point, he urges her to come to the hospital as soon as she feels pain and vessel contractions. But Marga explains to him that resting at home is better for her: *'My cardiologist always tells me: "You should come immediately", but I won't. When I lay down in bed, after a day the pain will dissolve. I'm okay with that. When I go to the hospital, I would have to enter the entire admission procedure again. In the end, a week is lost without getting any further'*. At first, Marga's doctor is surprised by her perspective. After a while he learns that Marga is capable of estimating what is right for her and he accepts this. He admires her for her positive attitude and sees her as an example for others. He says to her: *'[t]he way you do all this research is amazing.'*

Next to sharing her information with her doctor, Marga supports fellow-patients by providing them with answers by email and phone. Through an advertisement on the internet she searches for people with similar experiences and questions. This brings her into contact with several people who all share the same question: *why?* Together they learn that women develop the disease around their forties, whilst men are older, generally around fifty. But still they cannot find an answer on their primary question *'why me'*. In return, though, Marga is happy she can contribute something to other people's lives. Together they learn from their experiences with how to cope with their disease in their daily lives: *'Ah, that man feels tired as well, he lays down, he doesn't use the medication but just rests...'*

Three years after her first incidents, in the fall of 2008, Marga manages to slowly restart work: *'I remember it well, it was in August and I was sitting in the train, when I said to myself: I will work again!. They thought me crazy, but I wanted to because contact with colleagues is very important to me'*. Her boss and colleagues support her in resuming work. She is allowed to take a

break and come and go whenever she needs to. *'I was present. It felt therapeutic to just bike to my work, drink a coffee, talk to my colleagues and then go back home, even if it was for fifteen minutes'*.

Now, five years later, she still works and has a relatively stable condition. Yet, a lot has changed for her. There now is a 'life before' and 'life after' the cardiac incidents. Before, she was unhappily married to an irresponsible husband, and her life was hectic. In hindsight she realizes that her strong desire to accomplish all kinds of things at the same time contributed to the development of her illness. Feeling stressed was normal. Now she makes time for herself, she knows she needs rest and she cannot accomplish everything at once. She lives a new life, in a new house and, despite the impact of these changes, she feels at peace with herself and her situation. She is supported by her new partner: *'This is my time. My friend tells my children: 'your mother is lying down now to rest, don't ask any questions, this is her hour now (...) otherwise she won't cope.'*

## Phases of understanding

Marga stresses the importance of exploring the meaning of what happens to her, of gathering medical knowledge and of sharing with others. In Marga's narrative, three aspects of understanding can be recognised. The kinds of understanding, elaborated in hermeneutic philosophy, are presented in Marga's story. To us, the case is especially interesting, because it teaches us that these kinds of understanding follow one another in consecutive phases, building upon and strengthening each other. As to date, relatively few theoretical attention has been paid to the sequence of these steps in processes of understanding. First, her understanding is related to existential questions. Next, her understanding focuses on finding answers to more practical questions concerning her medical condition. Finally, her understanding becomes shared, acknowledged and validated by her cardiologist. We will now go into these phases of understanding in depth and relate them to theory.

### *Phase A: Marga's understanding as learning to respond to 'strangeness'*

Marga's understanding evolves gradually and in phases. At first, Marga relates to her condition as something exterior. At the beginning of her story, she tells us: *'I'm supposed to have a serious condition'*. Marga does not seem to acknowledge the presence of her condition. The disease is something Marga cannot relate to, something 'strange'. This strangeness can be seen in her description of the experience of her first attack. She tells that she felt very calm right after the cardiac incidents as if the news didn't have any meaning (yet). A similar kind of 'strangeness' is present when the cardiologist explains Marga's children what is going on with their mother. Marga and he try to reduce the strangeness of the situation by letting her children touch the tubes and intravenous line that is attached to her. By doing this, she and her cardiologist try to make her children familiar to the new situation.

Soon after Marga is discharged from the hospital and arrives home, she struggles with another kind of strangeness that confronts her. This time, the strangeness does not concern the (lack of) awareness of having a disease,

but the existential question *'why me?'*. Initially she expects her cardiologist to provide her with answers. She learns, however, that he can not answer her question because according to the medical knowledge it is unclear who develops cardiovascular spasm and who does not. The lack of meaning causes a struggle, characterized by uncertainty and anxiety. Marga is moved back and forth between her life as she knew it, and her experiences with a rare disease. In this phase, Marga inhabits her world as an interpretive being who moves between familiarity and strangeness (Kerdeman, 1998). Her understanding of her situation is not so much an 'outcome', but a process or mode of being (Schwandt, 1999).

At certain moments, Marga is able to integrate the disease into her life, and even to make use of her new experiences to reinterpret the past. This can be seen when she finally understands that her intuition several years earlier, when she felt severe pain in her chest, was actually right. At the time, she immediately phoned her general practitioner, but he told her not to worry. He assumed it was her chest muscle. The next day, her pain returned. Again, examination did not clarify her situation and this left her felt misunderstood. When she actually suffered from a heart attack a year later, Marga realized her suspicions had been right: *'I have had it before. They just didn't believe me because I was relatively young'*. We may state she experiences interpretive coherence (Schmid, 1998) and apprehends (Figal, 2004, p.3) her challenging experiences. In this moment of understanding, she reaches a (temporary) equilibrium between what is familiar and what is strange.

#### *Phase B: understanding as gaining insight through acquiring information*

Marga's life changes considerably after the initial incidents. She divorces, moves in with a new friend whom she eventually marries. In a way, she adjusts her life to her new situation. Yet, the move, leads to a recurrence of symptoms. This is the start of a new phase of understanding.. Marga's questions become more focused on medical information and on how to integrate her disease in her daily life. Questions she addresses are, for example *'how can I live a normal life with my disease?'*, *'why am I always tired and what are the consequences for my work and family?'*, and *'what are the side effects of my medicine?'* She expects that answers on these questions will support her in accepting her disease. In order to accept, she seeks to find answers by searching for information through the internet and other written sources. The main focus of her search is her need to deal with practical issues concerning how to cope with her disease on a daily basis. The internet becomes a means for Marga to learn about her disease and get a grip on her medical condition. It enhances her understanding of her disease both factually and emotionally as it provides her with *'a sense of security'*. The internet gives her a sense of understanding and contributes towards her psychosocial wellbeing by the reduction of uncertainty. Marga discovers that sharing experiences with others gives her peace. This has two possible reasons. Firstly, it feels good to be able to contribute to other people's lives. Secondly, she recognizes something of herself in other people's experiences. For example, Marga learns that other people are as tired as she is, and that there are a lot of women who developed the disease around their forties as well. She recognizes something and this, we may say, 'normalizes' her situation.

Marga not only reads the information concerning experiences of fellow patients. She also applies it to her situation and by doing that, the information gains meaning. For example when she reads that most people with coronary spasm have one spasmodic vessel. Initially she doesn't know how many of her vessels are spasmodic. She cannot discern what this means for her health, prognosis and medicine. The new information brings to the surface her preconceptions or the things she already knew about herself and her disease. It evokes new questions and in the end, when she finds answers, this contributes to her understanding. When Marga searches for information or experiences of fellow patients through the internet, her understanding is an 'act of exegesis'. She moves back and forth between the newly found information as 'text'. From a hermeneutical stance, we say she enters a hermeneutical circle in order to make sense of the information.

#### *Phase C: dialogical understanding as validation of authority*

Marga's cardiologist knows her zest for information. Every time they meet, he actively informs after her new findings. By doing this, he shows genuine interest. Consequently, they begin to share a common meaning. For example, one day Marga reads about the side-effects of a drug she is taking and recognizes it. She suffers from dizziness and wonders whether another, new drug would have less side-effects. This would however change her medicine cocktail, which is a subtly balanced mix. She shares this information with her cardiologist and together they deliberate on the consequences of possible side-effects for her daily life. By sharing her newly found information and her interpretations with her cardiologist, Marga enters a dialogue. She is not an 'agent' seeking 'intellectual control' over the information (Taylor, 2002, p.280). Instead, she takes part in a process with her cardiologist that is guided by 'what is to be understood' (Bernstein, 1983, p.162). Hence, the outcome is not solely 'her' individual understanding, but 'their' joint understanding. Along the way, their common understanding of the right mix of drugs in the context of her life develops.

We may say that gradually, as time moves on, a fusion of horizons takes place. By collecting information which her healthcare professionals could not provide, and then applying it in her contact with her cardiologist, Marga enhances her understanding of the situation. The openness of her cardiologist to what she has to say supports this interpretive process. From Marga's case we learn about this third phase of understanding, which is dialogical and continuously changing due to the different questions patients and professionals learn to ask themselves and each other (Widdershoven, 1999). Hermeneutic understanding means extending one's perspective, or broadening one's horizon (Gadamer, 1975). From a hermeneutic perspective, the broadening of one's horizon 'occurs' in a process of question and answer, in which both participants share their knowledge and understanding. 'It is no longer the will of the individual person, holding herself back or exposing herself that is determinative. Rather, the law of the subject matter is at issue in the dialogue (...)' (ibid, 1975, p. 347).

Marga tells *'I appreciate it a lot that he [her cardiologist] understands what I mean, also because he is not as familiar with this disease as I am'*. We can interpret this quote in two ways. First, the cardiologist's understanding is

directed towards what Marga brings into the conversation (her knowledge and experiences) in the sense of *apprehending* it. A second interpretation involves the cardiologist's response and the effect it has on their relationship. He responds positively to Marga's input and this makes her feel understood. He acknowledges and validates her point of view and her actions. This may have supported the process of making her experiences and knowledge her own (*Aneignung*). From this, we may conclude that Marga's understanding means 'being acknowledged' in her authority as a genuine partner in her treatment and recovery.

Gadamer pleads for a positive view on authority. He argues; 'If the prestige of authority takes the place of one's own judgment, then authority is in fact a source of prejudices' (1975, p.247). Authority provides a first understanding of what is at stake in a situation. A patient may accept that a clinician or nurse has more extensive knowledge, or has a better understanding. This does not preclude from a patients' critical questioning or sharing experiential knowledge. Marga accepts the knowledge of the cardiologist, but also brings in her own views and experiences. She combines acceptance of authority and critical questioning naturally. Her acknowledgement of the authority of her cardiologist contributes to her understanding: she regards him as a competent and supportive doctor. Yet, she does not blindly obey him. An example is her reaction when her chest pain returns. Her doctor informs her that generally, in the case of chest pains, patients should be admitted immediately. He advises her to do so. Marga, however, prefers to stay at home as long as possible. She knows her body and her condition, she knows when it's time to lay down and rest, and she knows when to use medicine or not.

Marga's experiential knowledge is in turn acknowledged by her cardiologist. For example when he actively informs after her newly found information. The fact that he invites her to share her insights, shows he values them. Acknowledgement of her experiential knowledge occurs less automatically when he responds to her wish to stay at home, despite of symptoms of a new incident. He is surprised by her perspective, but in the end trusts her ability to judge her own situation. Also in this event, he confirms the validity of her decision. His judgement of her decisions and actions as a patient express values like equality and inclusion. After some time, as he gets to know Marga better, he perceives her as a competent person. Thus, the relationship between Marga and her cardiologist includes space for Marga's experiential knowledge. She is being acknowledged and not overruled by general, law-like knowledge (Gadamer, 1960) or mechanisms of power.

In her relationship with the cardiologist, Marga herself gets authority, as her experiences are acknowledged as relevant and valid. Her authority is further developed in contacts with fellow patients and contributions to the internet. Experiential knowledge arises when personal experiences are consciously or unconsciously transformed into a personal insight that enables a patient to cope with individual illness and disability (Caron-Flinterman, 2005, p.2576). From a hermeneutic stance, practical knowledge precedes theoretical knowledge, but is not opposed to it (Widdershoven, 1999). Instead, both forms are related in a dialogical process of reflection.

## Conclusions and implications for practice

Understanding an illness experience can be regarded a learning process. The case example illustrated the process of understanding is closely interwoven with one's history and lifeworld. Understanding is not static, but changing and developing. The case we interpreted, learned that Marga's understanding has three phases. It evolves from meaning-making, directed towards relating to the strangeness of illness in the context of her life, through acquiring medical and practical information about her disease, to coming to a shared understanding with her physician. The three phases are fluid and mingled. They do not provide a stepwise method. Instead, they can help to interpret what is happening when there is a rupture between the ill person and the world.

The phases of understanding which can be seen in Marga's narrative, could have implications for medical practices. The first is related to the model of physician-patient relationships. The three phases of understanding reflect classical notions of the physician-patient relationship: from paternalism (where the patient does not understand because of the strangeness), through informative (where the focus is on objective information), to deliberative (focusing on shared decision making) (Emanuel and Emanuel, 1992). This shows that we might have to consider to combine models of the physician-patient relationship in a certain order, making way for more dialogical ways of interaction as the process of understanding unfolds.

In this case example, patient and physician cooperate. Their practice is a mutual endeavour, a joint learning process. A recommendation for further research concerns the question how healthcare professionals can gain information about the needs of patients. Could they 'discover' the needs of patients? Is it possible to 'reveal' needs? We pose this question, because the case illustrates that during the process of understanding, new themes and questions arise, that direct the conversation or treatment process. Maybe needs are not given, but created in the encounter itself (Widdershoven, 1999).

A requirement for a mutual dialogue is the acknowledgement of the practical knowledge of the patient. This requires the physician to be open and receptive. An open and receptive attitude can be stimulated by systematic self-evaluation and reflection (Widdershoven et al., 2009; Charon, 2008). Dialogical ethics can support practices of (moral) reflection and self-evaluation. It is focused on fostering a dialogue between practitioners in healthcare settings in order to improve quality of care (Widdershoven et al., 2009). It supports a process of mutual understanding between participants of the setting. In this way, dialogical ethics may support physicians and patients in working with the phases of understanding articulated in this paper.

Explicitly paying attention to phases of understanding may also enhance the diagnostic process due to a better recognition of the patient's dilemma's (Charon, 2001). Further research might explore the validity of the phases of understanding in other contexts and among groups of patients with a chronic illness. This may contribute to the conceptualization and practical application of concepts like self-management, compliance and adherence and shared decision making (Harding et al., 2008; Sandman et al., 2012).

\* male/female

\*\* For privacy reasons the name of the respondent is fictitious.



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